The Arc.
of New Jersey

Guide to Understanding SSI and SSDI

What is the Difference Between SSI and SSDI?

Supplemental Security Income (SSI)	Social Security Disability Insurance (SSDI)
SSI is strictly need-based, according to income and assets, and is funded by tax revenues. Regardless of the individual's guardianship status, the U.S. Social Security Administration no longer counts family income and resources when determining eligibility for SSI once the individual is 18 years of age.	SSDI pays benefits to you (the worker) and certain members of your family if you are "insured," meaning you worked long enough and paid Social Security taxes. When you retire, become disabled or pass away, your spouse and dependent children (including adults with disabilities) are eligible to receive partial benefits, called auxiliary benefits. The amount of the monthly benefit paid to the worker and dependents is based on the worker's employment history.
If found eligible for SSI, the person will automatically receive Medicaid. For more information about having both Medicaid and private health insurance, please visit: bit.ly/1cKUrQh	If the dependent child once received SSI/Medicaid benefits, but lost SSI/Medicaid because he/she began receiving SSDI benefits due to the worker's retirement, disability or death, the dependent child may be considered a "Disabled Adult Child" or "DAC" under section 1634 of the Social Security Act and may still be eligible to continue receiving Medicaid benefits.

SSI and SSDI Eligibility

Supplemental Security Income (SSI) eligibility includes:

- Have limited income/resources
- Meet Social Security's definition of disability
- Age 65 or older, blind or disabled

Social Security Disability Insurance (SSDI) eligibility includes: 1.usa.gov/1c0dXaQ

- The worker paid into Social Security long enough and
- Meets Social Security's definition of disability

Social Security Disability Insurance (SSDI) eligibility for *dependents* includes: 1.usa.gov/1dz3B31

- A parent(s) who is disabled or retired and entitled to Social Security benefits; or
- A parent who died after having worked long enough in a job where he or she paid Social Security taxes.

Read

Supplemental Security Income (SSI)

- **Become familiar with Social Security's SSI publication:** 1.usa.gov/1HpSoyw
- **Supplemental Security Income—Why is it important for people with developmental disabilities:** bit.ly/1JthYCq
- **Social Security Office Locator:** bit.ly/ssofficelocator

Social Security Disability Insurance (SSDI)

- **Become familiar with the government publications for SSDI:** 1.usa.gov/1GjnqXB
- **Social Security—Understanding Your Benefits:** 1.usa.gov/1HpUCOC
- **Benefits for your Children with Disabilities:**
- 1.usa.gov/1Fo55aT

Timeline

Create a "My Social Security" account to track your future or current benefits: www.ssa.gov/myaccount

Supplemental Security Income (SSI)

- **Apply for SSI:** www.socialsecurity.gov or call 800-772-1213
- **Webinar:** Understanding Your Social Security Retirement Benefits: For Parents of Individuals with I/DD vimeo.com/121907015

Social Security Disability Insurance (SSDI)

- **Apply for SSDI benefits:** 1.usa.gov/1IHfSQb
- **Social Security Act and Continued Medicaid Eligibility While Working (*Section 1619b Flyer*):** bit.ly/section1619b

Get Connected

As changes take place within the service delivery systems, it is vital for families to stay connected with an organization that can provide the most recent and important information. ***The Arc of New Jersey Family Institute and its Family Advocacy Program keep you informed, educated and up-to-date*** on all the latest changes that affect your loved one with an intellectual or developmental disability.

Sign up today for free!

- Family Member/Guardian Sign Up: bit.ly/caregiverfapregister
- Professional in the Field Sign Up: bit.ly/professionalfapregister

***Please type all links exactly as seen including capital letters.**

The Arc of New Jersey | 985 Livingston Avenue | North Brunswick, NJ 08902 | www.arcnj.org | info@arcnj.org | 732.246.2525

Updated 6/15

NJ Department of Human Services
Division of Developmental Disabilities

MEDICAID ELIGIBILITY for the SUPPORTS PROGRAM

2016	Supplemental Security Income (SSI)	NJ Care…Special Medicaid Program	NJ Workability
Overview	Federal income supplement program designed to help people who are “aged, blind, and/or disabled” who have little/no income. SSI provides monthly cash payment to meet basic needs for food, clothing, and shelter.	Special program that provides Medicaid for individuals who are 65 years of age or older, blind or disabled and are unable to afford the health care they need.	Offers full New Jersey Medicaid health coverage to individuals with disabilities who are working, and whose earnings would otherwise make them ineligible for Medicaid. Eligible individuals pay a small premium and receive full New Jersey Medicaid coverage.
Eligibility Criteria	• Aged (65+); blind; or disabled; & • Limited income and resources *(The monthly income limit is $764.25 & resource limit is $2000*); & • U.S. citizen or national, or in one of certain categories of aliens; & • Resident of one of the 50 States; D.C. Northern Mariana Islands; & • Not absent from the country for 30 consecutive days or more. You may obtain your current benefit information, award letters, etc. or make changes to your contact information by going to the My Social Security website: **www.ssa.gov/myaccount**	• Aged (65+) and/or determined to be blind or disabled by either the Social Security Administration (SSA) or the Division of Medical Assistance and Health Services (DMAHS); & • Resident of New Jersey; & • U.S. citizen or qualified alien (*Most immigrants who arrived after August 22, 1996 will be barred from Medicaid for five years from receipt of a Green Card)*; & • Financially eligible *(The monthly Income limit is $990 and Resource Limit is $4000).*	• Between the ages of 16–64; & • Working (full/part-time) with proof of employment; & • Determined “disabled” by the SSA, or DMAHS; & • *Financial limits*: Approximate earned income no more than $60,180 (gross income) per year for eligible individuals ($5,015 per month), or no more than $80,892 (gross income) per year for eligible couples ($6,741 per month) - both with permanent disability, both working; & • Unearned income (pensions, child support, etc.) up to $990 per month for eligible individuals or up to $1,335 for eligible couples; & • No more than $20,000 in liquid assets as an individual, or $30,000 as a couple. Please note: Social Security Disability Benefits, Railroad Retirement System Benefits (received by an individual on their own account), retirement accounts (like an IRA or 401K) and the value of owned home and car are all disregarded.
Application Process	Made through local Social Security offices. To locate an office, go to: **https://secure.ssa.gov/apps6z/FOLO/fo001.jsp** It is recommended to call your local office first to see if an appointment is needed.	Made at the County Welfare Agencies/Board of Social Services. To locate an office, go to: **www.nj.gov/humanservices/dfd/programs/njsnap/cwa/**	Made at the County Welfare Agencies/Board of Social Services. To locate an office, go to: **www.nj.gov/humanservices/dfd/programs/njsnap/cwa/**
Required Documents	• Proof of age; • Proof of citizenship; • Social Security card or record of SSN; • Documentation related to income & resources *(Copies of your checking account(s), savings account(s), trust(s) including life insurance and special needs, annuities, payroll slips, burial fund records, and other information about your income and the things you own. Be sure to include the account numbers for all documents.);* • Names, addresses, and phone numbers of doctors, hospitals and clinics that you have been to, if applying because you are disabled or blind. For a more complete list, go to: **www.ssa.gov/pubs/EN-05-11000.pdf**	• Proof of age; • Proof of citizenship; • Proof of marital status (if married); • Documentation related to Power of Attorney/Third Party Signator/Guardianship (if applicable); • Documentation related to income & resources *(Copies of your checking account(s), savings account(s), trust(s) including life insurance and special needs, annuities, copies of life insurance policies with cash value, etc.).*	• Proof of age; • Proof of citizenship; • Proof of marital status (if married); • Social Security card or record of SSN; • Documentation related to income & resources *(Copies of your checking account(s), savings account(s), trust(s) including life insurance and special needs, annuities, payroll slips, burial fund records, and other information about your income and the things you own. Be sure to include the account numbers for all documents);* • Proof of employment *(pay stubs, employment contract, etc.);* • Documentation related to Power of Attorney/Third Party Signator/Guardianship (if applicable).
Additional Information	**www.socialsecurity.gov/ssi/text-eligibility-ussi.htm** **1.800.772.1213**	See document: *Applying for Medicaid New Jersey Care…Special Medicaid Programs Check List.* **1.609.588.2556**	Division of Disability Services **1.888.285.3036**

What should I do if I am denied Medicaid or SSI because my income or resources are too high?

You should inquire about your eligibility for New Jersey Care…Special Medicaid Program or New Jersey WorkAbility.

What should I do if I lose my SSI and Medicaid coverage because I begin receiving Social Security Benefits on my parent's account and/or there was an increase in those benefits?

You may be eligible to continue receiving Medicaid benefits as a "1634 Disabled Adult Child" (DAC) if you meet the following criteria: (1) You are at least 18 years old; (2) You have become disabled or blind prior to age 22; (3) You have been receiving SSI on the basis of your disability; and (4) You have lost SSI as a result of your parent's insurance benefits under Social Security or as a result of an increase in those benefits.

If you have a letter from the Social Security Administration (SSA) verifying that you are eligible for DAC status, to your County Welfare Agencies (CWA) for consideration of Medicaid eligibility under the DAC status. If you do not have any documentation verifying that you are eligible for DAC status, it is recommended that you contact SSA and obtain a letter prior to going to your CWA.

What should I do if I lose my SSI and Medicaid coverage because of receiving SSDI resulting in my income exceeding the SSI income limit?

You may be eligible to continue receiving Medicaid benefits through the New Jersey Care…Special Medicaid Program option or New Jersey WorkAbility. You should contact your County Welfare Agency (CWA) and schedule an appointment to complete the application. Be sure to take the required documents with you.

Once I have been determined eligible for Medicaid, is that determination permanent?

No. If your income, resources or living arrangements change at any time, it may affect your eligibility. Both Medicaid and SSI conduct eligibility redeterminations on an ongoing basis to verify that you remain eligible. It is imperative that you comply with all redeterminations as failure to do so may cause your benefits to be suspended or terminated.

If I lose my Medicaid eligibility, will I still be able to access the Supports Program?

No. You will not be able to access the Supports Program unless you maintain Medicaid eligibility.

New Jersey Department of Human Services
Divison of Developmental Disabilities
www.nj.gov/humanservices/ddd

Section 1619(b): SSI and Continued Medicaid Eligibility

(Information for calendar year 2015)

Section 1619(b) of the Social Security Act allows individuals who are eligible for Supplemental Security Income (SSI) to continue to be eligible for Medicaid coverage when their earnings are too high to continue to receive SSI. This work incentive applies to individuals whose earnings are below New Jersey's threshold (currently $34,772 in 2015).

How It Helps You:

If you:

- Have been eligible for an SSI cash payment for at least 1 month;
- Still meet the disability requirement; **and**
- Still meet all other non-disability SSI requirements; **and**
- Need Medicaid benefits to continue to work; **and**
- Have gross earnings that are insufficient to replace SSI, Medicaid and publicly funded attendant care services.

1619(b) allows you to work and keep your Medicaid coverage without a Medicaid spend-down. You can continue to be eligible for Medicaid coverage until your gross annual income reaches a certain amount. New Jersey's threshold is currently $34,772 in 2015. You must also continue to meet all of the other SSI eligibility requirements, such as having less than $2000 in resources as a single person or $3000 as a couple.

How It Works:

- While you are earning income from work and need your Medicaid coverage **plus** you meet all other requirements for SSI (such as having less than $2,000 in resources), you may be eligible for 1619(b) Medicaid protection.

- You **must** report your earnings to the Social Security Administration (SSA) monthly.

- When your SSI cash payments stop due to reaching your Break Even Point (the point when your earnings cause your SSI check to go to zero), the local SSA office must determine your eligibility for 1619(b).
  Medicaid Use Test- The individual must depend on Medicaid coverage to continue working. The recipient must have: used Medicaid in the past year, or expect to use Medicaid within the next year, or need Medicaid if unexpected medical expenses arise. (Note: Ongoing Medicaid eligibility is required for services through the Division of Developmental Disabilities.)

- SSA will send you a notice of the decision for this Medicaid protection. This information will also be communicated to Medicaid. If there is an issue, please present your 1619(b) determination to Medicaid.

- With 1619(b) you may remain eligible for SSI, even though your cash benefit has stopped. If you begin earning less than your Break Even Point or you stop working, your SSI cash benefit will start again.

It is always very important to report your earnings to SSA each month to have your SSI cash benefit adjusted accurately

If an SSI beneficiary has gross earnings higher than the threshold amount for New Jersey, SSA may allow a higher threshold amount if it is documented with Social Security that a person has:

- Impairment-related work expenses; or
- Blind work expenses; or
- A plan to achieve self-support; or
- Personal attendant whose fees are publicly funded; or
- Medical expenses above the average State amount.

For more information, contact your local Social Security Administration, **WIL** (Work Incentives Liaison) online at https://secure.ssa.gov/ICON/main.jsp or NJWINS (Work Incentive Network Support) at http://www.njwins.org

New Jersey Department of Human Services
Division of Developmental Disabilities
www.nj.gov/humanservices/ddd

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is highly recommended for individuals with intellectual or developmental disabilities who turn 18 years of age and expect to pursue supports and services through the New Jersey Department of Human Services' Division of Developmental Disabilities.

- The federal Supplemental Security Income (SSI) program pays benefits to adults with disabilities who have limited income and resources.
- For adults age 18 and older, the U.S. Social Security Administration no longer counts parental income and resources when determining an individual's eligibility for SSI
- Every New Jersey resident who receives SSI will **automatically** receive New Jersey Medicaid. *Having SSI protects Medicaid eligibility for the future.*

Since Medicaid eligibility is a requirement for receiving Division-funded services, why is it important for 18-year-olds with intellectual and developmental disabilities to apply for SSI, rather than applying just for "regular" NJ Medicaid?

When a parent of an individual with intellectual and developmental disabilities (I/DD) retires, becomes disabled, or dies, the son/daughter starts to receive Social Security Disability (SSD), and the amount of the monthly SSD benefit is based on the parent's work history. Usually, the amount of the SSD benefit is too high for the adult child to be eligible for Medicaid; if the son/daughter previously received Medicaid it would be terminated when SSD begins – thereby jeopardizing their DDD services.

However, individuals with I/DD who previously had SSI are, in most cases, able to maintain their Medicaid eligibility – even when they receive a large monthly SSD benefit. Social Security designates this special group as a Disabled Adult Child under Section 1634 of the Social Security Act regarding DAC (§1634 DAC). This is why it is so important for individuals with I/DD to apply for SSI at age 18 and obtain Medicaid through their SSI eligibility, rather than applying just for NJ Medicaid. It is also very important for individuals with I/DD to maintain their monthly income and assets within the SSI eligibility limits.

What happens if an individual with I/DD is determined to be ineligible for SSI because he/she already receives Social Security Disability (SSD) on the parent's work history?

Occasionally, the parent of an individual with I/DD has retired, become disabled, or died *before* the son/daughter's 18th birthday. In these situations, it is likely that the son/daughter with I/DD has been receiving a substantial Social Security Disability (SSD) benefit on the parent's work history before the son/daughter could have applied for Supplemental Security Income (SSI). The Division recognizes that individuals in this situation are probably not able to obtain SSI or Medicaid. If this situation pertains to you please complete the Division's Medicaid Troubleshooting Form and forward it, along with your Social Security benefit verification letter, to the Division's Medicaid Eligibility Helpdesk at **DDD.MediEligHelpdesk@dhs.state.nj.us**.

Where can individuals and families go online for more information from the U.S. Social Security Administration?

For additional information, visit the U.S. Social Security Administration at **www.socialsecurity.gov**. For individuals receiving Supplemental Security Income (SSI) or Social Security benefits, it can be helpful to set up a personal online ***My Social Security*** account. The ***My Social Security*** account can be used to view and print the benefit verification letter; check the benefit and payment information and earnings record; change your address and phone number; and start or change direct deposit of the benefit payment.

For detailed information about Supplemental Security Income (SSI), visit www.socialsecurity.gov/ssi.

What if an individual with intellectual and developmental disabilities is not eligible for Supplemental Security Income (SSI) due to income or asset issues that are not explained above?

The monthly income and resource limits vary between SSI and NJ Medicaid. If an individual with intellectual and developmental disabilities (I/DD) has a monthly income and/or financial resources above the SSI limits, he/she can apply for NJ Medicaid – either "New Jersey Care" or "Workability" – by visiting the Board of Social Services in the county in which he or she lives. Contact information for New Jersey's County Boards of Social Services (welfare agencies) can be found at **www.nj.gov/humanservices/dfd/programs/njsnap/cwa/.**

State of New Jersey
DHS
Department of
Human
Services

Disabled Adult Children (§1634 DAC)

Eligibility Group Requirements*: An individual who was receiving Supplemental Security Income (SSI) benefits and who meets the following:

- Is at least 18 years of age;
- Has blindness or a disability which began before the age of 22;
- Has been receiving Supplemental Security Income (SSI) based on blindness or disability; and
- Has lost Supplemental Security Income (SSI) due to the receipt of Social Security benefits on a parent's record due to the retirement, death or disability of a parent.

*If the person meets **all** of the above criteria, they may qualify as a Disabled Adult Child under Section 1634 of the Social Security Act (regarding DAC). This designation comes from the Social Security Administration. Eligibility for Medicaid may continue as long as the person is determined blind or disabled. However, if the person receives income from another source or exceeds the resource limits, they may become ineligible for Medicaid coverage

What should an individual do if they lose their SSI benefits and Medicaid coverage because they are now receiving Social Security Disabled Adult Child (DAC) benefits, resulting in their income exceeding the SSI income limit?

You should have received a letter from the Social Security Administration (SSA) verifying that you may continue to be eligible for Medicaid coverage under this eligibility group (§1634 DAC). If you have not received this letter, or no longer have this letter, contact your Social Security Representative by calling 1-800-772-1213 (available Monday – Friday from 7am - 7pm) to request a Benefit Award letter verifying Social Security benefits as a Disabled Adult Child or Disabled Dependent Child who received SSI in the past.

To obtain Medicaid Eligibility for individuals applying who are expected to be enrolled on the Community Care Waiver (CCW):

You will need to complete the Medicaid Only-Community Care Waiver application that is sent to you and provide the necessary documents, including the letter from the SSA verifying that you may be eligible for DAC status for consideration of Medicaid eligibility under Section 1634 of the Social Security Act (regarding DAC).

To obtain Medicaid Eligibility for individuals who are expected to eventually be enrolled on the Supports Program:

You must contact your County Welfare Agency for an appointment to apply for Medicaid. You will need to complete the appropriate Medicaid application, and provide the necessary documents; including the letter from the SSA verifying that you may be eligible for DAC status for consideration of Medicaid eligibility under Section 1634 of the Social Security Act (regarding DAC), to the County Welfare Agency.

If you have any questions or any difficulty obtaining Medicaid for an individual who may have §1634 DAC status, please do not hesitate to contact your DDD Regional Office and ask to speak with your Case Manager. You may also email any questions to: **DDD.MediElighelpdesk@dhs.state.nj.us**

Produced by DHS Office of Publications 3/2014

The Arc of New Jersey

FACT SHEET

Persons with Intellectual and Developmental Disabilities (I/DD) Who Have Medicaid and Private Health Insurance

1. Can a person with a disability have both private health insurance and Medicaid?
Yes, a person with a disability can have both private health insurance and Medicaid. Individuals with I/DD who are age 18 and older frequently have both Medicaid and private health insurance through their parent's group health insurance coverage.

2. Why is it important for a person with I/DD who already has private health insurance, to have Medicaid also?
In order to access NJ Division of Developmental Disabilities (DDD) services at age 21, individuals with I/DD are required to have Medicaid.[1] The best way for a person with I/DD to receive Medicaid is by applying for Supplemental Security Income (SSI). When the individual is determined to be eligible for SSI, he/she will automatically receive Medicaid also. (See also the Fact Sheet on SSI.)

3. Is there any negative impact on a person's private health insurance if he/she has Medicaid also?
There is no negative impact on the person's private health insurance by having Medicaid also. The private health insurance is the "first payer", and Medicaid is the "payer of last resort."

4. If individuals have both private health insurance and Medicaid, will they lose access to the doctors they have seen through the parent's private insurance coverage?
When individuals with disabilities receive Medicaid in addition to their private health insurance, they will not lose access to any of the doctors they have seen through their private health insurance coverage.

5. In the future, DDD services will change to a Medicaid fee-for-service system. Will this change have any impact on individuals with I/DD who have their parent's private health insurance and also have Medicaid?
DDD's new fee-for-service system will not have any impact on a consumer's access to the parent's private health insurance coverage.

6. When a person has both private health insurance and Medicaid, will he/she have any additional benefits through the Medicaid coverage?
When medically necessary, Medicaid covers some health services that are usually not covered by private health insurance, e.g., incontinence supplies and personal care assistance services for people with significant disabilities who need help with the activities of daily living (ADLs), such as bathing, dressing, feeding, etc.

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[1] Occasionally, the parent of an individual with I/DD has retired, become disabled, or died before the son/daughter's 18th birthday. In these situations, it is likely that the son/daughter with I/DD has been receiving a substantial Social Security Disability (SSD) benefit on the parent's work history *before* they could have applied for SSI. DDD recognizes that individuals in this situation are probably not able to obtain SSI or Medicaid. There is a process to document this type of situation. Please contact info@arcnj.org for further information.

7. When a person starts to receive NJ Medicaid, what are the basic aspects of the Medicaid system that one should understand?
In New Jersey, the Medicaid system is known as NJ FamilyCare. Everyone who has Medicaid/NJ FamilyCare is required to be enrolled in a Medicaid managed care organization (MCO). Currently, there are 5 Medicaid MCOs in New Jersey:

- Aetna Better Health of New Jersey
- Amerigroup, New Jersey
- Horizon NJ Health
- United Healthcare Community Plan
- WellCare Health Plans of New Jersey

Within a couple of weeks of being eligible for Medicaid, an individual will need to select a Medicaid MCO, and if a selection is not made quickly, the person will be auto-assigned. However, if they want to switch to another MCO, they may do so without any penalty by calling 1-800-701-0710. For further information, please see the NJ Medicaid website:
http://www.state.nj.us/humanservices/dmahs/clients/medicaid/

8. Can a person with I/DD continue to have the parent's group health insurance after the age of 26?
All young adults can continue to be covered on their parents' private group health insurance until the age of 26. *However, under New Jersey law, when young adults have a disability, they can remain on their parent's fully insured group health plan after age 26 – and they can continue to have this private health insurance in addition to having Medicaid coverage.* To qualify for continuation of the parent's private group health insurance, the young adult child must be incapable of self-sustaining employment by reason of the disability and must remain chiefly dependent on the parent(s) for support and maintenance. Proof of incapacity must be furnished to the health insurance plan before the date on which the dependent coverage would normally end. The plan may require the parent to continue furnishing proof of disability and dependency in the future.

If possible, it is suggested that the parent contact the health insurance administrator at their place of employment a few months prior to their child's 26th birthday to obtain the proper forms and submit the necessary documentation in a timely manner. Occasionally, additional documentation of the disability may be required.

Although New Jersey law addresses continued coverage of a disabled dependent who was covered under the policy prior to the attainment of the limiting age, the law does not require that such coverage be maintained if the parent's coverage changes. For example, if the parent changes jobs after the child has attained age 26, the law does not require the new plan to make coverage available to the disabled adult child. Even though the coverage is not required it is possible the new plan will allow it.
By all means – ask!

9. Is there any reason to consider alternate insurance options?
If the group health plan under which a disabled child is being continued is subject to the rating requirements of the Affordable Care Act, the rate for an adult dependent child will be an adult rate (and not a child rate) as has been the case in prior years. Thus, the cost to continue an adult dependent child under a group plan may not be the best value. Parents should explore individual coverage options both in terms of monthly cost and the benefits provided. Information on individual coverage can be found on www.dobi.nj.gov/ihc/

Question:

What is elopement and do you have any suggestions for what to do about the fact that my child with autism elopes?

Answer: The warmer weather lends itself to fresh breezes through open windows and screen doors, kids running in and out in search of drinks and a dry towel from being in the pool. For families raising a child with autism with elopement issues, summer time can be an added worry as doors and windows may be less secure. Elopement, which can be defined as running away from or leaving a designated area such as a classroom or the home environment, is one of the highest priority of challenging behaviors for individuals with autism spectrum disorders.

Elopement can be a frightening experience for family members as well as the individual with an autism spectrum disorder. In dealing with elopement, prevention is the first step. This can take the form of putting dead bolts up high on all doors leading to the outside, and installing window guards to prevent escape or dangerous falls. Sometimes an individual may wander into a neighbor's yard or enter a neighbor's house, even in the middle of the night. Alerting them as well as local police that your family member with autism elopes can help everyone react more quickly in case the unfortunate does happen. For school-aged children, parents can work with the child study team to develop a comprehensive written plan to address issues of elopement. This written plan should include a Functional Behavior Assessment and Behavior Intervention Plan. The Functional Behavior Assessment can help to answer why the elopement occurs and the Behavior Intervention Plan can teach replacement skills instead of eloping.

There are a number of products available to families who are raising a child who elopes. These range from alarms that indicate when a door is opened, to identification bracelets to tracking devices.

One program, Project Lifesaver, is a rapid response and recovery program offered in all twenty-one counties of the state of New Jersey for individuals with autism, Alzheimer's and/or other disabilities. Project Lifesaver is a partnership with local law enforcement and is the self-proclaimed world's most reliable program for locating missing persons. "Project Lifesaver relies on proven radio technology and a specially trained search and rescue team. Clients who are enrolled in the program wear a personalized wristband that emits a tracking signal. When caregivers notify the local Sheriff's office that a person is missing, a search and rescue team responds to the wanderer's area and starts searching with the mobile locator tracking system." (The entire state of New Jersey is covered by Project Lifesaver so families vacationing in the Garden State can feel a sense of security. Even if a family is vacationing out of state, the Sheriff's office in that state may also be able to retrieve Project Lifesaver information.

There may be a cost associated with enrolling in the program and it may vary by county. For more information about addressing elopement as part of an Individualized Educational Program, please call us at 800.4.AUTISM. ■

Sheriff Office Contacts

Atlantic County	Sergeant Mark Lacy	609.625.2276
Bergen County	Sergeant John Calabrase	201.646.2200
Burlington County	Jackie Moore	609.265.5127
Camden County	Investigator Tom Brett	856.225.5470
Cape May County	Officer Paul Shelton	609.463.6430
Cumberland County	Sergeant Margurlio	856.451.4449
Essex County	Detective Lynch	973.621.4105
Gloucester County	Detective Hamilton	856.384.4600
Hudson County	Captain Willis	201.915.1300
Hunterdon County	George Muller	908.788.1166
Mercer County	Robert Hartpence	609.989.6100
Middlesex County	Sandra Mackiewicz	732.745.3381
Monmouth County	Barbara Rutan	732.431.7450
Morris County	Sergeant Laurel Burns	973.285.6600
Ocean County	Sergeant Weinberger	732.341.3451
Passaic County	Detective Jose Sayan	973.881.4200
Salem County	Sergeant Pennington	856.935.7510
Somerset County	David Syring	908.231.7140
Sussex County	Officer Krista Galante	973.579.0850
Union County	Kevin Buckley	908.527.4450
Warren County	Frank Stettner	908.475.6309

Puberty and Adolescence Resource

A Guide for Parents of Adolescents with Autism Spectrum Disorder

These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported in part by cooperative agreement UA3 MC 11054, Autism Intervention Research Network on Physical Health (AIR-P Network) from the Maternal and Child Health Bureau (Combating Autism Act of 2006, as amended by the Combating Autism Reauthorization Act of 2011), Health Resources and Services Administration, Department of Health and Human Service to the Massachusetts General Hospital.

AUTHORS' NOTE

This tool kit was developed in response to requests from parents for resources related to puberty for their child with ASD. Although there are excellent resources on puberty, we found gaps in the available resources related to autism. Our goal was to provide information that was limited or not available elsewhere. This Puberty and Adolescence Resource, also known as the [P.A.R.] Tool Kit, represents a joint effort of Parents and Professionals from the U.S. and Canada, to create what we hope is an intelligent, yet easy to read and share document for those who support an adolescent with an Autism Spectrum Disorder.

Some of the challenge in creating this tool kit involved the personal nature of puberty and sexuality. This is obviously a topic that requires sensitivity, and each family should address it within their own values and morals. We wanted to develop a tool kit that could provide general information, which is not easily found, but which is also specific enough to be as useful as possible for families.

We have tried to be respectful in the presentation of information. Still, we realize that some of the images and content in this tool kit could be overly personal for some parents. Of course, we encourage everyone to go through the material first, deciding what is most useful in his or her parenting style or in sharing with their child. You are also encouraged to seek guidance from your family's team of multidisciplinary specialists, social workers, family navigator, spiritual leader, etc. It was our goal to strike the best balance possible, knowing that some parents will prefer less information, and that others will want more!

We want to especially thank the parents and students who provided feedback on the development of this tool kit. Without their input, it simply could not have been completed.

For further info and resources visit: **www.autismspeaks.org/atn** or
www.autismspeaks.org/family-services/tool-kits

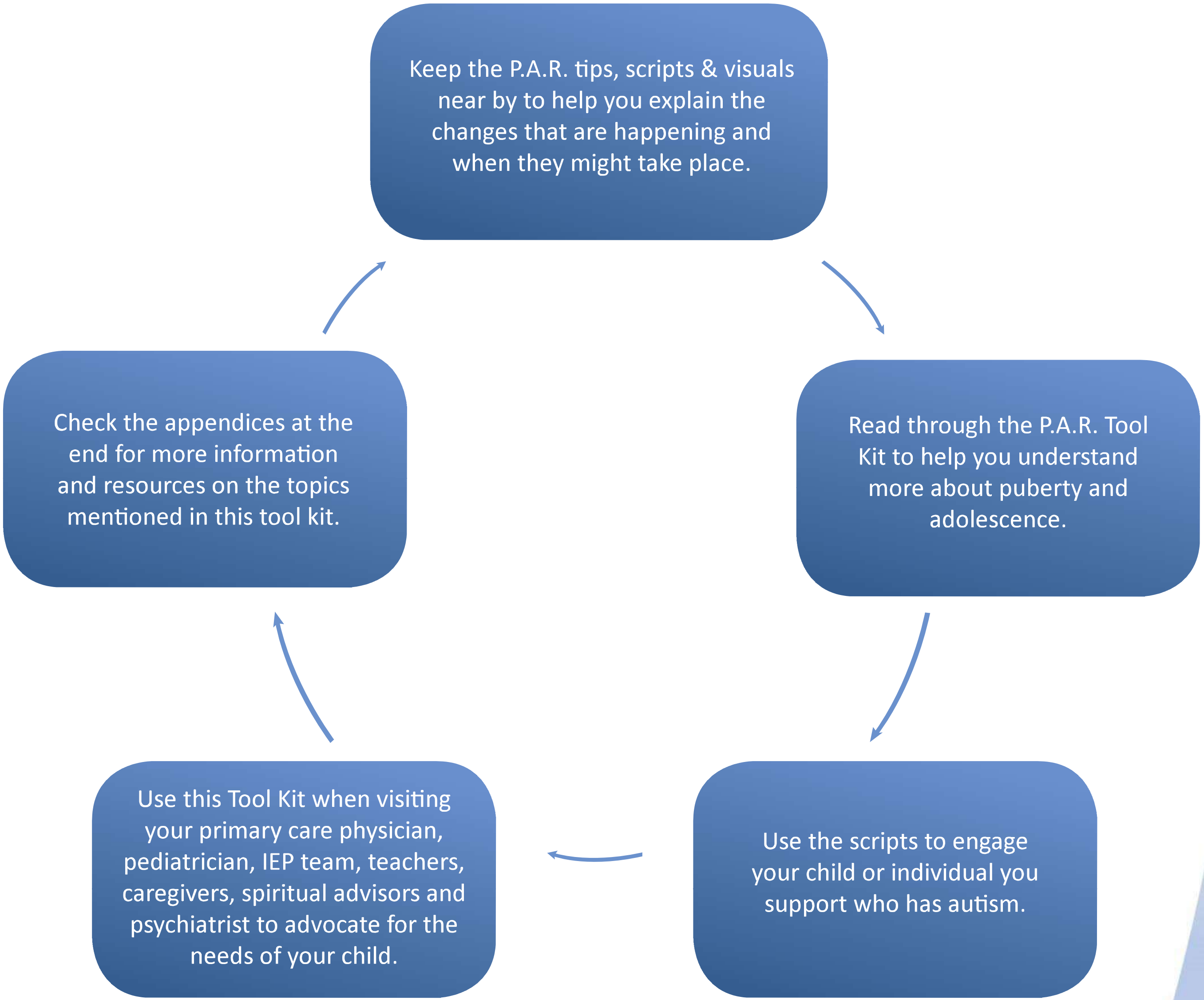
Sincerely,

The ATN/AIR-P Puberty and Adolescence Resource Workgroup

(Pictured left-right top) Parent Partner Authors- Kameena Ballard-Dawkins, Amy Kelly, Charlene Prochnau, Alicia Curran, BS and Rich Hahn (bottom) Professional Authors Dr. Kristin Sohl, Lisa Voltolina M.S., CCRP, Dr. Shawn Reynolds, Dr. Lisa Nowinski, Martha Y. Porras and Yolan Parrott Msc OT, OT(C).

How To Use This Tool Kit

A “**Tool Kit**” is a set of print or electronic materials that are designed to support families and providers of children affected by autism in the management of their care. Tool kits may also be targeted directly to the children to educate them or support them in the management of their own care. Tool kits provide information on a focused topic with a specific goal such as supporting a family through the puberty and adolescent stage for their child with ASD. Below are suggestions on how this tool kit might be best used. Please visit our ATN/AIR-P Tool Kits page to learn more about all of the tool kits we have available for parents and professionals to date.



Keep the P.A.R. tips, scripts & visuals near by to help you explain the changes that are happening and when they might take place.

Read through the P.A.R. Tool Kit to help you understand more about puberty and adolescence.

Use the scripts to engage your child or individual you support who has autism.

Use this Tool Kit when visiting your primary care physician, pediatrician, IEP team, teachers, caregivers, spiritual advisors and psychiatrist to advocate for the needs of your child.

Check the appendices at the end for more information and resources on the topics mentioned in this tool kit.

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INTRODUCTION

Puberty can be a time of mixed feelings for parents and pre-teens. It may be a time of pride and celebration as well as a time of worry and confusion. It is hard for pre-teens to understand the many changes that come along with puberty. Also, parents may feel unsure of how to explain these changes to their child.

Parents of pre-teens with ASD may find this time of transition especially difficult. The physical and emotional changes of puberty may seem out of sync with their child's social and academic development. Parents need the skills and confidence to talk about puberty and sexuality in order to confidently teach important life skills, including appropriate public and private behaviors, natural body changes and healthy social and romantic relationships.

A key to keep in mind is that while individuals with ASD often progress in ways that are different from other children, their bodies generally develop at a similar speed as their peers. Boys and girls experience changes in their bodies whether or not they have ASD. Children with ASD may have unique responses to what is happening to their bodies and may need additional guidance when navigating this time of transition.

All parents eventually face the challenge of teaching their children about the natural changes of puberty. However, parents of pre-teens with ASD may need the help of additional strategies to ease the transition. Our aim in developing this tool is to provide guidance on the subject of puberty that can be directly applied to pre-teens with ASD. In doing so, we hope to increase families' understanding of puberty and their ability to adapt to these changes with confidence.

This tool kit was a collaborative effort of parents of teens and pre-teens with ASD, physicians specializing in ASD, special educators and allied health professionals. It was designed to provide general information across a wide range of parents in hopes to provide a comprehensive perspective on puberty and adolescence. We recognize that many parents will deal with more significant challenges that we do not address in this tool kit, including but not limited to matters of sexual orientation and family planning. Therefore, this tool kit should not be seen as a substitute for personalized support when challenges are more specific and/or significant. It also does not take the place of any consultation with a physician, school or mental health provider, which is strongly recommended when needs are great.

Did You Know?

Several parents volunteered to collaborate on the development and writing of this tool kit. You will hear from them as a Parent Partner throughout this tool kit providing us with their personal tips and stories.

PUBERTY VS. ADOLESCENCE

Puberty and adolescence can be tricky concepts. Believe it or not, they do not mean the same thing and don't necessarily happen at the same time in development! Before we dive into more specific content, let's define these terms.

Puberty

- refers to the physical changes in the body that make a person able to sexually reproduce.

Adolescence

- is the period of emotional and social transition between childhood and adulthood.

This difference is important to keep in mind, especially when parenting pre-teens (sometimes referred to as tweens) with ASD. People with ASD often experience delayed development of social and emotional skills. They may not achieve the transition of adolescence until their late teens or early twenties. However, they will most likely undergo the physical changes of puberty within the typical time frame, which can be as early as 10 or 11 years of age.

What does all this mean? Simply put, many teens with ASD may experience the sensations of a physically mature body without the social, emotional or psychological maturity to understand these sensations.

Parent Partner's Tips:
Body Changes

- **Start early with teaching privacy**. With siblings and therapists often around, privacy is difficult to find, but is absolutely appropriate at a certain point in life. Help your child learn when that is and how to safely obtain it.
- **Model appropriate hygiene behavior.** Let your child watch you when you shave, put on deodorant or any other activities that maintain good hygiene if you feel it's suitable.
- **Use the correct language for body parts and body functions.** Our children are all going to grow up to be adults one day and need to be taught proper terms for mature subject.
- **Start practicing early.** The sooner you and your child can develop a routine, the sooner he or she will get used to it. Teaching skills early makes it easier to incorporate them into everyday life.

Parent Partner's Personal Story:

I never imagined back in 2002 when my sweet little 6 pound 11 ounce baby Annie was born that 12 years later, I would be intensely teaching her, step by step, how to shower independently, apply deodorant and practice changing menstrual pads. That's right. This is all in anticipation of The Big P. PUBERTY.

Once again, I find myself in the never-ending abyss of autism, not knowing what to expect in Annie's next stage of life. Although somewhat intimidating, it is also very exciting to see her blossoming into a beautiful young lady, and I feel privileged to go through this journey with her. Annie, like many of our children with ASD, has defied expectations - she learned to start talking when she was ten, she can now read and write, she loves to cook and she is always talking about "Mama and Annie". It's wonderful.

I hope this resource will help to remind you of the silver linings your child gives to you and your families. (It helps to remember these when we want to pull our hair out during the inevitable frustrating times!) On the next page are some of the things I've done so far to prepare Annie for becoming a young woman:

-Amy K., Parent Partner, Philadelphia, PA

For girls who are beginning menses (menstruation or periods), it is helpful if the caregiver can see a doctor who specializes in adolescent care and birth control BEFORE the actual event occurs. I had seen a specialist at my Children's Hospital in our Adolescent Specialty Care division three months before my daughter began her period, and THANK GOODNESS! Once it started, I was able to call the doctor directly that day and move ahead with the plan we had already discussed would work best for my daughter (in our case it is birth control pills that regulate her period to come fewer times a year). This gave me immediate peace of mind that she is protected, and that we at least have a manageable schedule to deal with an unpredictable journey through puberty.

My daughter began her period when she was 12 ½ years old and is minimally verbal. It's hard for her to tell me when she is uncomfortable… but I was reminded to watch for other signs. She indicated to me she was in pain by rubbing her tummy and I knew that was her way of telling me she had cramps so I kept her on a mild pain reliever (Ibuprofen). I also, to my dismay, found that she had completely removed AND shredded her soiled pad the next morning when she woke up before she came to get me. That told me it felt really uncomfortable and I needed to consider having her use the bathroom in the middle of the night, or at least get up before she did, so I could wake her and get her changed and comfortable. It's all learning!

Did you know that they make underwear specifically designed to help keep menstrual pads in place and more comfortable? This is KEY when you are looking at young women who have sensory issues to begin with and who may not fully understand what is happening in their bodies during menstruation, or how to have appropriate hygiene. Here's a link to one type, but if you Google search, there are other types.

http://www.amazon.com/Anigan-StainFree-High-Rise-Menstrual-Underwear/dp/B008V1XNSG/ref=pd_sim_sbs_hpc_1?ie=UTF8&refRID=0TGW-C2RZPB212H6YW2VJ

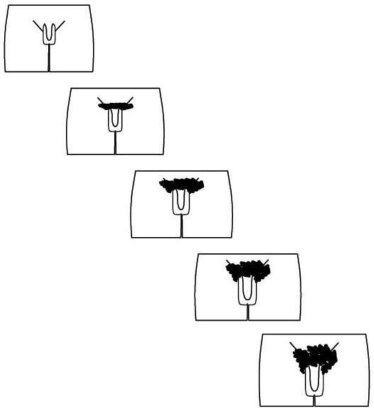
BODY CHANGES

It is important to give your child time to process the idea of his or her body changing before puberty actually starts. Boys will typically show signs of puberty around the age of 11 or 12. Girls usually experience changes in their bodies earlier, around the age of nine or 10.

It is natural for some parents to feel somewhat uncomfortable speaking to a young child about his or her body. To reduce discomfort, consider talking with your spouse, older children or trusted family or friends about your family's values, practices, and how to develop them in your child. Establishing family values (i.e. no pregnancies before marriage, etc.) can guide your interactions with your child and prepare you ahead of time for any questions that may come up.

Perhaps what may be just as important as establishing family values and practices is to gain a basic understanding of the body changes associated with puberty. One of the foundations for introducing the topic of puberty is to explain the changes that will happen to your child about his or her body parts. Make sure you can speak clearly, in a way your child can understand, so he or she will know what to expect as they grow.

Tanner Stages of Life



This chart can be used as a timeline, to show your child how hair will grow on male genitals.

http://kc.vanderbilt.edu/healthybodies/

Body Changes-Conversation Script

Get started by checking the picture resources we've provided. Then, add additional resources you discover through family, friends, and your community- that would be appropriate for your child based on their age, learning needs and abilities.

Starting a conversation about body changes is tough. Don't know where to begin? Here's a script to help you get started! (You can modify this depending on your child's maturity and verbal skills, of course.)

We're going to talk about some things that happen to everyone, even me. People's bodies change as they grow up, and I want to tell you about it so you know what's happening when your body starts changing too. It happens differently for everyone, and that's okay. The important thing is that we talk to each other, and that you know you can ask me questions whenever you want.

For the less verbal child with ASD, adjust language and information to the level of the child and add visual supports. Start saying something like…"the rule is that your body will change and I want to show you how. Everyone's body changes as we become a grown up. Your body is going to change like this (using pictures). You will start to look more like a grown up body like me (or another person)."

SELF-CARE AND HYGIENE

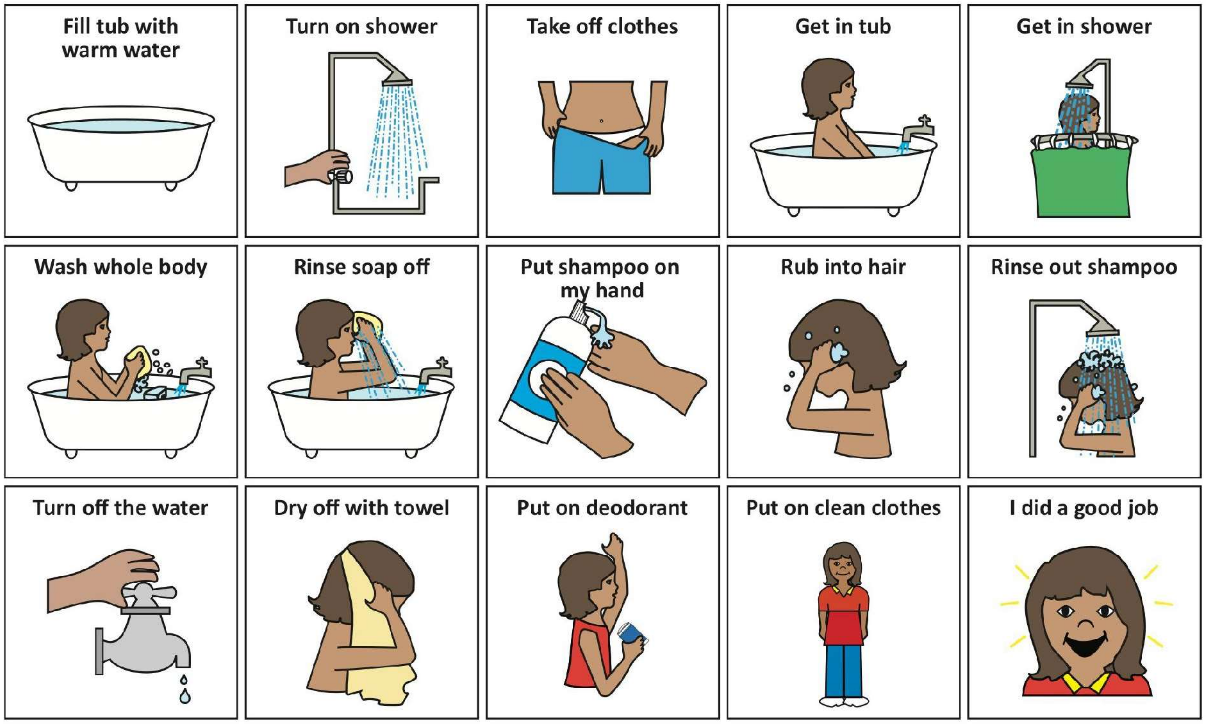
As puberty begins, there are many new challenges for kids to understand. Many children with ASD struggle with the changes in self-care and hygiene routines that is necessary for managing puberty. Here are some of the changes to expect and some ideas to help your child deal with them.

General hygiene

With puberty come sweat, oily skin, and pimples. Children will need to start bathing or showering daily to keep their bodies clean. Often, children with ASD are not aware of the social impacts poor hygiene may create. If it is appropriate, talk to your child (or set up a routine) about why he or she needs to bathe more frequently. Social Narratives can be a helpful way to teach children about why hygiene is important. If getting your child to become motivated to bathe is a struggle, you may need to introduce daily bathing as a “new house rule”, provide visual checklists and reminders to bathe, wash thoroughly, use soap and shampoo, etc. At this age, it may be increasingly hard for you to monitor how well your child is washing his or her body - another reason to teach independent bathing early.

This showering narrative can be used as a visual aide or as individual reminder cards to encourage good hygiene.

Appendix **Encouraging Good Hygiene – Showering Schedule Visuals**



Shaving

This can be extremely tricky, especially if your child struggles with tactile sensations. You will need to teach your child how to shave safely, as pain or even a cut may lead to future avoidance. This may be an area where children require assistance until you feel confident that they can shave safely on their own. Try different razors and shaving creams to find one your child prefers and accepts. Often, an electric razor is a better option for teenagers just starting out. Keep in mind that some people with ASD may be sensitive to the sounds of electric razors. If your child is very averse to shaving, you may need to work on increasing his or her comfort level first. To do this, start gradually with single steps (i.e. put on shaving cream and rinse off), short periods of time (i.e. turn razor on for 5 seconds and then off), or small areas (i.e. put on shaving cream and shave a small area). At first, your child may only tolerate these small exposures. Gradually work your way up and be patient. If shaving is not an option, these same incremental steps could be used with depilatory creams, which may have less of a sensory impact and require less fine motor skills.

Parent Partner's Personal Story:

"I am the proud mother of a 14-year-old son with autism. There have been several times during my journey of raising a child with autism that I find myself in unknown territory. I find myself at one of those places now: PUBERTY!

I have so many questions and concerns. How will I handle him during times of moodiness, or even aggression, now that he is bigger than I am? Will I ever get his acne under control? Is he scrubbing all the right places when showering and using enough deodorant? What level of independence and accountability is appropriate for him? How will I handle the time when he starts experimenting with masturbation? My list of questions could go on forever.

I do not have all the answers. However, I do know that across all the challenges we have faced during other transitions in his life, we have always figured it out. I have to keep focused on what is important: watching Samuel grow into a wonderful young man, who I am proud of, and being okay with not having all the answers today!"

-Alicia C., Parent Partner, Columbia, Missouri

Wearing deodorant

Adding a new step to the morning routine can be tough - your child may already have a well-established routine by this age. This can be a very crucial step when managing body changes. Try a variety of deodorants and antiperspirants (e.g., sticks, gels, sprays, etc.). Let your child pick which one he or she prefers - this may be helpful in motivating him or her to use it. Many teens do better when given a choice. Again, you may need a visual reminder for your child to put on the deodorant. You may also need to introduce it as a "new house rule" or provide rewards until your child integrates this step into his or her regular routine.

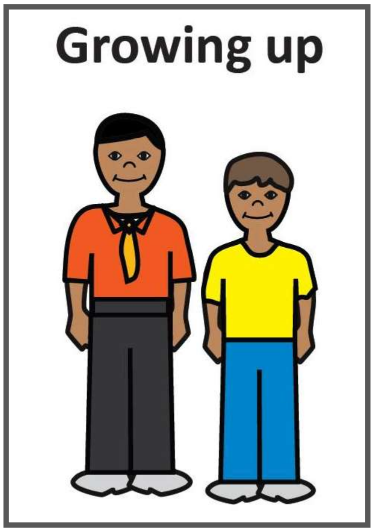


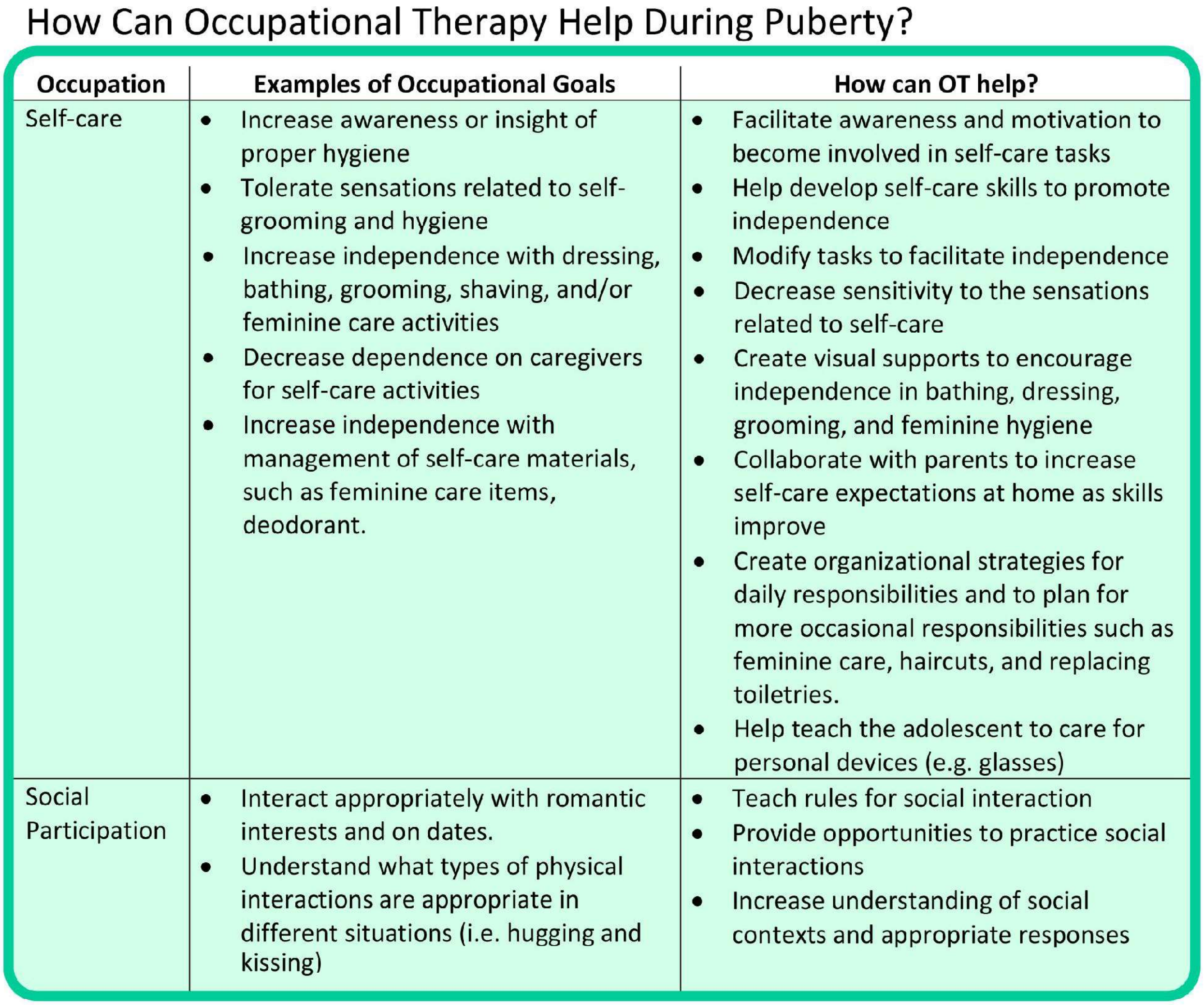
Image courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys:
www.vanderbilt.com/healthybody_boy

Wearing a bra

Most girls will accept this change quite well. However, adding a new item to the dressing routine can sometimes be tricky. Try a few styles of bra with your daughter to find one that fits well and that she finds comfortable. You may need to start with a less supportive bra, or training bra, until she is tolerant of a more supportive bra. Explain that this is a part of becoming a woman and experiencing body changes. You may need to re-introduce a visual schedule or check list with steps for dressing to remind her to put on the bra while getting dressed.

Self-care and Occupational Therapy

Many children with ASD need support to be successful in coping and adapting to body changes. An occupational therapist is an excellent resource to address many of these changes. Occupational therapy (OT) focuses on self-care, productivity and leisure. For children transitioning into young adulthood, occupational therapy could include: establishing independence in hygiene, dressing, sleeping, sexual health, completing chores, volunteer or paid work and socializing with friends, peers, co-workers or family. Occupational therapists work collaboratively with children and their families to set goals and strategies tailored to meet your family's specific preferences. Below is a chart preview from the 'Autism Speaks Occupational Therapy Tool Kit' that can be used as a visual guide to see if OT could be a resource for your family.



How Can Occupational Therapy Help During Puberty?

Occupation	Examples of Occupational Goals	How can OT help?
Self-care	• Increase awareness or insight of proper hygiene • Tolerate sensations related to self-grooming and hygiene • Increase independence with dressing, bathing, grooming, shaving, and/or feminine care activities • Decrease dependence on caregivers for self-care activities • Increase independence with management of self-care materials, such as feminine care items, deodorant.	• Facilitate awareness and motivation to become involved in self-care tasks • Help develop self-care skills to promote independence • Modify tasks to facilitate independence • Decrease sensitivity to the sensations related to self-care • Create visual supports to encourage independence in bathing, dressing, grooming, and feminine hygiene • Collaborate with parents to increase self-care expectations at home as skills improve • Create organizational strategies for daily responsibilities and to plan for more occasional responsibilities such as feminine care, haircuts, and replacing toiletries. • Help teach the adolescent to care for personal devices (e.g. glasses)
Social Participation	• Interact appropriately with romantic interests and on dates. • Understand what types of physical interactions are appropriate in different situations (i.e. hugging and kissing)	• Teach rules for social interaction • Provide opportunities to practice social interactions • Increase understanding of social contexts and appropriate responses

Wheeland, A. & OT Practicioner Advisory Committee. (2014). Occupational Therapy Across the Lifespan: Autism Speaks® Family Services Tool Kit. Available at www.autismspeaks.org/family-services/tool-kits/occupational-therapy

MENSTRUATION (HAVING A PERIOD)

Your daughter with ASD will experience a lot of changes during puberty, just like other girls do. Getting her first period is likely to be one of her biggest milestones during this time. ASD does not affect when girls start their periods, so many girls with ASD will most likely have her first period between the age of 9 and 11 years old.

Since it is impossible to know exactly when your daughter will get her first period, it is important to take her personal preferences, personality and her level of understanding into consideration when deciding when to discuss this topic. Keep in mind that pre-teens with ASD often need extra time to adjust to changes and new information, and they sometimes can become fixated on events that are unpredictable and potentially frightening. Since the first period usually comes about 12 to 18 months after starting breast development, it is often a good time to start discussing it as she is getting used to wearing a bra.

It is crucial to prepare your daughter for her first period ahead of time. Make sure you pick the right moment to prepare her for this. Consider what point in time will minimize the stress and anxiety of anticipating her period, while also maximizing her ability to process this information. There is no right way to do this for every child, so use your best judgment!

Once you are ready to talk to your daughter, there are some key topics to address

What does "having your period" mean?

If girls don't know or understand what periods are, they may be frightened that they are sick or injured. Making sure your child understands that monthly bleeding is absolutely normal, natural and healthy is crucial to reducing anxiety. Consider whether a social narrative might be helpful for your daughter, both as an instructive tool and as a reminder of what to expect each month.

Stomach cramps and body aches are normal.

Try to prepare your daughter for the physical sensations associated with monthly periods. Abdominal cramping, feeling tired and experiencing breast, stomach or low back soreness are all normal sensations, even though they are not very comfortable! Teach your daughter appropriate strategies for relieving discomfort. For example, it may be fully appropriate for your daughter to use a hot water bottle to reduce cramps or body pain independently, but pain-relieving medications should only be used with permission and under parental supervision. Of course, if these symptoms appear to be severe or interfere with daily activities, you should speak to her medical provider for additional options.

Pre-menstrual syndrome (PMS) is normal, too.

Girls with ASD can experience the same range of PMS symptoms as typically developing girls. However, their symptoms may lead to challenging behavior if they have trouble regulating their emotions. Like most girls, your daughter may feel cranky, depressed, tired and find it difficult to concentrate. If she understands why she is feeling this way, your daughter may feel more in control of her changing body. A social story, specific to your child's symptoms, may help. As with physical symptoms, you should speak with your child's medical provider if symptoms of PMS are severe or interfering with daily life.

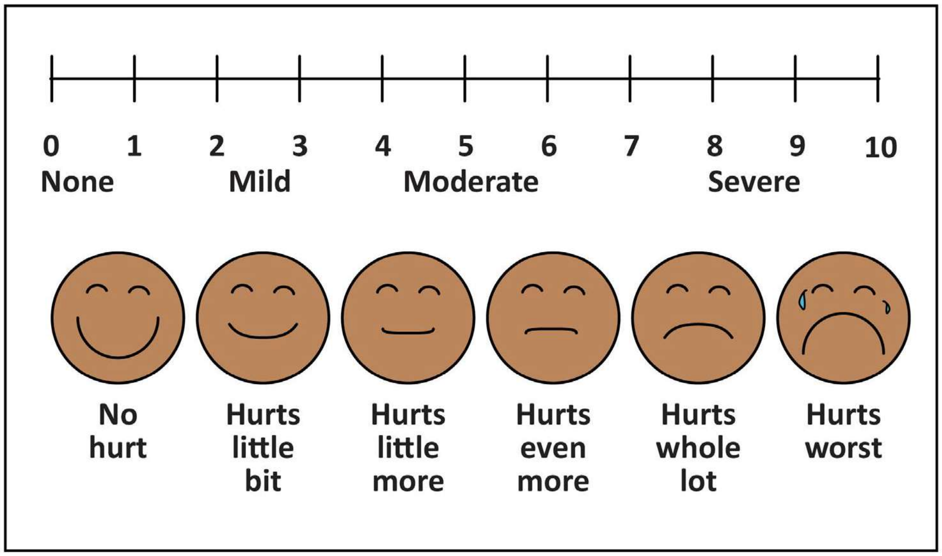
What are pads and tampons?

Once your child's periods have started, she will need to know what pads and tampons look like and how to use them. Consider going to the grocery store together to pick out different types to try. Girls of any age can use tampons, but they take practice and require regular changing to prevent any serious illness that could happen as a result of not changing your tampon frequently enough. It is often easier for girls who have newly started their period to use pads in the beginning, since they require less skill to replace and are, in and of themselves, a visual reminder to be changed. If your daughter uses visual supports, a visual schedule showing the steps involved in changing a pad, tampon or alternative sanitary product like a Diva Cup (a reusable menstrual cup that is a safe hygienic alternative) may be very useful.

Use this chart as a visual aide during menstruation, to help communicate during her puberty.

Teaching About Periods – Pain Scale

During her period, your daughter may feel tired and moody. Her stomach may swell or cramp. Using a pain scale like this can help her tell you how much she hurts or feels uncomfortable.



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http://kc.vanderbilt.edu/healthybodies/

It will be helpful to review this information with your child frequently, especially during the first several months after she starts her period. Reviewing the sensations, self-care and hygiene techniques each month will help turn these new skills into a habit. Experiencing a first period can be stressful and uncomfortable for your child. Natural hormonal changes may make it harder than usual for her to cope with unpleasant sensations or emotional states. Above all, remain calm and patient. This may be hard for you to talk about and for her to understand, so it may be stressful for both of you. Your continued support will ease the discomforts of this important life transition.

Parent Partner's Personal Tip: Menstruation

This is a worthwhile activity to do with your daughter after you've begun discussions about her first period.

> **Take your daughter with you to the grocery store the next time you need to purchase pads or tampons. Select other grocery items as usual and then head to the aisle for sanitary products. Show your daughter which products you are choosing and ask which one she thinks she would like. Let her choose an item and add it to your grocery cart to demonstrate that these products are a normal part of life, like milk and cereal. When you get home, let her help you take a closer look at the products you both chose in a casual, lighthearted way.**
>
> **-Amy K., Parent Partner, Philadelphia, PA**

PUBLIC OR PRIVATE?

Puberty and adolescence are times of body transformation and increased sex drive for individuals with and without ASD. Body exploration, sexual attraction and masturbation are all natural aspects of growing up and maturing. As we mentioned earlier, intellectual and social maturity do not necessarily go hand in hand with physical maturity: your child may experience real sexual impulses without fully understanding or knowing how to cope with the sensations. Conversations about sexuality are often uncomfortable for parents, but it is important to help guide your child toward appropriate behaviors and outlets.

One way to approach teaching appropriate social behaviors is to establish "Public and Private" rules. However, it is important to first make sure that the social concepts of "public" and "private" are well understood. In general terms:

Public

- means saying or doing something in front of strangers, siblings, relatives, friends, classmatesm, or teachers - even if they are familiar or well known.

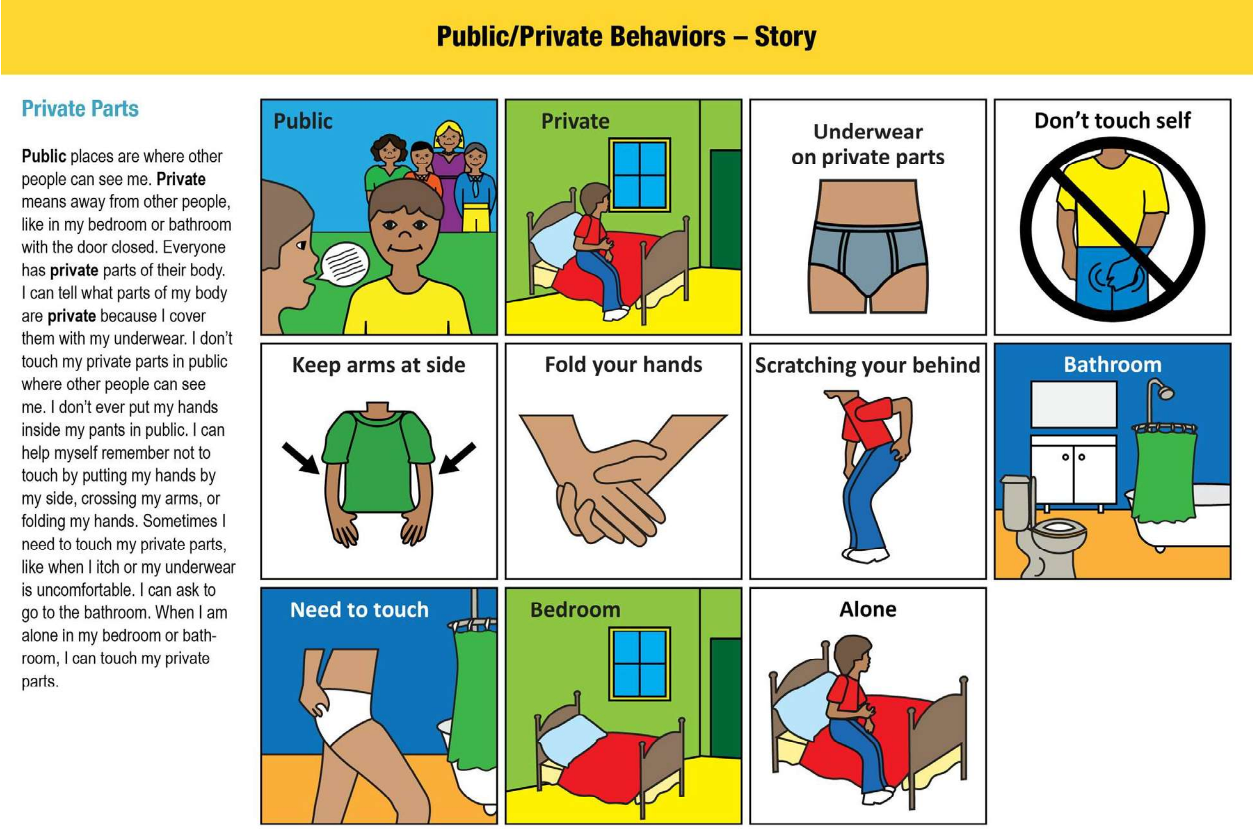
Private

- means saying or doing something by yourselff, with your parents or with a trusted doctor.

Consider creating a "Public or Private Places" list. Using this format, you can discuss behaviors that must be done in private (undressing, urinating, touching private parts).

For more info: **http://parents.teachingsexualhealth.ca/our-children/sexual-development**

Use these visual aides as individual cards to reinforce public and private behavior.



Public/Private Behaviors – Story

Private Parts

Public places are where other people can see me. **Private** means away from other people, like in my bedroom or bathroom with the door closed. Everyone has **private** parts of their body. I can tell what parts of my body are **private** because I cover them with my underwear. I don't touch my private parts in public where other people can see me. I don't ever put my hands inside my pants in public. I can help myself remember not to touch by putting my hands by my side, crossing my arms, or folding my hands. Sometimes I need to touch my private parts, like when I itch or my underwear is uncomfortable. I can ask to go to the bathroom. When I am alone in my bedroom or bathroom, I can touch my private parts.

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http://kc.vanderbilt.edu/healthybodies/

Addressing each topic specifically will help your child understand these broad concepts, which he or she may find difficult to generalize independently.

Depending on your child's needs and abilities, you may also create a similar list of "Public or Private People". Many children with ASD over-share personal information with people they trust. Over-sharing can lead to listener discomfort or to the spreading of rumors. In both cases, relationships can be damaged and people may feel hurt or uncomfortable.

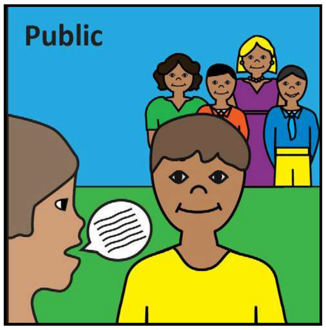
Consider creating a list of names of people with whom your child can share private information - and make sure the individuals on the "Private People List" are comfortable with being your child's confidante beforehand. Then, explain that the things we do in our "Private Places" must only be shared with our "Private People".

Perhaps foremost on parents' minds during this period of transition is the issue of masturbation. Of course, the guidance you provide your child should be aligned with your family's values. It is important, however, to teach your child about masturbation, even if you would prefer he or she not engage in the activity, as some children accidentally hurt themselves (e.g., rubbing too hard).

A Mother's Personal Story: Public or Private

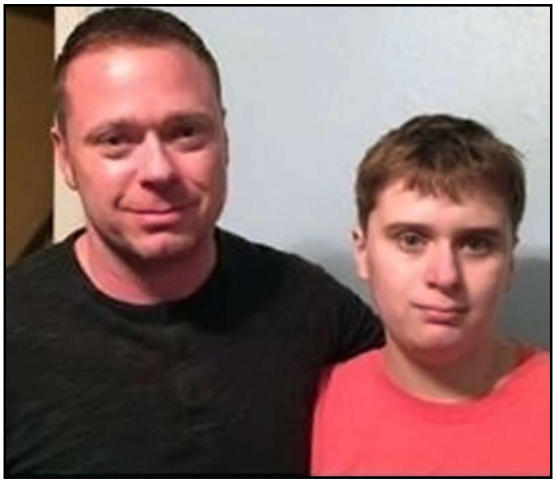
At 13, our son has started puberty and does not have the verbal skills nor the awareness of social boundaries. It became evident when we were in church and something was bothering him. When I asked, he said "the carrot nose" was bugging him and pointed to his pants. (Carrot nose was how he described his erection in terms he could relate to.) Although he didn't have any knowledge or direction in masturbation, he knows what feels good and has figured it out. We've been using redirection or distraction when necessary and simple instruction about how the activity he's engaging in is okay in private (his bedroom) but not in other areas of the house or community (church, school, shopping centers, etc.). So far, he has accepted this well and we haven't had a real problem - but, then again, we're just beginning!

-Charlene P., Parent Partner, Edmonton, AB Canada



Images courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys:
www.vanderbilt.com/healthybody_boys

A Father's Personal Story: Public or Private



As parents of children on the spectrum we face no shortage of challenges. Puberty, are you kidding?? Yep, it's here and it's our job to guide our children through this major life-changing event. My little Nic(holas) who used to fall asleep on my chest every night now is 12, almost looks me in the eyes and we wear the same shoe size. Although he has experienced a massive physical transformation, he's still very much a little boy. He has always been curious about his penis but we've not yet had to have a conversation about private time. When the time comes I will gladly educate him and would never shame my son for something that is perfectly normal.

-Rich H., Parent Partner, Des Moines, Iowa

STAYING SAFE: STRANGERS, SECRETS AND TOUCH

Parents always want their children to understand the rules of basic safety. This is especially hard for some pre-teens and teens with ASD because they may not know which adults are safe to trust. For years you have worked to build your child's ability to listen to others and comply with the requests and demands placed on him or her. However, as children get older, it is also important to help them identify what are safe and appropriate limits. Here are some key things to remember:

- **Be prepared to talk about and recognize sexual abuse in your child**. Remind him or her that his or her private parts are always private, so no one other than a person they trust, or a doctor or a nurse, is allowed to see, touch or talk about them. This goes both ways: remind your child that other people's private parts are not okay to see, touch, or talk about. It is also important to remind children and young adults that if someone touches their private parts in an unwanted way, they should tell a trusted adult immediately, even if that person is a relative, friend or caregiver.

- **Use visual supports to help your child learn concepts**. such as stranger awareness, good touch/ bad touch and public or private behaviors. Explain the difference between appropriate and inappropriate touching. For example, consider parts of the body that are sometimes okay to touch (arms) and parts of the body that are never okay to touch (hips).

> ***" My doctor suggested that I look for any tearing or swelling in my son's private areas while changing him, to check for signs of sexual abuse since he is non-verbal."***
>
> ***-Jezzrel T., Parent Partner, Los Angeles, CA***

- **Use role-playing to help your child practice new skills in real world environments.** Ask your child what he or she would do if someone were to touch him or her in a way that he or she didn't like. Start with appropriate types of touch (like a tap on the arm) and gradually build up to inappropriate touch (like touching private parts). Make sure your child understands that he or she should talk to you, another parent or trusted adult if he or she ever feels uncomfortable.

- **Collaborate with your child's school team** to make sure that they are incorporating safety skills into your child's program. The safety curricula should incorporate real life scenarios into the lessons to help your child transfer classroom learning into daily life. Turning the lesson into a game - like choosing scenarios from a stack of cards - will make a serious topic less stressful.

> ***"For individuals with ASD, 'Self-Determination' means more than choosing your own clothes or what to eat. It also means knowing that you have the right to say NO... I don't want you to touch me like that!"***
>
> ***-Kameena B.D., Parent Partner, Burbank, CA***

For more information on this sensitive subject please visit: http://www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse

Parent Partner's Personal Tip-Staying Safe: Strangers, Secrets and Touch

Tough conversations often feel easier when you've planned ahead. Here's a script to help get you started. Remember to speak clearly and adjust your language according to your child's verbal skills and level of understanding.

It is important that you know there are places on your body that no other person should touch in a sexual way until you are both mature adults. These body parts are called "private parts", and they include your [breasts, vagina, penis, etc.]. If anyone touches you on your private parts, you have to tell me - even if you don't want to, and even if the person who touches you is an adult or a friend from school that tells you not to tell. If someone makes you feel uncomfortable and gets into your personal space, tell them "NO"- to stop, and then tell me

For more information on this sensitive subject concerning behaviors to watch for – for those children with limited/non verbal please visit: http://www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse

If you suspect child abuse has happened, make the call...

The National Child Traumatic Stress Network offers the following advice:

"If a child discloses abuse, it is critical to stay calm, listen carefully, and NEVER blame the child. Thank the child for telling you and reassure him or her of your support. Please remember to call for help immediately. If you know or suspect that a child is being or has been sexually abused, please call the Childhelp® National Child Abuse Hotline at 1.800.4.A.CHILD (1.800.422.4453) If you need immediate assistance, call 911.

SAFETY PLANNING FOR RUNNERS AND WANDERERS: ELOPEMENT

Many children with ASD have challenges with elopement; that is, running away from the family or the safe place. When children move into puberty though, this behavior can increase, both in terms of frequency, as well as risk. Children run or wander for many different reasons. Some may leave the watchful eye of their parents in search of something interesting or fun like a train, elevator or a different environment like a swimming pool. Others run in response to stress, anxiety or excitement.

As kids get bigger, they run faster, which can make it tough for people caring for older kids and pre-teens with ASD who are at risk of running away at school or in public. Older children like teens and pre-teens can become harder to keep in the safe place (especially if they become taller than their parents!). Regardless of the circumstance or reasons, it's important to know what you can do to keep your child safe. This section is designed for all parents who are concerned about this

If your child is prone to **elopement** ***or wandering, there are many things you can do to support his or her safety.***

Security. First, consider securing your doors and windows from the inside or installing an alarm system that will ring when a door is opened. Many families find that they have to lock their doors and windows from the inside to ensure that their child is unable to leave without supervision. Make sure to have a key easily accessible to all adults in order to exit the house quickly, if needed.

Identification. Be sure that your child wears or carries some form of identification with him or her at all times. This is particularly important for individuals who are nonverbal, though even verbal teens can become overwhelmed in an unfamiliar situation and may not be able to give their name or phone number if they become separated from you. Shoe tags are a good option for children who cannot tolerate other wearable IDs, like bracelets. Temporary tattoos are appropriate for kids who only wander in unfamiliar settings. If your child is able to speak, help him or her practice telling people he or she has autism and needs help.

Technology. Technological devices can allow parents and caregivers to locate a child quickly in an emergency. Check out more resources at the end of this tool kit.

Preparation and Advocacy. Consider visiting your local Police and Fire Departments to introduce your child and alert them to your child's specific needs and behaviors. Encourage your public service agencies to learn about autism and how to help people with ASD in an emergency situation.

For more resources, visit: http://www.autismspeaks.org/wandering-resources

SAFETY PLANNING FOR INCREASED AGGRESSION

Kids experience lots of stress, as they become pre-teens and teenagers. This stress can sometimes be present itself as challenging behavior, and for some as aggression. Parents can be surprised at the changes their kids undergo. For example, younger kids are often motivated to spend time with their parents. But for some, this could stop being cool for them as they get a bit older. This may happen to families with children with and without autism!

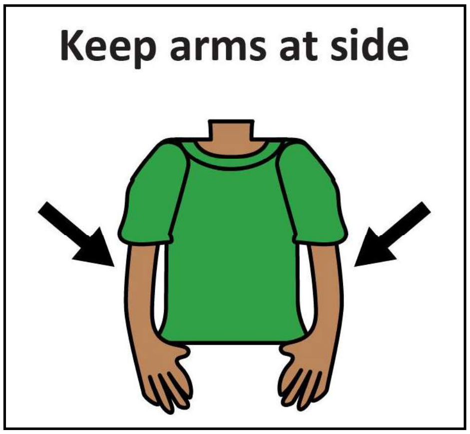


Image courtesy of Vanderbilt Healthy Bodies Tool Kit for Boys: www.vanderbilt.com/healthybody_boys

For pre-teens and adolescents with ASD who are developing, the challenges can be even greater. They may be experiencing new stress at school. They could also be experiencing hormonal changes to their body that happen as they are going through puberty. Many kids with autism have more social opportunities early in elementary school than they may have later on. This can create stress or sadness, too.

When we think about the ways that our kids with ASD express themselves, it's important to think about how this happens at different times. Most of us are better at expressing our feelings when we are calm and feeling well. When we get upset, we don't express ourselves as well, at all. (If you want proof of this, think about the last time you were in a big argument. Have you ever had the experience of thinking, "What I should have said was _________________!" It's hard to think of the right thing to say and the right way to say it when you are really upset.

When kids with ASD get upset, managing their own reactions and expressing themselves well can be a real struggle. Like all of us, they may react inappropriately and do things they regret afterwards.

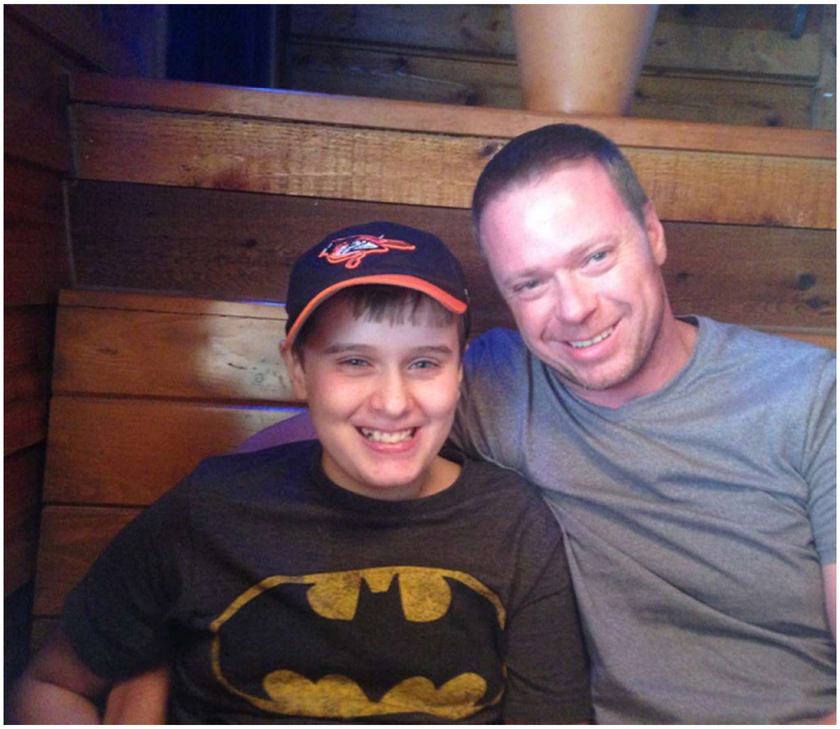
For some of our children, this can become dangerous. Kids who can't communicate verbally may act out physically toward objects or other people. They may even begin to self-harm or hurt themselves. This problem could become even bigger as the child gets bigger, of course.

Many parents are willing to be the "safe" person for their child. While it's good to avoid aggression in public, reinforcing the wrong behavior creates great stress for the parent and can put the child at personal risk too.

For more information about challenging behavior and how to establish more positive communication visit: www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit or call ***888-AUTISM2 (288-4762),*** or by email at: familyservices@autismspeaks.org

Parent Partner's Personal Story; Safety Planning for Increased Aggression

Nic's struggles with ASD and puberty have come with increases in aggression. He's bigger and stronger and his outbursts are more destructive, and to be honest dangerous. At the age of 12 he's already close to 150lbs and much larger than his older sister. School struggles at times with these changes- as do we at home. We are braving the rapids and looking forward to calmer waters as he adjusts to the hormone changes in his body.



-Rich H., Parent Partner, Des Moines, Iow

Growing up can be stressful for anyone, and our Nic is no exception. He is afraid that as he grows older he will no longer be able to "be a kid" and enjoy the fun that comes with it. We just remind him that getting older is not a bad thing and he will always be our little boy.

In puberty, kids often experience different emotions in a more intense way than they used to. This means they may need more or perhaps different strategies to manage these feelings. So, what can parents do to help their children? Here are some ideas that might help:

The earlier you start, the better things may turn out. Even young children naturally find activities to help them when they are upset. Parents need to be aware of their child's go-to activities and how he or she can access them during tough times.

It's much easier to prevent a meltdown than to handle it when it's happening. This means adjusting your schedule to make sure the stress your child experiences is reasonable. It's important to expose kids to some stress, so that they can learn how to manage it - but this needs to be at a reasonable level.

Keep working with your child to find strategies to help avoid the meltdown. For verbal children, you can talk about things they can do to soothe themselves when they start to get upset. This might be a favorite stuffed toy, listening to music or taking time by themselves. They can give you some ideas. For nonverbal kids, parents need to develop a list of things that are soothing and to have these available on short notice.

Share strategies with your child's school. For example, if your child has a hard time in the grocery store, think about a job he or she could do (like pushing the cart), an enjoyable activity (like a video game) or a reward to look forward to (like a fun activity when you get home). When you think of these in advance, you can plan better than when your child having a meltdown in front of you.

Don't be shy to use positive reinforcement to prevent aggression. Don't be shy to use positive reinforcement to prevent aggression.

Make sure you have support. If your child becomes physically aggressive, make sure you have the supports you need to minimize the risk to yourself and to him or her. Special training in nonviolent communication and safety strategies may be very helpful to you and your teen to help keep everyone safe during an aggressive episode.

Parent Partner's Personal Story: Safety Planning for Aggression

Life has always been difficult for us with all of the tantrums and running in the street. But, in my opinion, my daughter really turned into a different person around nine years old. Originally, I thought it was because my ex and I had just separated. After that happened, her behavior became more aggressive toward me.

She's high functioning and speaks very well, but she would completely stop talking and do things like spit, scratch and bite during times when she was frustrated, nervous or anxious. The second I asked any other parent for help, all I got was somber looks of pity, pats on the back and a fist to the chin - telling me to hang in there. That's pretty much when I knew to shut down life, as we knew it, because I was in for a hell of a ride!

I became determined to make life better for my family and me. I strongly requested to learn non-violent safety strategies from my Regional Center for her increased aggression, property destruction and elopement. I also worked with an outpatient program to get **Therapeutic Behavioral Services** *in the home. I spoke to our* ***Psychiatrist*** *about adding* ***medication*** *that could help and held an IEP meeting to request an assessment from an* ***Occupational Therapist, Family Counseling****, social skills activities and elopement observation.*

I was completely stressed out and not finding any relief when ***residential placement*** *was suggested to me. At the time, the thought of "sending my daughter away" was heart wrenching. I did everything I could to cancel out the option.*

After many more upsets, I voluntarily placed her in a residential family environment. I'm so glad I did! My daughter absolutely needed all of this time to be able to process things for herself. As all of this has been going on, I've made sure to see my daughter often and also give her lots of breaks in her scheduling and lots of encouragement to let her know that she is beautiful! I also let her know that she is always in a safe place to be herself with me and that she can talk to me and safely touch me whenever she needs to.

Although we're not completely through puberty yet, my daughter is now becoming such a pleasure and joy to be around once again. She makes more grown up jokes and even talks about her future, which gives me hope that she'll be okay. Above all, I believe that she is a budding advocate for herself and for others with ASD, now that she is starting to be able to express her feelings more... and she's only 11!

I feel like I made the right decision for my own situation and what was right for my child during this pivotal time. My sacrifice still hurts, but I will do whatever it takes to make sure my daughter has a great quality of life - including asking for help to provide it

-Kameena B.D., Parent Partner, Burbank, CA

SAFETY PLANNING FOR RUNNERS AND WANDERERS: ELOPEMENT

When problems with puberty or mental health become hard to manage, that's when a professional can help. Services can come from a lot of different places. Usually one or two of these can make a big difference.

The first step in finding the appropriate therapeutic services is to identify what is challenging for you and your child. Look to your trusted team of teachers, doctors and therapists to discuss any new challenges. Is your child anxious about the added responsibility of self-care in puberty? Are hormone changes contributing to increased irritability, aggression or moodiness? Are you and your partner finding it difficult to teach new skills? There are a number of helpful therapeutic services and supports that may be helpful.

The Autism Speaks- Autism Treatment Network Team at the Children's Hospital of Los Angeles-Boone Fetter Clinic, along with their Parent Partner- Kameena and her daughter Keena, who has ASD.

The chart below shows different types of services and counseling. Feel free to use it during a discussion with your child's doctor or another professional regarding your family's needs.

Therapeutic Services and Family Counseling

Medication Management – When symptoms such as anxiety, depression, irritability, mood swings, self-injury or aggression become too much to manage with behavioral intervention alone, a consultation with a doctor with expertise in medication management and autism can be invaluable. Closely monitored medication treatment can be helpful in reducing symptoms and achieving mood and behavioral stability. For some teens, these interventions can be time limited and may be discontinued as behaviors stabilize after puberty.

Family Therapy – Puberty can be a stressful and challenging time. Parents may benefit from meeting with a family therapist or couples counselor to manage the stress of parenting a teen with special needs. In addition, family therapy can be helpful in supporting the transition toward greater independence. As with all teens, many teens with ASD will begin to assert increasing independence throughout puberty and a family therapist can be helpful in identifying safe and appropriate ways to encourage your teen's independence while continuing to provide the extra support that may be needed.

Legal & Financial Planning – Puberty often marks the beginning of a teen's transition to adulthood. As such, it is an important time to consider the long-term legal and financial needs of your child. Will your teen need the support of a legal guardian? If so, who will that be? How should your teen's money be managed? What plans are needed for your teen's medical, educational and legal decision-making after he/she turns 18 years old?

Cognitive Behavioral Therapy (CBT) – CBT is a type of psychotherapy that can be helpful in teaching teens new coping skills to manage anxiety and stressful situations. Therapy can also be helpful in addressing issues of self-esteem and identity development, as many teens become increasingly aware of how they are different than their neurotypical peers. Be sure that your therapist has experience working with teens with autism spectrum disorders.

INTERNET SAFETY

Keep in mind that as children move into adolescence, they are becoming more and more computer savvy. Many of our children have already passed us by in their knowledge of the Internet! It is crucial that parents are very involved with their children when accessing information on the Internet. This can include inappropriate adult content, but can also include cyber bullying, which is hard, if not impossible, for an Internet filter to catch.

Safety Planning for Internet Users:

Individuals who use the Internet may be easy targets of cyber bullying, pornography, phishing or identity theft. Teach your child the signs of cyber bullying and other Internet threats, such as strangers who seem to know personal information about you, people who send aggressive or sexual messages, people who lie about you and any other people who make you feel uncomfortable.

There are filters that can be used to help limit access to dangerous and inappropriate material to pre-teens and adolescents, but perhaps the best filter is the parent's direct time with the child, to help him or her navigate web searches safely. Your child is much less likely to access something you don't want him or her to see if you are supervising him or her!

Search these key words online for more info and details:

- *Block Ads or Websites*
- *Web Filtering*
- *Internet Parental Controls*
- *Age Restricted Content*

There are also several social networking sites designed specifically for individuals with ASD. Two notable resources are **WeAreAutism.org** and **WrongPlanet.net**. These are user-led web communities designed for individuals with neurological differences. Chat rooms, blogs and discussion forums provide users with opportunities to share their thoughts and establish, sustain and grow relationships.

Internet Safety Parent Tips:

Make sure your child knows what to do if any of these problems occur while they are online. Before your child uses the Internet independently, establish the proper Internet etiquette or ***Netiquette*** *ground rules:*

- **Never give out personal or private information, like your real name, account numbers, passwords, and address or phone number to others you do not know.**
- **Do not continue interactions with people that make you feel bad by saying mean things or calling you names.**
- **Do not send money or private banking information to others that may be nice to you but are untrustworthy, especially if they do not match their photo(s) and refuse to see you in person (or on video chat) for a long time.**
- **Tell a family member or trusted adult if people are making you feel bad or asking you to do, say or show things you don't want to do.**

AS ATN/AIR-P NETWORK FOR FAMILY-PATIENT CENTERED CARE

The Autism Speaks Autism Treatment Network (ATN) is a ground-breaking collaboration of hospitals, physicians, researchers and families at 14 specialty center locations or “sites,” across the United States and Canada. We are working together to develop the most effective approach to medical care by providing families with state of the art, multidisciplinary healthcare for children and teens affected by autism. The ATN was established to provide a place for families to go for high quality, coordinated medical care for children and adolescents with autism and associated conditions.

Family Centered Care.

At Autism Speaks ATN centers, parents experience a welcoming environment focused on family well-being. In addition to maintaining the highest standard of medical care, ATN experts carry out innovative research to develop more effective treatment standards for the wider community.

Our Care Model: Whole Care for the Whole Family.

The ATN Care Model represents a comprehensive, coordinated, multidisciplinary care approach for children with ASD. It promotes a high standard of coordinated care for the whole child and family. An ATN center is– a place that provides the highest level of direct care and clinical expertise and also serves as a resource for local families, community physicians, behavioral practitioners and educational advocates -- a cornerstone of the family’s care community.

See more and find an ATN in your community at: **www.autismspeaks.org/atn**

Contact us:

888-AUTISM 2 (288-4762)

En Español: 888-772-9050

Email: **atn@autismspeaks.org**

AUTISM SPEAKS®
ATN
Autism Treatment Network

AIR P
Autism Intervention Research
Network on Physical Health

RESOURCES

The Autism Speaks Family Services Department offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism http://www.autismspeaks.org/family-services

If you are interested in speaking with a member of the ***Autism Speaks Family Services Team*** contact the ***Autism Response Team (ART) at 888-AUTISM2 (288-4762)***, or by email at: familyservices@autismspeaks.org.

ART En Español al 888-772-9050.

Books

Taking Care of Myself, A Healthy Hygiene, Puberty & Personal Curriculum for Young People with Autism. 2003, Future Horizons; Wrobel, Mary.

The Care & Keeping of You: The Body Book for Girls. 1998, Pleasant Company Publications; Valerie Schaefer.

The Care and Keeping of You 2: The Body Book for Older Girls. 2013, Turtleback Books; Cara Familian Natterson.

From diapers to dating: A parent's guide to raising sexually health children. 2008, William Morrow Paperbacks; Debra Haffner.

Sex Education for Parents of Children with Autism Spectrum Disorder. 2002, Steege Publications; Mark Steege and Shannon L. Peck.

Visual Aides

Visual Aides for Learning: Adolescent Girl Pack
www.visualaidsforlearning.com/adolescent-girl.html

Visual Aides for Learning: Adolescent Boy Pack
www.visualaidsforlearning.com/adolescent-boy.html

Websites

Autism Speaks Challenging Behaviors Tool Kit:
www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit

Autism Speaks Safety Project Tool Kit:
www.autismspeaks.org/family-services/autism-safety-project/sexual-abuse

Autism Speaks Transition Tool Kit:
www.autismspeaks.org/family-services/tool-kits/transition-tool-kit

Autism Speaks ATN Teen Sleep Tool Kit Quick tips:
www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit

Autism Speaks Occupational Therapy Tool Kit:
www.autismspeaks.org/family-services/tool-kits/occupational-therapy

Puberty in Kids with Developmental Disabilities-Acne Treatment:
www.acnetreatment.net/puberty-in-kids-with-developmental-disabilities

An online resource and community for Autism and Asperger's:
www.wrongplanet.net

Healthy Bodies for Boys/Girls:
Kc.vanderbilt.edu/healthybodies

Websites cont'd

Autism Speaks Challenging Dealing with big physical and emotional changes in your adolescent:
www.abilitypath.org/areas-of-development/delays--special-needs/autism/articles/puberty-and-your-child-with-autism.html

Menstruation Management and Disabilities:
autismbeacon.com/images/uploads/supporting-women-carer.pdf

http://www.teachingsexualhealth.ca/

DVDs & Videos

Be Safe- Movie & Workshop, Save a Life: Teach Students to Interact With Police.
Besafethemovie.com

Specialty OT Services for Transitioning Adolescents- Shaving video:
www.youtube.com/watch?v=SLG6AqkASaY

Managing Puberty, Social Challenges, and (Almost) Everything: A Video Guide for Girls PREVIEW:
youtu.be/wQwNBIlL4gY

A Boy's Puberty Video:
youtu.be/XdW_uU7sxMI

ACKNOWLEDGEMENTS

This publication was developed by members of the Autism Speaks Autism Treatment Network / Autism Intervention Research Network on Physical Health (AS ATN/AIR-P) - Behavioral Health Sciences Committee. Special thanks to our Parent Partners: Kameena Ballard-Dawkins-Children's Hospital of Los Angeles, CA Amy Kelly-Children's Hospital of Philadelphia, PA, Charlene Prochnau-University of Glenrose at Edmonton, Alberta Canada, Alicia Curran, BS-Thompson Center, University of Missouri and to Rich Hahn of Des Moines, IA and to our AS ATN/AIR-P professionals: Kristin A. Sohl, MD, FAAP (our lead autism expert) MU Thompson Center, University of Missouri Child Health Department, Lisa Voltolina, M.S., CCRP, Oregon Health & Science University; Shawn Reynolds, PhD, R.Psych, Glenrose Rehabilitation Hospital, Edmonton, Alberta Canada; Lisa Nowinski Ph.D., Lurie Center-MGH, Boston, Massachusetts; Yolan Parrott, MSc OT, OT(C), Glenrose Rehabilitation Hospital, Edmonton, Alberta, Canada.

A Special Thanks to:

Vanderbilt Kennedy Center/Vanderbilt Leadership Education in

Neurodevelopmental Disabilities (LEND)

Division of Developmental Medicine; and Cassandra Newsom, PsyD, Assistant Professor of Pediatrics,
Division of Developmental Medicine, Director of Psychological Education, Treatment and Research
Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center
Kylie Beck, BA and Courtney Taylor, MDiv

Tessa Milman, OTD, OTR/L
Clinical Instructor OT 251: Across the Lifespan: Occupation, Health and Disability
Herman Ostrow School of Dentistry
Division of Occupational Science and Occupational Therapy
University of Southern California

OT Practitioner Advisory Committee/
Alison Wheeland, MA, OTR/L
Occupational Therapy Doctoral Candidate
University of Southern California

Children's Hospital of Los Angeles AS ATN/AIR-P site
Autism Parent Advisory Board | The Boone Fetter Clinic,
for their input

This was edited, designed, and produced by Autism Speaks Autism Treatment Network / Autism Intervention Research Network on Physical Health communications department. We are grateful for review and suggestions by many, including by families associated with the Autism Speaks Autism Treatment Network. This publication may be distributed as is or, at no cost, may be individualized as an electronic file for your production and dissemination, so that it includes your organization and its most frequent referrals. For revision information, please contact atn@autismspeaks.org.

These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported in part by cooperative agreement UA3 MC 11054, Autism Intervention Research Network on Physical Health (AIR-P Network) from the Maternal and Child Health Bureau (Combating Autism Act of 2006, as amended by the Combating Autism Reauthorization Act of 2011), Health Resources and Services Administration, Department of Health and Human Service to the Massachusetts General Hospital. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS. Images for this tool kit were purchased from Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) Vanderbilt Kennedy Center®. Written October 2014.

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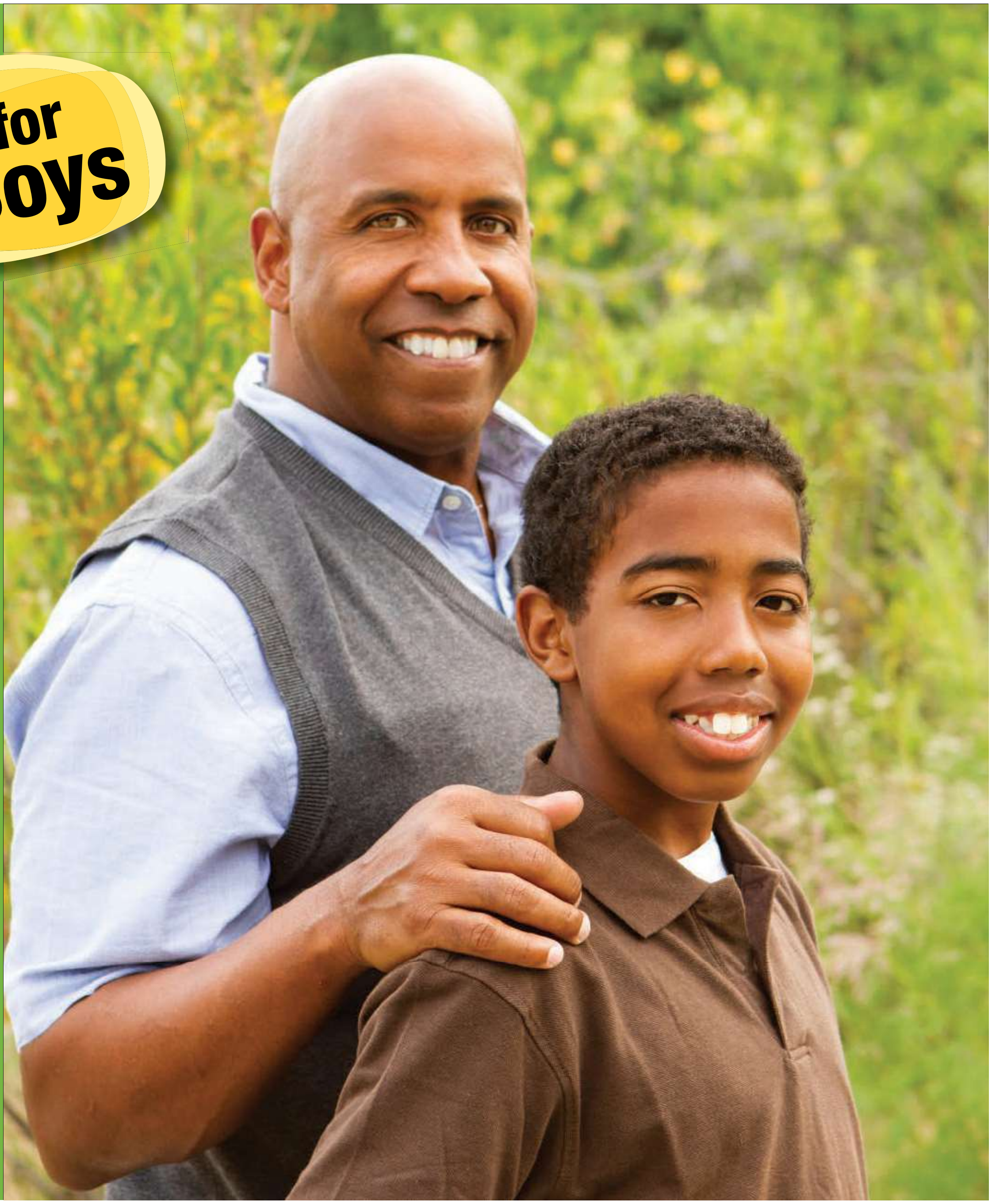
LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Healthy Bodies

for Boys



A Parent's Guide on Puberty for Boys with Disabilities

Table of Contents

An appendix with social stories and visual supports may be downloaded at: kc.vanderbilt.edu/HealthyBodies

Appendix and visuals can be found online at:

kc.vanderbilt.edu/HealthyBodies

Puberty can be a stressful and confusing time, especially for you and your son with an Intellectual and/or Developmental Disability (I/DD). In spite of delays in other areas, children with I/DD usually enter puberty around the same time as other children their age. Some boys with I/DD, including those with spina bifida and cerebral palsy, may start puberty early (called precocious puberty). This toolkit gives you resources and tips on how to talk to your son about these sensitive topics.

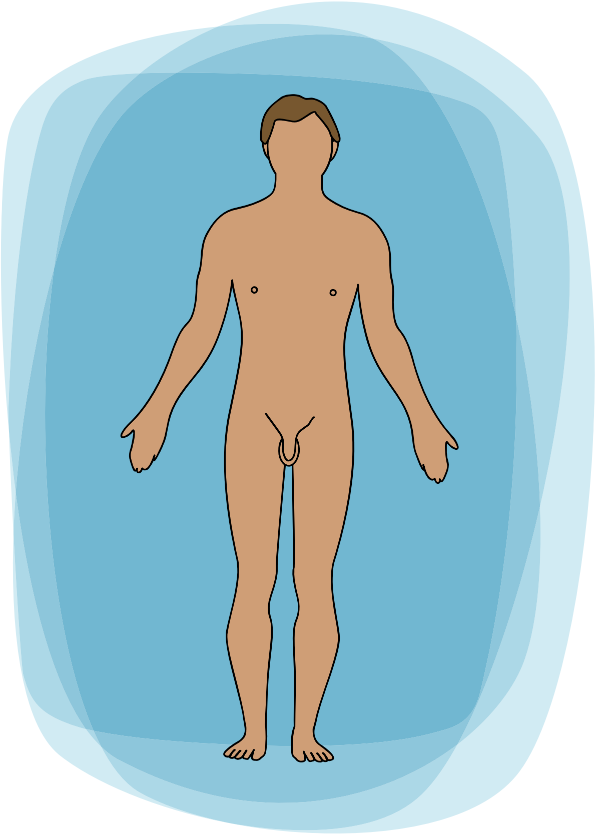
Talking To My Son About These Things

Start early. Talk with your son before obvious signs of puberty begin.

Teach body parts. Use the formal words for body parts (e.g., penis, erection) and bodily functions (e.g., urinate, ejaculation). This prevents confusion and gives your son words to use later when learning about puberty, cleanliness, and reproduction. See *Teaching Body Parts Appendix* for a visual you can use to teach your son the names for body parts and how his body is changing.

Use supports. You know the ways your child learns best. Teach about puberty the same way you teach about other important topics. For example, if your son learns best with repetition, break information down into simple facts and review them often. If he learns best with pictures, try using visual supports or social stories. These supports make hard-to-understand topics clearer. Review the supports we have developed to get ideas about how to teach skills (see *Teaching Body Parts Appendix*). Change them to fit your son's learning style.

Ask a professional. Talk to your son's doctors, teachers, or therapists for other ideas. ■



See Teaching Body Parts Appendix

No Couch Potatoes! Helping Your Son Stay Active

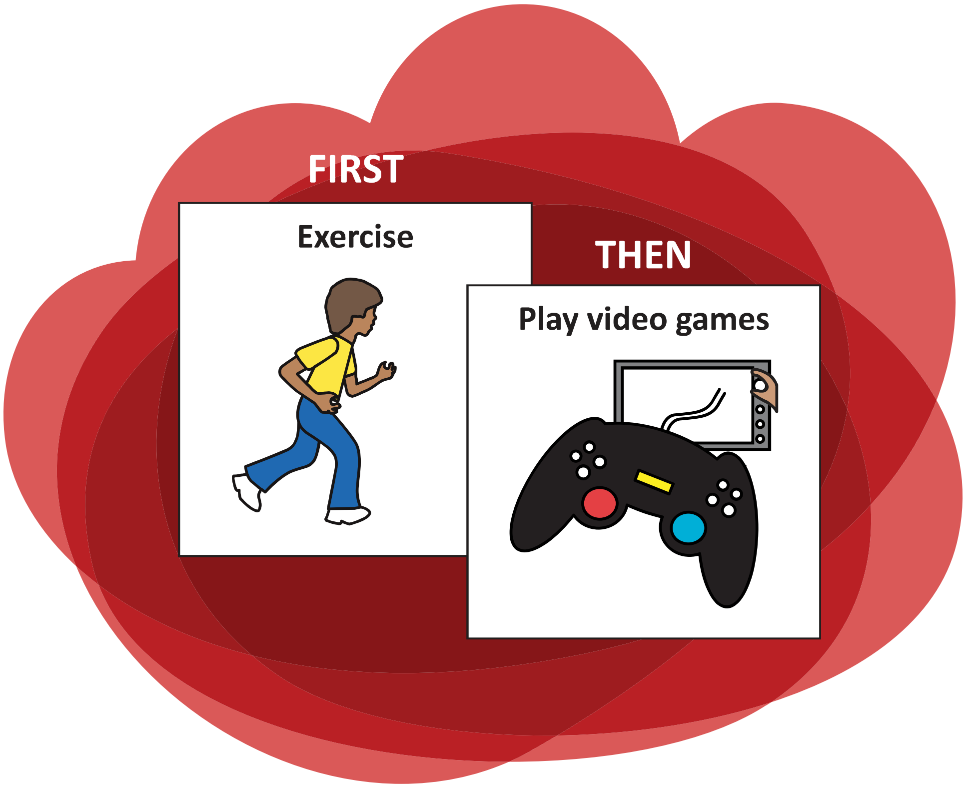
It is important to teach your son how to be healthy from a young age. Hormone changes and some medications can cause weight gain during puberty. Regular exercise and a healthy diet can prevent weight gain and improve mood and self-esteem. Starting these healthy habits early is the best way to help your child be an active adult.

How To Start

Schedule physical activities. Make sure your son has a scheduled time every day for active play, such as hiking, playing games outside, and riding bikes. If he has trouble getting started, provide a menu of options or just join in! Make fun, physical activities a part of your family's daily routine.

Ask a professional. If your son has a motor impairment, ask his doctor, occupational therapist, or physical therapist for safe exercise ideas. Look for adapted or supported sports activities in your area that either are designed for teens with disabilities or that provide accommodations to include your child.

Make exercise rewarding. As your son gets older, switch from "play time" to exercise, sports, or family activity time (such as taking a walk together). If your child does not like exercise, you can encourage it by giving him a reward afterward. At this age, it is helpful to offer rewards that are not food. Try using visual supports such as a First/Then Board. For example, show him "First Exercise" followed by something preferred, like "Then Video Games." See the First/Then Board Appendix for a blank template that you can try at home. ■



See First/Then Board Appendix

Encouraging Good Hygiene

Good hygiene can improve your son's self-esteem and independence. Good hygiene habits can also reduce the amount of time you spend completing these tasks for him.

Make a picture book. A picture book may be a good starting point for teaching self-care. You and your son can create it together. The amount of information (more or fewer pictures) depends on your child's reading level and memory. Include pictures of supplies needed (e.g., specific body wash, deodorant, razor), and a visual picture schedule of the steps to use them. This picture book can also help your son select items on a shopping trip or gather the items needed for specific tasks, such as showering. Using a picture book may give him a feeling of control and responsibility for completing hygiene tasks.

Create hygiene kits. Think about making hygiene kits for different tasks. You can use old shoe boxes, clear plastic containers, or baskets. Let your son help choose the containers. On the outside of the box, put pictures or a list of the items in the box and a picture of the key task (e.g., shaving). See *Encouraging Good Hygiene Appendix* for pictures you and your son can use to create a kit. Here are a few examples of kits and contents:

- **Shower**: Shampoo, conditioner, face wash, soap
- **Dental**: Toothbrush, toothpaste, dental floss, mouthwash
- **Shaving**: Razor, shaving cream, picture of parts of face to shave
- **Morning Routine**: Body lotion, deodorant, facial cleansing wipes, face lotion, hair brush

Common Trouble Spots: Dirty Hair

As children enter puberty, they may need to wash their hair more frequently. Your son may struggle with keeping his hair clean because the motor aspects of the task may be difficult. He may find the feel of shampoo or water unpleasant. Some children with I/DD may not pay close attention to what their classmates are doing and wearing. Because of this, they may not understand that clean hair is socially important.

- **Make it routine**. Make a schedule to show your son how frequently he should complete hygiene tasks and the steps to complete them. See *Encouraging Good Hygiene Appendix* for an example of a showering schedule.
- **Singing in the shower**. To help your son learn how long to stay in the shower or bathtub, create a music CD of a few songs equal to the length of time he should bathe. Each song change can signal to him when to move to the next step on the schedule.
- **Soften up**. Does your child hate scrubbing his hair with his hands? Let him use a soft sponge to apply shampoo. If the water pressure bothers your child, let him use a cup or pitcher to rinse his hair or use a showerhead with adjustable pressure.
- **A picture is worth a thousand words**. Write a story that explains the importance of showering daily and keeping hair clean. Have fun. Take a picture of your son and other family members when they first wake up in the morning (bed-head and all!) and then when they are clean and dressed. Talk about what other people might think if you went to work or school looking like you did when you first woke up.

See Encouraging Good Hygiene Appendix

Common Trouble Spots: Sweat and Body Odor

Sweat glands become more active during puberty, so it is important to teach boys to control body odor by using deodorant, changing their clothes daily, washing their dirty clothes weekly, and keeping their bodies clean.

- **Don't forget your visuals.** Use checklists and stories to remind your son of what steps to follow to clean his body and why. See *Encouraging Good Hygiene Appendix* for a sample story about managing sweat and body odor.
- **Action schedule**. If your son needs reminders of what area of the body to scrub next, you can use an action schedule that shows which action or step comes next. Include shampooing and rinsing, and body parts to wash with soap. Laminate the schedule so it can hang in the shower. Another option is to use an old Ken® doll, action figure, or laminated paper doll. Separate and number each body part. Attach the doll to the bathroom or shower wall with Velcro. As your son washes each body part, he can place that part of the doll's body in a container labeled "finished."
- **Obstacles**. If applying deodorant is physically challenging for your son, try different types, such as spray deodorant or roll-on. If he has trouble bathing independently due to motor impairments, try adaptive equipment like bath seats, a removable showerhead, scrubbing gloves, or extended/easy-grip scrubbing handles.
- **Smells too strong**. Involve your son in selecting hygiene products, particularly regarding the scent. Some children may prefer unscented products if they are bothered by strong smells. Many products labeled for "sensitive skin" are unscented.
- **Acne**. For some teens, acne can be a problem due to increased oil in their skin, hormone changes, hygiene, and even genetics. Check with your child's doctor about safe over-the-counter acne medications, such as creams, lotions, or washes that contain medications like salicylic acid or benzoyl peroxide. Take a picture of your teen's face or use a line drawing. Circle the areas where medication should be applied daily. Teach your teen to avoid sensitive spots like eyes, nostrils, and the mouth. Also, consider pre-medicated wipes to make application easier. If your teen has body acne, medicated body washes are also available.

See Encouraging Good Hygiene Appendix

Common Trouble Spots: Body Hair and Shaving

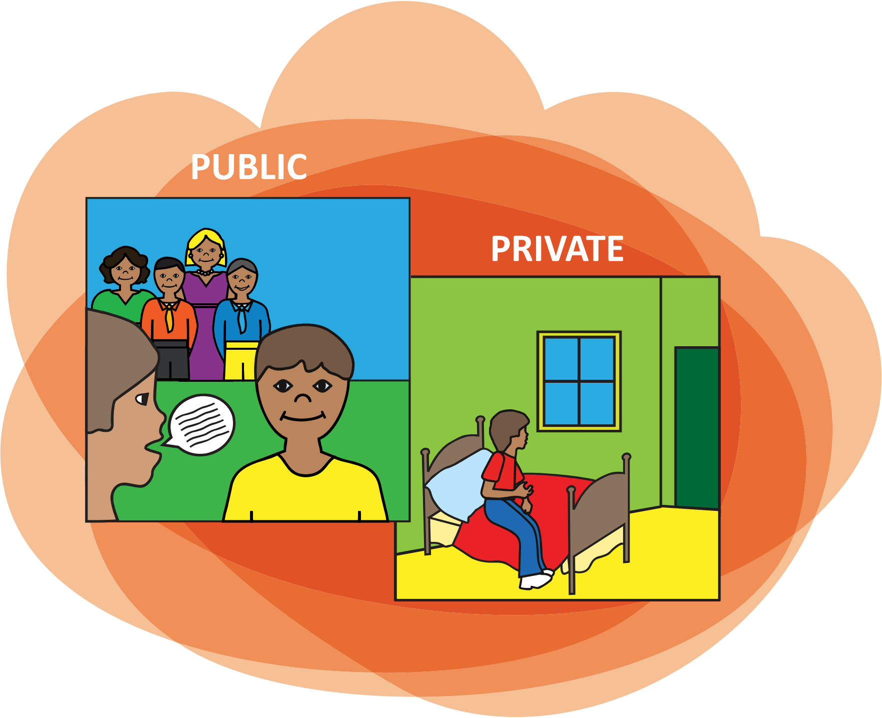
Body hair begins to grow and change during puberty. Use a drawing of the male body (like the one in the *Teaching Body Parts Appendix*) to teach your son where hair grows to prepare him for his changing body. Some adults and teenagers want to shave body hair.

- **Model shaving**. Let your son watch you or an older sibling shave and list the steps. Have him practice with you, step by step. Write down or take pictures of each step for a visual schedule. To help him remember where to shave and where not to shave, use a photo or drawing of a person, and color or number the areas that should be shaved.
- **Schedule shaving dates**. If your son can shave (or does so with assistance), use a calendar with pictures or marks as a reminder of how often to shave and when to change his razor.
- **Limit shaving cream**. If your child needs help with portion control or operating shaving cans, try using travel-sized packets of shaving cream or a shaving brush.
- **Select the right razor**. Boys who struggle with fine motor tasks may benefit from electric razors instead of a traditional razor with a blade. If the traditional razor with a blade is preferred, ask your occupational therapist about weighted razors or a razor universal cuff to help improve grip on the razor.

Common Trouble Spots: Clean Teeth and Breath

- **Create a Visual Schedule**. Use pictures to show the steps of brushing teeth. See *Encouraging Good Hygiene Appendix* for pictures to help your son learn to brush independently.
- **Choose the right toothbrush**. A vibrating or weighted toothbrush may help children who have difficulty holding a toothbrush and brushing their own teeth. Look for a toothbrush with soft bristles.
- **Show when and how long**. Build brushing into your son's daily schedule with picture reminders. Timers may help remind him how long to brush. Dentists recommend two minutes! 🟩

See Encouraging Good Hygiene Appendix



Appropriate and Inappropriate Public Behaviors

Does your son ever do or say things in public you wish he didn't? Your child needs help learning what is okay to do in public and what is okay to do only in private. Private behaviors include things like going to the bathroom, passing gas, touching private parts for any reason, and changing clothes, just to name a few. Using socially appropriate behaviors will help your son fit in with his peers and reduce the chances of being bullied or abused. Children who know the difference between appropriate and inappropriate public behavior are less likely to get in trouble with the school or police as they get older.

Teaching These Skills to My Son

- **Start early**. Talk about public and private behaviors as a family and set some ground rules, such as: "We are only naked in the bathroom or in our own bedroom with the door closed" or "We put on our clothes or pajamas before we leave the bathroom or bedroom." Remind your child about the rules using simple words or pictures. Use the same rules for everyone in the family!
- **Use visuals**. Make a list of places that are public and places that are private. Then you can come up with examples of behaviors that are okay in each setting. Use visuals to help your son understand and remember these rules. Look at *Public/Private Behaviors Appendix* for ideas and printable pictures to teach the concept of *Public* and *Private*.
- **Use stories**. Stories also can help your child understand these rules and why we have them. Think about the behaviors that are problematic for your child, and write a story that sets clear rules about when and where that behavior is okay. See *Public/Private Behaviors Appendix* for a story about public versus private behavior.

**See Public/
Private Behaviors
Appendix**

- **Redirect.** Tell your son where to go to perform private behaviors using simple words or pictures. For example, say something like, “You can do that in your (bedroom, bathroom)” or show him a visual labeled “Private.” Direct him to a private area when he does things such as touching private parts or adjusting underwear.
- **When private can’t be private.** Some boys will need help with private tasks, such as getting dressed, bathing, or toileting. Teach your son how and who to ask for help with these private behaviors when he is in public places, such as a school or a restaurant. This could include teaching him to plan ahead, ask quietly, or use picture cards or gestures.

Touching Private Parts

All kids at some point will discover their private parts. Every family has their own values and beliefs about this behavior, and it is okay to teach your child what your family believes. It is a normal part of development for boys and girls to touch themselves at times, and it is almost impossible to stop this behavior completely. Teaching your son when and where this behavior is allowed may be the best option. Punishing, shaming, or giving it a lot of attention may actually make it happen more. It also may make your child less likely to ask you or the doctor important questions.

It is important to know the facts. Touching private parts does not cause blindness, make you “go crazy,” stunt growth, or damage your body parts. It is not always associated with thinking about sex, either. Some young people touch themselves because it is a calming sensory experience. Some children might touch their private parts because they itch or hurt, which could be a sign of an infection. If your child is touching so much that it gets in the way of doing other activities, you notice irritated skin, or you have other concerns, talk to a doctor.

You can teach your child which parts of the body are “private parts” by describing them as the parts of the body covered by a swimsuit or underwear. You can find examples of visuals and social stories to talk about private parts and about touching in *Private Parts Appendix*.

If your son is touching his private parts in public, you will want to stop the behavior quickly and quietly. You can use a visual to remind him of the rule, such as “No Hands in Pants” or a visual to cue a behavior that he can’t do at the same time, such as “Hands on Table.” Use a First/Then Visual of “Wash Hands” then “Reward” to interrupt the behavior. Before going out, consider bringing activities that will keep his hands active, like a fidget or a handheld game. If you are at home, you may want to use a visual to give him a choice of “No Hands in Pants” or go to a “Private” place. ■

See Public/
Private Behaviors
Appendix

Puberty can be hard for all children. Friends, social skills, and appearance matter more. Your son may need help handling stress and fitting in with other peers. As children move from elementary to middle and high school, clothing, dating, and driving become more important. Developmental differences may become more noticeable. Think about the social situations your son will face and how things like clothing, haircuts, and age-appropriate interests can impact his “social world.”

How You Can Help Your Son Socially

Get him involved in activities he enjoys with other peers. Find groups that do things your son enjoys, such as individual or team sports, a club that fits with his interests, or a youth group. Talk to the group leader about your son’s needs and ideas about how to include him. Contact local advocacy groups to learn more about what is available in your area. If no appropriate group exists, consider starting one.

Talk to your son’s teacher or school counselor about peer sensitivity training. Programs exist to help other children understand your child’s strengths and challenges. Teaching peers about why your son has differences in his communication, learning, and/or mobility can increase empathy and understanding. Many groups provide “toolkits,” websites, and lists of local resources to help promote peer sensitivity and inclusion. See the resources listed on page 15.

Hair. Take your son to get an age-appropriate haircut. Part of growing up is having clothing and hairstyles like your peers. Although this may not be your top priority, it may be important to your son and his peers.

- Look at magazines and talk to other parents to get ideas for styles. Think about haircuts that are easy for him to maintain. Let him choose pictures of haircuts he likes and share them with the barber.
- Set the appointment for a time when the shop is not as busy and consider asking for a longer appointment time in case your son needs a break. Take distractions, like an electronic tablet or a game to help him tolerate the haircut.
- Talk to your son’s occupational therapist about self-care skills (such as brushing and styling hair) and adaptive equipment that can help him be independent.

Clothes. When shopping for clothing for your son, it is important to recognize age-appropriate clothing trends. What are other children wearing when you visit your child at school? To find out where other teenagers get clothes, you can look at magazines, talk to other parents, or take an older sibling or cousin with you when you shop.

If your son is able to make choices, give him different clothing options. You can take him shopping, buy and lay out several shirts to pick from, or use a choice board with pictures. If your child has strong clothing preferences, or trouble with buttons, zippers, and snaps, and you would like him to consider other options, try slowly introducing new shirts or pants. Keep in mind comfort, fit, and your son’s favorite colors and textures. Use a social story to explain about how children, teenagers, and adults dress differently. For example, switching from velcro shoes to slip-ons or covering elastic wastebands with untucked shirts can help your son dress more like peers. Work with your occupational therapist on dressing skills.

See Moods and Feelings Appendix

What if my son doesn't care?
Puberty and being a teenager are about increasing independence and expressing individuality. Even if clothing does not seem to matter to your child, small things like a different style of pants or a new haircut can go a long way toward helping him feel included and preventing him from being teased. Helping him look and dress his age may make it easier for peers to get to know how great your son is on the inside too!

Augmentative Communication Devices. If your son uses a communication device with voice production, make sure that the voice matches his age and gender.

Moods and Feelings

Moodiness can be normal during puberty. You can teach your child to express these feelings. If your child is verbal, use your words to label feelings ("It sounds like you're feeling angry," or "So when he did that, it made you sad.") If your child is less verbal, use visuals like cartoons, photos, sign language, or word cards. *Moods and Feelings Appendix* includes pictures of emotions your son can use to let you know how he feels. Consider getting support from a counselor or therapist who is familiar with your child's diagnosis and can give you other strategies.

More Than "Moody"

Sometimes mood changes can be caused by something more serious, like medical problems. For example, thyroid problems (which are common in children with Down syndrome) can look like depression by affecting mood, appetite, and activity level. Mood changes also can be a symptom of depression or anxiety. Children with disabilities can have typical teenage moodiness, but they also can develop other mental health problems that should be treated. Watch for **changes** in their typical behavior like the ones listed below.

- **Emotions**: Crying, shouting, laughing for no clear reason
- **Behavior**: Pacing, rocking, rubbing hands together, picking at skin
- **Aggression**: Hitting, biting, scratching, head-banging, throwing items
- **Appetite**: Eating more or less
- **Wellness**: Complaining about headaches, stomach aches, or other body aches
- **Sleep**: Sleeping more or less, trouble falling or staying asleep, nightmares
- **Thinking**: Seeming confused, having trouble focusing, seeing things that are not there
- **Energy**: Moving more or less, acting withdrawn, not doing things they used to enjoy

Talk to your child's doctor about any changes that you see. Keep track of them using a diary, data sheet (see *Diary Appendix*), or an electronic phone or tablet application. Write down what you see and when you see it. ■

See Diary Appendix

Nocturnal Emissions

Many teen boys ejaculate while sleeping when they enter puberty. This is called a nocturnal emission. Some people may refer to this as a *wet dream*. The penis will release semen, a fluid that contains sperm. **This is a normal process that is not in your son's control**.

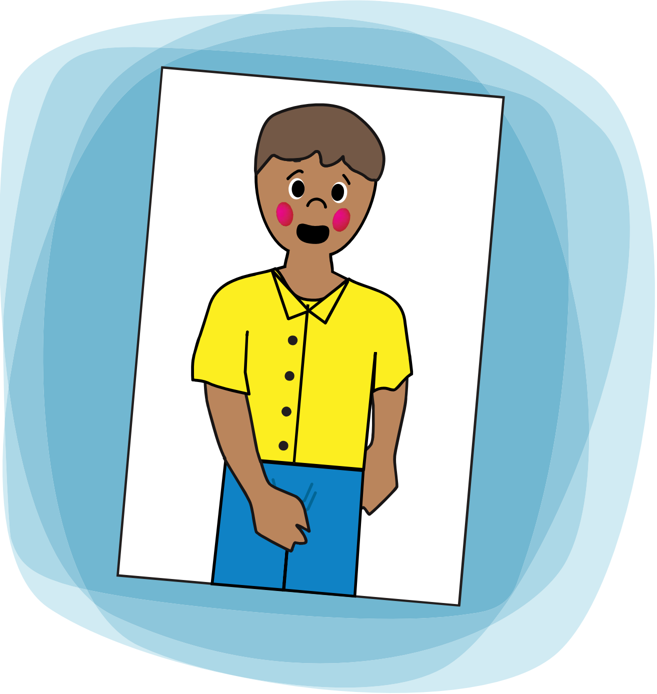
Nocturnal emissions may appear as a wet, sticky spot on his underwear, pajamas, or sheets. Nocturnal emissions usually start between ages 13 and 17, with an average age of around 14. It is very important to prepare your son for this event so that he does not think he has done something wrong. This is a natural part of puberty.

Preparing My Son for Nocturnal Emissions

- **Know the difference.** Your son may think he wet the bed after a nocturnal emission. He may hide it from you or be afraid to tell you about it. Explain to him what has happened and that it is normal.
- **Make connections**. It may help to link nocturnal emissions to other changes in your son's body during puberty, such as hair growth, becoming taller, and testicles and penis growth.
- **Encourage independence.** Nocturnal emissions cannot be prevented. Teach your son what to do after they happen. This may include changing sheets, putting underwear in a laundry basket, and washing his private parts with a wipe or wet cloth.
- **Use visuals**. Use a visual schedule to help your son clean up after a nocturnal emission. This may include cleaning up with tissues, stripping the bed and placing the sheets in a laundry basket, or starting the laundry. See *Teaching About Erections Appendix* for pictures you can use to help your son be more independent in cleaning up. If your son is unable to change the sheets or clean himself independently, find a way for him to let you know that he needs help. One option is using a cue card or a door hanger to communicate with you. A door hanger can be found in *Teaching About Erections Appendix*. Just cut it out and laminate it for regular use.
- **Keep it private.** Nocturnal emissions are a private matter. Teach your son that he can talk about it with parents, doctors, or the school nurse only. Teach your son that he should not discuss it with friends, teachers, or strangers.
- **Stay positive.** Nocturnal emissions are a natural part of puberty. **Reacting negatively (shaming, laughter, punishment) will not stop them**. Instead, respond in a calm, matter-of-fact way, and focus on teaching your son how to handle it.
- **Ask**. Ask your son's doctor for help teaching him about puberty and body changes.

See Teaching About Erections Appendix

Erections



During puberty, most teenage boys have several erections throughout the day. This is a normal part of puberty for boys and often not within their control. Erections can happen for many different reasons. At this age, they can happen from something as simple as pants rubbing against the body, or just "out of the blue." Because they may be out of your son's control, erections in public can be unavoidable and embarrassing for him.

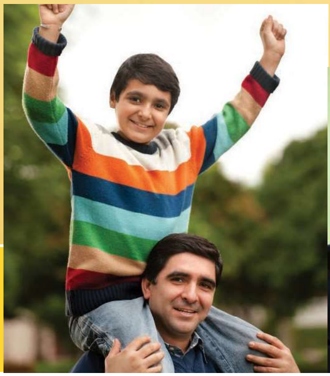
Things That May Help

- Create or use the social story in *Teaching About Erections Appendix* to talk to your son about erections.
- Remind him that this is one of those things he can talk about with his doctor and you, but not with friends, teachers, or strangers.
- Give him some ideas about what to do when it happens in public:
    - Stay seated, and eventually it will go away
    - Carry his books low to block his private area
    - Tie a jacket around his waist
- Well-fitting briefs may make erections less obvious and keep everything in place. Avoid sweatpants and other loose-fitting pants.

Boxers or Briefs

Helping your son choose boxers or briefs depends on what issue is most important to you and your son. Boxer shorts may be easier to pull on and off. Briefs may provide more support. Take your son with you to the store to pick out a few different types. Let him try them out at home to see what he likes best. ■

See Teaching About Erections Appendix



Appendix and visuals can be found online at:

kc.vanderbilt.edu/HealthyBodies

Organizations

- ☐ Vanderbilt Kennedy Center: kc.vanderbilt.edu
- ☐ Autism Society of America www.autism-society.org
- ☐ Autism Speaks: www.autismspeaks.org
- ☐ Easter Seals: www.easterseals.com
- ☐ National Down Syndrome Society: www.ndss.org
- ☐ National Parent Technical Assistance Center: www.parentcenternetwork.org
- ☐ American Society for Deaf Children: www.deafchildren.org
- ☐ United Cerebral Palsy: www.ucp.org

Visual Support Resources

- ☐ http://card.ufl.edu/content/supports/start.html
- ☐ www.kidaccess.com/index.html
- ☐ Do 2 Learn: www.do2learn.com
- ☐ Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Websites

- ☐ National Information Center for Children and Youth With Disabilities. *Sexuality education for children and youth with disabilities.* Available at http://nichcy.org/schools-administrators/sexed
- ☐ Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center: www.pacer.org/bullying
- ☐ www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
- ☐ kc.vanderbilt.edu/kennedy_files/OralHealthTips.pdf
- ☐ http://kidshealth.org/teen/sexual_health/#cat20015
- ☐ www.freewebs.com/kidscandream/main.htm

Social Stories–Information and Examples

- ☐ Gray, C., & White, A. L. (2002). *My social stories book*. Philadelphia, PA: Jessica Kingsley Publishers.
- ☐ www.thegraycenter.org/social-stories/what-are-social-stories
- ☐ www.bbbautism.com/pdf/article_27_Social_Stories.pdf

Books

- ☐ Gravelle, K., Castro, N., & Castro, C. (1998). *What's going on down there? Answers to questions boys find hard to ask*. New York: Walker and Company.
- ☐ Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty, and personal curriculum for young people with autism*. Arlington, TX: Future Horizons.
- ☐ Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks galore for the real world*. Raleigh, NC: Tasks Galore. www.tasksgalore.com
- ☐ Bellini, Scott, *Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with autism spectrum disorders and other social difficulties* (2006). Autism Asperger Publishing Co., Shawnee Mission, KS.
- ☐ Middleman, A. B., & Pfeifer, K. G. (2006). *Boy's guide to becoming a teen: Getting used to life in your changing body*. American Medical Association.
- ☐ Madaras, L., & Madaras, A., Sullivan, S. (2007). *What's happening to my body? Books for boys: A growing-up guide for parents and sons*. Newmarket Press.
- ☐ Baker, Jed (2009) *Social skills picture book for high school and beyond*. www.mayer-johnson.com/the-social-skills-picture-book-for-high-school-and-beyond
- ☐ Meehan, Cricket, *The right to be safe: Putting an end to bullying behavior* (2011). Search Institute Press.

This publication was developed and written by Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) long-term trainees Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; Doctor of Audiology student, Elizabeth Harland; Cong Van Tran, PhD; and LEND faculty members Jennifer Bowers, RN, MSN, CPNP, Pediatric Nurse Practitioner, Division of Developmental Medicine; and Cassandra Newsom, PsyD, Assistant Professor of Pediatrics, Division of Developmental Medicine, Director of Psychological Education, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. It was edited, designed, and produced by the Communications and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) with the support of the Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). We are grateful for review and suggestions by many, including faculty of TRIAD and members of Autism Tennessee.

This publication may be distributed as is or, at no cost, may be individualized as an electronic file for your production and dissemination so that it includes your organization and its most frequent referrals. For revision information, please contact courtney.taylor@vanderbilt.edu, (615) 322-5658, (866) 936-8852.

This publication was made possible by Grant No. T73MC00050 from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS. Photos ©istockphoto.com. Printed June 2013.

VANDERBILT KENNEDY CENTER
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Cuerpos sanos

Para niños varones

Una guía sobre la pubertad para padres de niños varones con discapacidades

Índice

Puede descargar un anexo con historias
sociales y apoyos visuales en:
kc.vanderbilt.edu/HealthyBodies

Puede encontrar un anexo con apoyos visuales en

kc.vanderbilt.edu/HealthyBodies

La pubertad puede ser una etapa confusa y llena de tensión, especialmente para usted y su hijo con una discapacidad intelectual o del desarrollo (DI/DD). Aunque tengan retraso en otras áreas, los niños con DI/DD normalmente llegan a la pubertad a la misma edad que los otros niños. Algunos niños con DI/DD, incluidos los que tienen espina bífida y parálisis cerebral, pueden llegar antes a la pubertad (llamada pubertad precoz). En este manual puede encontrar recursos y consejos sobre cómo hablar con su hijo sobre estos temas tan difíciles.

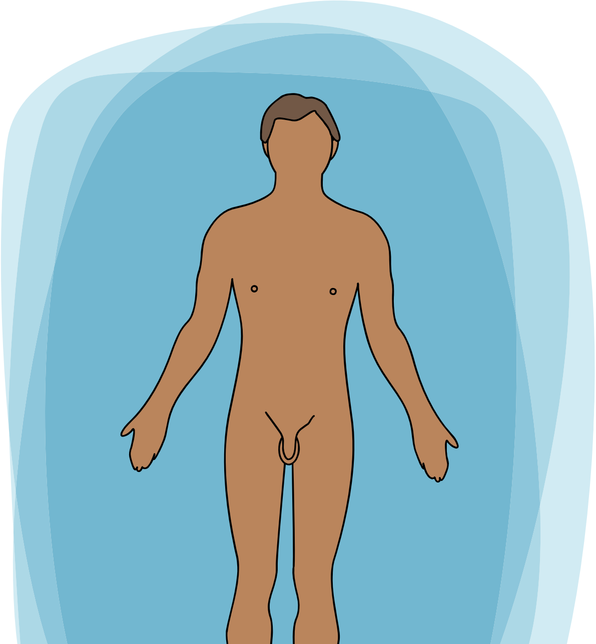
Hablar con mi hijo de esas cosas

Empiece pronto. Hable con su hijo antes de que sean visibles los signos de la pubertad.

Enseñe cómo llamar las partes del cuerpo. Use las palabras apropiadas para las partes del cuerpo (p. ej., pene, erección) y las funciones del cuerpo (p. ej., orinar, eyaculación). Esto evita confusiones y le da a su hijo el vocabulario que usará luego cuando aprenda sobre la pubertad, el aseo personal y la reproducción. Puede usar los apoyos visuales del *Anexo Las partes del cuerpo* para enseñar a su hijo cómo llamar a las partes del cuerpo y cómo está cambiando su cuerpo.

Use materiales de apoyo. Usted sabe cómo aprende mejor su hijo. Enséñele sobre la pubertad de la misma manera que le enseña sobre otras cosas. Por ejemplo, si su hijo aprende mejor repitiendo algo muchas veces, divida la información en datos sencillos y practique muchas veces. Si aprende mejor con dibujos, pruebe a usar apoyos visuales o historias sociales. Estos apoyos le ayudarán a que entienda cosas difíciles de una manera más clara. Si necesita ideas, revise los materiales que hemos preparado para enseñar estas habilidades (vea el *Anexo Las partes del cuerpo*). Usted puede adaptarlos a la forma en que su hijo aprende mejor.

Pregunte a un profesional. Hable con los doctores, maestros o terapeutas de su hijo para que le den otras ideas. ■



Vea el Anexo Las partes del cuerpo

Es importante que el niño aprenda a estar sano desde que es pequeño. Los cambios en las hormonas y algunas medicinas pueden causar que suba peso durante la pubertad. Hacer ejercicio regularmente y comer bien puede ayudar a su hijo a que no aumente de peso, tenga mejor humor y más confianza en sí mismo. Comenzar pronto estos hábitos saludables es la mejor manera de ayudar a su hijo a convertirse en un adulto activo.

Cómo empezar

Programe actividades físicas. Cada día su hijo debe tener tiempo para jugar de forma activa, como ir a caminar, jugar afuera o andar en bicicleta. Si le es difícil empezar, dele varias opciones para escoger o ¡vaya con él! Incluya siempre actividades físicas divertidas en la rutina diaria de su familia.

Pregunte a un profesional. Si su hijo tiene un impedimento, pregunte a su doctor, terapeuta ocupacional o terapeuta físico para que le den ideas de ejercicios seguros. Cerca de su casa, busque actividades deportivas adaptadas o con apoyos que estén diseñadas para adolescentes con discapacidades o que tengan modificaciones para poder incluir a su hijo.

Recompense el ejercicio. A medida que su hijo se hace mayor, cambie de "tiempo para jugar" a tiempo de hacer ejercicio, deportes o actividades familiares (como pasear juntos). Si su hijo no quiere ejercitarse, puede animarlo dándole un premio o recompensa después. A esta edad, es mejor no dar comida como recompensa. Pruebe a usar apoyos visuales como un tablero Primero-Después. Por ejemplo, muestre "Primero ejercicio", seguido de algo preferido, como "Después videojuegos". En el *Anexo Tablero Primero-Después* encontrará una plantilla en blanco que puede usar en casa. ■

Vea el Anexo Tablero Primero-Después

Fomentar el aseo personal

La buena higiene puede mejorar la independencia y la confianza de su hijo. Además, si tiene buenos hábitos de aseo personal, usted pasará menos tiempo realizando estas tareas de aseo por él.

Haga un libro de dibujos. Un libro de dibujos puede ser un buen punto de partida para enseñarle sobre higiene y el aseo personal. Usted y su hijo lo pueden crear juntos. La cantidad de información (más o menos dibujos) depende del nivel de lectura y la memoria de su hijo. Incluya dibujos de las cosas que necesita (p. ej., jabón líquido, desodorante, rasuradora) y una agenda visual con los pasos necesarios. Este libro de dibujos también puede ayudar a su hijo a escoger lo necesario cuando va de compras, o a preparar las cosas que necesitará para hacer una tarea específica, como ducharse. Usar un libro de dibujos puede ayudarle a sentir que tiene control y que es responsable de completar su propio aseo personal.

Prepare estuches de aseo. Puede preparar estuches para las distintas tareas. Se pueden usar cajas de zapatos viejas, recipientes de plástico transparente o canastas para guardar las cosas. Deje que su hijo escoja los recipientes. En la parte de afuera del estuche, ponga dibujos o listas de los artículos que hay dentro y un dibujo de la tarea que va a hacer (p. ej. rasurarse). Vea el *Anexo Fomentar el aseo personal* para buscar dibujos que usted y su hijo pueden usar para crear el estuche de aseo. Estos son ejemplos de lo que puede contener:

- **Ducharse**: Champú, acondicionador, jabón líquido para la cara, barra de jabón.
- **Cepillarse los dientes**: Cepillo de dientes, pasta dental, hilo dental, enjuague bucal.
- **Rasurarse**: Afeitadora, crema de rasurar, dibujo de las partes de la cara que se rasuran.
- **Rutina de la mañana**: Crema corporal, desodorante, toallitas húmedas, crema para la cara, cepillo de pelo.

Puntos problemáticos: cabello sucio

Al entrar en la pubertad, los niños pueden tener que lavarse el cabello más a menudo. Su hijo puede tener dificultad lavándose el pelo porque le puede ser difícil realizar los movimientos. Quizá no le guste sentir el champú o el agua. Algunos niños con DI/DD quizá no presten atención a lo que hacen sus compañeros o cómo se visten. Debido a esto, puede que no entiendan la importancia social de llevar el pelo limpio.

- **Hágalo una rutina.** Prepare una agenda o calendario que muestre a su hijo cuán a menudo tiene que completar las tareas de aseo y los pasos que debe realizar. En el *Anexo Fomentar el aseo personal* verá un ejemplo de los pasos para ducharse.
- **Cante en la ducha.** Para ayudar a su hijo a saber cuánto tiempo estar en la regadera o en la tina, copie canciones en un CD de música que duren el mismo tiempo que debe asearse, cada cambio de canción puede ser una señal de que tiene que pasar al siguiente paso.
- **Más suave.** ¿Detesta su hijo lavarse el pelo con las manos? Dele una esponja suave para aplicar el champú. Si la presión del agua molesta a su hijo, deje que use una taza o jarra para enjuagarse el pelo o use una regadera en la que se pueda ajustar la presión.
- **Una imagen vale más que mil palabras.** Escriba una historia que explique la importancia de bañarse y lavarse el cabello a diario. Diviértanse. Tome una foto de su hijo y de los otros miembros de la familia cuando se acaban de despertar por la mañana (¡pelo despeinado y todo!) y luego otra después de bañarse y vestirse. Hable de lo que otras personas pueden pensar si uno fuera a trabajar o a la escuela tal y como cuando se acaban de despertar.

Vea el Anexo Fomentar el aseo personal

Puntos problemáticos: sudor y olor corporal

Durante la pubertad se empieza a sudar más, así que es importante enseñar a los niños a controlar el olor usando desodorante, cambiarse de ropa a diario, lavar la ropa sucia una vez a la semana y mantenerse aseados.

- **No olvide los apoyos visuales.** Use listas e historias para recordarle a su hijo los pasos que necesita seguir para asearse y por qué. El *Anexo Fomentar el aseo personal* tiene una historia social sobre cómo controlar el sudor y el olor corporal.
- **Agenda o Guía.** Si su hijo necesita que le recuerden cuál es la siguiente parte del cuerpo que necesita lavarse, puede usar una agenda o guía que muestre qué acción o paso viene después. Incluya los pasos de lavarse el cabello con champú y enjuagarse, y las partes del cuerpo que tiene que lavarse con jabón. Plastifique (enmique) la guía y cuélguela en la regadera. Otra opción es usar un muñeco Ken® viejo, una figura de acción o un muñeco recortable de papel enmicado. Separe y numere cada parte del cuerpo. Cuelgue el muñeco en el baño con Velcro. A medida que su hijo se lava las partes del cuerpo, puede colocar la parte correspondiente del muñeco en una bolsa o caja que diga "limpio".
- **Obstáculos.** Si aplicarse desodorante es algo difícil para su hijo, pruebe distintos tipos, como el desodorante de bola o en rociador. Si le cuesta trabajo bañarse solo debido a las dificultades de movimiento, pruebe con equipos como sillas de baño, una regadera de mano, manoplas para lavarse o cepillos de mango largo y fáciles de agarrar, etc.
- **Huele demasiado fuerte.** Anime a su hijo para que escoja sus productos de aseo, sobre todo los perfumados. Hay niños a quienes les molestan los olores fuertes y prefieren los productos sin olor. Muchos productos que dicen en la etiqueta "para piel sensible" no tienen olor.
- **Acné.** Algunos adolescentes sufren de acné (granitos) debido al aumento de la grasa de la piel, los cambios en las hormonas, la higiene y hasta la genética. Pregunte al médico de su hijo sobre los productos para el acné que no necesitan receta, como cremas, lociones y líquidos que contienen medicamentos como el ácido salicílico o el peróxido de benzoílo. Tome una foto de la cara de su hijo o use un dibujo y marque con círculos las áreas donde se debe aplicar el producto a diario. Enseñe a su hijo que hay que evitar las zonas sensibles como los ojos, los agujeros de la nariz y la boca. También considere comprar las toallitas que contienen el medicamento y que facilitan la aplicación. Si su hijo tiene acné en el cuerpo, también venden jabón líquido con medicamento.

Vea el Anexo Fomentar el aseo personal

Puntos problemáticos: vello corporal y rasurarse/afeitarse

Durante la pubertad, empieza a crecer y a cambiar el vello en el cuerpo. Use un dibujo del cuerpo de un hombre (como el del *Anexo Las partes del cuerpo*) para enseñar a su hijo dónde crece el vello y para prepararlo para los cambios que verá en su cuerpo. Algunos adultos y adolescentes quieren rasurarse el vello del cuerpo.

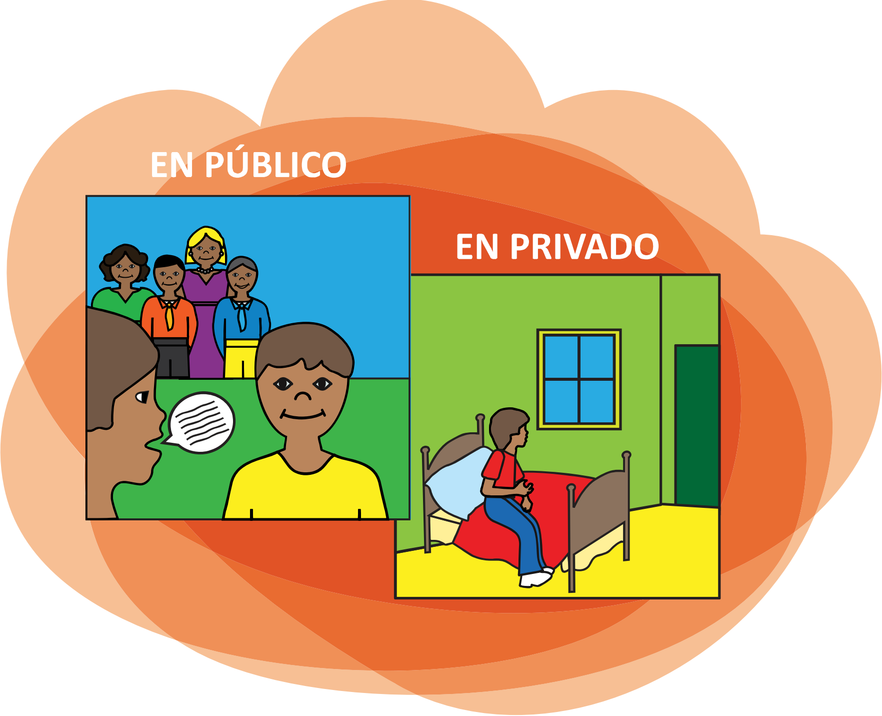
- **Demuestre cómo afeitarse.** Permita que su hijo lo mire a usted o a un hermano mayor mientras se rasura, y escriba los pasos. Haga que su hijo practique con usted, paso por paso. Escriba o tome fotografías de cada paso para hacer una guía o agenda visual. Para ayudarle a recordar dónde tiene que rasurarse, use una foto o dibujo de una persona y coloree o numere las áreas que hay que rasurar.
- **Anote las fechas en que se debe afeitar.** Si su hijo puede rasurarse (o si lo hace con ayuda), use un calendario con dibujos o marcas como recordatorio de cada cuando tiene que rasurarse y cuándo tiene que cambiar la afeitadora.
- **Limite la espuma de rasurar.** Si su hijo necesita ayuda con el control de cantidades o manejando el frasco de espuma, trate de usar los frasquitos de espuma para viajes o una brocha de afeitar.
- **Busque la rasuradora correcta.** Los niños que tienen problemas con las manos pueden preferir una rasuradora eléctrica, en lugar de la afeitadora. Si prefiere la afeitadora tradicional, pregunte a su terapeuta ocupacional si las afeitadoras con contrapeso o un manguito universal pueden ayudarle a sujetarlas.

Puntos difíciles: lavarse los dientes y el aliento

- **Haga una agenda visual.** Use dibujos que muestren los pasos de cepillarse los dientes. En el *Anexo Fomentar el aseo personal* puede ver imágenes que le muestran a su hijo cómo cepillarse los dientes él solo.
- **Escoja el cepillo de dientes correcto.** Un cepillo que vibre o tenga contrapeso puede ayudar a los niños que tengan dificultad para agarrar el cepillo de dientes y cepillarse. Busque un cepillo de cerdas suaves.
- **Demuestre cuándo y cuánto tiempo.** Acostumbre a su hijo a cepillarse a diario, incluyendo recordatorios en un calendario. Las alarmas también pueden recordarle por cuánto tiempo tiene que cepillarse. ¡Los dentistas recomiendan dos minutos! 🟩

Vea el Anexo Fomentar el aseo personal

IV. Por favor, ¡aquí, no!



Comportamiento apropiado e inapropiado en público

¿Hace o dice su hijo cosas en público que usted preferiría que no hiciera? Su hijo necesita aprender lo que está bien hacer en público y lo que está bien hacer en privado. Los comportamientos privados incluyen, por ejemplo, ir al baño, expulsar gases, tocarse las partes íntimas por cualquier motivo y cambiarse de ropa. Saber comportarse apropiadamente en la sociedad puede ayudar a su hijo a encajar con sus compañeros y que haya menos posibilidades de que lo acosen o maltraten. Los niños que entienden la diferencia entre los comportamientos que están bien o están mal en público pueden tener menos problemas en la escuela o con la policía cuando se hacen mayores.

Enseñar estas habilidades a su hijo

- **Comience pronto.** Hable sobre los comportamientos públicos y privados en familia y ponga reglas como, por ejemplo: "Solo puedes estar desnudo en el baño o en tu recámara con la puerta cerrada" o "Nos ponemos la ropa o la pijama antes de salir del baño o de la recámara". Recuerde las reglas a su hijo usando palabras o dibujos sencillos. ¡Tenga las mismas reglas para todos en la familia!
- **Use apoyos visuales.** Haga una lista de lugares que son públicos y lugares que son privados. Luego puede pensar ejemplos de comportamientos que están bien en cada uno de esos lugares. Use apoyos visuales para ayudar a su hijo a entender y recordar esas reglas. Vea el *Anexo Comportamientos en público o en privado* para buscar ideas e imágenes que se pueden imprimir para enseñarle los conceptos de en *público* y en *privado*.
- **Use historias.** Las historias ayudan a su hijo a entender estas reglas y por qué las tenemos. Piense en los comportamientos que son un problema para su hijo y escriba una historia que explique claramente cuándo y dónde está bien hacer eso. En el *Anexo Comportamientos en público o en privado* puede ver ejemplos de historias sobre cosas que se hacen en público y en privado.

Vea el Anexo Comportamientos en público y en privado

- **Dirija**. Diga a su hijo dónde puede hacer esas cosas privadas usando palabras o dibujos sencillos. Por ejemplo, diga algo como: "Puedes hacer eso en tu (recámara, baño)" o muéstrele una tarjeta visual que diga "En privado". Diríjale a un lugar privado cuando se toque sus partes íntimas o cuando se ajuste la ropa interior.
- **Cuando lo privado no puede ser privado.** Algunos niños necesitarán ayuda con tareas que se hacen en privado, como vestirse, bañarse o hacer sus necesidades. Enseñe a su hijo a quién puede pedir ayuda para estos actos privados cuando está en lugares públicos, como la escuela o en un restaurante. Esto incluye enseñarle a planear, pedir ayuda discretamente o usar gestos o tarjetas.

Tocarse las partes íntimas

Todos los niños, en algún momento, descubren sus partes íntimas. Cada familia tiene sus propios valores y creencias sobre este comportamiento, y está bien que usted le enseñe a su hijo lo que su familia cree. El tocarse a veces es una parte normal del desarrollo de los niños y las niñas, por lo que es casi imposible impedir este comportamiento por completo. Enseñar a su hijo cuándo y dónde está permitido hacer eso puede ser una mejor opción. Castigar, avergonzar o llamar mucho la atención puede hacer que el comportamiento ocurra todavía más, o también puede hacer que el niño ya no quiera preguntarle cosas importantes a usted o al doctor.

Es importante conocer los hechos. Tocarse las partes íntimas no va a causar ceguera, ni uno se "vuelve loco", ni se deja de crecer o se lastima las partes íntimas. No siempre está asociado a pensar en el sexo. Algunos jovencitos se tocan porque es una sensación que los calma. Algunos niños pueden tocarse las partes íntimas porque sienten picor o dolor, lo cual podría ser señal de una infección. Si su hijo se toca tanto que le impide hacer otras actividades, si nota la piel irritada, o tiene otras inquietudes, hable con el doctor.

Para enseñar al niño cuáles son las "partes íntimas" se puede decir que son las que se cubren con el traje de baño o la ropa interior. Puede encontrar ejemplos de apoyos visuales e historias sociales para hablar de las partes íntimas y sobre tocarse en el *Anexo Partes íntimas*.

Si su hijo se toca las partes íntimas en público, usted quiere que deje de hacerlo rápida y silenciosamente. Puede usar un apoyo visual para recordarle esta regla, como "No tocarse" o una imagen para que haga otra cosa que no puede hacer al mismo tiempo, como "Manos sobre la mesa". Para interrumpir el comportamiento, use un Tablero Primero-Después con las imágenes de "Lavarse las manos" y luego "Premio". Antes de salir, considere traer actividades para que tenga las manos ocupadas, como un jueguito o videojuego de mano. Si está en casa, puede usar un apoyo visual para que escoja "No tocarse" o ir a un sitio "En privado". ■

Vea el Anexo Comportamientos en público y en privado

La pubertad puede ser difícil para todos los niños. Los amigos, las destrezas sociales y la apariencia importan más ahora. Su hijo quizá necesite ayuda para controlar el estrés y encajar con los compañeros. Cuando los niños pasan de la escuela primaria a la secundaria y luego a la preparatoria (High School), la ropa, salir con chicas y manejar ganan importancia. Ahora, las diferencias en su desarrollo se pueden notar más. Piense en las situaciones sociales por las que tendrá que pasar su hijo y cómo las cosas como la vestimenta, el corte de pelo o los intereses acorde a su edad pueden ganar importancia en el “mundo social”.

Cómo puede ayudar a su hijo en la parte social

Haga que participe en actividades que le gustan con otros compañeros. Encuentre grupos que hagan las actividades que disfruta su hijo, como deportes individuales o de equipo, un club sobre algo que le interese, o un grupo juvenil. Hable con el líder de ese grupo sobre las necesidades de su hijo e ideas sobre cómo incluirlo. Contacte a grupos de ayuda locales para saber más sobre lo que hay disponible en su área. Si no encuentra ningún grupo, considere empezar uno.

Hable con el maestro o consejero de la escuela sobre entrenar a los compañeros. Existen programas para ayudar a los otros niños a entender las cualidades y los retos de su hijo. Enseñar a los compañeros sobre por qué su hijo se comunica, aprende, camina o se mueve de manera diferente puede ayudar a que lo entiendan más. Muchos grupos tienen folletos con consejos, sitios web y recursos locales para ayudar a promover la comprensión y la inclusión. Vea la lista de recursos en la página 15.

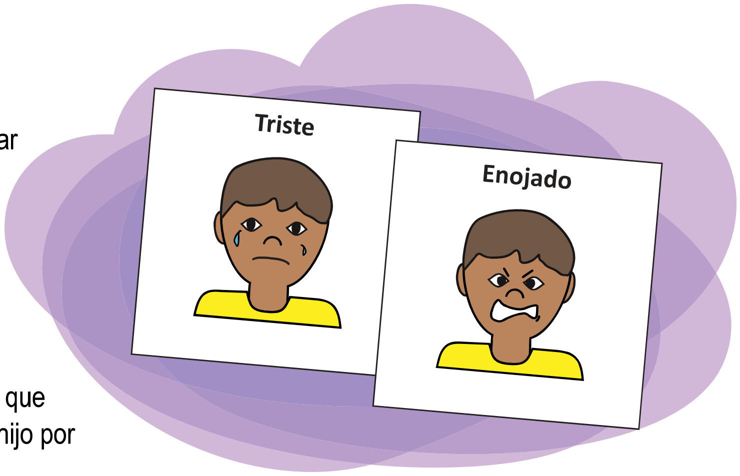
Cabello. Lleve a su hijo a que le corten el pelo acorde con su edad. Parte de crecer es llevar la ropa y el cabello cortado como los chicos de su edad. Aunque esto puede que no sea su mayor prioridad, puede que sea muy importante para su hijo y los otros chicos.

- Mire en revistas o hable con otros padres para darse una idea de la moda. Piense en cortes de pelo que sean fáciles de mantener. Deje que escoja la foto del corte de pelo que prefiere y que se la dé al peluquero.
- Haga una cita a una hora en la que la peluquería no tenga muchos clientes y considere pedir tiempo extra en caso de que su hijo necesite descansar. Traiga algo para distraerlo como una tableta electrónica o un juego para ayudar a su hijo a tolerar el corte de pelo.
- Hable con el terapeuta ocupacional sobre el cuidado personal de su hijo (como cepillarse y peinarse) y equipo con adaptaciones que le pueda ayudar a ganar independencia.

Vestuario. Cuando vaya de compras para su hijo es importante buscar ropa que siga la moda para su edad. ¿Cómo se visten los otros niños? Fíjese cuando vaya a la escuela. Para saber dónde compran su ropa otros adolescentes, puede mirar revistas, hablar con otros padres o llevar a un hermano o primo mayor con usted cuando vaya de compras.

Si puede hacerlo, deje que su hijo escoja entre varias opciones. O puede decirle que escoja usando dibujos en un tablero. Puede llevarlo de compras, o comprar varias camisas y mostrárselas para que escoja. También puede usar el tablero con dibujos o fotos. Si su hijo tiene preferencias fuertes en cuanto a la ropa, o si tiene dificultad con los botones o cierres, introduzca otras opciones de camisas o pantalones poco a poco. Busque ropa que sea cómoda, que le quede bien y considere los colores y texturas que prefiere el niño. Use una historia social para explicar que los niños, los adolescentes y los adultos se visten de manera diferente. Por ejemplo, cambiar los zapatos con velcro por zapatos tipo mocasín, o dejarse la camisa por fuera, si el pantalón tiene cinturilla elástica, puede ayudar a que su hijo se vista más como los compañeros. Trabaje con el terapeuta ocupacional en enseñarle a vestirse.

Vea el Anexo Humor y sentimientos



¿Qué pasa si a él no le importa?
La pubertad y la adolescencia consisten en ganar independencia y expresar la individualidad. Incluso si pareciera que a su hijo no le importa la ropa, algunas cosas pequeñas como un estilo diferente de pantalón o un nuevo corte de pelo pueden ayudar mucho a que se sienta incluido. Puede evitar que se rían de él. ¡Vestirse más como de su edad puede ayudar a que los compañeros sepan qué gran persona es su hijo por dentro también!

Dispositivos de comunicación. Si su hijo usa un dispositivo de comunicación con producción de voz, asegúrese de que la voz sea del mismo sexo y edad.

Humor y sentimientos

Los cambios de humor pueden ser normales durante la pubertad. Usted puede enseñar a su hijo a expresar sus sentimientos. Si su hijo puede hablar, use las palabras para nombrar los sentimientos (“parece que estás enojado” o “cuando él hizo eso, te pusiste triste”). Si su hijo no usa palabras, use apoyos visuales como caricaturas, fotos, lenguaje de señas o tarjetas con palabras escritas. El *Anexo Humor y sentimientos* incluye imágenes de emociones que su hijo puede usar para hacerle saber cómo se siente. Considere consultar a un consejero o terapeuta que esté familiarizado con el diagnóstico de su hijo y que pueda darle otras estrategias.

Más que “malhumorado”

A veces los cambios de humor pueden ser a causa de otros problemas más graves, como problemas médicos. Por ejemplo, los problemas de la tiroides (que son comunes entre los niños con síndrome de Down) pueden parecer depresión ya que afectan el humor, el apetito y el nivel de actividad. Los cambios de humor también pueden ser un síntoma de depresión o ansiedad. Los chicos con discapacidades pueden estar malhumorados como los adolescentes típicos, pero también pueden desarrollar problemas de salud mental que necesitan ser tratados. Vigile si se dan **cambios** en su comportamiento típico, como los que se destacan a continuación:

- **Emociones**: Llora, grita, se ríe sin que haya motivo claro para ello
- **Comportamiento**: Pasearse, balancearse, restregarse las manos, pellizcarse la piel
- **Agresión**: Golpear, morder, arañar, golpearse la cabeza, lanzar cosas
- **Apetito**: Comer más o menos
- **Bienestar**: Quejarse de dolor de cabeza, dolor de estómago u otros dolores del cuerpo
- **Sueño**: Dormir más o menos, problemas para quedarse dormido, pesadillas
- **Pensamiento**: Parece confundido, problemas de concentración, ver cosas que no están ahí
- **Energía**: Moverse más o menos, actuar retraído, no hacer cosas que antes le gustaba hacer

Hable con el doctor de su hijo sobre los cambios que ve. Guarde notas en un diario, hoja de datos (vea el *Anexo Diario*) o una aplicación de teléfono electrónico o tableta. Escriba lo que ve y cuándo lo ve. ■

Vea el Anexo Diario

Emisiones nocturnas

Muchos chicos adolescentes eyaculan mientras duermen cuando llegan a la pubertad. Esto se llama emisión nocturna. Algunas personas lo llaman *sueño húmedo*. El pene liberará semen, un líquido que contiene esperma. **Este es un proceso normal que no está bajo el control del niño.**

Las emisiones nocturnas pueden aparecer como manchas húmedas, pegajosas en la ropa interior o la pijama, o en las sábanas. Las emisiones nocturnas empiezan normalmente entre los 13 y los 17 años, pero en promedio empiezan a los 14 años. Es muy importante que prepare a su hijo para este evento de manera que no piense que ha hecho algo malo. Esta es una parte normal de la pubertad.

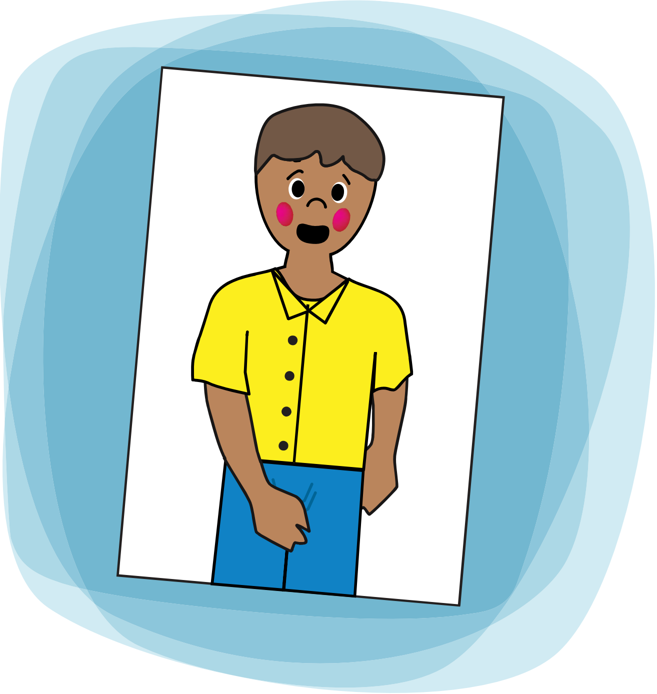
Preparar a mi hijo para las emisiones nocturnas

- **Sepa la diferencia.** Su hijo puede pensar que se orinó en la cama después de una emisión nocturna. Puede esconderlo o tener miedo de decirle a usted. Explíquele que lo que ha pasado es normal.
- **Relacione.** Puede ayudarle si relaciona las emisiones nocturnas con los otros cambios que están pasando en el cuerpo de su hijo durante la pubertad. Por ejemplo la aparición del vello, el aumento de estatura, el crecimiento del pene y los testículos.
- **Anime a la independencia.** Las emisiones nocturnas no se pueden prevenir. Enseñe a su hijo qué hacer cuando le pasen. Esto puede incluir cambiar las sábanas, poner el calzoncillo en la canasta de la ropa sucia y lavarse las partes íntimas con una toallita húmeda.
- **Use apoyos visuales.** Use un programa visual para ayudar a su hijo a lavarse después de una emisión nocturna. Esto puede incluir limpiarse con toallitas o pañuelos de papel, quitar las sábanas y ponerlas en la canasta de la ropa sucia, o ponerlas en la lavadora. En el *Anexo Enseñar sobre las erecciones* verá dibujos que puede usar para ayudar a su hijo a ser más independiente en el aseo personal. Si su hijo no puede cambiar las sábanas o lavarse independientemente, enséñele cómo avisar de que necesita su ayuda. Una opción sería usar una tarjeta o un letrero que pueda colgar en la puerta para comunicarse con usted.
Puede ver ese letrero para la puerta en el *Anexo Enseñar sobre las erecciones*. Solo recórtelo y enmíquelo (lamínelo) para usarlo con frecuencia.

- **En privado.** Las emisiones nocturnas son un asunto privado. Enseñe a su hijo que solo puede hablar de ellas con los padres, doctores o la enfermera de la escuela. Enséñele que no debe hablar de ellas con los amigos, los maestros o los desconocidos.
- **Ser positivo.** Las emisiones nocturnas son una parte natural de la pubertad. **Las reacciones negativas (avergonzarle, reírse, castigarle) no van a detenerlas.** En su lugar, responda de manera calmada, directa y con el enfoque en enseñar a su hijo qué hacer.
- **Pregunte.** Pida al doctor de su hijo que le ayude a la hora de enseñarle sobre la pubertad y los cambios en el cuerpo.

Vea el Anexo Enseñar sobre las erecciones

Erecciones



Durante la pubertad, la mayoría de los adolescentes tienen varias erecciones durante el día. Esta es una parte normal de la pubertad y los chicos no las pueden controlar. Las erecciones pueden ocurrir por muchos motivos. A esta edad pueden pasar por algo simple como el frote del pantalón contra el cuerpo o "porque sí". Debido a que su hijo no puede controlarlas, las erecciones en público pueden ser inevitables y penosas para él.

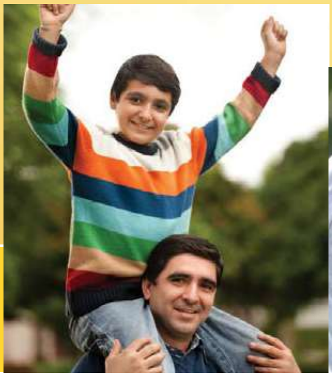
Cosas que pueden ayudar

- Cree o use la historia social del *Anexo Enseñar sobre las erecciones* para hablarle a su hijo acerca de las erecciones.
- Recuérdele que esta es una de esas cosas de las que se pueden hablar con el doctor y con usted, pero no con los amigos, maestros o desconocidos.
- Dele algunas ideas sobre qué hacer si le pasa eso en público:
  - Quedarse sentado, con el tiempo se le va a pasar.
  - Cargar los libros muy abajo, para tapar las zonas íntimas.
  - Atarse una chaqueta o chamarra a la cintura.
- Los calzoncillos del tamaño apropiado pueden hacer las erecciones menos obvias y contener todo en su sitio. Evite los pantalones de deportes y pantalones muy anchos.

Calzoncillos bóxer o trusas

Ayudar a su hijo a escoger el tipo de calzoncillo depende de qué es más importante para usted y su hijo. Los calzoncillos bóxer pueden ser más fáciles de poner y quitar. Las trusas o calzones cortos pueden sujetar más. Lleve a su hijo a la tienda para escoger varios tipos distintos. Déjele que se los pruebe en la casa para ver qué tipo prefiere. ■

Vea el Anexo Enseñar sobre las erecciones



Puede encontrar un anexo con apoyos visuales en

kc.vanderbilt.edu/HealthyBodies

Organizaciones

☐ Vanderbilt Kennedy Center: vkc.mc.vanderbilt.edu

☐ Autism Society of America: www.autism-society.org

☐ Autism Speaks: www.autismspeaks.org

☐ Easter Seals: www.easterseals.com

☐ National Down Syndrome Society: www.ndss.org

☐ National Parent Technical Assistance Center: www.parentcenternetwork.org

☐ American Society for Deaf Children: www.deafchildren.org

☐ United Cerebral Palsy: www.ucp.org

Recursos sobre apoyos visuales

☐ http://card.ufl.edu/content/supports/start.html

☐ www.kidaccess.com/index.html

☐ Do 2 Learn: www.do2learn.com

☐ Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Sitios web

☐ National Information Center for Children and Youth With Disabilities. *Información sobre la sexualidad para niños y jóvenes con discapacidades. Disponible en:* http://nichcy.org/schools-administrators/sexed

☐ Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center: www.pacer.org/bullying

☐ www.autismspeaks.org/family-services/tool-kits/dental-tool-kit

☐ vkc.mc.vanderbilt.edu/assets/files/tipsheets/oralhealthtips.pdf

☐ http://kidshealth.org/teen/sexual_health/#cat20015

☐ www.freewebs.com/kidscandream/main.htm

Historias sociales - información y ejemplos

☐ Gray, C., & White, A. L. (2002). *My social stories book*. Philadelphia, PA: Jessica Kingsley Publishers.

☐ www.thegraycenter.org/social-stories/what-are-social-stories

☐ www.bbbautism.com/pdf/article_27_Social_Stories.pdf

Libros

☐ Gravelle, K., Castro, N., & Castro, C. (1998). *What's going on down there? Answers to questions boys find hard to ask*. New York: Walker and Company.

☐ Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty, and personal curriculum for young people with autism*. Arlington, TX: Future Horizons.

☐ Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks galore for the real world*. Raleigh, NC: Tasks Galore. www.tasksgalore.com

☐ Bellini, Scott, *Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with autism spectrum disorders and other social difficulties* (2006). Autism Asperger Publishing Co., Shawnee Mission, KS.

☐ Middleman, A. B., & Pfeifer, K. G. (2006). *Boy's guide to becoming a teen: Getting used to life in your changing body*. American Medical Association.

☐ Madaras, L., & Madaras, A., Sullivan, S. (2007). *What's happening to my body? Books for boys: A growing-up guide for parents and sons*. Newmarket Press.

☐ Baker, Jed (2009) *Social skills picture book for high school and beyond*. www.mayer-johnson.com/the-social-skills-picture-book-for-high-school-and-beyond

☐ Meehan, Cricket, *The right to be safe: Putting an end to bullying behavior* (2011). Busque: Institute Press.

Esta publicación fue desarrollada y escrita por los experimentados investigadores en práctica de Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND): Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; estudiante de doctorado de Audiología, Elizabeth Harland; Cong Van Tran, PhD; y los profesores de LEND Jennifer Bowers, RN, MSN, CPNP, Enfermera Pediátrica de Práctica Avanzada, División de Medicina del Desarrollo y Cassandra Newsom, PsyD, Profesora Auxiliar de Pediatría, División de Medicina del Desarrollo, Directora de Educación Psicológica, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. Fue editada, diseñada y producida por el personal de Diseño Gráfico y Difusión del Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) con apoyo de Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). Les agradecemos la revisión y sugerencias de numerosos miembros del personal de TRIAD y de Autism Society of Middle Tennessee.

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Esta publicación fue posible, en parte, gracias al siguiente financiamiento: Grant N.º T73MC00050 de Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Sus contenidos son la responsabilidad única de los autores y no representan necesariamente las posturas oficiales del MCHB, HRSA, HHS. Fotos ©istockphoto.com. 12/2014.

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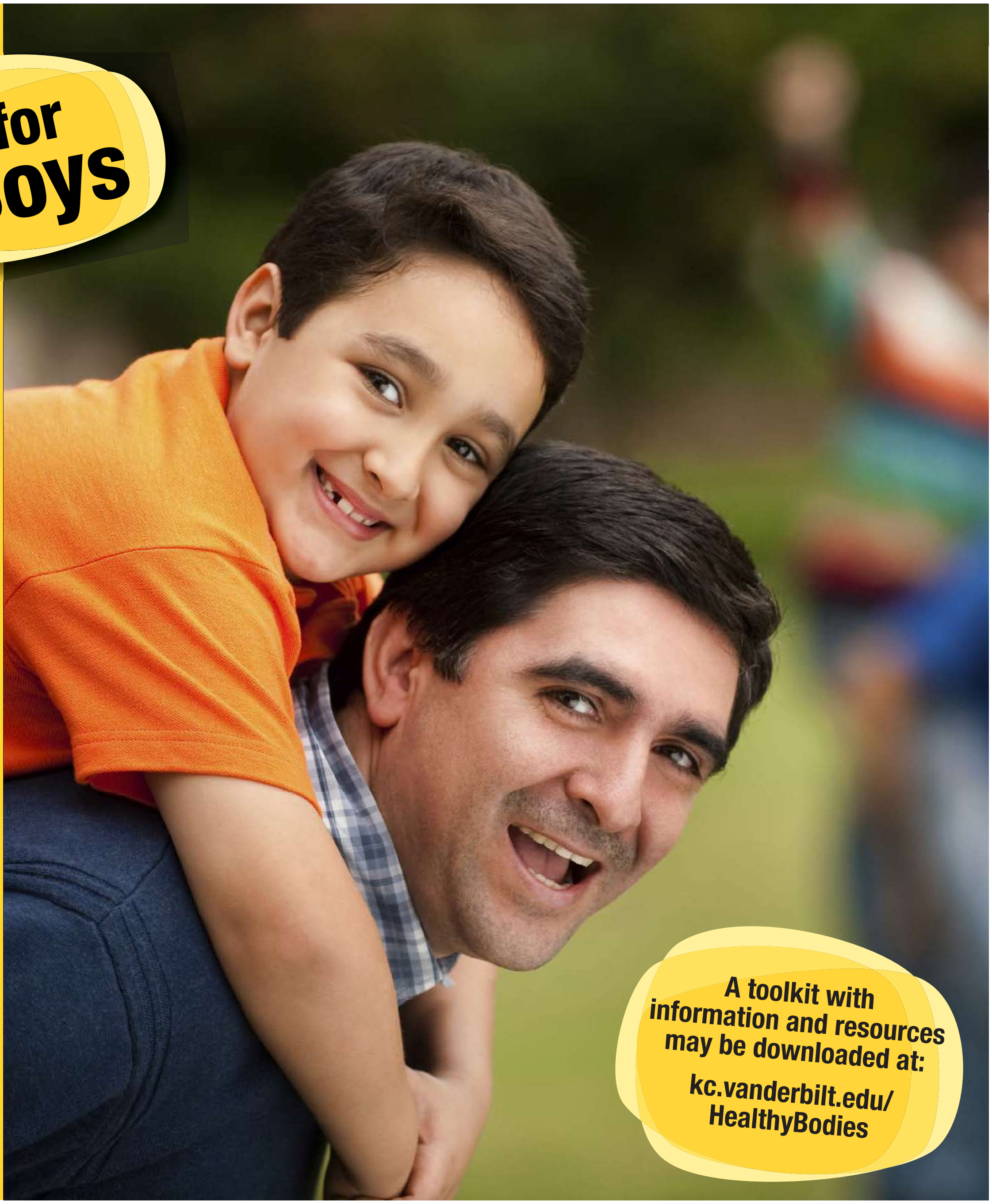
LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Healthy Bodies – Appendix

for Boys



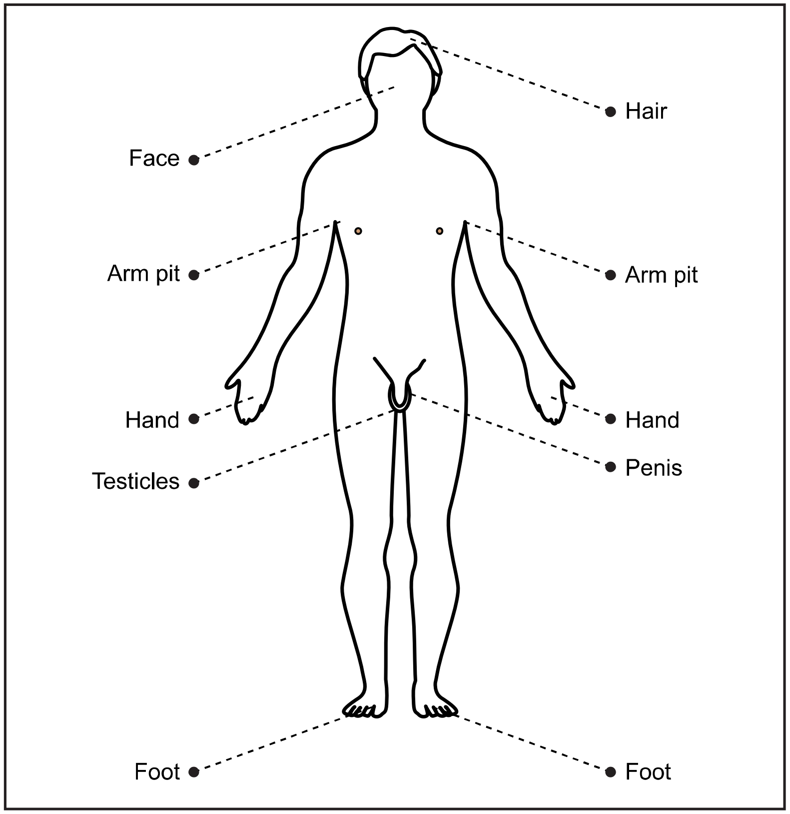
A toolkit with information and resources may be downloaded at:
kc.vanderbilt.edu/HealthyBodies

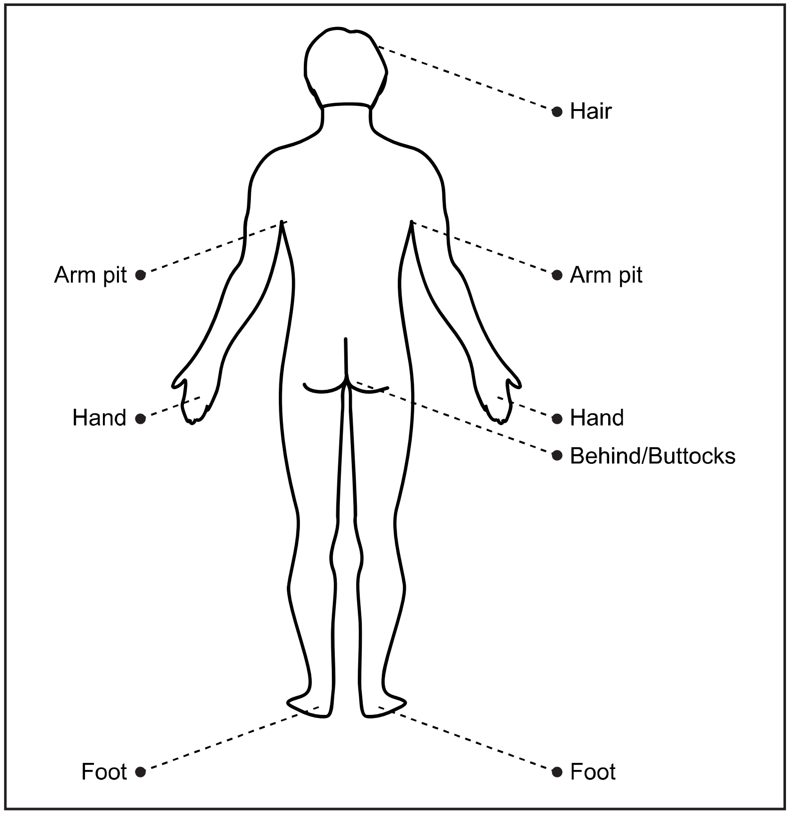
A Parent's Guide on Puberty for Boys with Disabilities

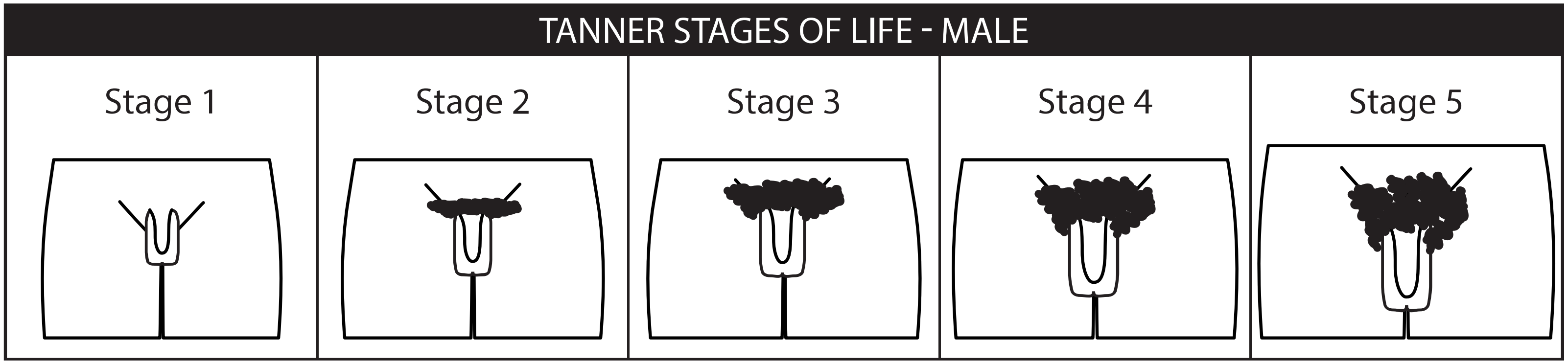
Teaching Body Parts – Visuals

Use these pictures to teach the names of body parts. After teaching, you can cover the names of body parts and make a game out of asking your son to name them. You can also cut out the names and have your son physically place them on the picture.

The Tanner Stages (below) can show him how his penis and testicles will change and hair will grow.







First/Then Board – Blank Template

To motivate your child to do things that may be hard or unpleasant for him, like exercise, try using a visual support like a First/Then Board. Put the less-preferred activity *first* and the rewarding activity *second*. For example, “First Exercise” followed by “Then Video Games.” You can use pictures or words, depending on your child’s reading skills. You can also laminate these cards and use velcro with pictures or a dry-erase marker to make them reusable.

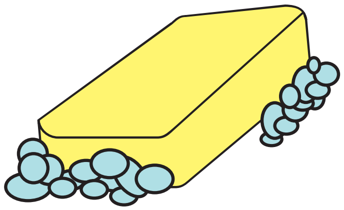
REMEMBER: Always put the more fun activity in the Then box. This shows your child what he is working to earn.

First **Then**

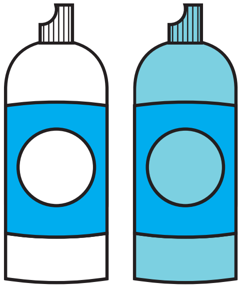
First **Then**

Encouraging Good Hygiene – Hygiene Supplies Visuals

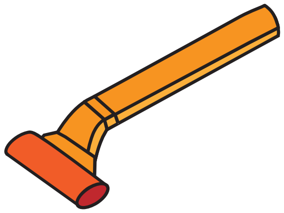
Soap



Shampoo/Conditioner

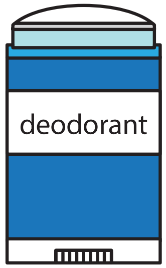


Razor

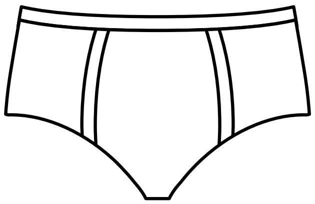


Shaving cream

Deodorant

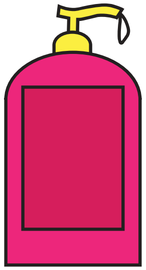


Clean underwear



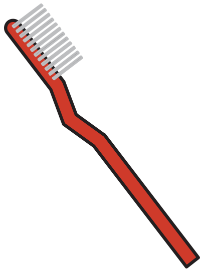
Wet wipe

Lotion



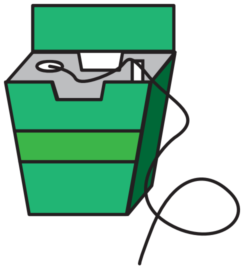
Hair brush

Toothbrush



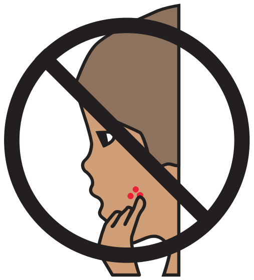
Toothpaste

Floss



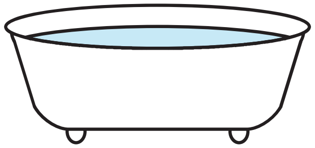
Take medicine

Don’t pick at acne

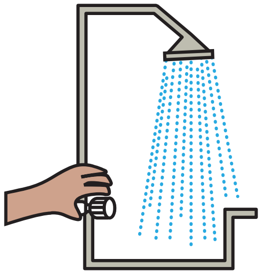


Encouraging Good Hygiene – Showering Schedule Visuals

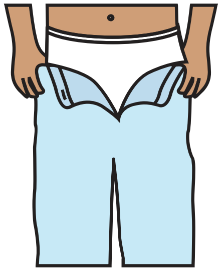
Fill tub with warm water



Turn on shower

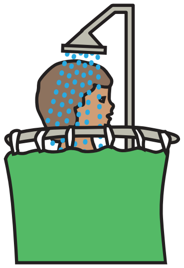


Take off clothes



Get in tub

Get in shower

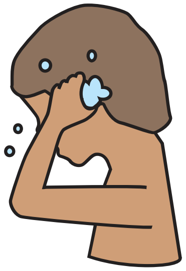


Wash whole body

Rinse soap off

Put shampoo on my hand

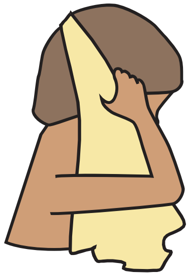
Rub into hair



Rinse out shampoo

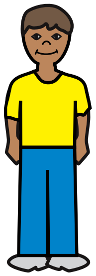
Turn off the water

Dry off with towel

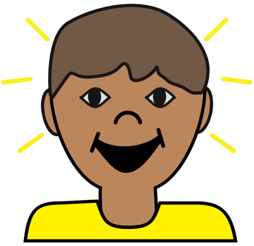


Put on deodorant

Put on clean clothes

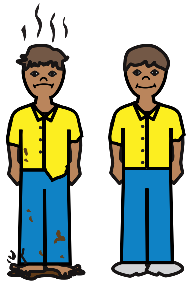


I did a good job

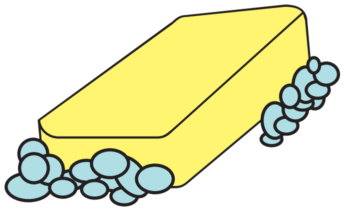


What's That Smell?

I am growing up and my body is changing. I am growing hair in my armpits and on my private parts. Sometimes my armpits and private parts may smell bad. This smell is called body odor. People don't like to smell body odor. If I smell bad, people may not want to be around me. I can stop body odor by washing my hair, armpits, private parts and feet every day with warm water and soap. After I wash, I can put deodorant on my armpits. Deodorant will help my underarms smell nice and stay dry. I will use deodorant under my arms every morning to get rid of my body odor. I like to smell nice. Smelling good will make my parents, friends, and teachers happy too.

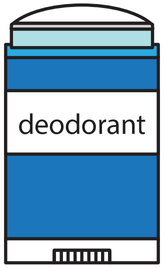

Messy vs. neat


Wash hair

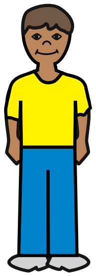

Soap


Wash whole body


Put on deodorant



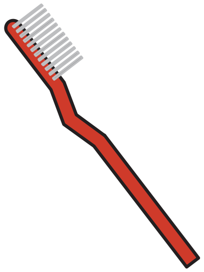
Deodorant


Put on clean clothes


Smell nice

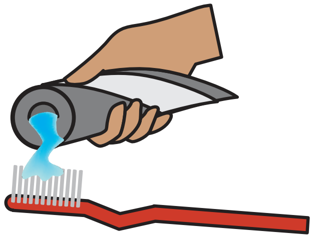
Encouraging Good Hygiene – Brushing Teeth Schedule Visuals

Toothbrush

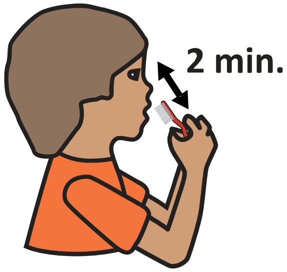


Toothpaste

Squeeze toothpaste on toothbrush



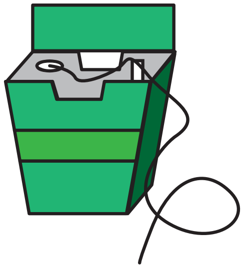
Brush teeth



Spit in sink

Rinse with water

Floss



Public/Private – Sort Board Blank Template

You can teach your son about what behaviors are okay for public places and what activities should be kept private using pictures. In the activity below, you can help him sort which activities and places are public versus private. You can use the pictures on the pages to follow or add your own pictures.

Once your son understands what public and private mean, you can use the "public" and "private" pictures as a visual reminder. For example, if he begins picking his nose, hold up the "private" card and tell him to find a private place.

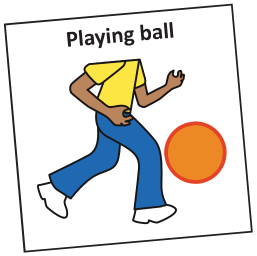
These pictures or visual reminders also can be used to prepare your son for going to a public place, such as an outing to a restaurant.

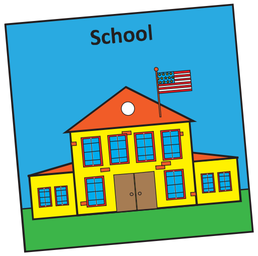
Public

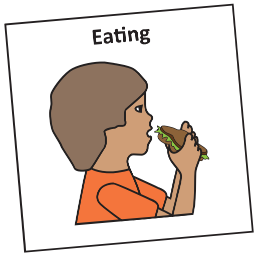
Private

Public/Private – Sort Board

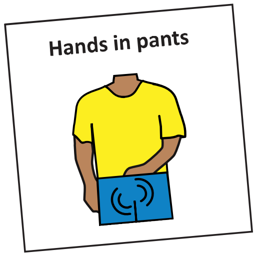
Public

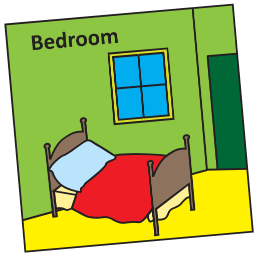


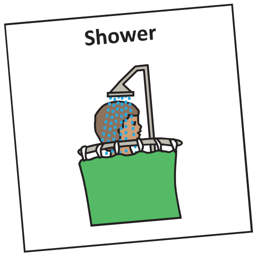




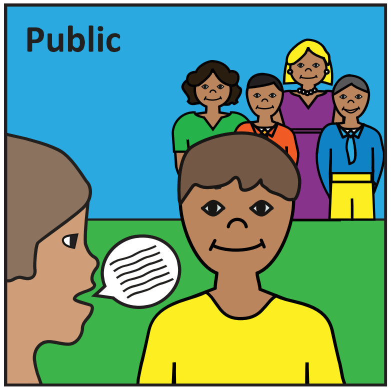
Private

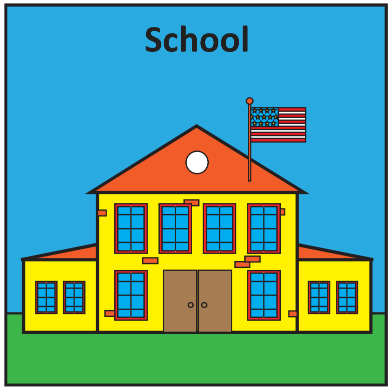


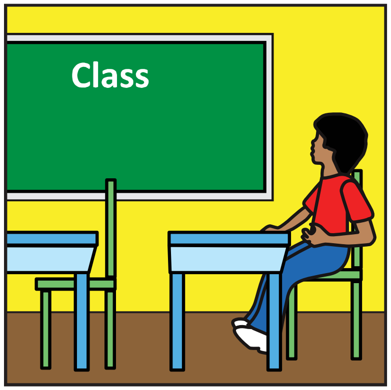


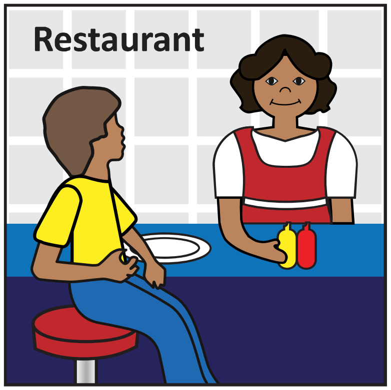


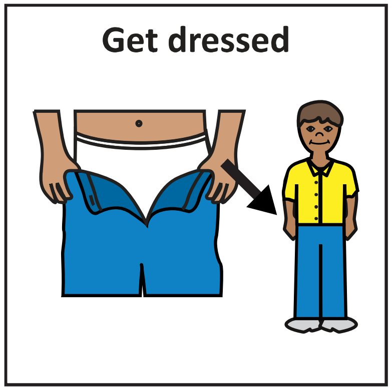
Public/Private Behaviors – Visuals

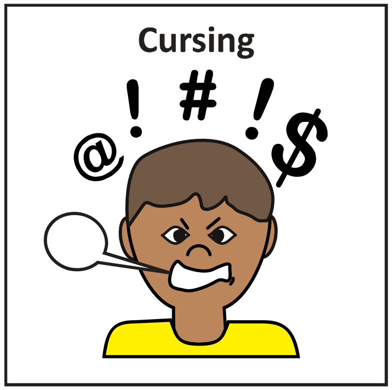


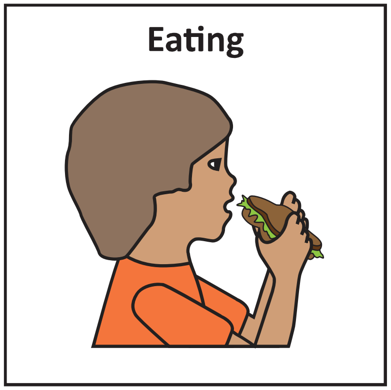


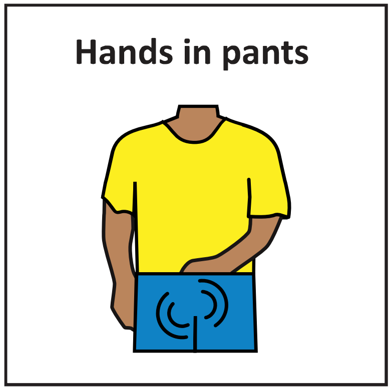


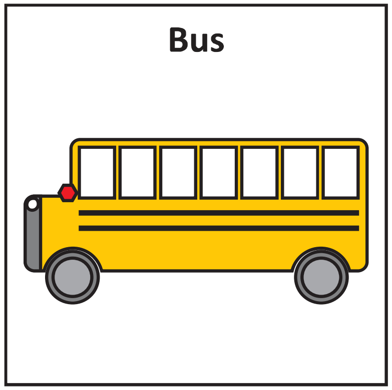






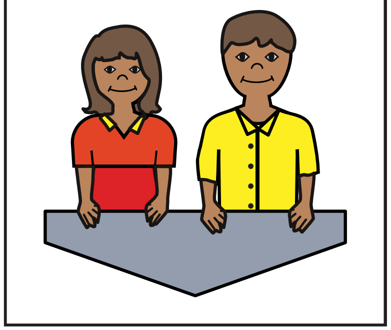


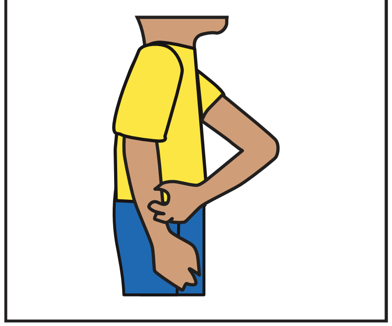




Public/Private Behaviors – Visuals


Passing gas

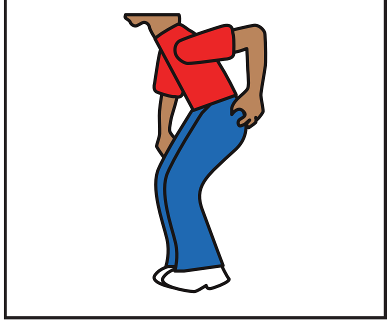

Hands on table


Scratching your arm


Bathroom stall

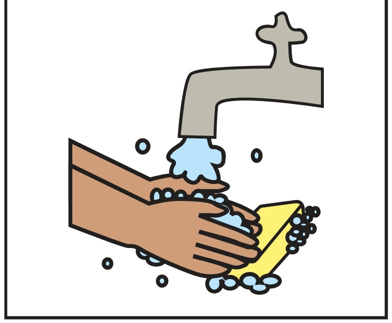

Bedroom


Bathroom

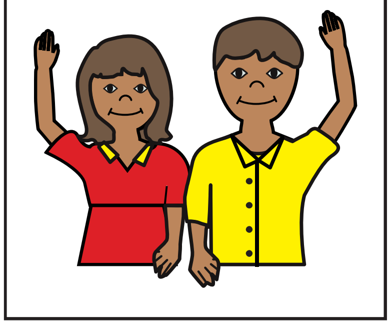

Scratching your behind


Alone

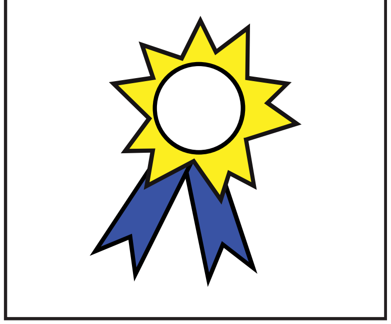

No hands in pants


Washing hands


Playing ball


Wave

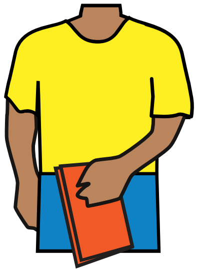

Reward


Reward

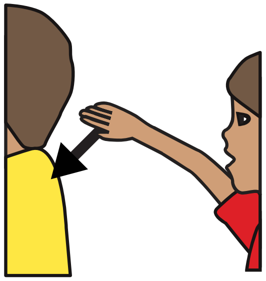

Special activity

Public/Private Behaviors – Visuals

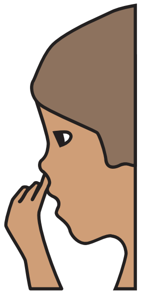
Hold book in Front



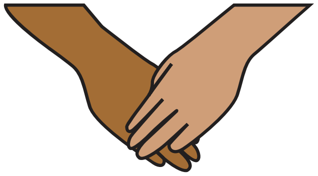
Pats on the back



Picking your nose



Holding hands



High five

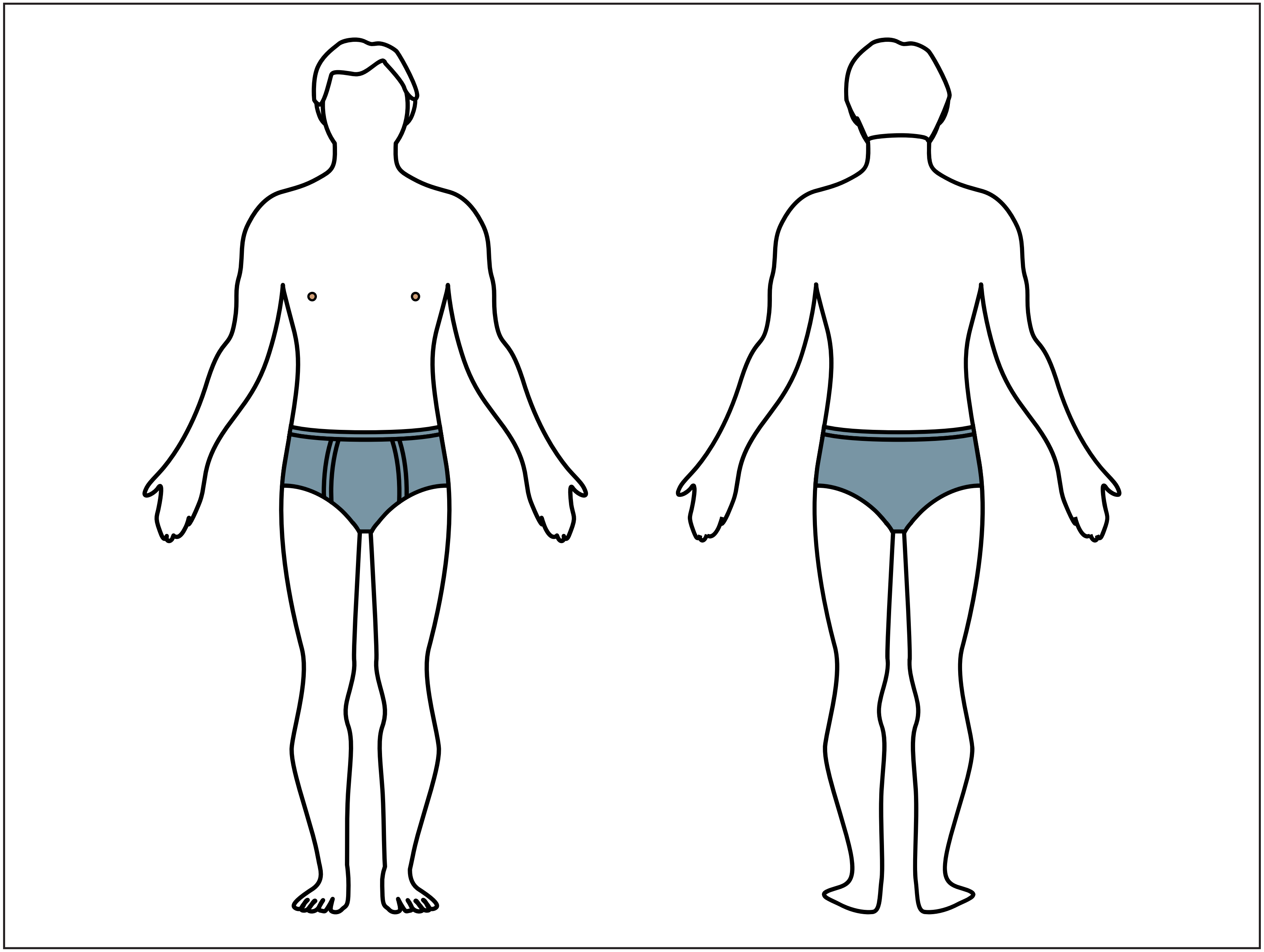
Hug

Kiss

Private Parts – Visuals

Teach your child where he can touch others and where it is okay for others to touch him by using these figures. Point to a body part and say “Can we touch?” If yes, put a green circle on that body part for “go.” If no, put a red circle for “stop.”

For example, your son should put a green circle on the hand but a red circle on the bottom. You can use the same activity and ask “Where can people touch me?”



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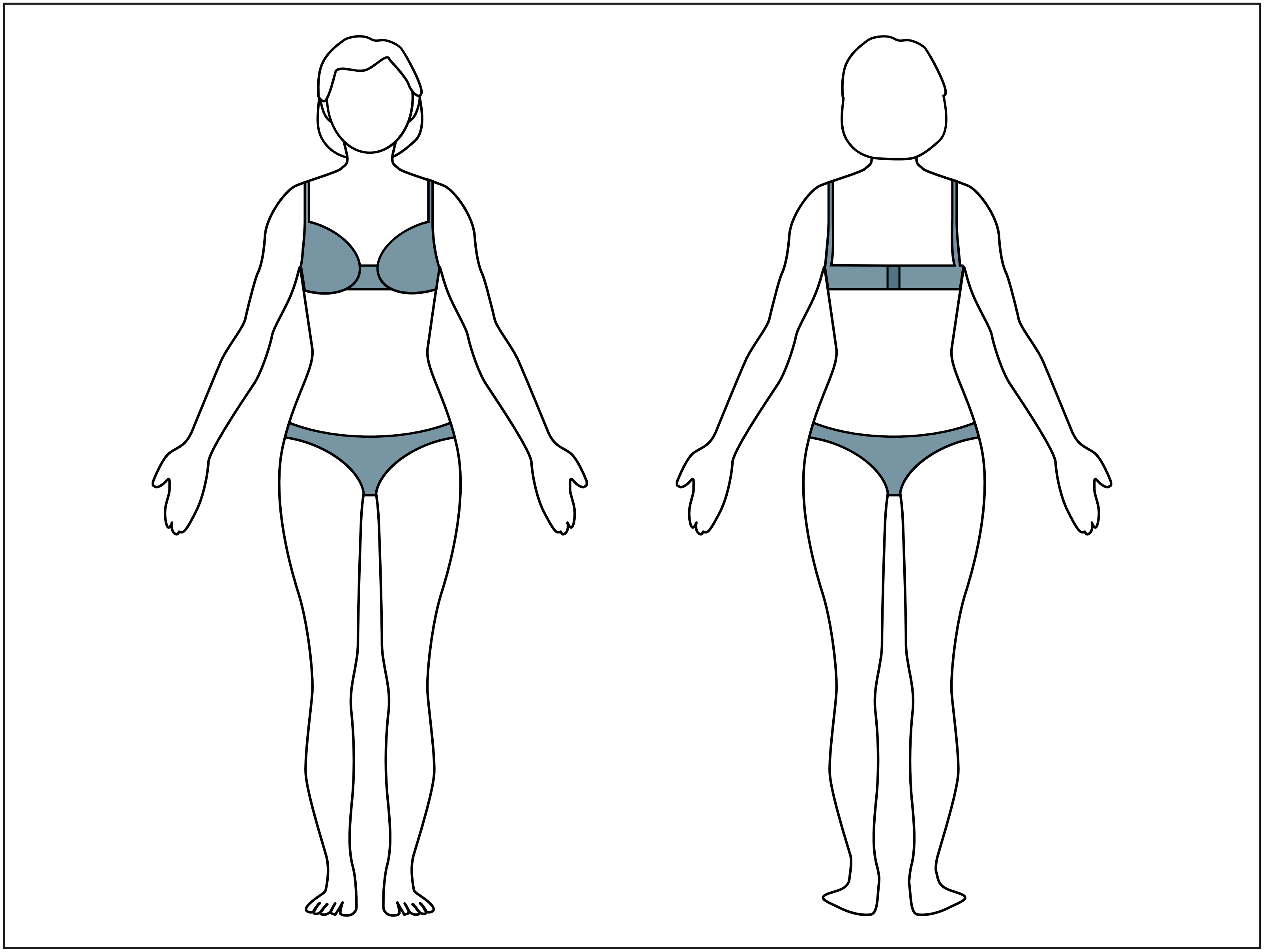
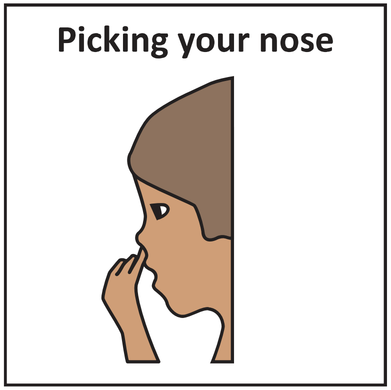
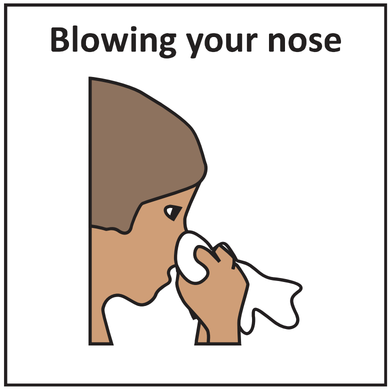
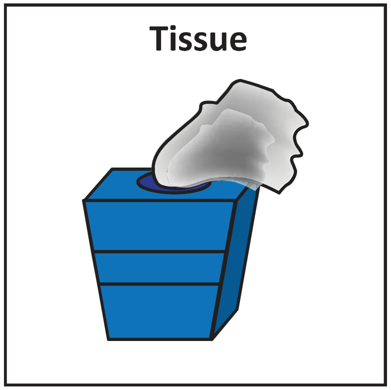


Picking Your Nose is Private

Sometimes I might pick my nose in private. I will only pick my nose when something is stuck in my nose, and I can't blow it out with a tissue. Picking my nose can spread germs. I should use a tissue when I pick or blow my nose. I must wash my hands after I touch my nose. People don't want to see me pick my nose. When I need to pick my nose, I will go to a private place, like inside the bathroom with the door closed. I will not pick my nose in front of other people or talk about picking my nose to other people.


Picking your nose


Blowing your nose


Tissue


Washing hands

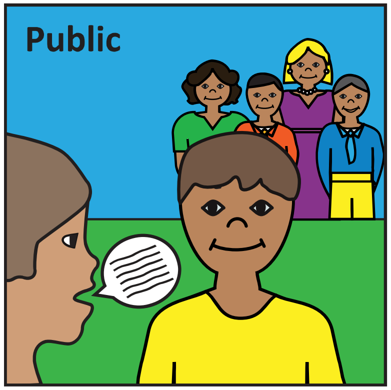

Bathroom stall


Private

Public/Private Behaviors – Story

Private Parts

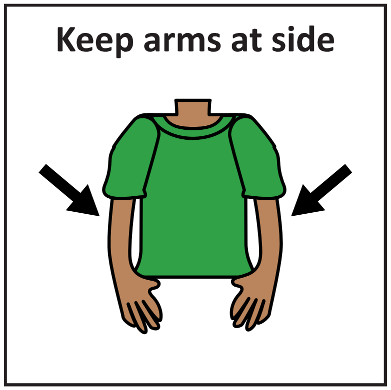
Public places are where other people can see me. **Private** means away from other people, like in my bedroom or bathroom with the door closed. Everyone has **private** parts of their body. I can tell what parts of my body are **private** because I cover them with my underwear. I don't touch my private parts in public where other people can see me. I don't ever put my hands inside my pants in public. I can help myself remember not to touch by putting my hands by my side, crossing my arms, or folding my hands. Sometimes I need to touch my private parts, like when I itch or my underwear is uncomfortable. I can ask to go to the bathroom. When I am alone in my bedroom or bathroom, I can touch my private parts.

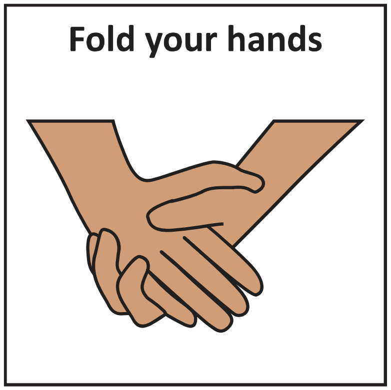

Public


Private


Underwear on private parts


Don't touch self


Keep arms at side


Fold your hands


Scratching your behind


Bathroom


Need to touch


Bedroom


Alone

But It Feels Good!

I don't touch my private parts in public where other people can see me. When I am alone in my bedroom or bathroom with the door shut, I can touch my private parts. When I touch my private parts, sometimes it feels good. Some people like how it feels when they touch their own private parts. It's okay to touch my private parts when I am alone. Sometimes touching my private parts can be messy. I will clean my hands and private parts when I am done. I will not talk about touching my private parts with others. If I have questions or if touching hurts, I will ask my _________ (insert doctor or trusted adult's name.)


Don't touch self


Alone


Bedroom


Bathroom


Closed door


Washing hands


Clean up


Don't talk about it with others


Talk to dad

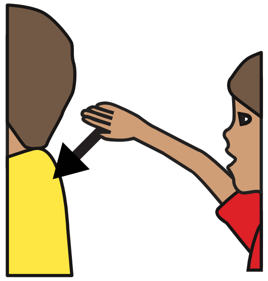
To Touch or Not to Touch, That is the Question!

When I am with my friends and family, it's usually okay to touch them and for them to touch me on the arm, back, shoulders, or hands. These are "Go" areas of the body. For example, I can give high-fives, pat them on the back, or touch them on the arm to get their attention. It's not okay for me to touch other people on parts of their body covered by underwear, such as their buttocks, breasts, penis, or vagina. It's not okay for anyone (but my doctor/parent/_______)* to touch me on parts of my body covered by my underwear either. These are private parts of the body and are "Stop" areas. If someone touches me in my private area, I should say "STOP" or "NO" and tell my Mom, Dad, or teachers. Sometimes my Mom, Dad, _______ (insert name of trusted adult) and my doctor will need to see my private areas to help me stay clean and healthy. If I don't want them to see my private areas, I can ask them for privacy.

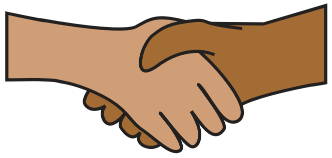
* May need to alter to include caregivers or medical professionals who need to assist with daily living skills or perform needed medical procedures.

High five

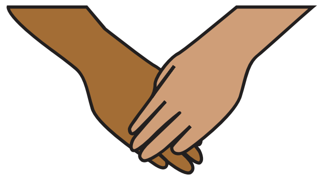
Pats on the back



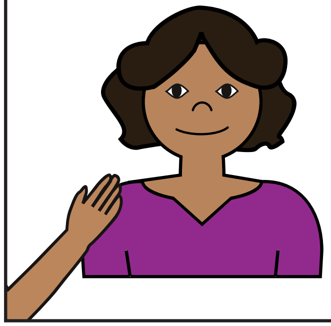
Shaking hands



Holding hands

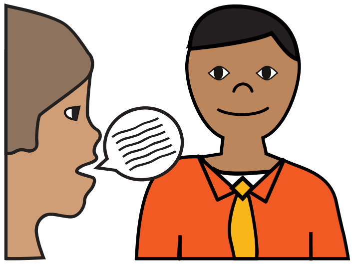


Touch shoulder



Swimsuit

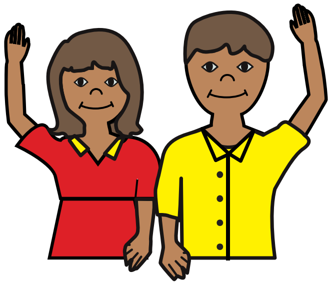
Talk to dad



Family, Friends, and Others

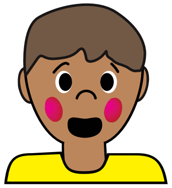
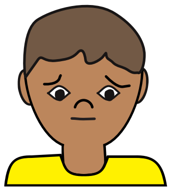
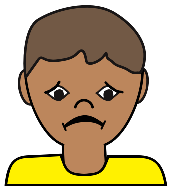
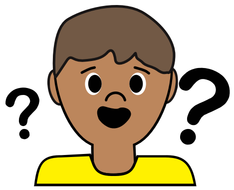
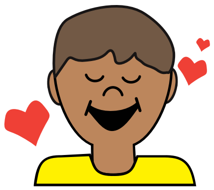
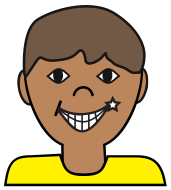
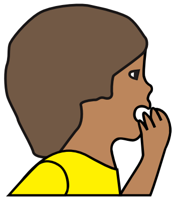
Using a sorting game to explain relationships can help your child understand what type of behavior is appropriate for different types of relationships. For example, strangers are in the far column, and your child can see that it is okay to wave or shake hands with them. Behaviors that are in the first row are for romantic partners and spouses. Family and friends fall in between. Your family can decide what behaviors should be included in each box. You may want to take pictures of people to illustrate each group.

Practice. Take it with you on outings and use it to help your child understand how to greet someone. For example, get out the chart when your child sees someone they know from school and show them what behaviors are okay to use to say hello.

Married or dating	Family	Friends	Others & strangers
Kiss 	Hug 	High five 	Wave 

Moods and Feelings – Emotions Visuals

These picture cards show different feelings and facial expressions. You can use these cards to a) label how your son is feeling and b) help him tell you how he feels. For example, if he seems happy, show him the “Happy” card while you label that feeling (“You seem happy today”). He can learn to give you the card to tell you how he feels, too.

Sad 	**Depressed** 	**Embarrassed** 	**Angry** 	**Shocked** 
Disappointed 	**Hurt** 	**Confused** 	**Frustrated** 	**Excited** 
Happy 	**Relaxed** 	**Curious** 	**Love** 	**Proud** 
Lazy 	**Ready to work** 	**Tired** 	**Grumpy** 	

Moods and Feelings – Diary

Keep track of your son's mood and behavior using a diary like this one. We have filled out the first line as an example. You can take this diary sheet to your son's next medical visit and talk about your concerns.

Date	Hours of sleep	Appetite	Behavior	Medications/ Supplements
1-8-2012	8-10 hrs, up with nightmare 11-4	Skipped breakfast		

Teaching About Erections: Handling Nocturnal Emissions – Story

When I have a wet dream

Sometimes when I wake up in the morning my underwear will be wet. I did not pee in the bed. I had a “wet dream.” This is normal.

I will take off my dirty pajamas and underwear. I will put them in the hamper. My parents will be proud of me for putting my dirty clothes away.

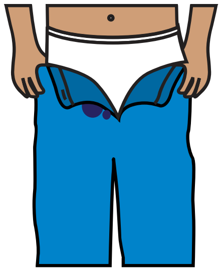
I will wash my private parts with a warm washcloth so I will be clean. Then I will put on clean underwear and pants.

Next I will let my parents know that my sheets are dirty. I can use my words or I can hang a sign on my door.

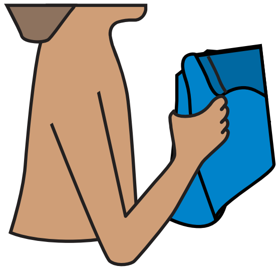
I can take the dirty sheets off my bed and put them in the hamper. This will help my mom and dad.

Wet dreams are a normal part of becoming a grown-up. I can take care of myself when I have a wet dream.

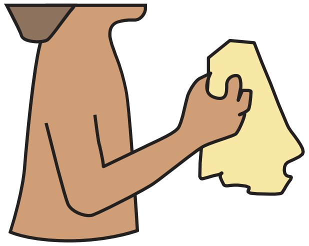
Take off dirty clothes



Put dirty clothes in hamper

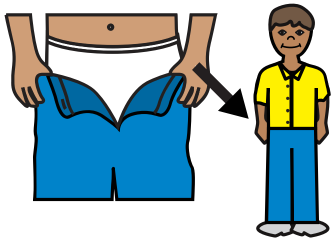


Clean up

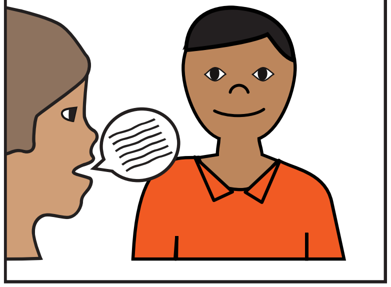


Wash private parts

Put on clean clothes

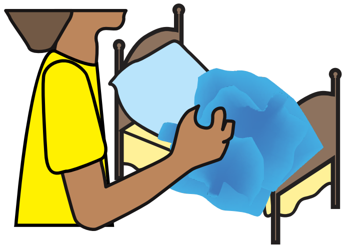


Tell mom or dad sheets are dirty



Door hanger

Take off sheets

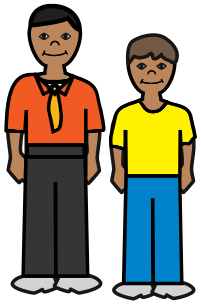


Put dirty sheets in hamper


SHEETS
ARE
DIRTY

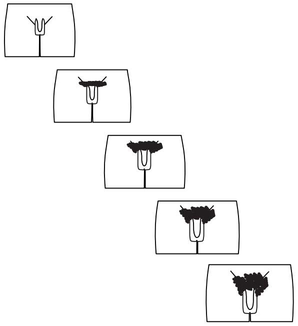
Teaching About Erections: Becoming A Man – Story

Growing up



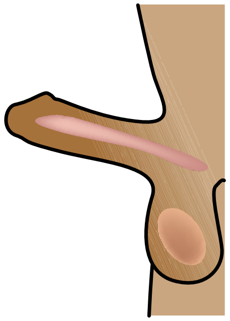
I am growing up. My body is getting taller and bigger.

Tanner Stages of Life



My penis and testicles are growing and changing, too.
I will grow hair under my arms and between my legs.
This is normal.

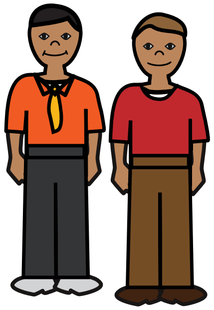
Erection



Sometimes when I touch my penis, it will get harder and longer. This is called an erection.

Sometimes erections happen when I don't want them to. I can sit quietly until it goes away or ask to go to the bathroom.

Adult men



Erections are a normal part of growing up. They happen to all men, even my _____ (insert male figure in child's life).

Erections are private. I should not talk about my penis or erections in public. If I have questions, I can ask _____ (insert name of trusted adult) when we are alone.

This publication was developed and written by Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) long-term trainees Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; Doctor of Audiology student, Elizabeth Harland; Cong Van Tran, PhD; and LEND faculty members Jennifer Bowers, RN, MSN, CPNP, Pediatric Nurse Practitioner, Division of Developmental Medicine; and Cassandra Newsom, PsyD, Assistant Professor of Pediatrics, Division of Developmental Medicine, Director of Psychological Education, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. It was edited, designed, and produced by the Communications and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) with the support of the Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). We are grateful for review and suggestions by many, including faculty of TRIAD and members of Autism Tennessee.

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This publication was made possible by Grant No. T73MC00050 from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS. Cover photo and illustrations top of page 1 ©istockphoto.com 06/2013

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LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

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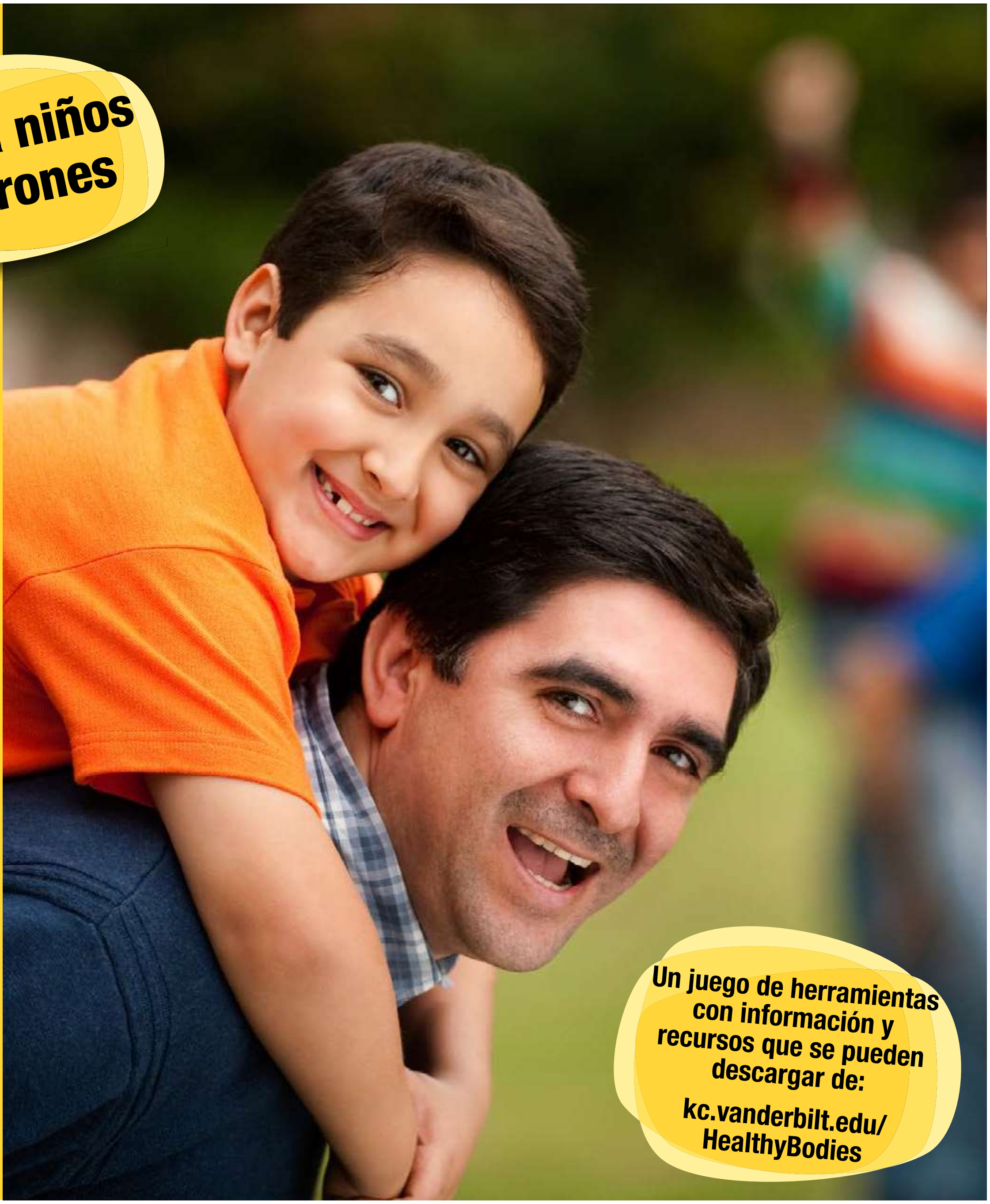
Cuerpos Sanos – Anexo



Para niños varones

Un juego de herramientas con información y recursos que se pueden descargar de:

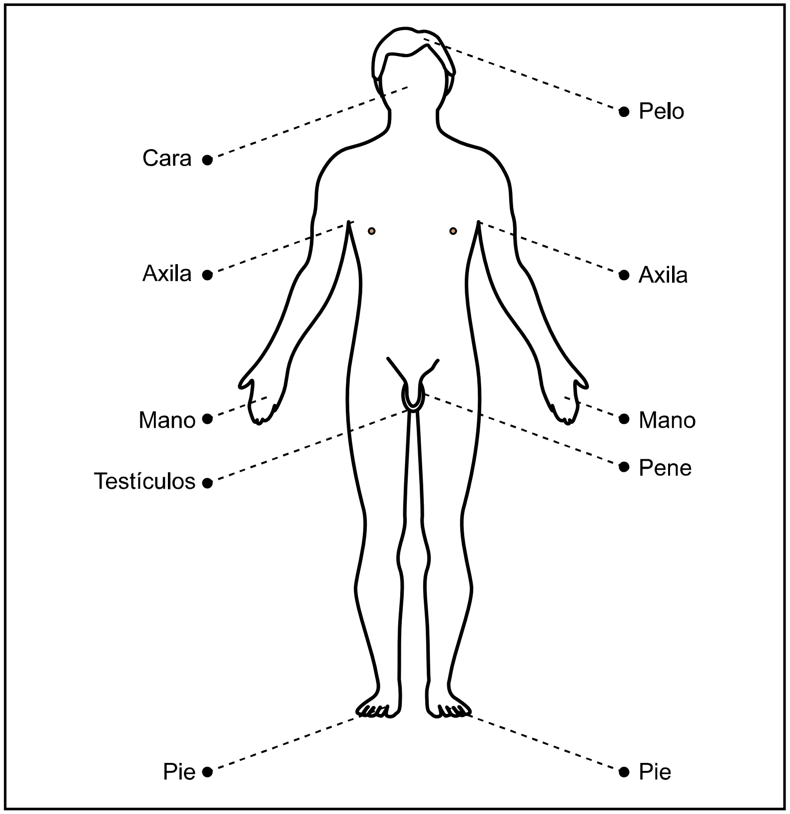
kc.vanderbilt.edu/HealthyBodies

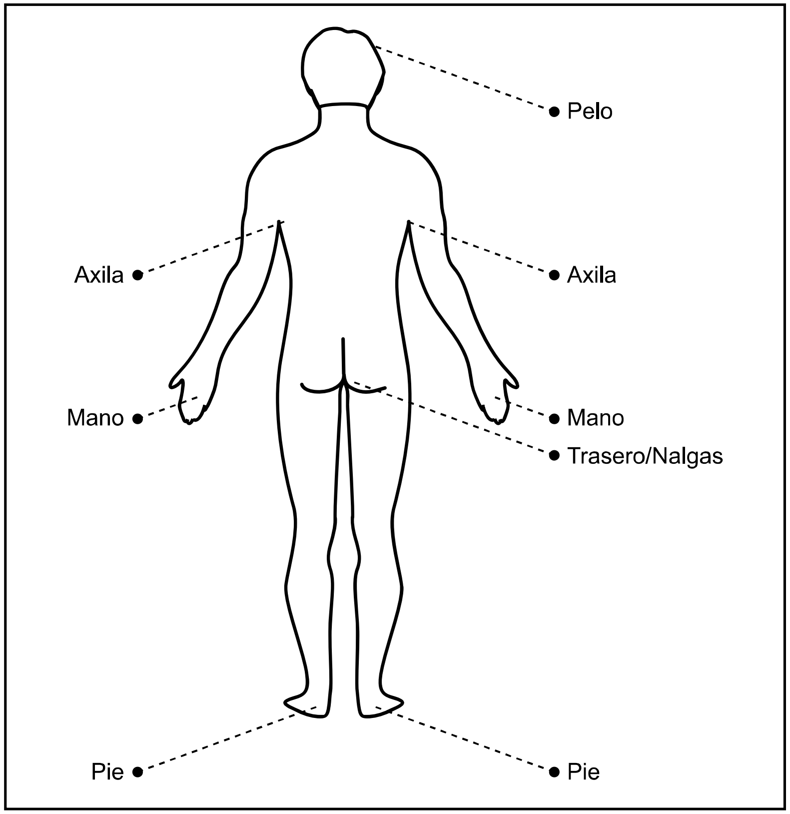
Una guía sobre la pubertad para padres de niños varones con discapacidades

Las partes del cuerpo – Apoyos visuales

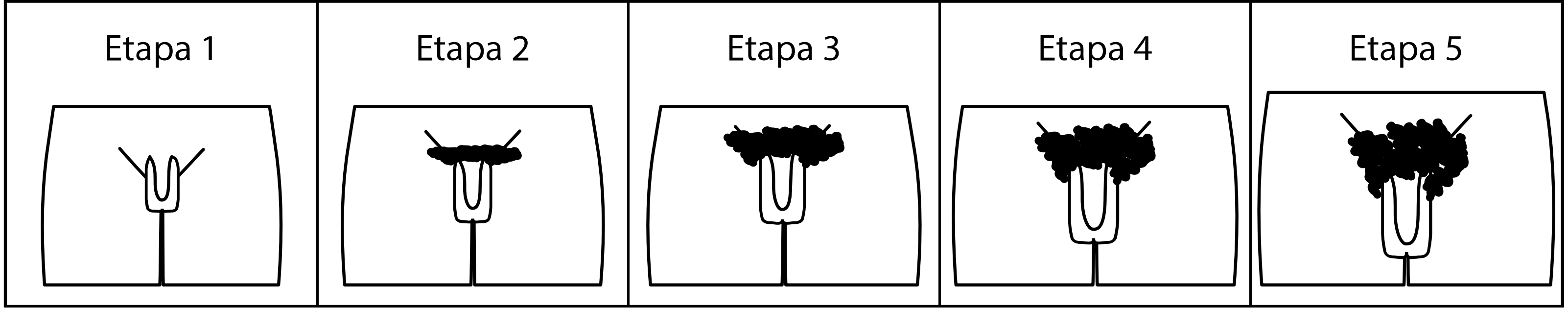
Use estos dibujos para que el niño aprenda los nombres de las partes del cuerpo. Después de enseñárselas, puede cubrir los nombres y jugar a que su hijo le diga los nombres de las partes. También puede hacer tarjetitas con los nombres y que su hijo coloque las tarjetitas sobre el dibujo.

Las Etapas de Tanner (abajo) pueden mostrarle los cambios que verá en su pene y testículos, y cómo le crecerá el vello.





ETAPAS DE LA VIDA DE TANNER EN EL HOMBRE



Tablero Primero-Después – Plantilla en blanco

Para motivar a su hijo a hacer cosas que quizá le cuesten trabajo o que no le agraden, como hacer ejercicio, trate de usar apoyos visuales como un Tablero Primero-Después. Ponga la actividad que le gusta poco en el recuadro de Primero y la actividad de recompensa en Después. Por ejemplo, “Primero ejercicio” seguido de “Después videojuegos”. Puede usar dibujos, o si su hijo sabe leer, palabras. Puede enmicar o laminar las tarjetas y pegar los dibujos con velcro, o usar una pizarra blanca con plumones o marcadores que se puedan borrar.

RECUERDE: Siempre ponga la actividad más divertida en el espacio de “Después”. Eso le muestra al niño lo que ganará por su esfuerzo.

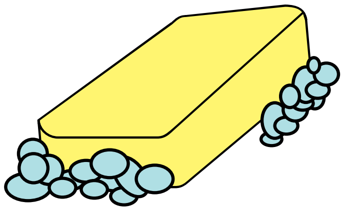
Primero **Después**

Primero **Después**

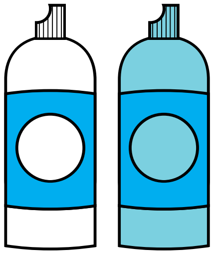
Anexo

Fomentar el aseo personal – Imágenes de artículos para el aseo

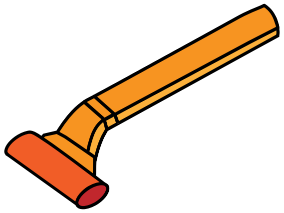
Jabón



Champú/
Acondicionador

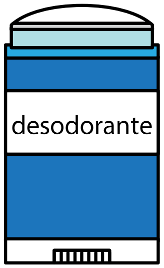


Afeitadora

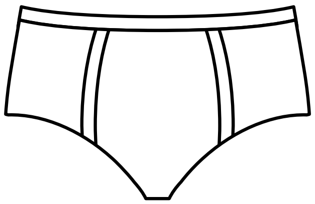


Crema de rasurar

Desodorante

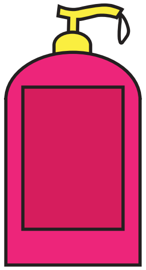


Ropa interior limpia



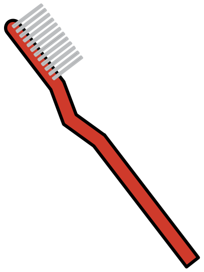
Toallitas húmedas

Crema



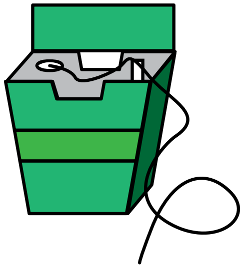
Cepillo de pelo

Cepillo de dientes



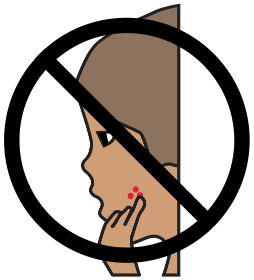
Pasta dental

Hilo dental



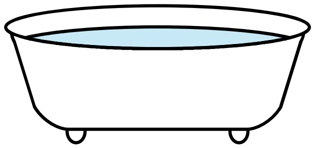
Tomar medicina

No tocarse los granos

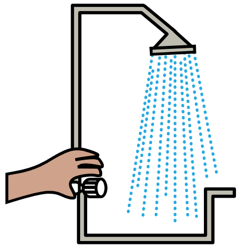


Fomentar el aseo personal – Imágenes de los pasos para bañarse

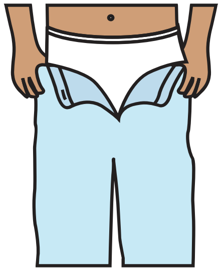
Llenar la tina con agua caliente



Abrir la llave de la ducha

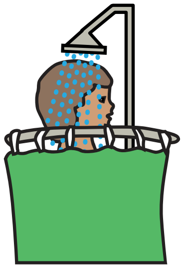


Quitarse la ropa



Meterse en la tina

Meterse en la ducha

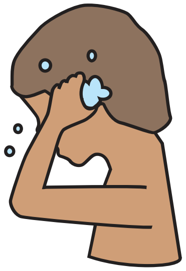


Lavarse todo el cuerpo

Quitarse el jabón

Ponerse champú en la mano

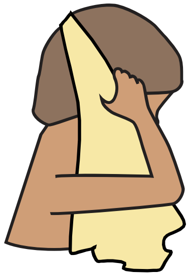
Lavarse el pelo



Enjuagarse el pelo

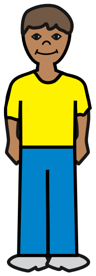
Cerrar la llave del agua

Secarse con la toalla

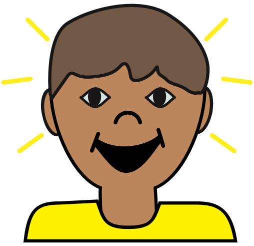


Ponerse desodorante

Ponerse ropa limpia



Lo hice muy bien

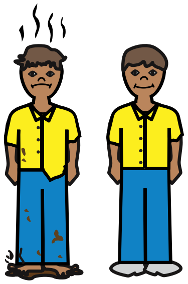


Fomentar el aseo personal – Historia

¿Qué es ese olor?

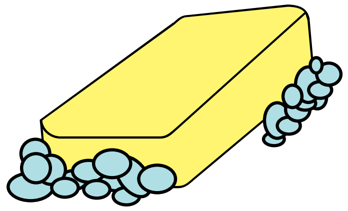
Estoy creciendo y mi cuerpo está cambiando. Me está saliendo pelo en las axilas y en las partes íntimas. A veces mis axilas y mis partes intimas huelen mal. Ese olor se llama olor corporal. A la gente no le gusta el olor corporal. Si yo huelo mal, la gente no va a querer estar cerca de mí. Yo me puedo quitar el olor corporal si me lavo todos los días el pelo, las axilas, las partes íntimas y los pies con agua templada y jabón. Después de lavarme, me puedo poner desodorante en las axilas; con el desodorante me huelen bien y están secas. Yo me voy a poner desodorante todas las mañanas para no oler mal. Me gusta oler bien. Si huelo bien mis padres, amigos y maestros estarán contentos también.

Sucio - Limpio



Lavarse el pelo

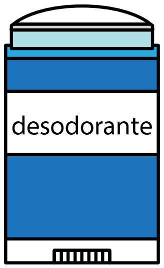
Jabón



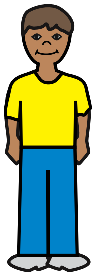
Lavarse todo el cuerpo

Ponerse desodorante

Desodorante



Ponerse ropa limpia

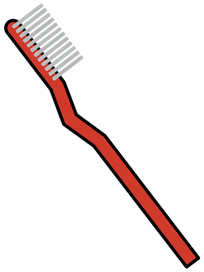


Oler bien

Anexo

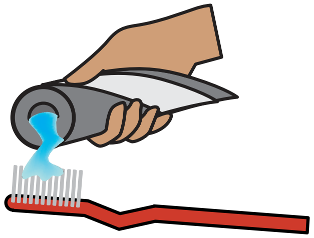
Fomentar al aseo personal – Imágenes de los pasos para cepillarse los dientes

Cepillo de dientes

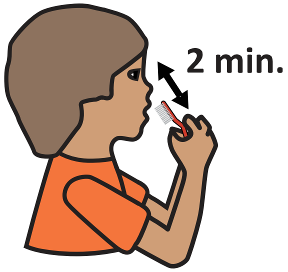


Pasta dental

Apretar para que salga la pasta



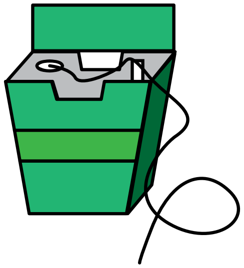
Cepillarse los dientes



Escupir en el lavabo

Enjuagarse la boca

Hilo dental



En público o en privado - Tabla para clasificar, plantilla en blanco

Usando dibujos, puede enseñar a su hijo los comportamientos que son aceptables en sitios públicos y las cosas que se deben hacer solo en privado. La siguiente actividad puede ayudarlo a clasificar las cosas que se hacen en público o en privado. Puede usar los dibujos de las páginas siguientes o hacer sus propios dibujos.

Cuando su hijo entienda qué significa en público y en privado, usted también podrá usar las tarjetas de “En público” y “En privado” como un apoyo visual para ayudarle a recordar. Por ejemplo, si se mete el dedo en la nariz, muéstrele la tarjeta de “En privado” y dígale que vaya a un sitio privado para hacer eso.

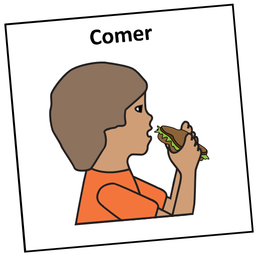
Estos dibujos o apoyos visuales también se pueden usar para preparar a su hijo cuando va a un lugar público, como un restaurante.

En público

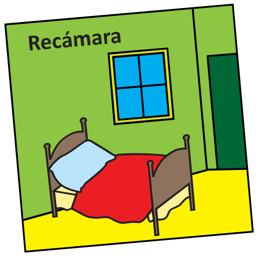
En privado

En público o en privado – Tabla para clasificar

En público



En privado

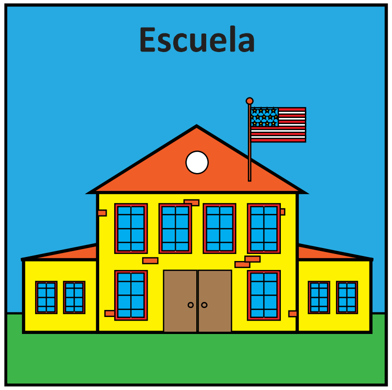


Anexo

Comportamientos en público o en privado – Imágenes

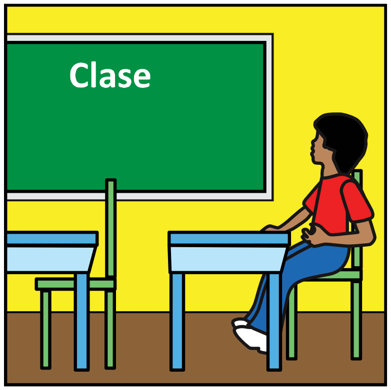

En público


En privado

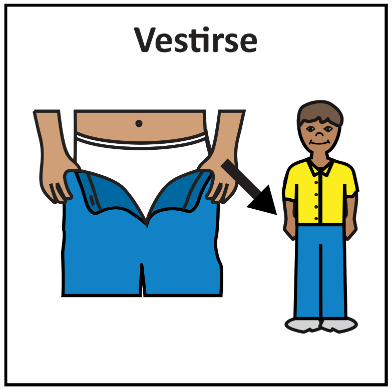

Escuela


Supermercado


Templo/Iglesia


Clase

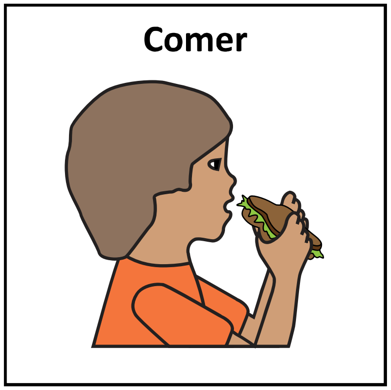

Restaurante


Vestirse


Hablar con un amigo

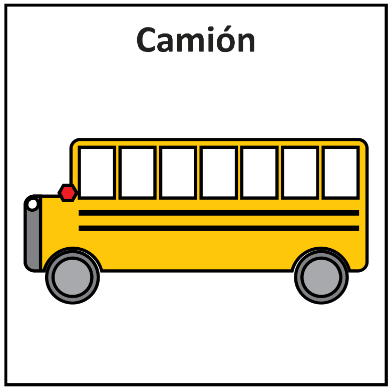

Decir palabrotas


Bailar


Comer


Tocarse las partes

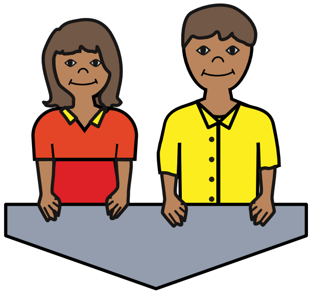

Ducha/Regadera


Camión

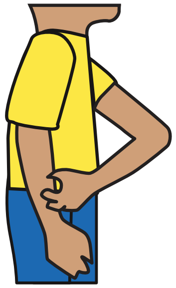
Comportamientos en público o en privado – Imágenes

Expulsar gases

Manos en la mesa



Rascarse un brazo

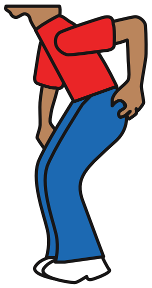


Excusado

Recámara

Cuarto de baño

Rascarse el trasero



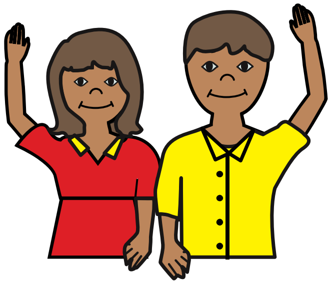
Solo

No tocarse las partes

Lavarse las manos

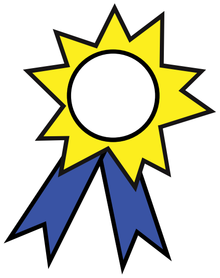
Jugar a la pelota

Saludar



Recompensa

Recompensa

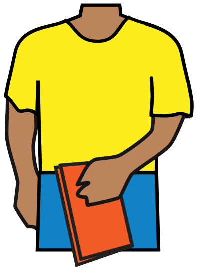


Actividad especial

Anexo

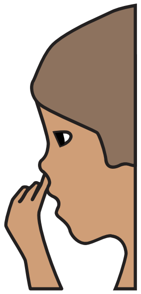
Comportamientos en público o en privado – Imágenes

Poner un libro delante

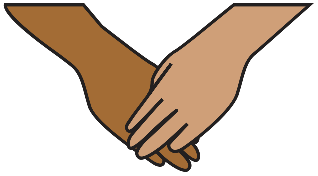


Golpecitos en la espalda

Meter dedo en la nariz



Agarrarse las manos



¡Chócala!

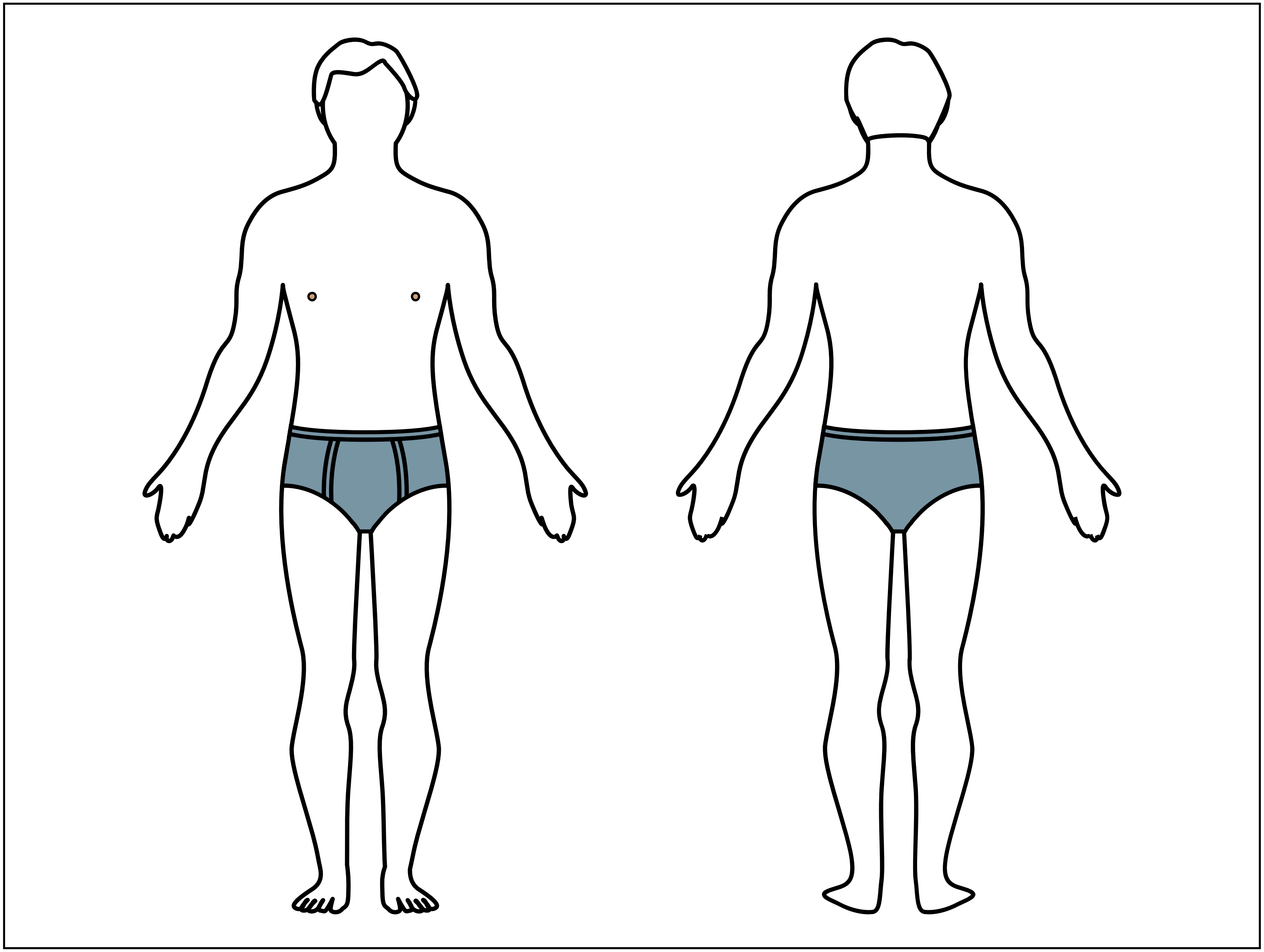
Abrazar

Besar

Suplemento Partes íntimas – Apoyos visuales

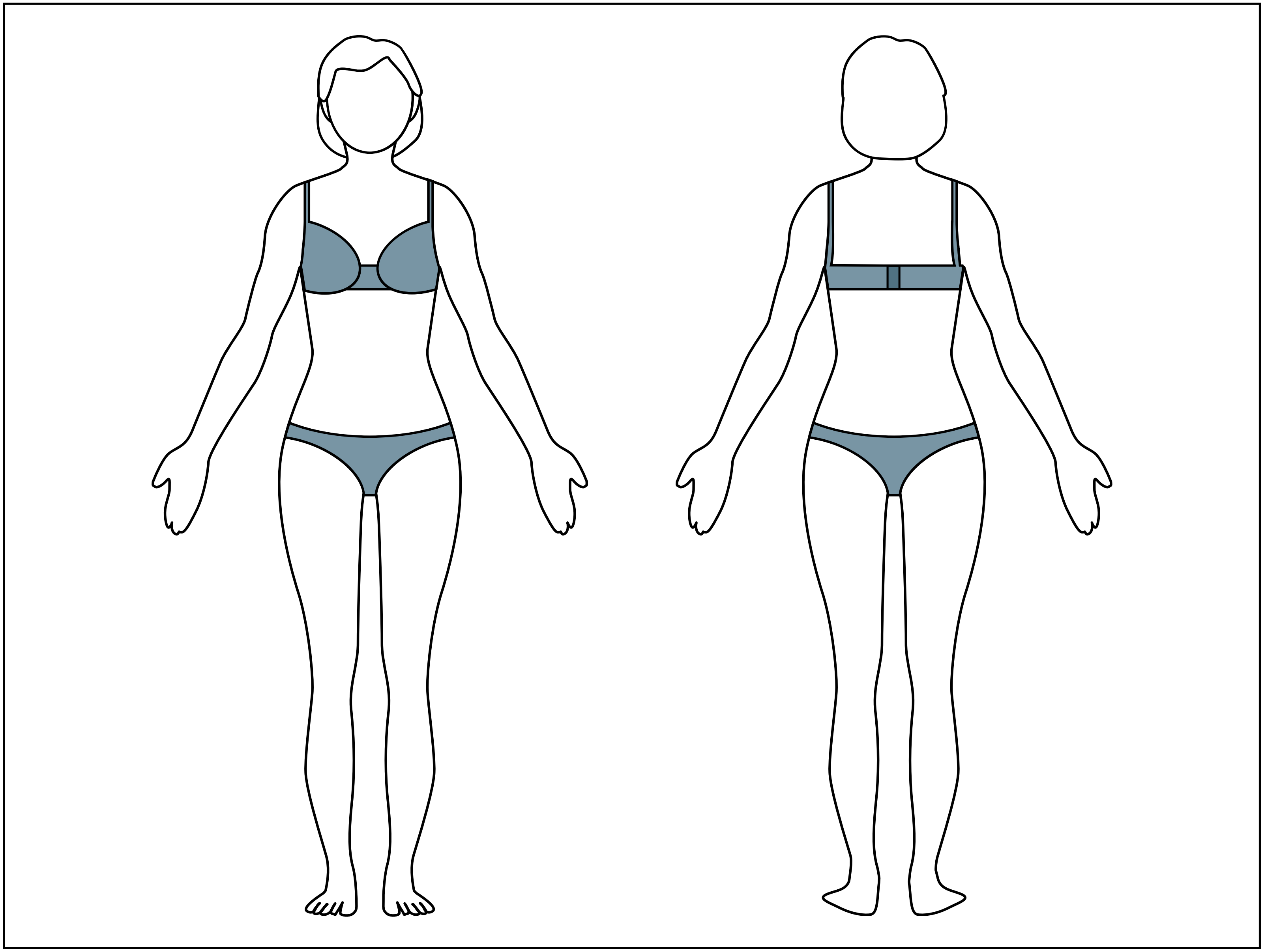
Con estas figuras, enseñe a su hijo dónde pude tocar a otras personas y dónde está bien que le toquen a él. Apunte a una parte del cuerpo y pregunte: "¿Se puede tocar?". Si es que sí, ponga un círculo verde en esa parte del cuerpo, "Adelante". Si esa parte del cuerpo no se puede tocar, ponga un círculo rojo de "Alto".

Por ejemplo, su hijo debe poner un círculo verde en la mano, pero otro rojo en el trasero. Luego puede usar la misma actividad para "¿Dónde me puede tocar la gente?".



Suplemento

Partes íntimas – Apoyos visuales



Comportamientos en público o en privado – Historia

Meterse el dedo en la nariz se hace en privado

A veces puede que quiera meterme el dedo en la nariz en privado. Solo me meteré el dedo en la nariz cuando tenga algo dentro y no pueda hacerlo salir sonándome la nariz. Meterse el dedo en la nariz puede esparcir gérmenes. Cuando me meto el dedo en la nariz o me sueno, debo usar un pañuelo de papel. Tengo que lavarme las manos después de meterme el dedo en la nariz. A la gente no le gusta verme con el dedo en la nariz. Cuando tengo que meterme el dedo en la nariz voy a un sitio en privado, como el cuarto de baño, con la puerta cerrada. No voy a meterme el dedo en la nariz enfrente de otras personas ni hablar con la gente sobre meterme el dedo en la nariz.

Anexo

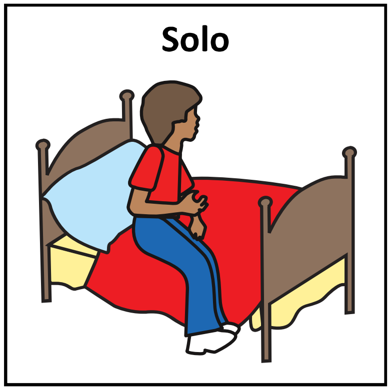
Comportamientos en público o en privado – Historia

Partes íntimas

En público significa que estoy en un sitio donde la gente me ve.

En privado es cuando no me ve nadie, como en mi recámara o en el baño con la puerta cerrada.

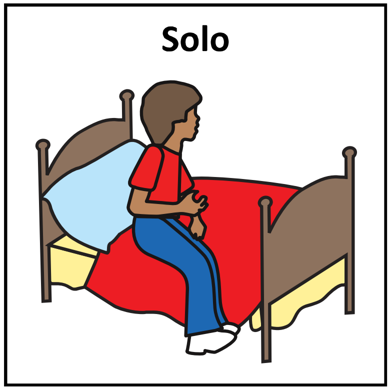
Todos tenemos partes íntimas en el cuerpo. Son las que se cubren con la ropa interior. No me toco las partes íntimas en público donde otros me pueden ver. Tampoco me meto las manos por dentro del pantalón cuando estoy en público. Para recordar esto, puedo poner las manos a los lados, meterlas en los bolsillos, cruzar los brazos o agarrarme las manos. A veces si me pica algo o si el calzoncillo me molesta, puedo preguntar si puedo ir al baño. Cuando estoy solo, en mi cuarto o en el baño, puedo tocarme las partes íntimas.

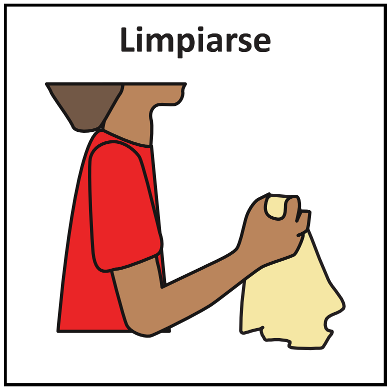


Comportamientos en público o en privado – Historia

¡Pero me gusta!

No me toco las partes íntimas en público donde otros me pueden ver. Cuando estoy solo en mi recámara o en el baño con la puerta cerrada, puedo tocarme las partes íntimas. Cuando me toco las partes íntimas, a veces me gusta. A algunas personas les gusta tocar sus propias partes íntimas. Está bien tocarme cuando estoy solo. A veces al tocarme las partes íntimas termino ensuciándome. Entonces me lavaré las manos y las partes íntimas cuando termine. Yo no le hablaré a nadie sobre tocarme las partes íntimas. Si tengo preguntas o si me duele al tocarme, le preguntaré a mi __________ (ponga el nombre del doctor o un adulto de confianza).





Comportamientos en público o en privado – Historia

Tocar o no tocar, ¡esa es la cuestión!

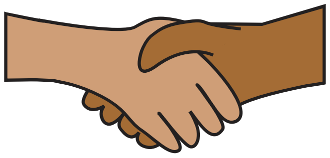
Cuando estoy con mi familia y amigos, normalmente está bien tocarles y que me toquen el brazo, la espalda, los hombros o las manos. Estas áreas del cuerpo están permitidas, “Adelante”. Por ejemplo, puedo chocar las manos con ellos, darles palmaditas en la espalda, o tocarles el brazo para que me presten atención. No está bien tocar a otras personas en las partes que van cubiertas con la ropa interior, como el trasero, los senos, el pene o la vagina. No está bien que nadie (excepto mi doctor/madre o padre/_______)* me toque a mí en las partes del cuerpo que van cubiertas con la ropa interior. Estas son las partes íntimas del cuerpo y son áreas donde hay que hacer “Alto”. Si alguien me toca en la zona íntima, yo debo decir “PARA” o “ALTO” o “NO” y decirle a mi mamá, mi papá, o mi maestra. A veces mi mamá, mi papá o _______ (escriba el nombre de un adulto de confianza) y mi doctor querrán ver mis partes íntimas para ayudarme a estar sano y limpio. Si no quiero que miren mis partes íntimas, puedo pedirles privacidad.

* Puede cambiar el texto si tiene que incluir cuidadores o profesionales que le asisten con las necesidades diarias o al realizar procedimientos médicos.

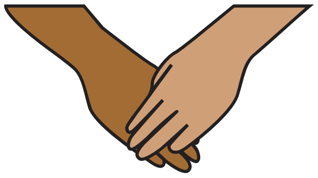
¡Chócala!

Golpecitos en la espalda

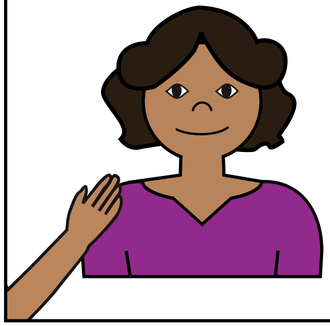
Estrechar la mano



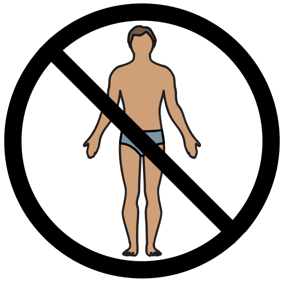
Agarrarse las manos



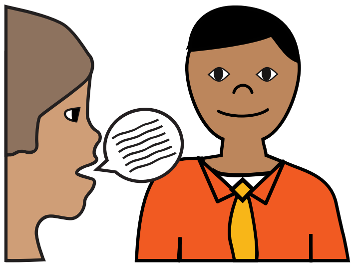
Tocar el hombro



Traje de baño



Hablar con papá

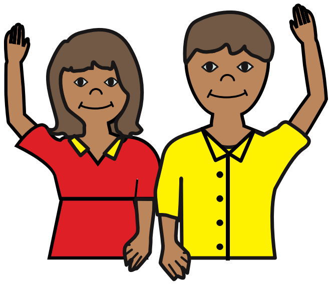


Comportamientos en público o en privado - Historia

Familia, amigos y otros

Un juego de clasificar puede ayudar a explicar las relaciones a su hijo de manera que entienda el tipo de comportamiento que es apropiado para los distintos tipos de relaciones. Por ejemplo, los desconocidos están en la última columna, y su hijo puede ver que está bien saludarlos o estrecharles la mano. Los comportamientos de la primera columna son para los novios o esposos. La familia y amigos están entre estos dos. Su familia puede decidir qué comportamientos deben incluirse en cada recuadro. Quizá quiera tomar fotos de personas como ejemplo de cada grupo.

Práctica. Lleve este juego cuando salga y úselo para enseñar a su hijo cómo saludar a la gente. Por ejemplo saque el diagrama cuando su hijo se encuentra a alguien de la escuela para mostrarle qué comportamiento está bien para decir hola.

Casados o novios	Familia	Amigos	Otros y desconocidos
Besar 	Abrazar 	¡Chócala! 	Saludar 

Enseñar sobre las erecciones: Emisiones nocturnas – Historia

Cuando tengo un sueño húmedo

A veces cuando me despierto por la mañana, la ropa interior está húmeda. No me oriné en la cama. Tuve un "sueño húmedo". Esto es normal.

Me quitaré la pijama y el calzoncillo sucio. Los pondré en la canasta de la ropa sucia. Mis padres se alegrarán porque yo pongo en su sitio la ropa sucia.

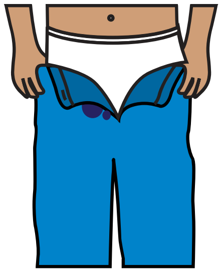
Me limpiaré las partes íntimas con una toallita con agua templada. Luego me pondré un calzoncillo limpio y los pantalones.

Después le diré a mis padres que las sábanas están sucias. Puedo decirlo con palabras o colgar un letrero en mi puerta.

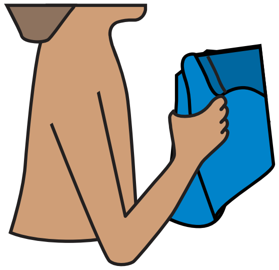
Puedo quitar las sábanas sucias de la cama y ponerlas en la canasta de la ropa sucia. Así ayudo a mi mamá y a mi papá.

Los sueños húmedos son una parte normal de hacerse mayor. Yo sé qué tengo que hacer cuando tengo un sueño húmedo.

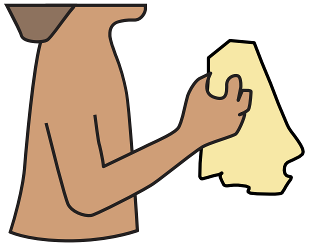
Quitarse la ropa sucia



Poner en la canasta de ropa sucia

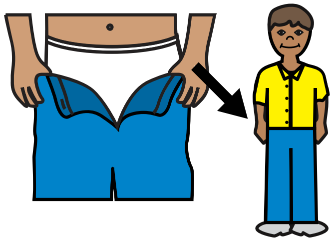


Asearse

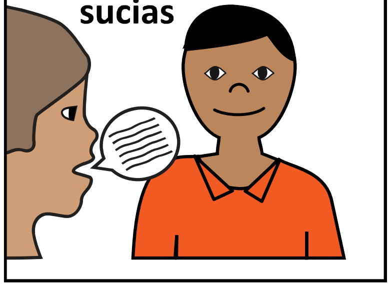


Lavarse las partes íntimas

Ponerse ropa limpia

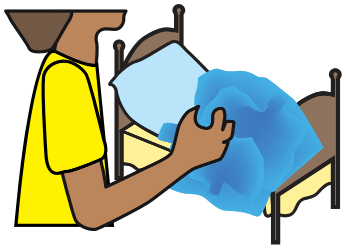


Decir a mamá o papá que las sábanas están sucias



Letrero para la puerta

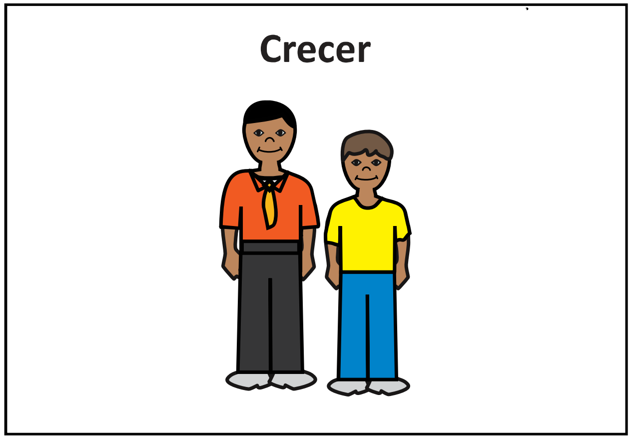
Quitar las sábanas



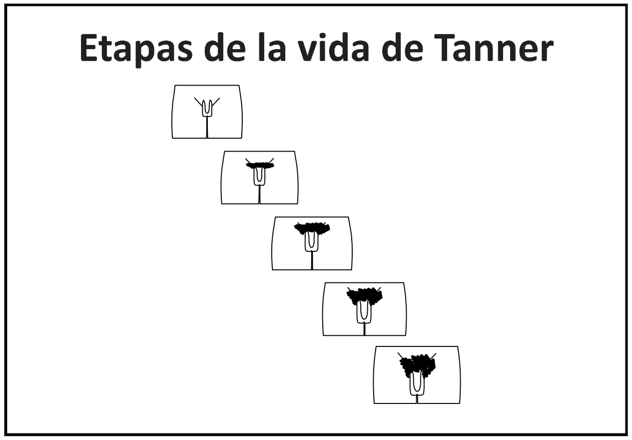
Poner las sábanas con la ropa sucia


LAS SÁBANAS ESTÁN SUCIAS

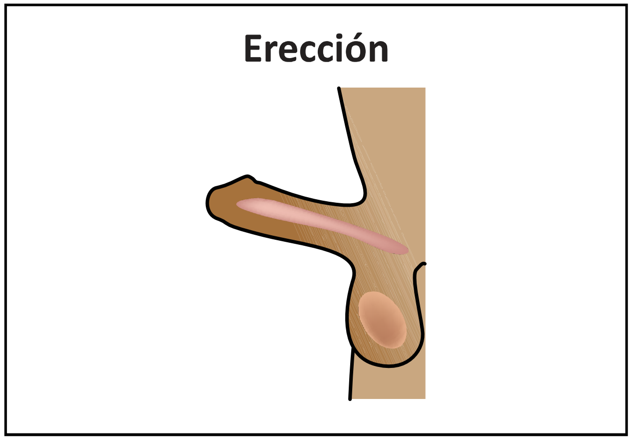
Enseñar sobre las erecciones: Convertirse en hombre – Historia



Estoy creciendo. Mi cuerpo se hace más alto y más grande.



Mi pene y mis testículos también están creciendo y cambiando. Me saldrá pelo en las axilas y entre las piernas. Esto es normal.



A veces cuando me toco el pene, se alarga y se pone duro. Esto se llama una erección.

A veces tengo erecciones cuando no quiero. Me siento tranquilamente hasta que se pase, o pido ir al baño.

Las erecciones son una parte normal de crecer. Todos los hombres las tienen, hasta mi _____ (nombre una figura masculina en la vida del niño).

Las erecciones son privadas. No hablo de mi pene o las erecciones en público. Si tengo preguntas, puedo preguntar a _____ (nombre de un adulto de confianza) cuando estamos solos.

Humor y sentimientos - Diario

Puede anotar el estado de humor y comportamientos de su hijo en una tabla-diario como esta. Hemos escrito en la primera línea para que vea un ejemplo. Puede llevar esta hoja a la próxima visita médica que tenga para hablar sobre lo que le preocupa.

Fecha	Horas de sueño	Apetito	Comportamiento	Medicinas/ Suplementos
1-8-2012	8-10 hrs, despertó con pesadilla 11-4	No desayunó		

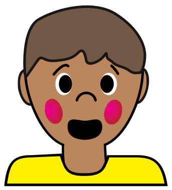
Humor y sentimientos – Tarjetas de emociones

Estas tarjetas muestran las distintas emociones y expresiones faciales. Pueden usarse estas tarjetas para: a) Darle nombre a la manera en la que se siente su hijo y b) ayudar a decirle a él como se siente usted. Por ejemplo, si él está contento, muestre la tarjeta que dice “Contento” al tiempo que le dice: “Hoy parece que estás contento”. Él puede aprender a darle a usted la tarjeta para decir cómo se siente, también.

Triste

Deprimido

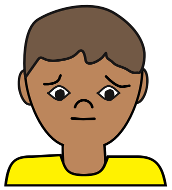
Apenado



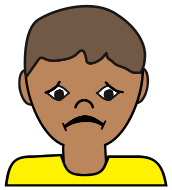
Enojado

Sorprendido

Decepcionado



Dolido



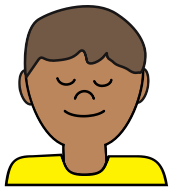
Confundido

Frustrado

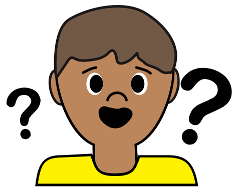
Ilusionado

Contento

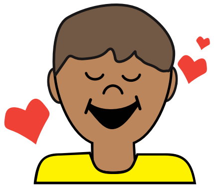
Relajado



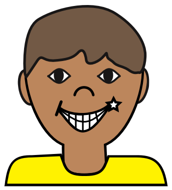
Curioso



Amoroso

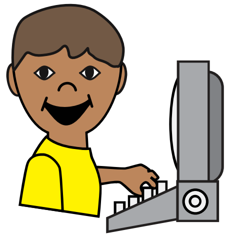


Orgulloso

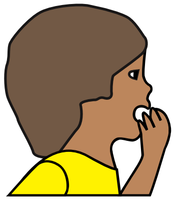


Perezoso

Listo para trabajar



Cansado



Gruñón

Esta publicación fue desarrollada y escrita por los experimentados investigadores en práctica de Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND): Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; estudiante de doctorado de Audiología, Elizabeth Harland; Cong Van Tran, PhD; y los profesores de LEND Jennifer Bowers, RN, MSN, CPNP, Enfermera Pediátrica de Práctica Avanzada, División de Medicina del Desarrollo y Cassandra Newsom, PsyD, Profesora Auxiliar de Pediatría, División de Medicina del Desarrollo, Directora de Educación Psicológica, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. Fue editada, diseñada y producida por el personal de Diseño Gráfico y Difusión del Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) el apoyo de Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). Les agradecemos la revisión y sugerencias a numerosos miembros del personal de TRIAD y de Autism Society of Middle Tennessee.

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Esta publicación fue posible, en parte, gracias al siguiente financiamiento: Grant N.° T73MC00050 de Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Sus contenidos son la responsabilidad única de los autores y no representan necesariamente las posturas oficiales del MCHB, HRSA, HHS. Foto de la portada e ilustraciones en la parte superior de la pág. 1. ©istockphoto.com. 12/2014.

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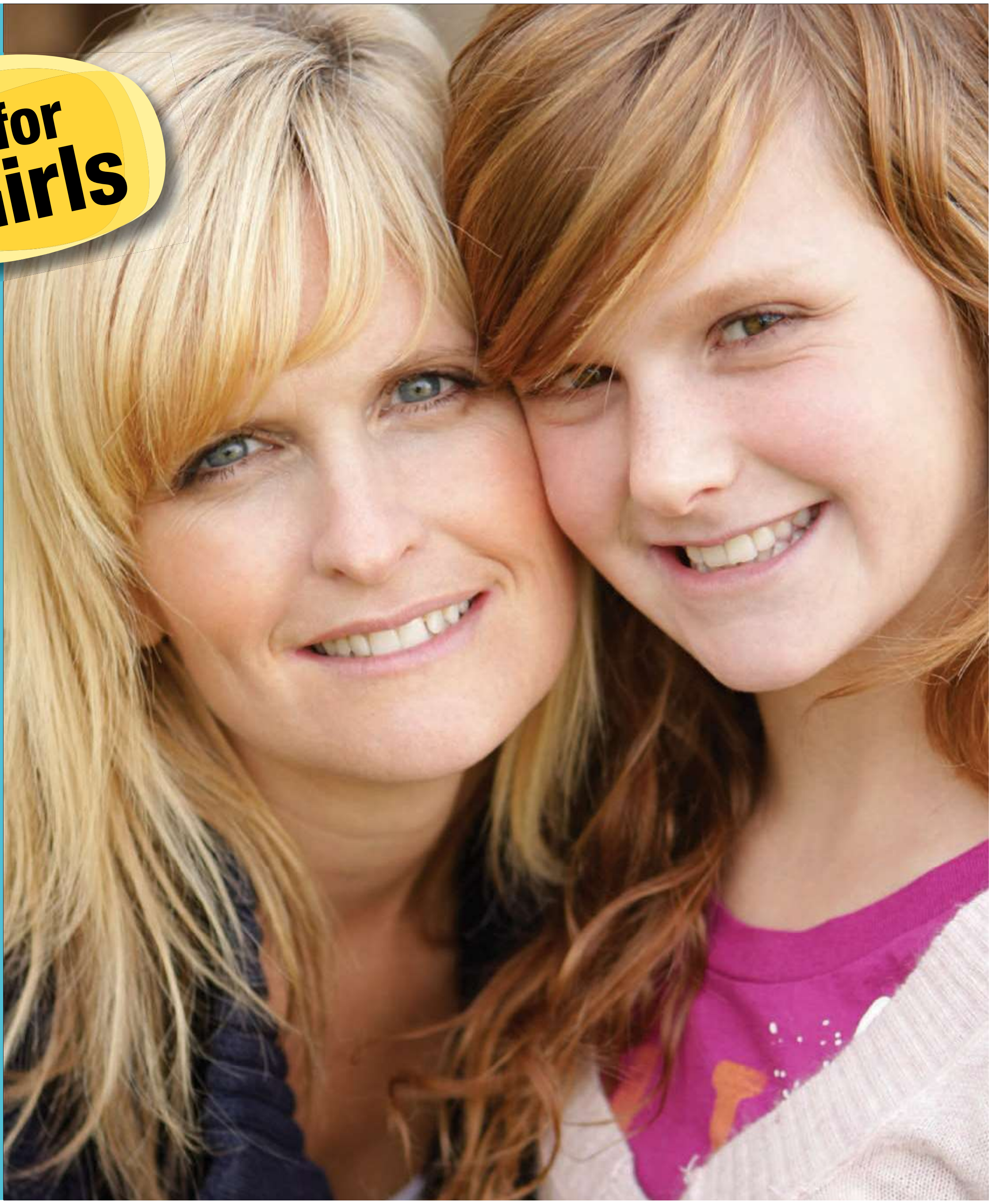
Healthy Bodies

for Girls



A Parent's Guide on Puberty for Girls with Disabilities

Table of Contents

An appendix with social stories and visual supports may be downloaded at: kc.vanderbilt.edu/HealthyBodies

Appendix and visuals can be found online at:

kc.vanderbilt.edu/HealthyBodies

Puberty can be a stressful and confusing time, especially for you and your daughter with an Intellectual and/or Developmental Disability (I/DD). In spite of delays in other areas, children with I/DD usually enter puberty around the same time as other children their age. Some children with I/DD, including children with spina bifida and cerebral palsy, may start puberty early (called precocious puberty). This toolkit gives you resources and tips on how to talk to your daughter about these sensitive topics.

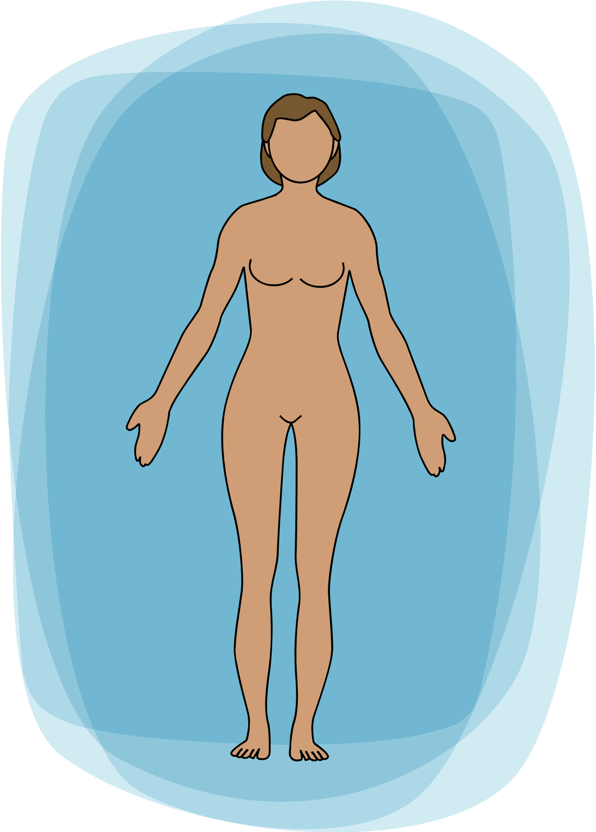
Talking To My Daughter About These Things

Start early. Talk with your daughter before obvious signs of puberty begin.

Teach body parts. Use the formal words for body parts (e.g., vagina, breast) and bodily functions (e.g., urinate, period). This prevents confusion and gives your child words to use later when learning about puberty, cleanliness, and reproduction. See *Teaching Body Parts Appendix* for a visual you can use to teach your daughter the names for body parts and to explain how her body is changing.

Use supports. You know the ways your daughter learns best. Teach about puberty the same way you teach about other important topics. For example, if your daughter learns best with repetition, break information down into simple facts and review them often. If she learns best with pictures, try using visual supports or social stories. These supports make hard-to-understand topics clearer. Review the supports we have developed to get ideas about how to teach skills (see *Teaching Body Parts Appendix*). Change them to fit your daughter's learning style.

Ask a professional. Talk to your child's doctors, teachers, or therapists for other ideas. ■



See Teaching Body Parts Appendix

No Couch Potatoes! Helping Your Daughter Stay Active

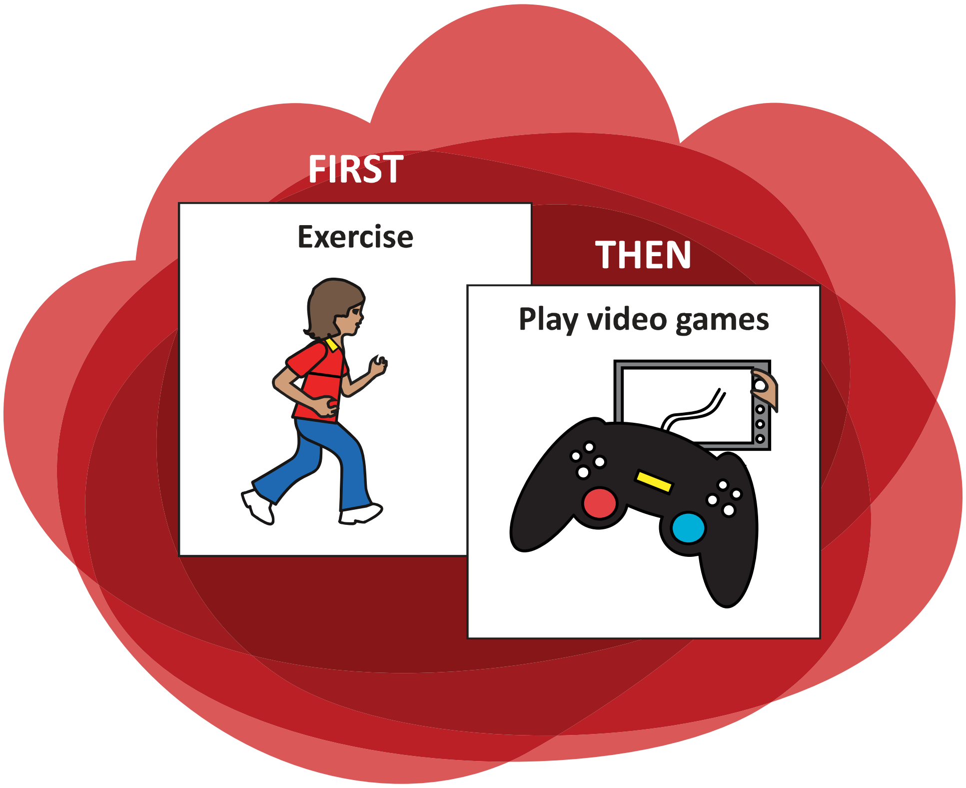
It is important to teach your child how to be healthy from a young age. Hormone changes and some medications can cause weight gain during puberty. Regular exercise and a healthy diet can prevent weight gain and improve mood and self-esteem. Starting these healthy habits early is the best way to help your daughter become an active adult.

How To Start

Schedule physical activities. Make sure your daughter has a scheduled time every day for active play, such as hiking, playing games outside, and riding bikes. If she has trouble getting started, provide a menu of options or join in! Make fun, physical activities a part of your family's daily routine.

Ask a professional. If your daughter has a motor impairment, ask her doctor, occupational therapist, or physical therapist for safe exercise ideas. Look for adapted or supported sports activities in your area that either are designed for teens with disabilities or that provide accommodations to include your child.

Make exercise rewarding. As your daughter gets older, switch from 'play time' to exercise, sports, or family activity time (such as taking a walk together). If she does not like exercise, you can encourage it by giving a reward afterward. At this age, it is helpful to offer rewards that are not food. Try using visual supports such as a First/Then Board. For example, show your child "First Exercise" followed by something preferred, like "Then Video Games." See the First/Then Board Appendix for a blank template that you can try at home. ■



See First/Then Board Appendix

Encouraging Good Hygiene

Good hygiene can improve your daughter's self-esteem and independence. Good hygiene habits can also reduce the amount of time you spend completing these tasks for her.

Make a picture book. A picture book may be a good starting point for teaching self-care. You and your daughter can create it together. The amount of information (more or fewer pictures) depends on your child's reading level and memory. Include pictures of supplies needed (e.g., specific body wash, deodorant, pads), and a visual picture schedule of the steps to use them. This picture book can also help her select items on a shopping trip or gather the items needed for specific tasks, such as showering. Using a picture book may give your daughter a feeling of control and responsibility for completing hygiene tasks.

Create hygiene kits. Think about making hygiene kits for different tasks. You can use old shoe boxes, clear plastic containers, or baskets. Let your daughter help choose the containers. On the outside of the box, put pictures or a list of the items in the box and a picture of the key task (e.g., showering). See *Encouraging Good Hygiene Appendix* for pictures you and your daughter can use to create a kit. Here are a few examples of kits and contents:

- **Shower**: Body wash, shampoo, conditioner, face wash, soap, razor, shaving cream
- **Dental**: Toothbrush, toothpaste, dental floss, mouthwash
- **Menstruation**: Assorted sized pads, wet wipes, pain reliever (if able to take medication independently), a change of underwear
- **Morning Routine**: Body lotion, deodorant, facial cleansing wipes, face lotion, hair brush

Common Trouble Spots: Dirty Hair

As girls enter puberty, they may need to wash their hair more frequently. Your daughter may struggle with keeping her hair clean because the motor aspects of the task may be difficult. She may find the feel of shampoo or water unpleasant. Some girls with I/DD may not pay close attention to what their classmates are doing and wearing. Because of this, they may not understand that clean hair is socially important.

- **Make it routine.** Make a schedule to show your daughter how frequently she should complete hygiene tasks and the steps to complete them. See *Encouraging Good Hygiene Appendix* for an example of a showering schedule.
- **Singing in the shower.** To help your daughter learn how long to stay in the shower or bathtub, create a music CD of a few songs equal to the length of time she should bathe. Each song change can signal to her when to move to the next step on the schedule.
- **Soften up.** Does your daughter hate scrubbing her hair with her hands? Let her use a soft sponge to apply shampoo. If the water pressure bothers her, let her use a cup or pitcher to rinse her hair or use a showerhead with adjustable pressure.
- **A picture is worth a thousand words.** Write a story that explains the importance of showering daily and keeping hair clean. Have fun. Take a picture of your daughter and other family members when they first wake up in the morning (bed-head and all!) and then when they are clean and dressed. Talk about what other people might think if you went to work or school looking like you did when you first woke up.

See Encouraging Good Hygiene Appendix

Common Trouble Spots: Sweat and Body Odor

Sweat glands become more active during puberty, so it is important to teach girls to control body odor by using deodorant, changing their clothes daily, washing their dirty clothes weekly, and keeping their bodies clean.

- **Don't forget your visuals.** Use checklists and stories to remind your daughter of what steps to follow to clean her body and why. See *Encouraging Good Hygiene Appendix* for a sample story about managing sweat and body odor.
- **Action schedule**. If your daughter needs reminders of what area of the body to scrub next, you can use an action schedule that shows which action or step comes next. Include shampooing and rinsing, and body parts to wash with soap. Laminate the schedule so it can hang in the shower. Another option is to use an old Barbie® doll, action figure, or laminated paper doll. Separate and number each body part. Attach the doll to the bathroom or shower wall with Velcro. As your daughter washes each body part, she can place that part of the doll's body in a container labeled "finished."
- **Obstacles**. If applying deodorant is physically challenging for her, try different types, such as spray deodorant or roll-on. If she has trouble bathing independently due to motor impairments, try adaptive equipment like bath seats, a removable showerhead, scrubbing gloves, or extended/easy-grip scrubbing handles.
- **Smells too strong**. Involve your daughter in selecting hygiene products, particularly regarding the scent. Some girls may prefer unscented products if they are bothered by strong smells. Many products labeled for "sensitive skin" are unscented.
- **Acne**. For some teens, acne can be a problem due to increased oil in their skin, hormone changes, hygiene, and even genetics. Check with your child's doctor about safe over-the-counter acne medications, such as creams, lotions, or washes that contain medications like salicylic acid or benzoyl peroxide. Take a picture of your teen's face or use a line drawing. Circle the areas where medication should be applied daily. Teach your teen to avoid sensitive spots like eyes, nostrils, and the mouth. Also, consider pre-medicated wipes to make application easier. If your teen has body acne, medicated body washes are also available.

See Encouraging Good Hygiene Appendix

Common Trouble Spots: Body Hair and Shaving

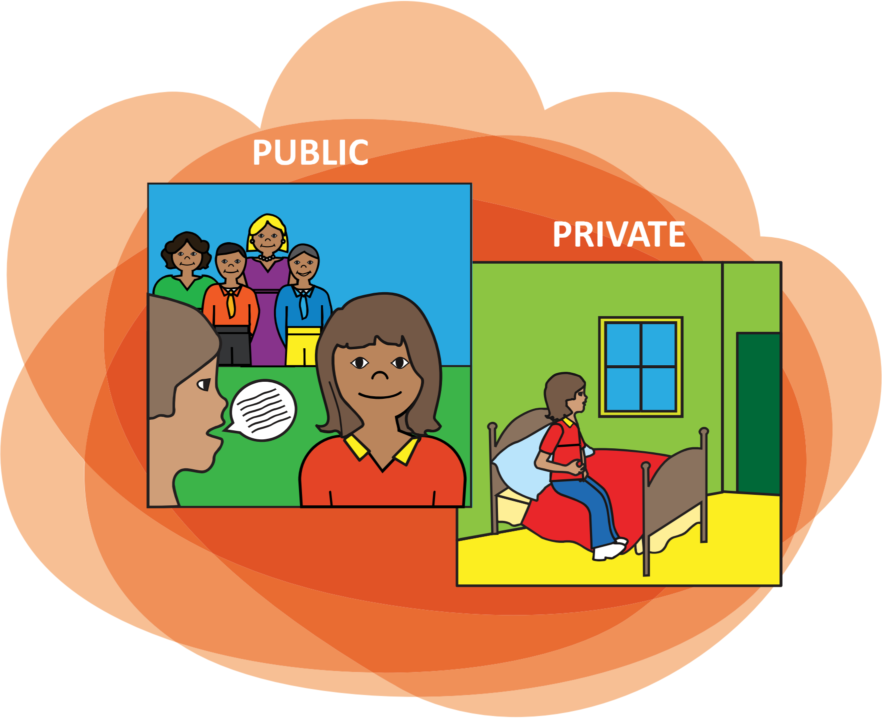
Body hair begins to grow and change during puberty. Use a drawing of the female body (like the one in the *Teaching Body Parts Appendix*) to teach your child where hair grows to prepare her for her changing body. Some adults and teenagers want to shave body hair.

- **Model shaving**. Let your daughter watch you or an older sibling shave and list the steps. Have her practice with you, step by step. Write down or take pictures of each step for a visual schedule. To help her remember where to shave and where not to shave, use a photo or drawing of a person, and color or number the areas that should be shaved.
- **Schedule shaving dates**. If your daughter can shave (or does so with assistance), use a calendar with pictures or marks as a reminder of how often to shave and when to change her razor.
- **Limit shaving cream**. If your child needs help with portion control or operating shaving cans, try using travel-sized packets of shaving cream or a shaving brush.
- **Select the right razor**. Girls who struggle with fine motor tasks may benefit from electric razors instead of a traditional razor with a blade. If the traditional razor with a blade is preferred, ask your occupational therapist about weighted razors or a razor universal cuff to help improve grip on the razor.

Common Trouble Spots: Clean Teeth and Breath

- **Create a Visual Schedule**. Use pictures to show the steps of brushing teeth. See *Encouraging Good Hygiene Appendix* for pictures to help your daughter learn to brush independently.
- **Choose the right toothbrush**. A vibrating or weighted toothbrush may help children who have difficulty holding a toothbrush and brushing their own teeth. Look for a toothbrush with soft bristles.
- **Show when and how long**. Build brushing into your daughter's daily schedule with picture reminders. Timers may help remind her how long to brush. Dentists recommend two minutes! 🟩

See Encouraging Good Hygiene Appendix



Appropriate and Inappropriate Public Behaviors

Does your daughter ever do or say things in public you wish she hadn't? Your child needs help learning what is okay to do in public and what is okay to do only in private. Private behaviors include things like going to the bathroom, passing gas, touching private parts for any reason, and changing clothes, just to name a few. Using socially appropriate behaviors will help your daughter fit in with her peers and reduce the chances of being bullied or abused. Children who know the difference between appropriate and inappropriate public behavior are less likely to get in trouble with the school or police as they get older.

Teaching These Skills To My Daughter

- **Start early**. Talk about public and private behaviors as a family and set some ground rules, such as: "We are only naked in the bathroom or in our own bedroom with the door closed," or "We put on our clothes or pajamas before we leave the bathroom or bedroom." Remind your daughter about the rules using simple words or pictures. Use the same rules for everyone in the family!
- **Use visuals**. Make a list of places that are public and places that are private. Then you can come up with examples of behaviors that are okay in each setting. Use visuals to help your daughter understand and remember these rules. Look at *Public/Private Behaviors Appendix* for ideas and printable pictures to teach the concept of Public and Private.
- **Use stories**. Stories also can help your daughter understand these rules and why we have them. Think about the behaviors that are problematic for your child, and write a story that sets clear rules about when and where that behavior is okay. See *Public/Private Behaviors Appendix* for stories to teach your daughter about public versus private behaviors related to touching her own and other peoples' bodies.

See Public/
Private Behaviors
Appendix

- **Redirect.** Tell your daughter where to go to perform private behaviors using simple words or pictures. For example, say something like, “You can do that in your (bedroom, bathroom),” or show her a visual labeled “Private.” Direct your child to a private area when she does things such as touching private parts or adjusting underwear.
- **When private can’t be private.** Some children will need help with private tasks, such as getting dressed, bathing, or toileting. Teach your daughter how and who to ask for help with these private behaviors when she is in public places, such as a school or a restaurant. This could include teaching her to plan ahead, ask quietly, or use picture cards or gestures.

Touching Private Parts

All kids at some point will discover their private parts. Every family has their own values and beliefs about this behavior, and it is okay to teach your daughter what your family believes. It is a normal part of development for boys and girls to touch themselves at times, and it is almost impossible to stop this behavior completely. Teaching your child when and where this behavior is allowed may be the best option. Punishing, shaming, or giving it a lot of attention may actually make it happen more. It also may make your daughter less likely to ask you or the doctor important questions.

It is important to know the facts. Touching private parts does not cause blindness, make you “go crazy,” stunt growth, or damage your body parts. It is not always associated with thinking about sex, either. Some young people touch themselves because it is a calming sensory experience. Some children might touch their private parts because they itch or hurt, which could be a sign of an infection. If your daughter is touching so much that it gets in the way of doing other activities, you notice irritated skin, or you have other concerns, talk to a doctor.

You can teach your child which parts of the body are “private parts” by describing them as the parts of the body covered by a swimsuit or underwear. You can find examples of visuals and social stories to talk about private parts and about touching in *Private Parts Appendix*.

If your daughter is touching her private parts in public, you will want to stop the behavior quickly and quietly. You can use a visual to remind her of the rule, such as “No Hands in Pants,” or a visual to cue a behavior that she can’t do at the same time, such as “Hands on Table.” Use a First/Then Visual of “Wash Hands” then “Reward” to interrupt the behavior. Before going out, consider bringing activities that will keep her hands active, like a fidget or a handheld game. If you are at home, you may want to use a visual to give her a choice of “No Hands in Pants” or go to a “Private” place. ■

See Public/ Private Behaviors Appendix

Puberty can be hard for all children. Friends, social skills, and appearance matter more. Your daughter may need help handling stress and fitting in with other peers. As children move from elementary to middle and high school, clothing, dating, and driving become more important. Developmental differences may become more noticeable. Think about the social situations your daughter will face and how things like clothing, haircuts, and age-appropriate interests can impact her "social world."

How You Can Help Your Daughter Socially

Get her involved in activities she enjoys with other peers. Find groups that do things she enjoys, such as individual or team sports, a club that fits with her interests, or a youth group. Talk to the group leader about her needs and ideas about how to include her. Contact local advocacy groups to learn more about what is available in your area. If no appropriate group exists, consider starting one.

Talk to your daughter's teacher or school counselor about peer sensitivity training. Programs exist to help other children understand your child's strengths and challenges. Teaching peers about why your daughter has differences in her communication, learning, and/or mobility can increase empathy and understanding. Many groups provide "toolkits," websites, and lists of local resources to help promote peer sensitivity and inclusion. See the resources listed on page 19.

Hair. Take your daughter to get an age-appropriate haircut. Part of growing up is having clothing and hairstyles like your peers. While this may not be top on your priority list, it may be important to your daughter and her peers.

- Look at magazines and talk to other parents to get ideas for styles. Think about haircuts that are easy for her to maintain. Let her choose pictures of haircuts she likes and share them with the hair dresser.
- Set the appointment for a time when the shop is not as busy and consider asking for a longer appointment time in case your daughter needs a break. Take distractions, like an electronic tablet or a game to help her tolerate the haircut.
- Talk to your daughter's occupational therapist about self-care skills (e.g., brushing and styling hair) and adaptive equipment that can help her be independent.

Makeup. Many girls start wearing makeup during puberty. Talk to your daughter about your family's rules about makeup. Pay attention to what other girls in her school do and at what age. If you decide to let your daughter try wearing makeup, start simple, such as with a tinted lotion, lip gloss, or powder. Ask for help from an older sister, aunt, or even a professional at a make-up counter in selecting natural looking and age-appropriate options and applying them correctly.

Clothes. When shopping for clothing for your daughter, it is important to recognize age-appropriate clothing trends. What are other girls wearing when you visit your child at school? To find out where other teenagers get clothes, you can look at magazines, talk to other parents, or take an older sibling or cousin with you when you shop. For example, switching from velcro shoes to slip-ons or covering elastic wastebands with untucked shirts can help your daughter appear more fashionable.

If your daughter is able to make choices, give her different clothing options. You can take her shopping, buy and lay out several shirts to pick from, or use a choice board with pictures.
If your child has strong clothing preferences, or trouble with buttons, zippers, and snaps,

See Moods and Feelings Appendix

and you would like her to consider other options, try slowly introducing new tops, pants, or skirts. Keep in mind comfort, fit, and her favorite colors and textures. Use a story to explain about how children, teenagers, and adults dress differently. Work with your occupational therapist on dressing skills.

What if my daughter doesn't care? Puberty and being a teenager are about increasing independence and expressing individuality. Even if clothing does not seem to matter to your child, small things like a different style of pants or a new haircut can go a long way toward helping her feel included and preventing her from being teased. Helping her look and dress her age may make it easier for peers to get to know how great your daughter is on the inside too!

Augmentative Communication Devices. If your daughter uses a communication device with voice production, make sure that the voice matches her age and gender.

Moods and Feelings

Moodiness can be normal during puberty. You can teach your daughter to express these feelings. If she is verbal, use your words to label feelings ("It sounds like you're feeling angry," or "So when he did that, it made you sad.") If your child is less verbal, use visuals like cartoons, photos, sign language, or word cards. *Moods and Feelings Appendix* includes pictures of emotions your child can use to let you know how she feels. Consider getting support from a counselor or therapist who is familiar with her diagnosis and can give you other strategies.

More Than "Moody"

Sometimes mood changes can be caused by something more serious, like medical problems. For example, thyroid problems (which are common in children with Down syndrome) can look like depression by affecting mood, appetite, and activity level. Mood changes also can be a symptom of depression or anxiety. Children with disabilities can have typical teenage moodiness, but they also can develop other mental health problems that should be treated. Watch for **changes** in their typical behavior like the ones listed below.

- **Emotions**: Crying, shouting, laughing for no clear reason
- **Behavior**: Pacing, rocking, rubbing hands together, picking at skin
- **Aggression**: Hitting, biting, scratching, head-banging, throwing items
- **Appetite**: Eating more or less
- **Wellness**: Complaining about headaches, stomach aches, or other body aches
- **Sleep**: Sleeping more or less, trouble falling or staying asleep, nightmares
- **Thinking**: Seeming confused, having trouble focusing, seeing things that are not there
- **Energy**: Moving more or less, acting withdrawn, not doing things she used to enjoy

Talk to your daughter's doctor about any changes that you see. Keep track of them using a diary, data sheet (see *Diary Appendix*), or an electronic phone or tablet application. Write down what you see and when you see it. Remember to note the dates when her period starts and stops. ■

See Diary Appendix

VI. Bras, Tampons, and Pads! Oh My!

As your daughter approaches puberty, her body begins to change. She will develop breast buds and then in a year or two, she will likely begin menstruation (sometimes called "getting your period"). These changes are a normal part of puberty. However, they can be scary if your daughter does not understand what is happening. You can use stories and pictures to help your daughter understand her changing body (see *Teaching Body Parts Appendix*) and feel prepared.

Introducing Bras to My Daughter

Start training. Help your daughter get used to wearing something under her clothes by using training bras, camisoles, tank tops with thin straps, and/or sports bras.

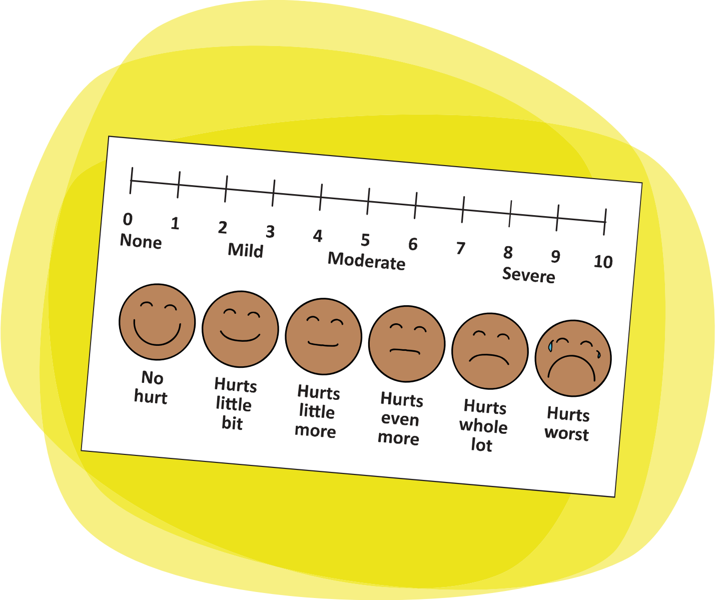
Keep it comfortable. Think about buying a bra that snaps in front or pulls on easily if bras are hard for your daughter to fasten. Try bras without an underwire or itchy fabrics, like lace. Consider taking your daughter to a shop that offers professional fittings. Call ahead and make an appointment to be sure they can accommodate her needs. Ask your daughter's occupational therapist for other ideas about fit, special (adaptive) bras, and learning the motor steps to put on a bra.

Helping My Daughter Prepare for Her Period

- **Start early.** Children enter puberty at different ages (usually from ages 9-15), and children with some disabilities may enter puberty even earlier. Periods usually start about a year or two after a girl develops breast buds. The appropriate time to talk and teach about menstruation is before your daughter has her first period.
- **Talk about it.** Though it may feel uncomfortable, you should talk directly about menstruation with your daughter. Talking to her about it in a clear, matter-of-fact way will help her understand that having a period is normal and will make her less afraid. Make sure she knows that the blood does not mean she is hurt.
- **Be approachable.** Use positive statements ("That is a good question") to encourage your daughter to talk to you. Stay calm and try not to seem embarrassed. This will help your daughter feel safe talking to you, and you can teach her the real facts about periods.
- **Use everyday opportunities.** When you purchase tampons or pads or see a commercial for them on television, use these moments to start a conversation with your daughter about menstruation.
- **Use the right terms.** Answer questions using simple language and correct terms (such as breasts, vagina, pads, and tampons).
- **Consider her learning style.** Teach your daughter about menstruation in a way that works best for her. For example, if she learns best with visual aids, try using pictures or videos instead of stories or lists.
- **Ask a professional.** Ask your daughter's doctor for help teaching her about puberty and body changes.

See Teaching About Periods Appendix

Teaching My Daughter About Periods



What she will see. You should explain to your daughter that she will see what looks like blood in her underwear or in the toilet bowl. You can prepare her for what she may find when her period starts by adding food coloring or markings to a pair of underwear. Make sure she understands that this blood is normal, and it does not mean she is hurt.

What she will feel. Explain that some women feel different during their periods. She may feel tired and moody. Her stomach may swell or cramp. Give your daughter a way to tell you about how she feels. Use role-play, picture cards, a communication board, or a number or picture scale to tell you her level of pain (See *Teaching About Periods Appendix* for a pain scale your daughter can use.) Tell your daughter's doctor about her symptoms.

Who she can talk to. Teach her that her period is private. Let her know that she can talk with her parents, her doctor, or the school nurse about her period. She should not talk about her period with boys, casual friends, or strangers. See the activity in *Teaching About Periods Appendix* to teach about public/private behaviors.

How to keep it private. Find ways for your daughter to bring pads to school that are not obvious. Let your daughter help pick out an attractive but practical container for her pads that is private but is easy to use. Examples would be a special bag, carrying case, or purse that she keeps in her backpack, locker, or in the school nurse's office.

Teaching My Daughter About Self-care

- **Try pads first.** We recommend starting with pads and changing to tampons if necessary. Your daughter may find tampons harder to use if she has motor difficulties. It is also less clear when tampons need to be changed. If the flow becomes too heavy for pads to be effective, talk with your daughter's doctor about other options.
- **Give her a choice.** Purchase different sizes and types of pads before the onset of menstruation. Before and after shopping, talk about different features of pads like wings and thickness. Let your daughter try pads out and pick one that feels comfortable. After deciding which pad she likes, take your daughter shopping with you and use a picture card to help her independently find the box on the store shelf and place it in the cart for purchase.
- **Demonstrate.** You or other women in your family can show or model the steps of wearing and changing pads in short, simple steps.

See Teaching About Periods Appendix

- **Make a schedule.** The steps of changing pads can be shown on a visual schedule, pocket schedule, or bathroom folder. See *Teaching About Periods Appendix* for an example of a pocket schedule. This helps your daughter be more independent and can make regularly changing pads part of her daily routine. When making a schedule, think about normal breaks during the school day and at home as good times to change tampons or pads.
- **Make a visual guide.** You can mark underwear with an outline of the pad to remind your daughter where she should place it.
- **Practice.** Practice wearing thin pads or liners before your daughter starts her period to help her get used to how they feel. Girls with sensory sensitivities may need more practice to feel comfortable. Try using a timer and reward her for wearing the pad for longer amounts of time.
- **Make it easy.** Work with your daughter's teacher to make it easy for her to ask for a bathroom break when she needs to change her pad. If she feels embarrassed or has trouble asking for what she needs, handing the teacher a cue card, a token, or simply scheduling regular bathroom breaks during that week may help avoid accidents.
- **Consider adapting.** Your daughter may struggle with the motor skills needed to change pads, underwear, or clothes. Adaptive clothing may make changing pads and underwear easier. Ask your daughter's occupational therapist for ideas. Explore other adaptive clothing options online. You may be able to adapt clothing yourself by adding Velcro or Snaps to the sides of underwear or buying elastic waist pants. You can buy pads without difficult-to-remove wrappers, or you can remove the wrappers and store them unwrapped for your daughter to use. You can also place pull-tabs on the paper covering the pad so that it is easier to remove.
- **Help her help herself**. It is important to help your daughter become as independent as possible in her self-care. Using the strategies above may help her learn to manage her period with less assistance. However, young women with I/DD often need extra help with these types of hygiene tasks. Ask your daughter's school if an aide or school nurse can assist her. Share the tips in this brochure and the ones you develop at home with the other caretakers in your daughter's life.

Whenever you start teaching any of these methods, break them down into short, simple steps. Help your daughter practice and give her feedback. Praise her as she learns these new skills! ■

See Teaching About Periods Appendix

Female Exam

For women with disabilities, the female exam (also called "gynecological exam") and menstrual control may be challenging. In this section, you will find tips on preparing your daughter for the exam. There also is information on how to know if menstrual control might be helpful and, if so, how to choose it.

Why My Daughter Needs an Exam

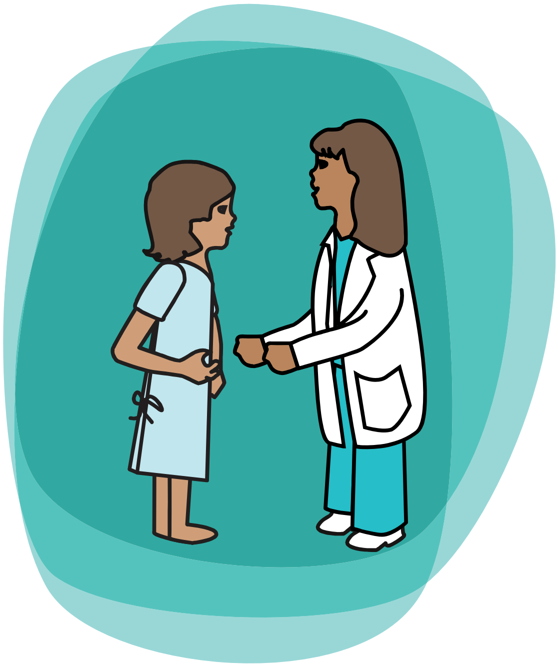
According to accepted guidelines, all women age 21 and over should receive pap smears to screen for cervical cancer. These exams should begin earlier for women who are having sex. Even if your daughter is not sexually active, she needs to see a gynecologist for screening and preventative care. Also, breast cancer screening (mammograms) should begin around age 40.

Establishing a positive relationship with a gynecologist early helps your daughter access good care if problems arise. Research has found that women with intellectual disabilities are 72% less likely than women without disabilities to get pap smears and 45% less likely to have mammograms. *Don't let your daughter be one of them.* Find a gynecologist who is willing to work with you and your daughter to develop an individualized prevention plan.

Teaching Her What to Expect During the Exam

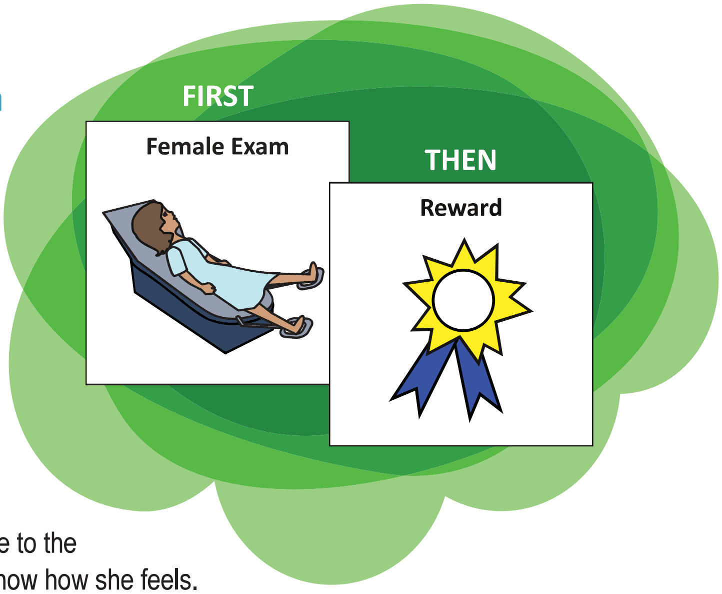
Explain ahead of time what will happen at the visit. It may help for the doctor/nurse to explain each step to your daughter as the exam happens (e.g., "Next, I am going to _____"). A practice visit to the office with a tour of the exam room may also reassure her.

- The doctor/nurse will make sure your body is healthy. They will look at and touch your private parts during the exam. They will not touch your private parts at other times.
- You will take off your clothes during the exam. This includes your underwear and bra. The nurse will give you a gown to wear.
- You will then lie on your back or on your side on an exam table with a sheet over you.
- The doctor/nurse will touch your breasts, armpits, stomach, and vagina to make sure you are healthy.
- The doctor/nurse may need to put a tool, called a speculum, inside your vagina to see inside. The speculum may feel cold and uncomfortable, but stay calm and take slow, deep breaths. It will be over quickly.
- You can ask the doctor/nurse any questions you have during your visit.
- You can put your clothes back on after the exam.



See Teaching About the Female Exam Appendix

Preparing My Daughter for the Exam



- Show your daughter a picture schedule of what will happen at the exam. (See *Teaching About the Female Exam Appendix* for picture schedule example.)
- Help your daughter make a list of questions she has about puberty, her period, or the exam.
- Practice or role-play how to ask questions before the visit.
- Bring your daughter's visual pain scale to the visit so she can let the doctor/nurse know how she feels.
- Call the office ahead of time to let them know about your daughter's needs and preferences.
- If your daughter has a motor impairment, you can ask about any special equipment that she may need. If your daughter has trouble lying on her back, ask about different positions for the female exam. If your daughter's provider does not know about alternate positions, ask your occupational therapist for suggestions. Make sure staff members at the office are willing and able to help position your daughter on the exam table safely.
- It is okay to talk with the doctor about adapting the exam to your daughter's needs.
  - Ask about the purpose of each procedure and if there are alternatives that may be easier for your daughter to handle.
  - Break the exam into more than one visit or ask for extra time if needed.
  - Ask the doctor/nurse to meet with you and your daughter first, before she takes off her clothes, instead of asking questions after she is in a gown.
  - Ask the doctor/nurse to think about ways to make the amount of time she is on the table as short as possible.

Helping My Daughter Feel More Relaxed

- Bring something relaxing or distracting to the exam, like music, a hand-held device (electronic tablet, phone, game), or a book that your daughter enjoys.
- Practice relaxation before the exam, and bring visuals to prompt her through the relaxation exercise.
- Ask your provider about medicine that may help your daughter to relax during the exam.
- Ask your provider about the option of sedating your daughter for the exam if these other strategies do not work for her.
- Plan something special for you and your daughter after the visit. Let her choose an activity she enjoys or a special treat, and talk about it before and during the visit. Use a visual, such as a First/Then Board to remind her what will happen after the visit is done.

See Teaching About the Female Exam Appendix

Menstrual Control

You may not think that your daughter needs birth control, but women use it for many reasons. Obviously, it prevents pregnancy. However, it also helps control menstrual bleeding, which can be heavy, painful, or irregular. Women are sometimes required to use birth control if they are taking medications (like epilepsy medication) that could harm their babies if they become pregnant.

If your daughter experiences heavy bleeding and pain with her period, birth control medication may provide some relief. Some options may make her flow lighter, while other options may stop her period altogether. Doctors also prescribe birth control medications to treat painful conditions like endometriosis or help manage severe acne.

To choose the best menstrual and birth control method for your daughter, include her in the choice as much as possible. **Talk to her doctor/nurse about how to use it, the side effects, and possible risks**.

Birth Control for My Daughter

Birth Control Pills:

- May prevent pregnancy and control bleeding.
- They must be taken every day.
- If your daughter has mobility limitations, it is important to know that these pills can cause blood clotting. You should talk to your daughter's medical provider about this.
- Some pills limit periods to four times a year or less.
- Different pills affect different hormones. Your daughter may need to try a few different types of pills before finding the one that works best for her.

Birth Control Shot:

- The shot contains a hormone and is given every three months.
- It makes periods lighter over time.
- Think about how your daughter tolerates shots before choosing this method.
- The medicine will stay in your daughter's body for about three months, so ask the doctor/nurse about what can be done if your daughter doesn't respond well to the medication.
- Weight gain is one possible side effect you should discuss with the doctor.

Transdermal Patches:

- A patch is placed on the skin and worn for three weeks. It is then taken off for one week so that your daughter can have her period.
- Sometimes the patch may fall off too early or cause skin irritation.
- If your daughter has sensory sensitivities, she may not like the feel of the patch on her skin.
- If your daughter has motor difficulties, she may have trouble peeling the sticker and putting the patch on her skin.

See Teaching About Periods Appendix

Birth Control Implant:

- A rod with medicine can be inserted in the arm under the skin by a health care provider.
- The rod is plastic, about the size of a matchstick.
- Insertion usually takes about a minute. Removal takes about three minutes.
- This rod releases medicine that prevents pregnancy and controls bleeding over time.
- This method lasts up to three years but can be removed at any time.

Intrauterine Device:

- An intrauterine device (IUD) is placed in the vagina by a healthcare provider.
- Placement can be painful for some women who have never had a vaginal childbirth.
- The effectiveness of the IUD lasts at least 5 years and up to 10 years depending on the type.
- An IUD can make flow lighter over time and reduce painful periods. Some women experience irregular spotting. Talk to your daughter's doctor/nurse about possible side effects.

Appendix and visuals can be found online at:

kc.vanderbilt.edu/HealthyBodies

Organizations

☐ Vanderbilt Kennedy Center: kc.vanderbilt.edu

☐ Autism Society of America www.autism-society.org

☐ Autism Speaks: www.autismspeaks.org

☐ Easter Seals: www.easterseals.com

☐ National Down Syndrome Society: www.ndss.org

☐ National Parent Technical Assistance Center: www.parentcenternetwork.org

☐ American Society for Deaf Children: www.deafchildren.org

☐ United Cerebral Palsy: www.ucp.org

Visual Support Resources

☐ http://card.ufl.edu/content/supports/start.html

☐ www.kidaccess.com/index.html

☐ Do 2 Learn: www.do2learn.com

☐ Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Websites

☐ National Information Center for Children and Youth With Disabilities. *Sexuality education for children and youth with disabilities.* Available at http://nichcy.org/schools-administrators/sexed

☐ Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center: www.pacer.org/bullying

☐ www.autismspeaks.org/family-services/tool-kits/dental-tool-kit

☐ kc.vanderbilt.edu/kennedy_files/OralHealthTips.pdf

☐ http://kidshealth.org/teen/sexual_health/girls/menstruation.html

☐ http://kidshealth.org/teen/sexual_health/#cat20015

☐ www.freewebs.com/kidscandream/main.htm

Social Stories–Information and Examples

☐ Gray, C., & White, A. L. (2002). *My social stories book*. Philadelphia, PA: Jessica Kingsley Publishers.

☐ www.thegraycenter.org/social-stories/what-are-social-stories

☐ www.bbbautism.com/pdf/article_27_Social_Stories.pdf

☐ www.tinsnips.org/Media/social/menstruation2.pdf

Books

☐ Jukes, M., (1998). *Growing up: It's a girl thing: Straight talk about first bras, first periods, and your body changing*. New York: Borzoi Book Publisher.

☐ Schaefer, V. (1998). *Care and keeping of you: Body book for girls*. American Girl Library (Middleton, WI) Pleasant Company Publications.

☐ Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty, and personal curriculum for young people with autism*. Arlington, TX: Future Horizons.

☐ Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks galore for the real world*. Raleigh, NC: Tasks Galore. www.tasksgalore.com

☐ Bellini, Scott, *Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with autism spectrum disorders and other social difficulties* (2006). Autism Asperger Publishing Co., Shawnee Mission, KS.

☐ Baker, Jed (2009) *Social skills picture book for high school and beyond*. www.mayer-johnson.com/the-social-skills-picture-book-for-high-school-and-beyond

☐ Meehan, Cricket, *The right to be safe: Putting an end to bullying behavior* (2011). Search Institute Press.

This publication was developed and written by Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) long-term trainees Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; Doctor of Audiology student, Elizabeth Harland; Cong Van Tran, PhD; and LEND faculty members Jennifer Bowers, RN, MSN, CPNP, Pediatric Nurse Practitioner, Division of Developmental Medicine; and Cassandra Newsom, PsyD, Assistant Professor of Pediatrics, Division of Developmental Medicine, Director of Psychological Education, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. It was edited, designed, and produced by the Communications and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) with the support of the Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). We are grateful for review and suggestions by many, including faculty of TRIAD and members of Autism Tennessee.

This publication may be distributed as is or, at no cost, may be individualized as an electronic file for your production and dissemination so that it includes your organization and its most frequent referrals. For revision information, please contact courtney.taylor@vanderbilt.edu, (615) 322-5658, (866) 936-8852.

This publication was made possible by Grant No. T73MC00050 from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS. Photos ©istockphoto.com. Printed June 2013.

VANDERBILT KENNEDY CENTER
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Cuerpos sanos

Para niñas

Una guía sobre la pubertad para padres de niñas con discapacidades

Índice

Puede descargar un anexo con historias sociales y apoyos visuales en: kc.vanderbilt.edu/HealthyBodies

Puede encontrar un anexo con apoyos visuales en

kc.vanderbilt.edu/HealthyBodies

La pubertad puede ser una etapa confusa y llena de tensión, especialmente para usted y su hija con una discapacidad intelectual o del desarrollo (DI/DD). Aunque tengan retraso en otras áreas, las niñas con DI/DD normalmente llegan a la pubertad a la misma edad que las otras niñas. Algunas niñas con DI/DD, incluidas las que tienen espina bífida y parálisis cerebral, pueden llegar antes a la pubertad (llamada pubertad precoz). En este manual puede encontrar recursos y consejos sobre cómo hablar con su hija sobre estos temas tan difíciles.

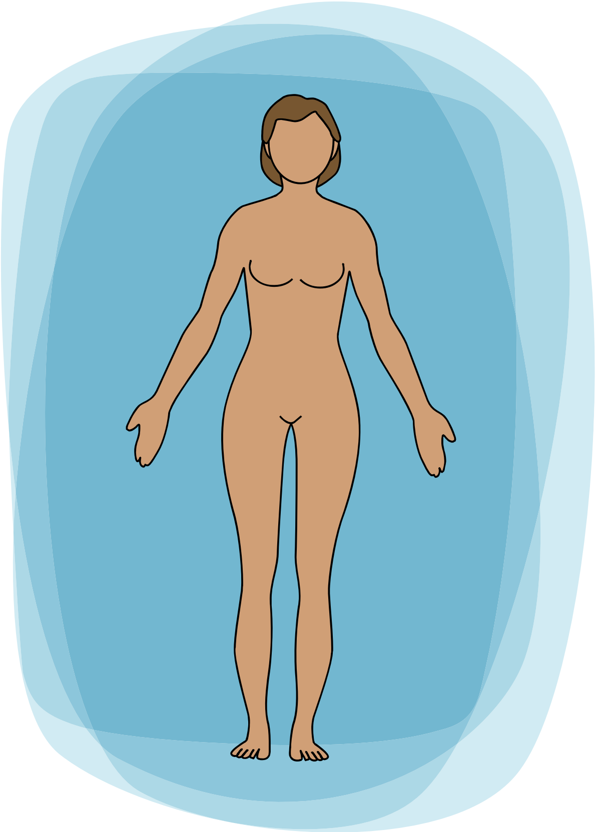
Hablar con mi hija de esas cosas

Empiece pronto. Hable con su hija antes de que sean visibles los signos de la pubertad.

Enseñe cómo llamar las partes del cuerpo. Use las palabras apropiadas para las partes del cuerpo (p. ej., vagina, senos) y las funciones del cuerpo (p. ej., orinar, periodo). Esto evita confusiones y le da a su hija el vocabulario que usará luego cuando aprenda sobre la pubertad, el aseo personal y la reproducción. Puede usar los apoyos visuales del *Anexo Las partes del cuerpo* para enseñar a su hija cómo llamar a las partes del cuerpo y cómo está cambiando su cuerpo.

Use materiales de apoyo. Usted sabe cómo aprende mejor su hija. Enséñele sobre la pubertad de la misma manera que le enseña sobre otras cosas. Por ejemplo, si su hija aprende mejor repitiendo algo muchas veces, divida la información en datos sencillos y practique muchas veces. Si aprende mejor con dibujos, pruebe a usar apoyos visuales o historias sociales. Estos apoyos le ayudarán a que entienda las cosas difíciles de una manera más clara. Si necesita ideas, revise los materiales que hemos preparado para enseñar estas habilidades (vea el *Anexo Las partes del cuerpo*). Usted puede adaptarlos a la forma en la que su hija aprende mejor.

Pregunte a un profesional. Hable con los doctores, maestros o terapeutas de su hija para que le den otras ideas. ■



Vea el Anexo Las partes del cuerpo

Es importante que la niña aprenda a estar sana desde que es pequeña. Los cambios en las hormonas y algunas medicinas pueden causar que suba de peso durante la pubertad. Hacer ejercicio regularmente y comer bien puede ayudar a su hija a que no aumente de peso, tenga mejor humor y más confianza en sí misma. Comenzar pronto estos hábitos saludables es la mejor manera de ayudar a su hija a convertirse en una adulta activa.

Cómo empezar

Programe actividades físicas. Cada día, su hija debe tener tiempo para jugar de forma activa, como ir a caminar, jugar afuera o andar en bicicleta. Si le es difícil empezar, dele varias opciones para escoger o ¡vaya con ella! Incluya siempre actividades físicas divertidas en la rutina diaria de su familia.

Pregunte a un profesional. Si su hija tiene un impedimento, pregunte a su doctor, terapeuta ocupacional o terapeuta físico para que le den ideas de ejercicios seguros. Cerca de su casa, busque actividades deportivas adaptadas o con apoyos que estén diseñadas para adolescentes con discapacidades o que tengan modificaciones para poder incluir a su hija.

Recompense el ejercicio. A medida que su hija se hace mayor, cambie de "tiempo para jugar" a tiempo de hacer ejercicio, deportes o actividades familiares (como pasear juntos). Si su hija no quiere ejercitarse, puede animarla dándole un premio o recompensa después. A esta edad, es mejor no dar comida como recompensa. Pruebe a usar apoyos visuales como un tablero Primero-Después. Por ejemplo, muestre "Primero ejercicio", seguido de algo preferido, como "Después videojuegos". En el *Anexo Tablero Primero-Después* encontrará una plantilla en blanco que puede usar en casa. ■

Vea el Anexo Tablero Primero-Después

Fomentar el aseo personal

La buena higiene puede mejorar la independencia y la confianza de su hija. Además, si tiene buenos hábitos de aseo personal, usted pasará menos tiempo realizando estas tareas de aseo por ella.

Haga un libro de dibujos. Un libro de dibujos puede ser un buen punto de partida para enseñarle sobre higiene y aseo personal. Usted y su hija lo pueden crear juntas. La cantidad de información (más o menos dibujos) depende del nivel de lectura y la memoria de su hija. Incluya dibujos de las cosas que necesita (p. ej., jabón líquido, desodorante, toallas femeninas) y una agenda visual con los pasos necesarios. Este libro de dibujos también puede ayudar a su hija a escoger lo necesario cuando vaya de compras o a preparar las cosas que necesitará para hacer una tarea específica, como ducharse. Usar un libro de dibujos puede ayudarla a sentir que tiene control y que es responsable de completar su propio aseo personal.

Prepare estuches de aseo. Puede preparar estuches para las distintas tareas. Se pueden usar cajas de zapatos viejas, recipientes de plástico transparente o canastas para guardar las cosas. Deje que su hija escoja los recipientes. En la parte de afuera del estuche, ponga dibujos o listas de los artículos que hay dentro y un dibujo de la tarea que va a hacer (p. ej. ducharse). Vea el *Anexo Fomentar el aseo personal* para buscar dibujos que usted y su hija pueden usar para crear el estuche de aseo. Estos son ejemplos de lo que puede contener:

- **Ducharse**: Jabón líquido, champú, acondicionador, jabón para la cara, afeitadora, crema de rasurar.
- **Cepillarse los dientes**: Cepillo de dientes, pasta dental, hilo dental, enjuague bucal.
- **Menstruación**: Distintas toallas femeninas, toallitas húmedas, analgésicos (solo si es capaz tomar medicinas ella sola), ropa interior para cambiarse.
- **Rutina de la mañana**: Crema corporal, desodorante, toallitas húmedas, crema para la cara, cepillo de pelo.

Puntos problemáticos: cabello sucio

Al entrar en la pubertad, las niñas pueden tener que lavarse el cabello más a menudo. Su hija puede tener dificultad lavándose el pelo porque le puede ser difícil realizar los movimientos. Quizá no le guste sentir el champú o el agua. Algunas niñas con DI/DD quizá no presten atención a lo que hacen sus compañeras o cómo se visten. Debido a esto, puede que no entiendan la importancia social de llevar el pelo limpio.

- **Hágalo una rutina.** Prepare una agenda o calendario que muestre a su hija cuán a menudo tiene que completar las tareas de aseo y los pasos que debe realizar. En el *Anexo Fomentar el aseo personal* verá un ejemplo de los pasos para bañarse.
- **Cante en la ducha**. *Para ayudar a su hija a saber cuánto tiempo estar en la regadera o en la tina, copie canciones en un CD de música que duren el mismo tiempo que debe asearse, cada cambio de canción puede ser una señal para pasar al siguiente paso.*
- **Más suave.** ¿Detesta su hija lavarse el pelo con las manos? Dele una esponja suave para aplicar el champú. Si la presión del agua molesta a su hija, deje que use una taza o jarra para enjuagarse el pelo o use una regadera en la que se pueda ajustar la presión.
- **Una imagen vale más que mil palabras.** Escriba una historia que explique la importancia de bañarse y lavarse el cabello a diario. Diviértanse. Tome una foto de su hija y de los otros miembros de la familia cuando se acaban de despertar por la mañana (¡pelo despeinado y todo!) y luego otra después de bañarse y vestirse. Hable de lo que otras personas pueden pensar si uno fuera a trabajar o a la escuela tal y como cuando se acaban de despertar.

Vea el Anexo Fomentar el aseo personal

Puntos problemáticos: sudor y olor corporal

Durante la pubertad se empieza a sudar más, así que es importante enseñar a las niñas a controlar el olor usando desodorante, cambiarse de ropa a diario, lavar la ropa sucia una vez a la semana y mantenerse aseadas.

- **No olvide los apoyos visuales.** Use listas e historias para recordarle a su hija los pasos que necesita seguir para asearse y por qué. El *Anexo Fomentar el aseo personal* tiene una historia sobre cómo controlar el sudor y el olor corporal.
- **Agenda o Guía.** Si su hija necesita que le recuerden cual es la siguiente parte del cuerpo que necesita lavarse, puede usar una agenda o guía que muestre qué acción o paso viene después. Incluya los pasos de lavarse el cabello con champú y enjuagarse, y las partes del cuerpo que tiene que lavarse con jabón. Plastifique (enmique) la guía y cuélguela en la regadera. Otra opción es usar una muñeca Barbie® vieja, una figura de acción o una muñeca de papel enmicada. Separe y numere cada parte del cuerpo. Cuelgue la muñeca en el baño con velcro. A medida que su hija se lava las partes del cuerpo, puede colocar la parte correspondiente de la muñeca en una bolsa o caja que diga "limpio".
- **Obstáculos.** Si aplicarse desodorante es algo difícil para su hija, pruebe distintos tipos, como el desodorante de bola o en rociador. Si le cuesta trabajo bañarse sola debido a las dificultades de movimiento, pruebe con sillas de baño, una regadera de mano, manoplas para lavarse o cepillos de mango largo y fáciles de agarrar, etc.
- **Huele demasiado fuerte.** Anime a su hija para que escoja sus productos de aseo, sobre todo los perfumados. Hay niñas a quienes les molestan los olores fuertes y prefieren los productos sin olor. Muchos productos que dicen en la etiqueta "para piel sensible" no tienen olor.
- **Acné.** Algunas adolescentes sufren de acné (granitos) debido al aumento de la grasa de la piel, los cambios en las hormonas, la higiene y hasta la genética. Pregunte al médico de su hija sobre los productos para el acné que no necesitan receta, como cremas, lociones y líquidos que contienen medicamentos como el ácido salicílico o el peróxido de benzoílo. Tome una foto de la cara de su hija o use un dibujo y marque con círculos las áreas donde se debe aplicar el producto a diario. Enseñe a su hija que hay que evitar las zonas sensibles como los ojos, los agujeros de la nariz y la boca. También considere comprar las toallitas que contienen el medicamento y que facilitan la aplicación. Si su hija tiene acné en el cuerpo, también venden jabón líquido con medicamento.

Vea el Anexo Fomentar el aseo personal

Puntos problemáticos: vello corporal y rasurarse

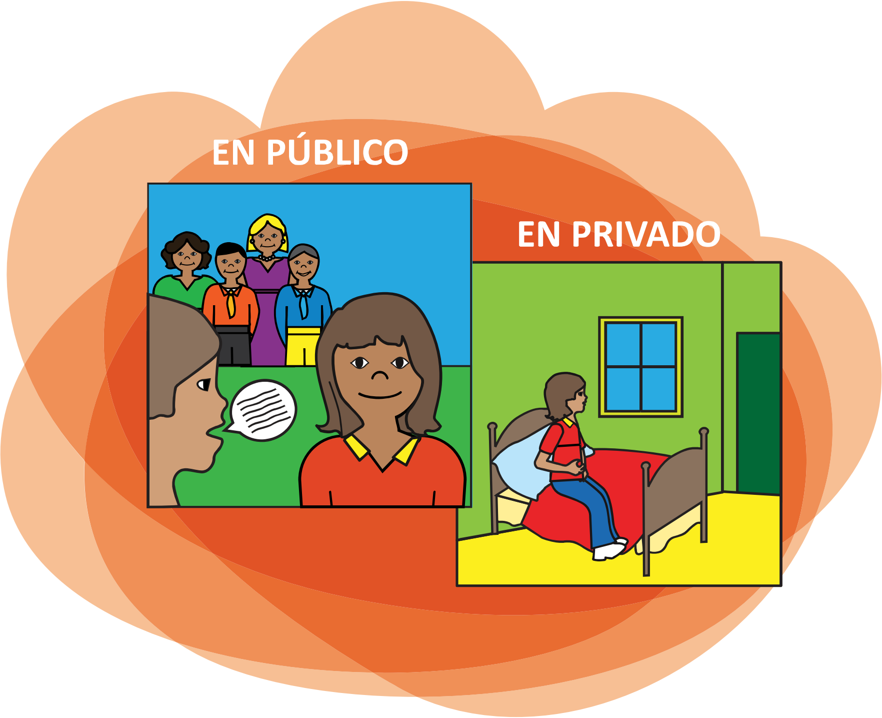
Durante la pubertad, empieza a crecer y a cambiar el vello en el cuerpo. Use un dibujo del cuerpo de una mujer (como el del *Anexo Las partes del cuerpo*) para enseñar a su hija dónde crece el vello y para prepararla para los cambios que verá en su cuerpo. Algunos adultos y adolescentes quieren rasurarse o depilarse el vello del cuerpo.

- **Demuestre cómo afeitarse o depilarse.** Permita que su hija la vea a usted o a una hermana mayor mientras se rasura o depila, y escriba los pasos. Haga que su hija practique con usted, paso por paso. Escriba o tome fotografías de cada paso para hacer una guía o agenda visual. Para ayudarla a recordar dónde no tiene que rasurarse, use una foto o dibujo de una persona y coloree o numere las áreas que hay que rasurar.
- **Anote las fechas en que se debe afeitar.** Si su hija puede rasurarse (o si lo hace con ayuda), use un calendario con dibujos o marcas como recordatorio de cada cuando tiene que rasurarse y cuándo tiene que cambiar la afeitadora.
- **Limite la espuma de rasurar.** Si su hija necesita ayuda con el control de cantidades o manejando el frasco de espuma, trate de usar los frasquitos de espuma para viajes o una brocha de afeitar.
- **Busque la rasuradora correcta.** Las niñas que tienen problemas con las manos pueden preferir una rasuradora eléctrica, en lugar de las afeitadoras tradicionales. Si prefiere la afeitadora tradicional, pregunte a su terapeuta ocupacional si las afeitadoras con contrapeso o un manguito universal pueden ayudarle a sujetarlas.

Puntos difíciles: lavarse los dientes y el aliento

- **Haga una agenda visual.** Use dibujos que muestren los pasos de cepillarse los dientes. En el *Anexo Fomentar el aseo personal* puede ver imágenes que le muestran a su hija cómo cepillarse los dientes ella sola.
- **Escoja el cepillo de dientes correcto.** Un cepillo que vibre o tenga contrapeso puede ayudar a los niños que tengan dificultad para agarrar el cepillo de dientes y cepillarse. Busque un cepillo de cerdas suaves.
- **Demuestre cuándo y cuánto tiempo.** Acostumbre a su hija a cepillarse a diario, incluyendo recordatorios en un calendario. Las alarmas también pueden recordarle por cuánto tiempo tiene que cepillarse. ¡Los dentistas recomiendan dos minutos!! 🟩

Vea el Anexo Fomentar el aseo personal



Comportamiento apropiado e inapropiado en público

¿Hace o dice su hija cosas en público que usted preferiría que no hiciera? Su hija necesita aprender lo que está bien hacer en público y lo que está bien hacer en privado. Los comportamientos privados incluyen, por ejemplo, ir al baño, expulsar gases, tocarse las partes íntimas por cualquier motivo y cambiarse de ropa. Saber comportarse apropiadamente en la sociedad puede ayudar a su hija a encajar con sus compañeros y que haya menos posibilidades de que la acosen o maltraten. Los niños que entienden la diferencia entre los comportamientos que están bien o están mal en público pueden tener menos problemas en la escuela o con la policía cuando se hacen mayores.

Enseñar estas habilidades a su hija

- **Comience pronto.** Hable sobre los comportamientos públicos y privados en familia y ponga reglas como, por ejemplo: "Solo puedes estar desnuda en el baño o en tu recámara con la puerta cerrada" o "Nos ponemos la ropa o la pijama antes de salir del baño o de la recámara". Recuerde las reglas a su hija usando palabras o dibujos sencillos. ¡Tenga las mismas reglas para todos en la familia!
- **Use apoyos visuales.** Haga una lista de lugares que son públicos y lugares que son privados. Luego puede pensar ejemplos de comportamientos que están bien en cada uno de esos lugares. Use apoyos visuales para ayudar a su hija a entender y recordar esas reglas. Vea el *Anexo Comportamientos en público o en privado* para buscar ideas e imágenes que se pueden imprimir para enseñarle los conceptos de en público y en privado.
- **Use historias.** Las historias ayudan a su hija a entender estas reglas y por qué las tenemos. Piense en los comportamientos que son un problema para su hija y escriba una historia que explique claramente cuándo y dónde está bien hacer eso. En el *Anexo Comportamientos en público o en privado* puede ver ejemplos de historias sobre cosas que se hacen en público y en privado.

Vea el Anexo Comportamientos en público y en privado

- **Dirija**. Diga a su hija dónde puede hacer esas cosas privadas usando palabras o dibujos sencillos. Por ejemplo, diga algo como: "Puedes hacer eso en tu (recámara, baño)" o muéstrele una tarjeta visual que diga "En privado". Diríjala a un lugar privado cuando se toque sus partes íntimas o cuando se ajuste la ropa interior.
- **Cuando lo privado no puede ser privado.** Algunos niños necesitarán ayuda con tareas que se hacen en privado, como vestirse, bañarse o hacer sus necesidades. Enseñe a su hija a quién puede pedir ayuda para estos actos privados cuando está en lugares públicos, como la escuela o en un restaurante. Esto incluye enseñarle a planear, pedir ayuda discretamente o usar gestos o tarjetas.

Tocarse las partes íntimas

Todos los niños, en algún momento, descubren sus partes íntimas. Cada familia tiene sus propios valores y creencias sobre este comportamiento, y está bien que usted le enseñe a su hija lo que su familia cree. El tocarse a veces es una parte normal del desarrollo de los niños y las niñas, por lo que es casi imposible impedir este comportamiento por completo. Enseñar a su hija cuándo y dónde está permitido hacer eso puede ser una mejor opción. Castigar, avergonzar o llamar mucho la atención puede hacer que el comportamiento ocurra todavía más; o tambien, puede hacer que la niña ya no quiera preguntarle cosas importantes a usted o al doctor.

Es importante conocer los hechos. Tocarse las partes íntimas no va a causar ceguera, ni uno se "vuelve loco", ni se deja de crecer o se lastima las partes íntimas. No siempre está asociado a pensar en el sexo. Algunos jovencitos se tocan porque es una sensación que los calma. Algunas niñas pueden tocarse las partes íntimas porque sienten picor o dolor, lo cual podría ser señal de una infección. Si su hija se toca tanto que le impide hacer otras actividades, si nota la piel irritada o tiene otras inquietudes, hable con el doctor.

Para enseñar a la niña cuáles son las "partes íntimas" se puede decir que son las que se cubren con el traje de baño o la ropa interior. Puede encontrar ejemplos de apoyos visuales e historias sociales para hablar de las partes íntimas y sobre tocarse en el *Anexo Partes íntimas*.

Si su hija se toca las partes íntimas en público, usted quiere que deje de hacerlo rápida y silenciosamente. Puede usar un apoyo visual para recordarle esta regla, como "No tocarse" o una imagen para que haga otra cosa que no puede hacer al mismo tiempo, como "Manos sobre la mesa". Para interrumpir el comportamiento, use un Tablero Primero-Después con las imágenes de "Lavarse las manos" y luego "Premio". Antes de salir, considere traer actividades para que tenga las manos ocupadas, como un jueguito o videojuego de mano. Si está en casa, puede usar un apoyo visual para que escoja "No tocarse" o ir a un sitio "En privado". ■

Vea el Anexo Comportamientos en público y en privado

La pubertad puede ser difícil para todos los niños y niñas. Los amigos, las destrezas sociales y la apariencia importan más ahora. Su hija quizá necesite ayuda para controlar el estrés y encajar con los compañeros. Cuando los niños pasan de la escuela primaria a la secundaria y luego a la preparatoria (High School), la ropa, salir con chicos y manejar, ganan importancia. Ahora, las diferencias en su desarrollo se pueden notar más. Piense en las situaciones sociales por las que tendrá que pasar su hija y cómo las cosas como la vestimenta, el corte de pelo o los intereses acorde a su edad pueden ganar importancia en el "mundo social".

Cómo puede ayudar a su hija en la parte social

Haga que participe en actividades que le gustan con otros compañeros. Encuentre grupos que hagan las actividades que disfruta su hija, como deportes individuales o de equipo, un club sobre algo que le interese, o un grupo juvenil. Hable con el o la líder de ese grupo sobre las necesidades de su hija e ideas sobre cómo incluirla. Contacte a grupos de ayuda locales para saber más sobre lo que hay disponible en su área. Si no encuentra ningún grupo, considere empezar uno.

Hable con la maestra o consejera de la escuela sobre entrenar a los compañeros. Existen programas para ayudar a los otros niños a entender las cualidades y los retos de su hija. Enseñar a los compañeros sobre por qué su hija se comunica, aprende, camina o se mueve de manera diferente puede ayudar a que la entiendan más. Muchos grupos tienen folletos con consejos, sitios web y recursos locales para ayudar a promover la comprensión y la inclusión. Vea la lista de recursos en la página 15.

Cabello. Lleve a su hija a que le corten el pelo acorde con su edad. Parte de crecer es llevar la ropa y el cabello cortado como las chicas de su edad. Aunque esto puede que no sea su mayor prioridad, puede que sea muy importante para su hija y los otros chicos.

- Mire en revistas o hable con otros padres para darse una idea de la moda. Piense en cortes de pelo que sean fáciles de mantener. Deje que escoja la foto del corte de pelo que prefiere y que se la dé al peluquero.
- Haga una cita a una hora en la que la peluquería no tenga muchos clientes y considere pedir tiempo extra en caso de que su hija necesite descansar. Traiga algo para distraerla como una tableta electrónica o un juego para ayudar a su hija a tolerar el corte de pelo.
- Hable con el terapeuta ocupacional sobre el cuidado personal de su hija (como cepillarse y peinarse) y el equipo con adaptaciones que le pueda ayudar a ganar independencia.

Maquillaje. Muchas niñas empiezan a maquillarse durante la pubertad. Hable con su hija sobre las reglas de la familia sobre el maquillaje. Ponga atención a lo que hacen las otras chicas de la escuela y a qué edad. Si decide darle permiso a su hija para que se maquille, empiece con poco. Por ejemplo, puede usar una crema para la cara con color, brillo labial o polvo para la cara. Pida ayuda a una hermana mayor, una tía o, incluso, a una vendedora de maquillaje de un centro comercial para que le ayude a encontrar productos que luzcan naturales y apropiados para su edad, y que le enseñen cómo aplicarlos.

Vestuario. Cuando vaya de compras para su hija es importante buscar ropa que siga la moda para su edad. ¿Cómo se visten las otras niñas? Fíjese cuando vaya a la escuela. Para saber dónde compran su ropa otras adolescentes, puede mirar revistas, hablar con otros padres o llevar a una hermana o prima mayor con usted cuando vaya de compras. Por ejemplo, cambiar los zapatos con velcro por zapatos tipo mocasín, o dejarse la camisa por fuera, si el pantalón tiene cinturilla elástica, puede ayudar a que su hija se vista más como sus compañeras.

Si puede hacerlo, deje que su hija escoja entre varias opciones. Puede llevarla de

Vea el Anexo Humor y sentimientos

compras, o comprar varias camisas y mostrárselas para que escoja. También puede usar el tablero con dibujos o fotos. Si su hija tiene preferencias fuertes en cuanto a la ropa, o si tiene dificultad con los botones o cierres, y quiere que considere otras opciones, introduzca poco a poco otras camisas, pantalones o faldas. Busque ropa que sea cómoda, que le quede bien y considere los colores y texturas que prefiere la niña. Use una historia social para explicar que las niñas, las adolescentes y las mujeres adultas se visten de manera diferente. Trabaje con el terapeuta ocupacional en enseñarle a vestirse.

¿Qué pasa si a ella no le importa? La pubertad y la adolescencia consisten en ganar independencia y expresar la individualidad. Incluso si pareciera que a su hija no le importa la ropa, algunas cosas pequeñas como un estilo diferente de pantalón o un nuevo corte de pelo pueden ayudar mucho a que se sienta incluida y evitar que se rían de ella. ¡Vestirse más como de su edad puede ayudar a que los compañeros sepan qué gran persona es su hija por dentro también!

Dispositivos de comunicación. Si su hija usa un dispositivo de comunicación con producción de voz, asegúrese de que la voz sea del mismo sexo y edad.

Humor y sentimientos

Los cambios de humor pueden ser normales durante la pubertad. Usted puede enseñar a su hija a expresar sus sentimientos. Si su hija puede hablar, use las palabras para nombrar los sentimientos (“parece que estás enojada” o “cuando él hizo eso, te pusiste triste”). Si su hija no usa palabras, use apoyos visuales como caricaturas, fotos, lenguaje de señas o tarjetas con palabras escritas. El *Anexo Humor y sentimientos* incluye imágenes de emociones que su hija puede usar para hacerle saber cómo se siente. Considere consultar a un consejero o terapeuta que esté familiarizado con el diagnóstico de su hija y que pueda darle otras estrategias.

Más que “malhumorada”

A veces los cambios de humor pueden ser a causa de otros problemas más graves, como problemas médicos. Por ejemplo, los problemas de la tiroides (que son comunes entre los niños con síndrome de Down) pueden parecer depresión ya que afectan el humor, el apetito y el nivel de actividad. Los cambios de humor también pueden ser un síntoma de depresión o ansiedad. Los chicos con discapacidades pueden estar malhumorados como los adolescentes típicos, pero también pueden desarrollar problemas de salud mental que necesitan ser tratados. Vigile si se dan **cambios** en su comportamiento típico, como los que se destacan a continuación:

- **Emociones**: Llora, grita, se ríe sin que haya motivo claro para ello
- **Comportamiento**: Pasearse, balancearse, restregarse las manos, pellizcarse la piel
- **Agresión**: Golpear, morder, arañar, golpearse la cabeza, lanzar cosas
- **Apetito**: Comer más o menos
- **Bienestar**: Quejarse de dolor de cabeza, dolor de estómago u otros dolores del cuerpo
- **Sueño**: Dormir más o menos, problemas para quedarse dormida, pesadillas
- **Pensamiento**: Parece confundida, problemas de concentración, ver cosas que no están ahí
- **Energía**: Moverse más o menos, actuar retraída, no hacer cosas que antes le gustaba hacer

Hable con el doctor de su hija sobre los cambios que ve. Guarde notas en un diario, hoja de datos (vea el *Anexo Diario*) o una aplicación de teléfono electrónico o tableta. Escriba lo que ve y cuándo lo ve. Recuerde anotar las fechas en las que le empieza y le termina el periodo. ■

Vea Anexo Diario

¡Sostenes, tampones y toallas femeninas!

A medida de que su hija se acerca a la pubertad, su cuerpo empieza a cambiar. Le comenzarán a crecer los senos y luego, en uno o dos años, empezará la menstruación (a veces se llama "llegarle el periodo"). Estos cambios son normales en la pubertad. Sin embargo, si su hija no entiende lo que está pasando, puede sentir miedo. Puede usar historias y dibujos para ayudarla a entender cómo cambia su cuerpo (ver el *Anexo Las partes del cuerpo*) para prepararla.

Iniciar a mi hija en el uso del brasier

Entrenarla. Ayude a su hija a acostumbrarse a usar algo debajo de la ropa, como un sosten de entrenamiento, una camiseta o top de tirantes finos, o un brasier deportivo.

La comodidad es lo primero. Si su hija tiene dificultad para abrochar, puede buscar un brasier con el cierre por delante o que se coloque fácilmente. Pruebe sostenes sin aros y que no sean de telas que pican, como el encaje. Considere llevar a su hija a una tienda que tome medidas profesionales. Llame por adelantado y haga una cita para asegurarse que se acomodan a sus necesidades. Pida a la terapeuta ocupacional de su hija otras ideas sobre brasieres especiales y para que le enseñen los pasos necesarios para ponerse el brasier.

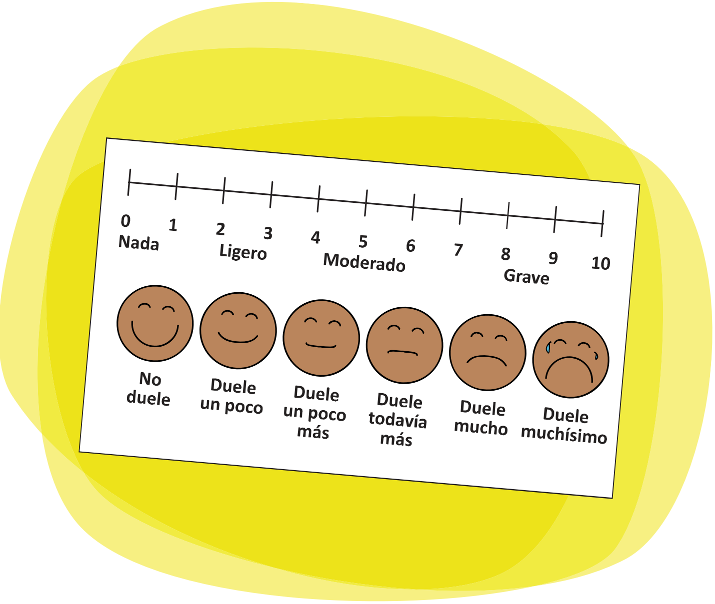
Ayudar a mi hija a prepararse para el periodo

- **Comience pronto.** Las niñas llegan a la pubertad a distintas edades (normalmente entre los 9 y15 años), y las niñas con discapacidades pueden empezar incluso antes. El periodo comienza, por lo general, uno o dos años después de que empiezan a crecer los senos. El momento apropiado para hablar de la menstruación es antes de que su hija tenga el primer periodo.
- **Hable sobre esto.** Aunque pueda ser incómodo, usted debe hablar directamente sobre la menstruación con su hija. Hablarle de manera clara y directa puede ayudarle a entender que tener el periodo es algo normal y esto le quitará el miedo. No olvide decirle que la sangre no significa que ella se ha lastimado.
- **Sea abierta.** Para animar a su hija a que le hable a usted, diga cosas positivas como "Es una buena pregunta". Manténgase calmada y trate de que no se vea que le da pena o vergüenza. Con esto su hija se sentirá bien al hablar con usted y podrá enseñarle la verdad sobre el periodo.

- **Aproveche las oportunidades diarias.** Cuando compre tampones o toallas femeninas, o vea comerciales en la televisión, use estos momentos para comenzar una conversación con su hija sobre la menstruación.
- **Use los términos correctos.** Conteste a las preguntas con un lenguaje sencillo y términos correctos (como senos, vagina, toallas femeninas y tampones).
- **Considere cómo aprende ella.** Enseñe a su hija sobre la menstruación de la forma que mejor aprenda ella. Por ejemplo, si ella aprende mejor con apoyos visuales, trate de usar dibujos o videos en vez de historias o listas.
- **Pregunte a un profesional.** Pida ayuda al doctor de su hija para enseñarle sobre la pubertad y los cambios de su cuerpo.

Vea el Anexo Enseñar sobre el periodo

Enseñar a mi hija sobre el periodo



Lo que verá. Debe explicar a su hija que verá lo que parece sangre en su calzón o en el inodoro. Para prepararla para lo que pueda encontrar cuando empiece su periodo, puede marcar la ropa interior con colorante para alimentos o marcadores. Asegúrese de que entienda que esta sangre no significa que se ha lastimado.

Lo que sentirá. Explique que algunas mujeres se sienten diferentes cuando tienen el periodo. Pueden encontrarse cansadas o estar de mal humor. Pueden tener hinchazón o les puede doler el vientre. Dé a su hija una manera de decirle cómo se siente. Use una demostración, tarjetas con dibujos, un tablero de comunicación o una escala numérica o con dibujos para que ella le explique cómo se siente (el *Anexo Enseñar sobre el periodo* tiene una escala del dolor que puede usar su hija). Explique sus síntomas al doctor de su hija.

A quién puede hablar. Enséñele que los periodos son algo privado. Explique que ella puede hablar de su periodo con sus padres, su doctor o la enfermera de la escuela. No debe hablar de su periodo con niños, amigos casuales o desconocidos. Vea la actividad del *Anexo Enseñar sobre el periodo* para que aprenda sobre lo que es correcto hacer en público y en privado.

Cómo mantenerlo privado. Busque maneras que no sean muy obvias de que su hija traiga toallas femeninas a la escuela. Su hija puede escoger un estuche atractivo, pero práctico, para sus toallas femeninas que sea privado y fácil de usar. Puede ser una bolsita especial, una cajita o un bolso que guarda en su mochila, armario o en la enfermería de la escuela.

Enseñar a mi hija sobre el aseo personal

- **Primero pruebe las toallas femeninas**. Le recomendamos que empiece con toallas y cambie luego a tampones, si fuera necesario. Su hija puede tener dificultad con los tampones si tiene dificultad con los movimientos. También es más difícil saber cuándo hay que cambiar de tampón. Si el flujo es tan fuerte que las toallas femeninas no son efectivas, hable con el doctor para ver otras opciones.
- **Deje que elija**. Compre diferentes tamaños y tipos de toallas femeninas antes de que comience la menstruación. Antes y después de ir de compras, hablen de aspectos como el grosor y si tienen alas. Deje que su hija escoja la que le resulte más cómoda. Después de decidir el tipo que más le gusta, lleve a su hija de compras y use una tarjetita con la caja de las toallas temeninas para ayudarla a que las encuentre ella sola en la tienda y que las ponga en el carrito para comprarlas.
- **Demuestre**. Usted u otras mujeres de la familia pueden demostrar en pasos simples y cortos cómo ponerse o cambiarse una toalla femenina.

Vea el Anexo
Enseñar sobre
el periodo

- **Haga una guía o agenda**. Los pasos para cambiarse la toalla femenina se pueden demostrar en una agenda visual, una guía de bolsillo o una carpeta para el baño. Vea en el *Anexo Enseñar sobre el periodo* un ejemplo de una guía de bolsillo. Esto puede ayudar a su hija a ser más independiente y hacer que cambiarse la toalla femenina sea parte de su rutina diaria. Cuando haga una agenda, piense en los descansos normales que hay durante el día de escuela y en casa como buenos momentos para cambiarse el tampón o la toalla femenina.
- **Haga una guía visual**. Puede marcar en un calzón el contorno de una toalla femenina para recordarle a su hija dónde tiene que colocarla.
- **Practique.** Antes de que le llegue el periodo, practique con toallas superdelgadas o de uso diario para que se acostumbre a la sensación de llevar una. Las niñas con sensibilidad sensorial puede que necesiten más práctica para sentirse cómodas. Puede probar usando un reloj o temporizador y darle premios si aguanta con la toalla puesta durante más y más tiempo.
- **Facilítelo**. Trabaje con la maestra de su hija para que ella pueda pedir ir al baño cuando necesite cambiarse de toalla femenina. Si le da pena o no puede pedir bien lo que necesita, puede dar a la maestra una tarjetita, una ficha o simplemente pueden programar tiempos de ir al baño regularmente para evitar accidentes.
- **Considere adaptaciones**. Su hija puede batallar con los movimientos necesarios para cambiarse la toalla femenina, la ropa interior, vestirse o desvestirse. Las adaptaciones en la ropa pueden facilitarle el cambiarse de calzón o de toalla. Pida ideas al terapeuta ocupacional de su hija. Explore las distintas opciones de ropa adaptada en Internet. Quizá pueda poner usted misma velcro o corchetes en los lados del calzón o comprar pantalones con cinturilla elástica. Busque toallas que no tengan envoltorios difíciles de quitar o guárdelas sin envolver para que las pueda usar su hija. También puede poner un poco de cinta adhesiva doblada en el papel que recubre la toalla para poder desenvolverla más fácilmente.
- **Ayúdela a ayudarse a sí misma.** Es importante que su hija sea tan independiente como sea posible en el aseo personal. Usar las estrategias mencionadas anteriormente puede ayudarla a saber qué hacer cuando tiene el periodo y necesitar menos asistencia. Sin embargo, las jóvenes con DI/DD quizá necesiten ayuda extra en estos casos. Pida ayuda en la escuela de su hija para que una enfermera o asistente la ayude. Comparta con los otros cuidadores en la vida de su hija las ideas de este folleto y otras que usted desarrolle en casa.

Siempre que empiece a enseñar estos métodos, divida las tareas en pasos cortos y sencillos. Ayude a su hija a practicarlos y dígale cómo lo está haciendo. ¡Elógiela mientras aprende estas tareas nuevas!

Vea el Anexo Enseñar sobre el periodo

El examen femenino

Para las mujeres con discapacidades, el examen femenino (también conocido como el "examen ginecológico") y el control de la menstruación pueden ser todo un reto. En esta sección, usted encontrará consejos para preparar a su hija para el examen. También hay información sobre cómo averiguar si el control de la menstruación podría ser útil, y de serlo, cómo escogerlo.

Por qué mi hija necesita un examen

De acuerdo con las guías establecidas, todas las mujeres mayores de 21 años deberían hacerse la prueba llamada Papanicolaou como comprobación de que no tengan cáncer del cuello del útero. Estos exámenes deberían comenzar más pronto para las mujeres que tienen relaciones sexuales. Incluso si su hija no es sexualmente activa, necesita ver al ginecólogo para los cuidados preventivos. Además, las pruebas para el cáncer de seno (mamografías) deberían comenzar alrededor de los 40 años.

Entablar una relación positiva con el ginecólogo a una edad temprana puede ayudar a su hija a recibir buenos cuidados médicos si es que tuviera problemas de ese tipo. Según ciertas investigaciones, las mujeres con discapacidades intelectuales tienen una probabilidad un 72% menor de recibir la prueba del Papanicolaou y es 45% menos probable que les hagan mamografías. No permita que su hija sea una de ellas. Encuentre un ginecólogo o ginecóloga que estén dispuestos a trabajar con usted para desarrollar un plan individualizado de prevención.

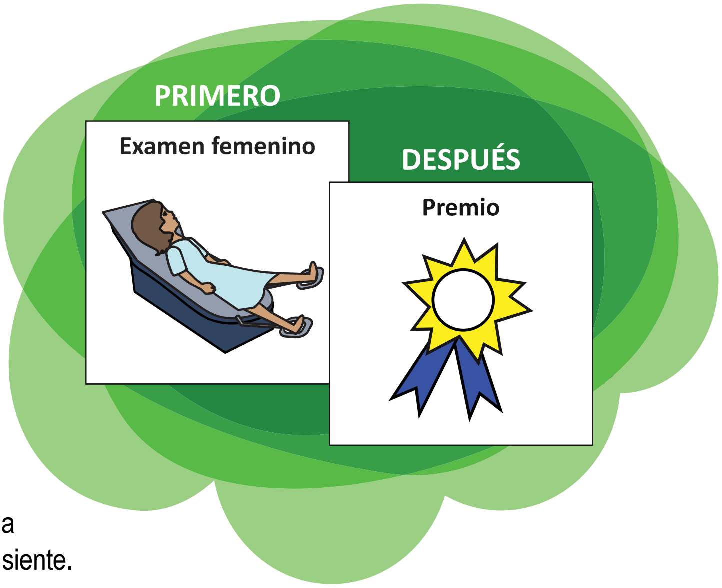
Explique qué se puede esperar durante el examen

Explique antes de ir a la cita, en qué consistirá la visita. Puede ayudar si la enfermera o doctor explican cada paso a su hija, a medida que se realiza el examen (p. ej. "Ahora, voy a _____"). Una visita de práctica al consultorio, en la que se le muestre la sala de examen, puede ayudar a calmar la ansiedad de su hija.

- El doctor o la enfermera se asegurará de que tu cuerpo esté sano. Te va a mirar y tocar las partes íntimas durante el examen. No te tocará las partes íntimas en ningún otro momento.
- Durante el examen tienes que desvestirte. Esto incluye quitarse el calzón y el brasier. La enfermera te dará una bata para que te la pongas.
- Luego te acostarás boca arriba o de lado en una camilla con una sábana por encima.
- El doctor o la enfermera te tocará los senos, las axilas, el vientre y la vagina para asegurarse de que estás sana.
- Puede que el doctor o la enfermera te ponga una especie de espejito dentro de tu vagina para ver por dentro. El espejito puede sentirse frío e incómodo, pero para calmarte puedes respirar hondo y despacio. Dentro de muy poco, ya habrá terminado.
- Durante tu visita, puedes preguntar lo que quieras al doctor o la enfermera.
- Después del examen, ya te puedes volver a vestir.

Vea el Anexo
Enseñar sobre el
examen femenino

Preparar a mi hija para el examen



- Muestre a su hija una guía o agenda visual sobre lo que pasará el examen. (Vea un ejemplo el Anexo *Enseñar sobre examen femenino*).
- Ayude a su hija a hacer una lista de preguntas y dudas que tenga sobre pubertad, el periodo o el examen.
- Practique en casa cómo hacer estas preguntas antes de la visita.
- Traiga la escala del dolor para que su hija pueda decirle al doctor o enfermera qué siente.
- Llame al consultorio antes de tiempo para contarles las necesidades y preferencias de su hija.
- Si su hija tiene una limitación de movimiento, puede pedir el equipo especial necesario. Si su hija tiene problemas para acostarse boca arriba, pregunte si hay distintas posturas en las que pueden hacer el examen femenino. Si el médico de su hija no conoce otras posturas, pida consejo a su terapeuta ocupacional. Asegúrese de que el personal esté dispuesto y pueda ayudar a colocar a su hija sobre la camilla de manera segura.
- Está bien hablar con el doctor sobre cómo adaptar el examen a las necesidades de su hija.
    - Pregunte cuál es el propósito de cada procedimiento y si hay alternativas que quizá sean más fáciles de soportar para su hija.
    - Reparta el examen en diferentes visitas o pida tiempo extra si lo necesita.
    - Pida al doctor o enfermera que se reúna con usted y su hija antes de que ella se desvista, así podrá contestar preguntas antes de que su hija se coloque la bata.
    - Pida al doctor o enfermera que busque formas de reducir lo más posible el tiempo que ella debe estar en la camilla.

Ayudar a mi hija a sentirse más relajada

- Traiga algo para relajar o distraer a su hija durante el examen, como música, un dispositivo electrónico (tableta, teléfono, videojuego de mano) o un libro que le guste.
- Practique la relajación antes del examen y traiga apoyos visuales que le recuerden cómo hacer el ejercicio de relajación.
- Pregunte al doctor si hay algún medicamento que le ayude a relajarse durante el examen.
- Pregunte al doctor si existe la opción de dar un sedante a su hija durante el examen, por si las otras estrategias no le funcionan.
- Planee algo especial para después de la visita. Deje que ella escoja un premio o actividad especial y hablen de esto antes de la visita y durante ella. Use algún apoyo visual, como el tablero Primero-Después, para recordarle lo que harán después de la visita.

Vea el Anexo Enseñar sobre el examen femenino

Control de la menstruación

Quizá usted piense que su hija no necesita un anticonceptivo, pero las mujeres lo usan por muchos motivos. Obviamente, evita los embarazos. Sin embargo, también ayuda a controlar el sangrado menstrual, que puede ser fuerte, doloroso o irregular. Las mujeres, a veces, están obligadas a usar un anticonceptivo si toman ciertas medicinas (como medicamentos para la epilepsia) que podrían ser malos para los bebés si quedaran embarazadas.

Si su hija sufre de muchos dolores o sangra mucho con el periodo, las medicinas para el control de la natalidad le pueden aliviar un poco. Algunas opciones pueden hacer que el flujo sea más ligero, mientras que otras le paran el periodo por completo. Los doctores también recetan las medicinas para el control de la natalidad para tratar enfermedades dolorosas como la endometriosis o para ayudar a mantener el acné grave bajo control.

Incluya a su hija lo más posible a la hora de escoger el mejor método de control de la natalidad (para evitar que quede embarazada) para ella. **Hable con su doctor o enfermera sobre cómo usarlo, sus efectos secundarios y posibles riesgos**.

Anticonceptivos para mi hija

Píldoras anticonceptivas:

- Pueden evitar el embarazo y controlar la cantidad de sangrado.
- Hay que tomarlas todos los días.
- Si su hija tiene limitaciones de movilidad, es importante saber si estas píldoras causarán coágulos en la sangre. Pregunte al doctor de su hija sobre esto.
- Algunas píldoras limitan los periodos a solo cuatro veces al año o menos.
- Hay diferentes píldoras que afectan las hormonas. Es posible que tengan que probar distintas píldoras hasta dar con la que mejor funciona con su hija.

Inyección de control de la natalidad:

- La inyección contiene una hormona que se pone una vez cada tres meses.
- Con el tiempo los periodos se vuelven más ligeros.
- Piense en cómo tolera su hija las inyecciones antes de escoger este método.
- La medicina permanece en el cuerpo de su hija unos tres meses, así que pregunte al doctor o enfermera qué hacer si su hija no responde bien al medicamento.
- La subida de peso es un efecto secundario que debería discutir con su doctor.

Parches transdérmicos:

- El parche se coloca en la piel y se mantiene por tres semanas. Luego se quita durante una semana para que su hija pueda tener el periodo.
- A veces el parche se cae antes de tiempo o causa irritación en la piel.
- Si su hija tiene sensibilidad sensorial, quizá no le guste la sensación de tener el parche sobre la piel.
- Si su hija tiene dificultades con las manos, le puede resultar difícil despegar el parche y ponérselo en la piel.

Vea el Anexo Enseñar sobre el periodo

Implante para el control de la natalidad:

- El médico le inserta una barrita con medicina en el brazo por debajo de la piel.
- La barrita es plástica, como del tamaño de un cerillo.
- Normalmente se tarda un minuto en insertarse. Sacarlo toma unos tres minutos.
- La barrita libera medicina que impide el embarazo y controla el sangrado con el tiempo.
- Este método dura hasta tres años, pero se puede retirar en cualquier momento.

Dispositivo intrauterino:

- El médico le coloca un dispositivo intrauterino (DIU) en la vagina.
- La colocación puede ser dolorosa para las mujeres que no han dado a luz vaginalmente.
- La efectividad del DIU dura por lo menos 5 años y hasta 10 años, dependiendo del tipo.
- Un DIU puede hacer que el flujo sea más ligero con el tiempo y reducir los periodos dolorosos. Algunas mujeres sangran de manera irregular. Hable con el doctor o enfermera de su hija sobre los posibles efectos secundarios.

Puede encontrar un anexo con apoyos visuales en

kc.vanderbilt.edu/HealthyBodies

Organizaciones

- ☐ Vanderbilt Kennedy Center: vkc.mc.vanderbilt.edu
- ☐ Autism Society of America: www.autism-society.org
- ☐ Autism Speaks: www.autismspeaks.org
- ☐ Easter Seals: www.easterseals.com
- ☐ National Down Syndrome Society: www.ndss.org
- ☐ National Parent Technical Assistance Center: www.parentcenternetwork.org
- ☐ American Society for Deaf Children: www.deafchildren.org
- ☐ United Cerebral Palsy: www.ucp.org

Recursos sobre apoyos visuales

- ☐ http://card.ufl.edu/content/supports/start.html
- ☐ www.kidaccess.com/index.html
- ☐ Do 2 Learn: www.do2learn.com
- ☐ Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Sitios web

- ☐ National Information Center for Children and Youth With Disabilities. *Información sobre la sexualidad para niños y jóvenes con discapacidades.* Disponible en http://nichcy.org/schools-administrators/sexed
- ☐ Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center: www.pacer.org/bullying
- ☐ www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
- ☐ vkc.mc.vanderbilt.edu/assets/files/tipsheets/oralhealthtips.pdf
- ☐ http://kidshealth.org/teen/sexual_health/girls/menstruation.html
- ☐ http://kidshealth.org/teen/sexual_health/#cat20015
- ☐ www.freewebs.com/kidscandream/main.htm

Historias sociales - información y ejemplos

- ☐ Gray, C., & White, A. L. (2002). *My social stories book*. Philadelphia, PA: Jessica Kingsley Publishers.
- ☐ www.thegraycenter.org/social-stories/what-are-social-stories
- ☐ www.bbbautism.com/pdf/article_27_Social_Stories.pdf
- ☐ www.tinsnips.org/Media/social/menstruation2.pdf

Libros

- ☐ Jukes, M., (1998). *Growing up: It's a girl thing: Straight talk about first bras, first periods, and your body changing*. New York: Borzoi Book Publisher.
- ☐ Schaefer, V. (1998). *Care and keeping of you: Body book for girls*. American Girl Library (Middleton, WI) Pleasant Company Publications.
- ☐ Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty, and personal curriculum for young people with autism*. Arlington, TX: Future Horizons.
- ☐ Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks galore for the real world*. Raleigh, NC: Tasks Galore. www.tasksgalore.com
- ☐ Bellini, Scott, *Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with autism spectrum disorders and other social difficulties* (2006). Autism Asperger Publishing Co., Shawnee Mission, KS.
- ☐ Baker, Jed (2009) *Social skills picture book for high school and beyond.* www.mayer-johnson.com/the-social-skills-picture-book-for-high-school-and-beyond
- ☐ Meehan, Cricket, *The right to be safe: Putting an end to bullying behavior* (2011). Busque: Institute Press.

Esta publicación fue desarrollada y escrita por los experimentados investigadores en práctica de Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND): Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; estudiante de doctorado de Audiología, Elizabeth Harland; Cong Van Tran, PhD; y los profesores de LEND Jennifer Bowers, RN, MSN, CPNP, Enfermera Pediátrica de Práctica Avanzada, División de Medicina del Desarrollo y Cassandra Newsom, PsyD, Profesora Auxiliar de Pediatría, División de Medicina del Desarrollo, Directora de Educación Psicológica, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. Fue editada, diseñada y producida por el personal de Diseño Gráfico y Difusión del Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) con apoyo de Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). Les agradecemos la revisión y sugerencias de numerosos miembros del personal de TRIAD y de Autism Society of Middle Tennessee.

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Esta publicación fue posible, en parte, gracias al siguiente financiamiento: Grant N.º T73MC00050 de Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Sus contenidos son la responsabilidad única de los autores y no representan necesariamente las posturas oficiales del MCHB, HRSA, HHS. Fotos ©istockphoto.com. 12/2014.

VANDERBILT KENNEDY CENTER
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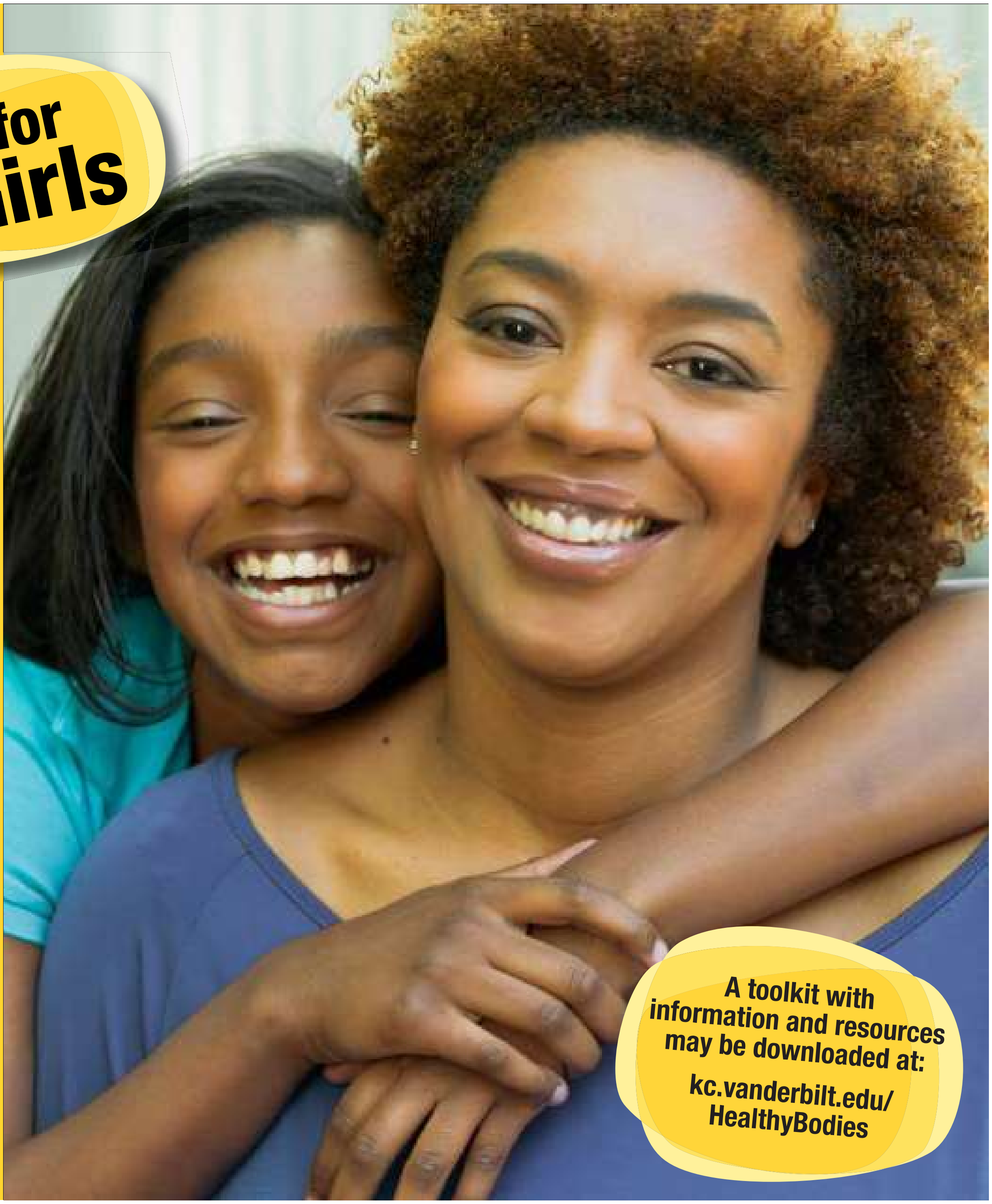
Healthy Bodies – Appendix



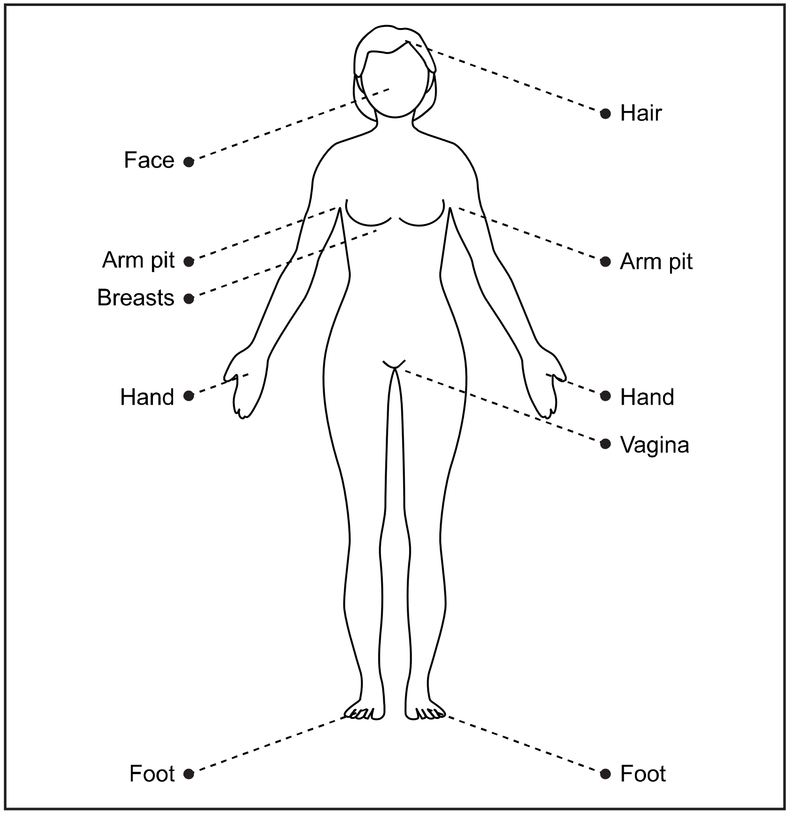
for Girls

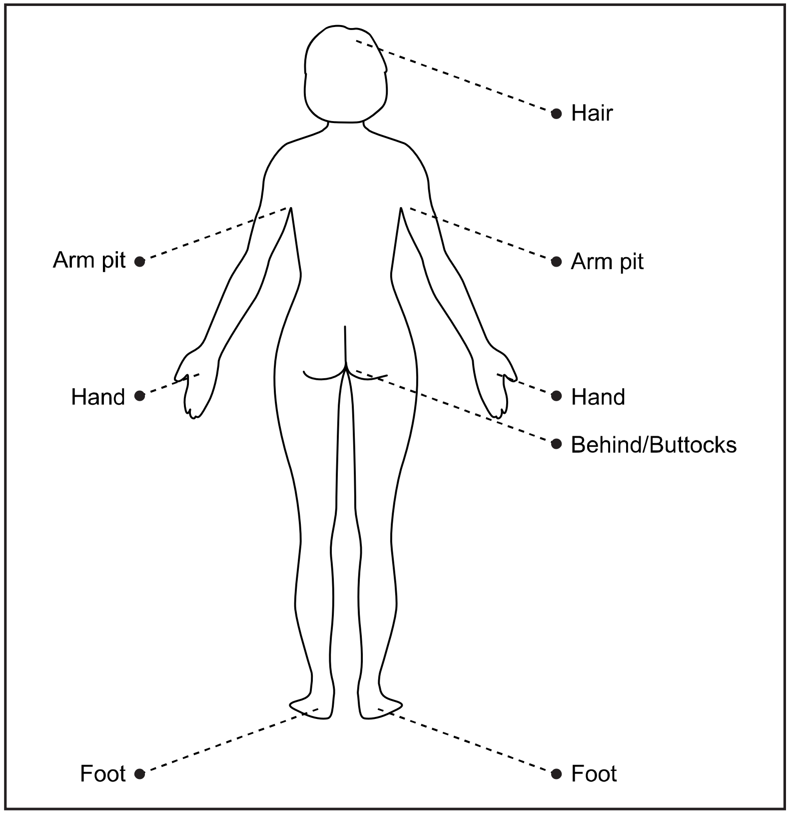
A toolkit with information and resources may be downloaded at:
kc.vanderbilt.edu/HealthyBodies

A Parent's Guide on Puberty for Girls with Disabilities

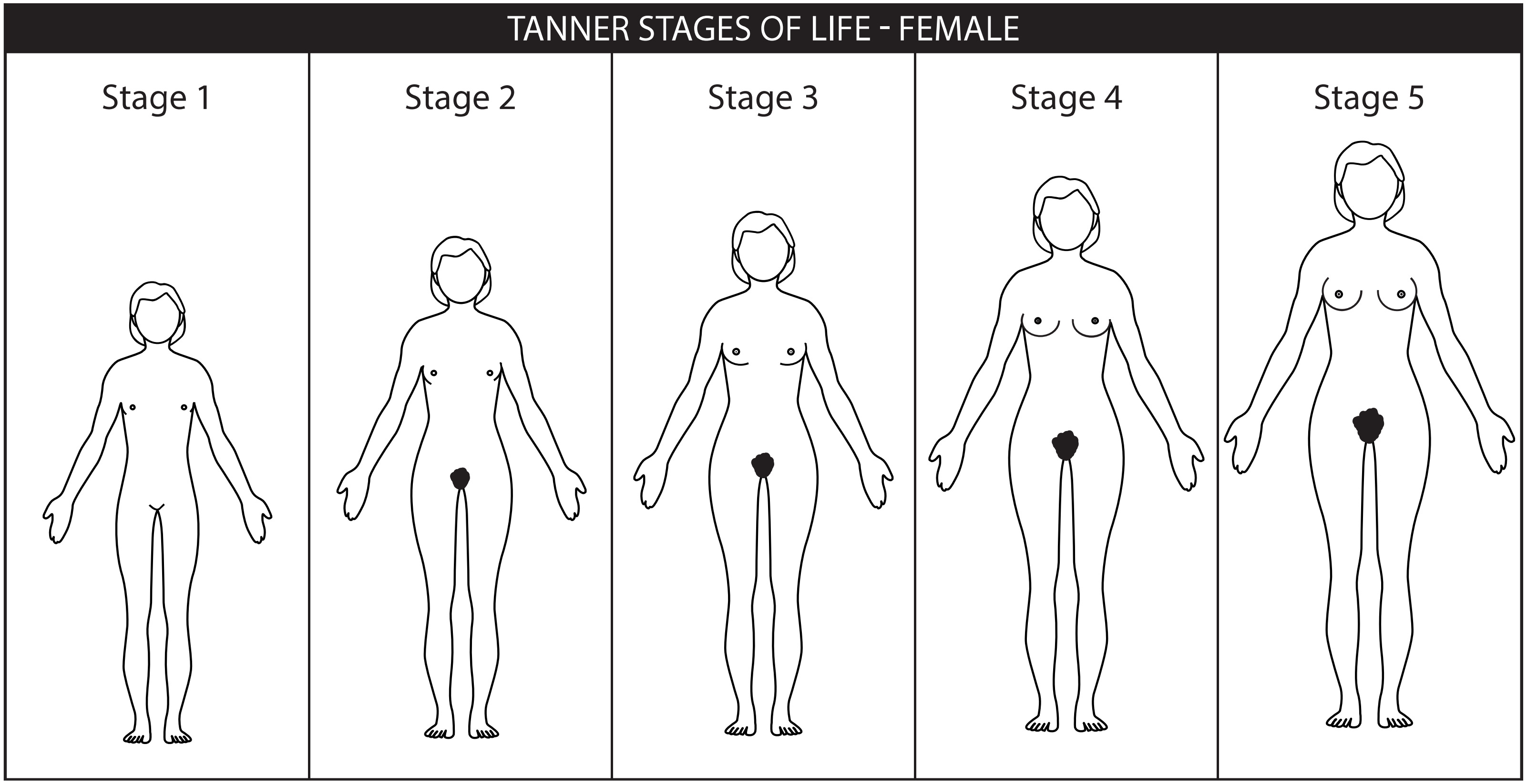
Teaching Body Parts – Visuals

Use these pictures to teach the names of body parts. After teaching, you can cover the names of body parts and make a game out of asking your daughter to name them. You can also cut out the names and have your daughter physically place them on the picture.





The Tanner Stages can show her how her breasts will change and hair will grow.



First/Then Board – Blank Template

To motivate your child to do things that may be hard or unpleasant for her, like exercise, try using a visual support like a First/Then Board. Put the less-preferred activity *first* and the rewarding activity *second*. For example, “First Exercise” followed by “Then Video Games.” You can use pictures or words, depending on your child’s reading skills. You can also laminate these cards and use velcro with pictures or a dry-erase marker to make them reusable.

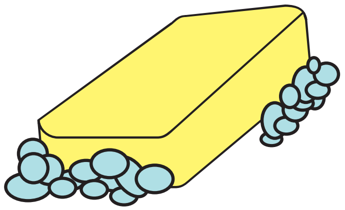
REMEMBER: Always put the more fun activity in the Then box. This shows your child what she is working to earn.

First **Then**

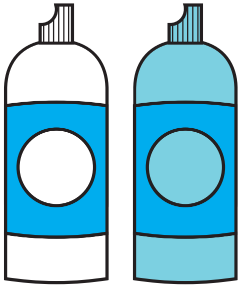
First **Then**

Encouraging Good Hygiene – Hygiene Supplies Visuals

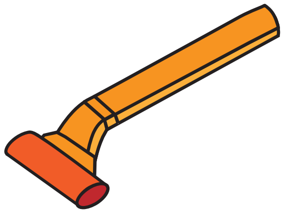
Soap



Shampoo/Conditioner

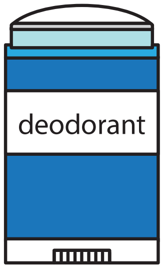


Razor

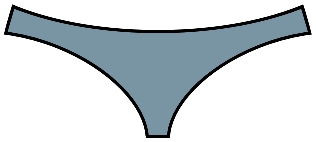


Shaving cream

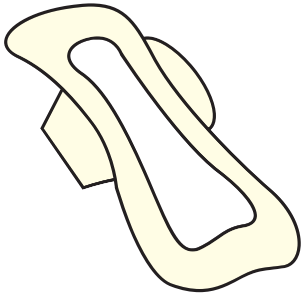
Deodorant



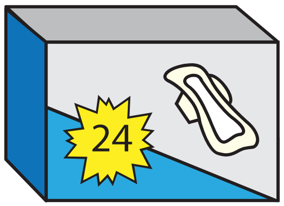
Clean panties



Maxi pad

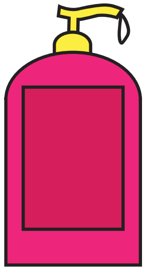


Box of Maxi pads



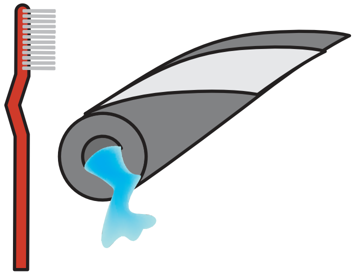
Wet wipe

Lotion

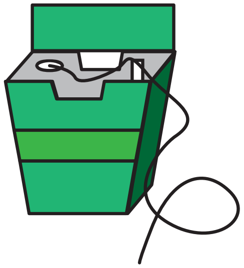


Hair brush

Toothbrush and toothpaste

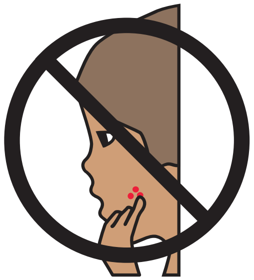


Floss



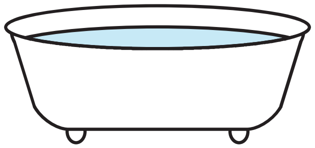
Take medicine

Don’t pick at acne

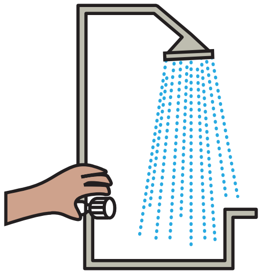


Encouraging Good Hygiene – Showering Schedule Visuals

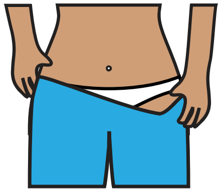
Fill tub with warm water



Turn on shower



Take off clothes



Get in tub

Get in shower

Wash whole body

Rinse soap off

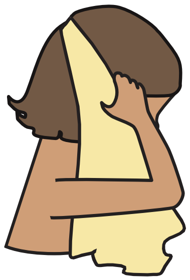
Put shampoo on my hand

Rub into hair

Rinse out shampoo

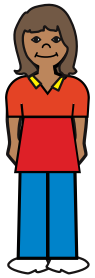
Turn off the water

Dry off with towel

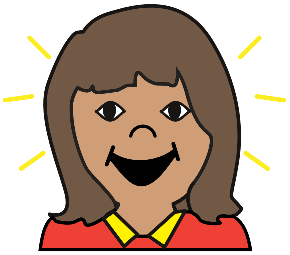


Put on deodorant

Put on clean clothes



I did a good job



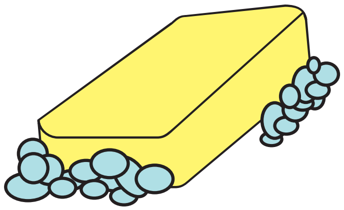
What's That Smell?

I am growing up and my body is changing. I am growing hair in my armpits and on my private parts. Sometimes my armpits and private parts may smell bad. This smell is called body odor. People don't like to smell body odor. If I smell bad, people may not want to be around me. I can stop body odor by washing my hair, armpits, private parts and feet every day with warm water and soap. After I wash, I can put deodorant on my armpits. Deodorant will help my underarms smell nice and stay dry. I will use deodorant under my arms every morning to get rid of my body odor. I like to smell nice. Smelling good will make my parents, friends, and teachers happy too.

Messy vs. neat

Wash hair

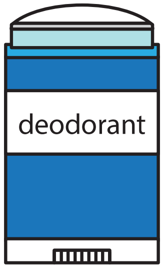
Soap



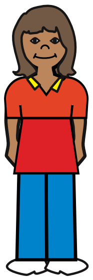
Wash whole body

Put on deodorant

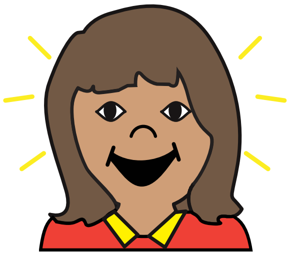
Deodorant



Put on clean clothes

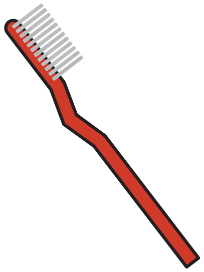


Smell nice



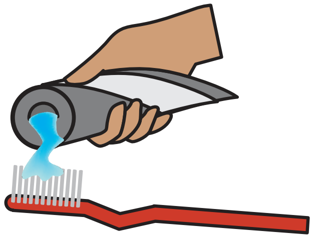
Encouraging Good Hygiene – Brushing Teeth Schedule Visuals

Toothbrush

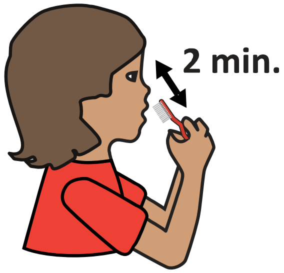


Toothpaste

Squeeze toothpaste on toothbrush



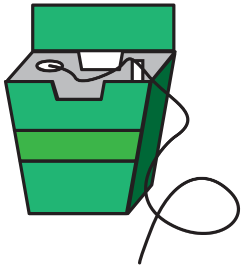
Brush teeth



Spit in sink

Rinse with water

Floss



Public/Private – Sort Board Blank Template

You can teach your daughter about what behaviors are okay for public places and what activities should be kept private using pictures. In the activity below, you can help her sort which activities and places are public versus private. You can use the pictures on the pages to follow or add your own pictures.

Once your daughter understands what public and private mean, you can use the “public” and “private” pictures as a visual reminder. For example, if she begins picking her nose, hold up the “private” card and tell her to find a private place.

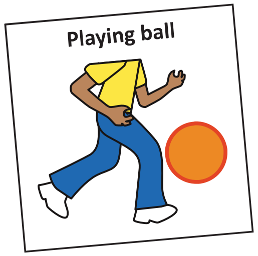
These pictures or visual reminders also can be used to prepare your daughter for going to a public place, such as an outing to a restaurant.

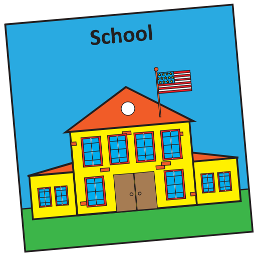
Public

Private

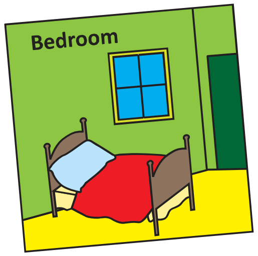
Public/Private – Sort Board

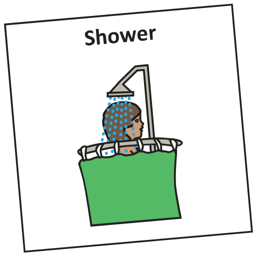
Public



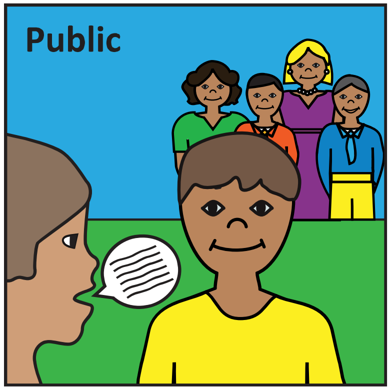


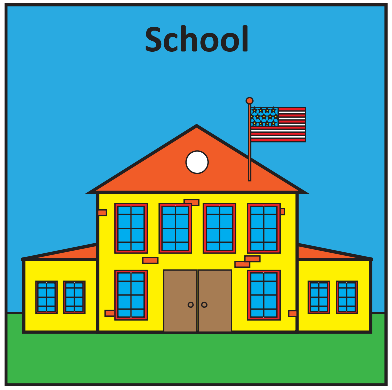
Private

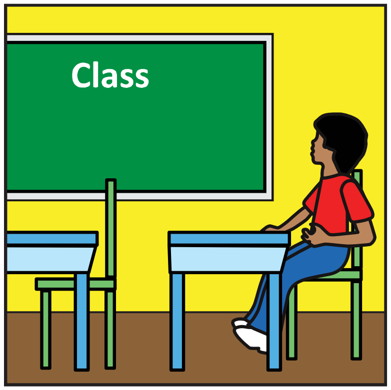


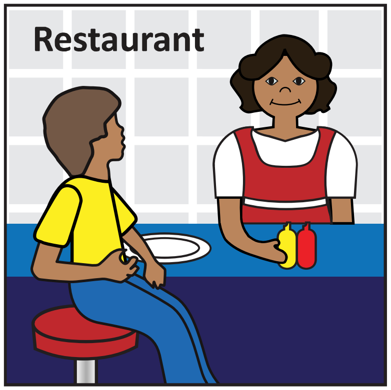


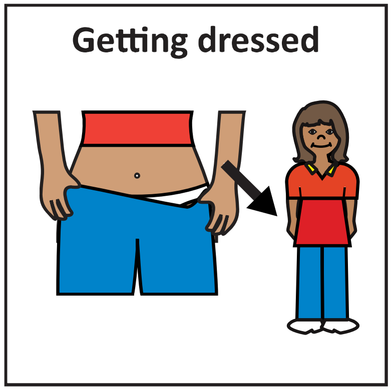
Public/Private Behaviors – Visuals

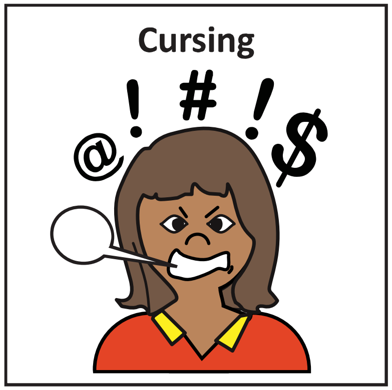


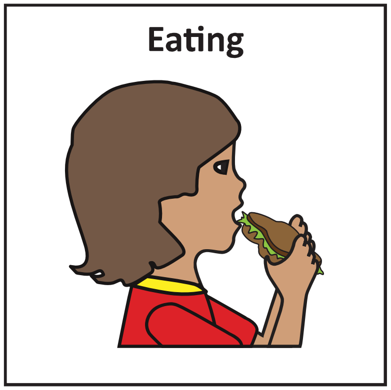


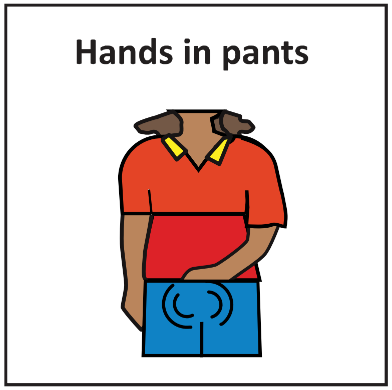


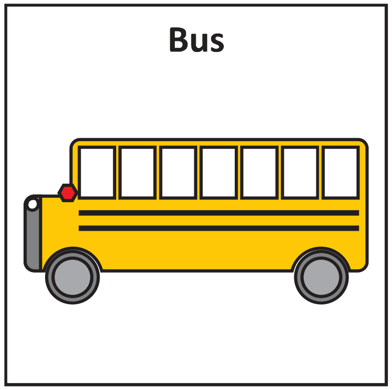






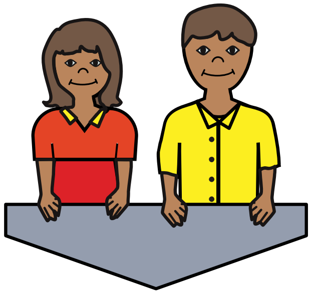




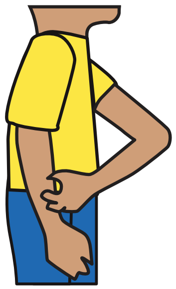


Public/Private Behaviors – Visuals

Passing gas



Hands on table

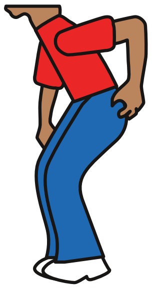


Scratching your arm

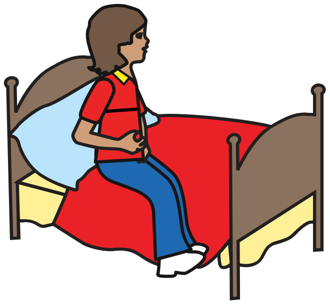
Bathroom stall

Bedroom

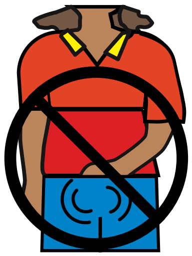
Bathroom



Scratching your behind



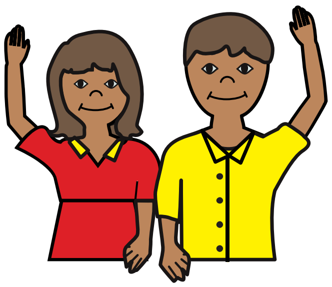
Alone



No hands in pants

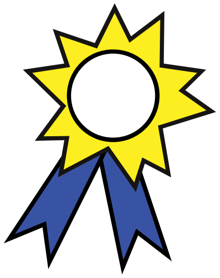
Washing hands

Playing ball



Wave

Reward

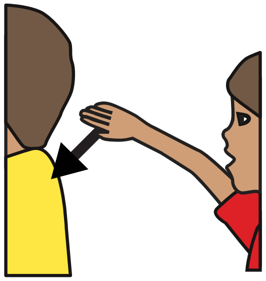


Reward

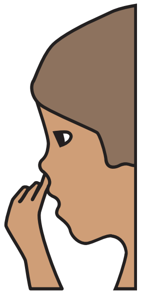
Special activity

Public/Private Behaviors – Visuals

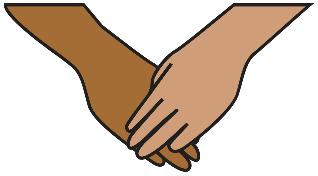
Pats on the back



Picking your nose



Holding hands



High five

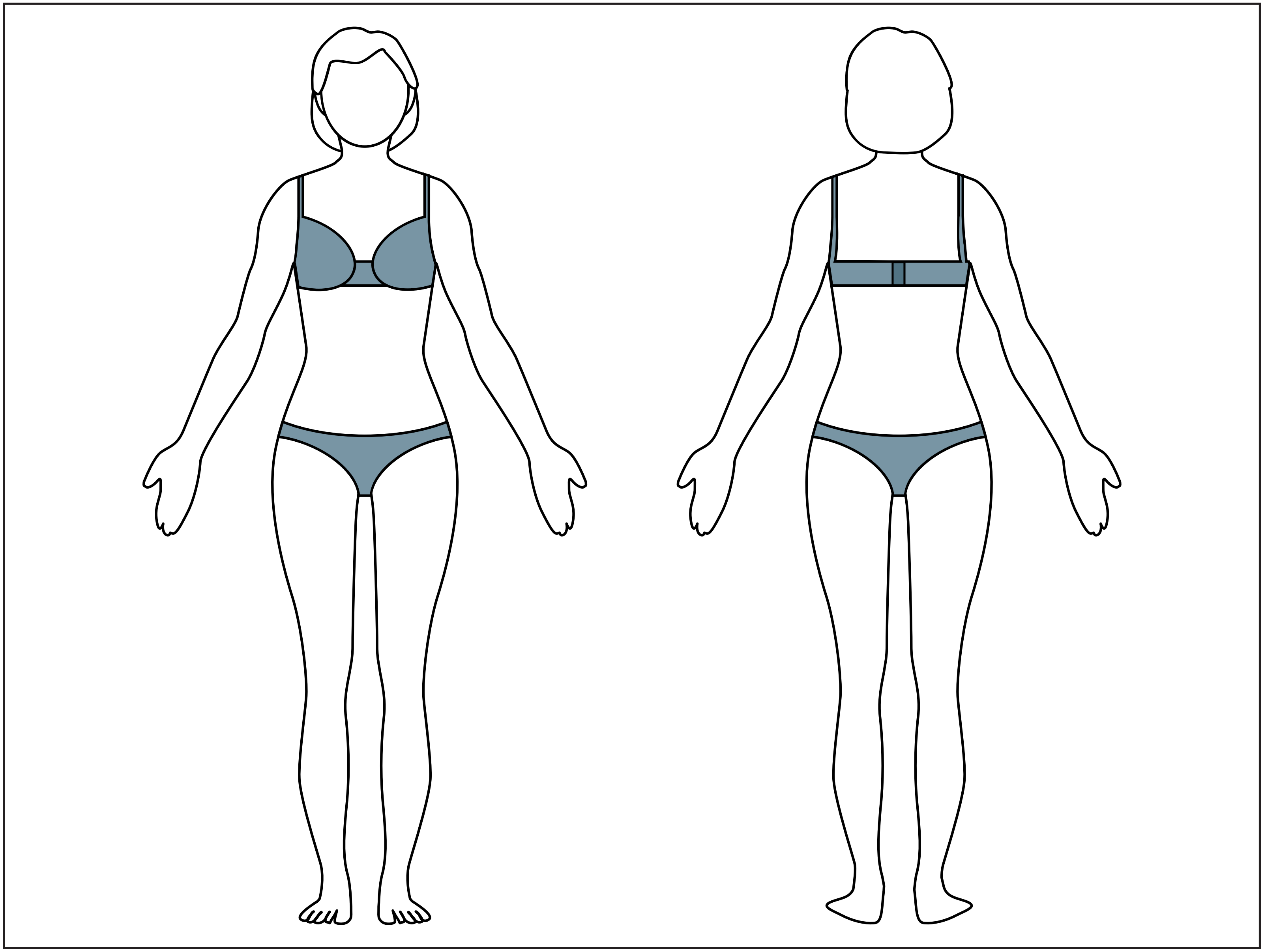
Hug

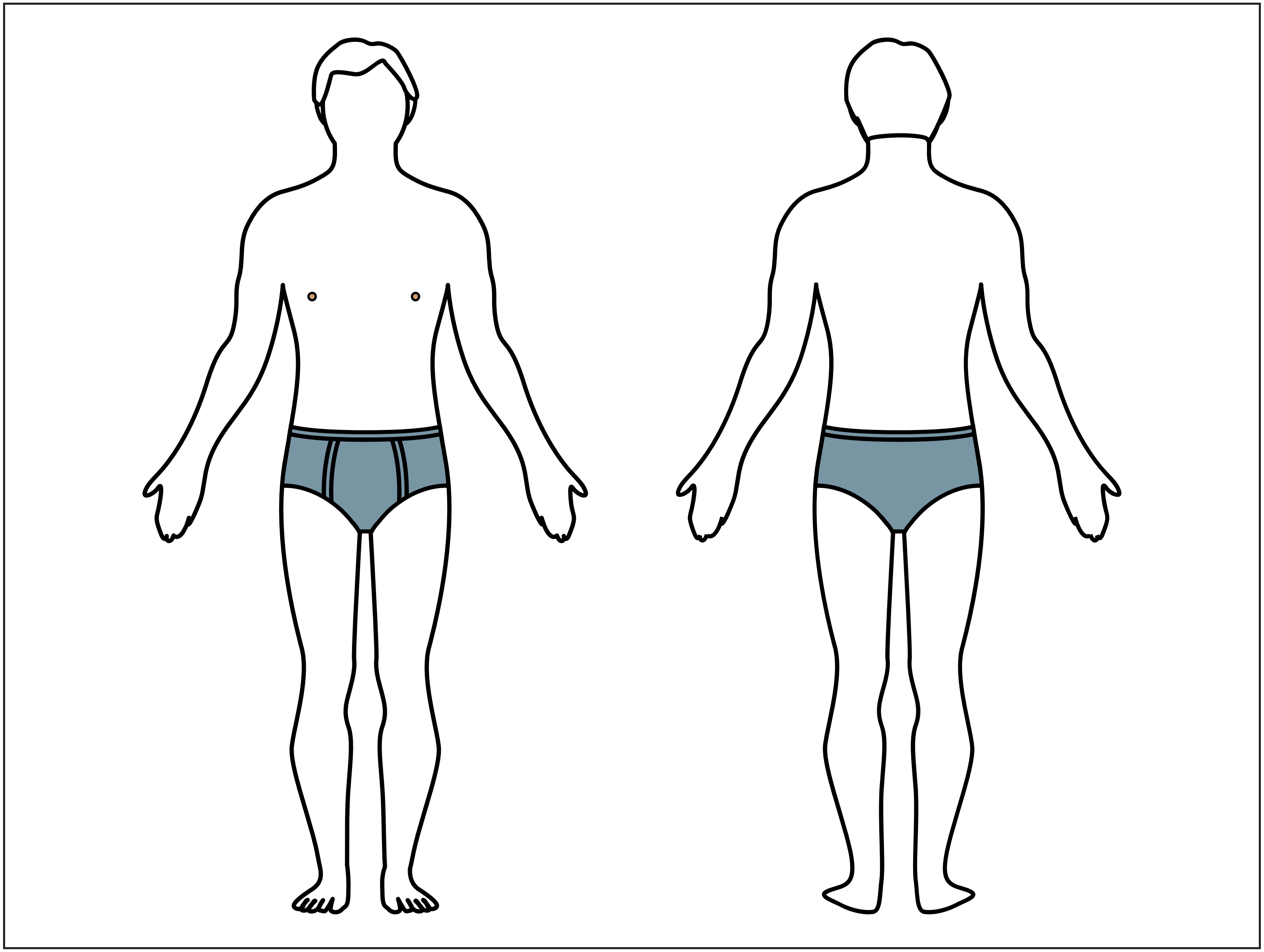
Kiss

Private Parts – Visuals

Teach your child where she can touch others and where it is okay for others to touch her by using these figures. Point to a body part and say “Can we touch?” If yes, put a green circle on that body part for “go.” If no, put a red circle for “stop.”

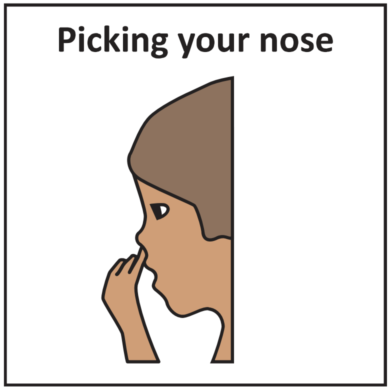
For example, your daughter should put a green circle on the hand but a red circle on the bottom. You can use the same activity and ask “Where can people touch me?”

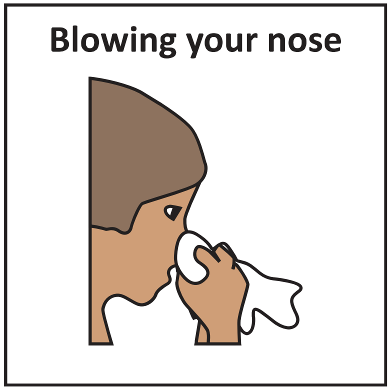


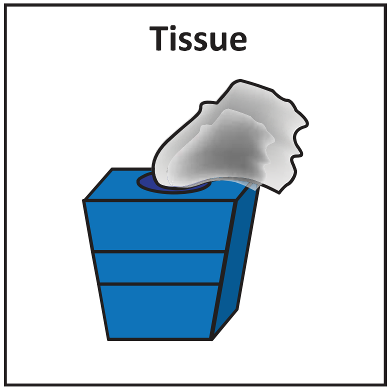


Picking Your Nose is Private

Sometimes I might pick my nose in private. I will only pick my nose when something is stuck in my nose, and I can't blow it out with a tissue. Picking my nose can spread germs. I should use a tissue when I pick or blow my nose. I must wash my hands after I touch my nose. People don't want to see me pick my nose. When I need to pick my nose, I will go to a private place, like inside the bathroom with the door closed. I will not pick my nose in front of other people or talk about picking my nose to other people.


Picking your nose


Blowing your nose


Tissue

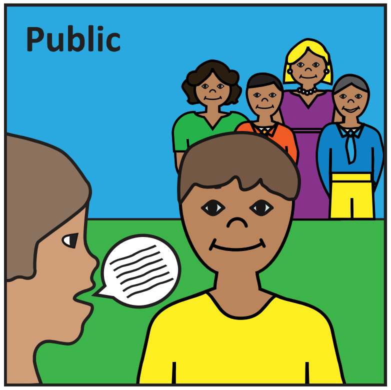

Washing hands

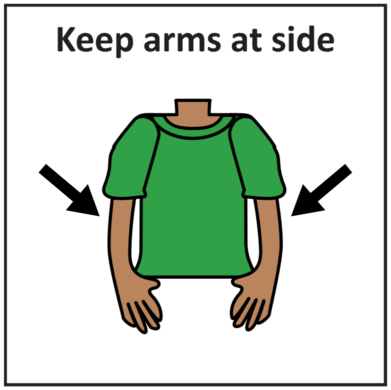

Bathroom stall

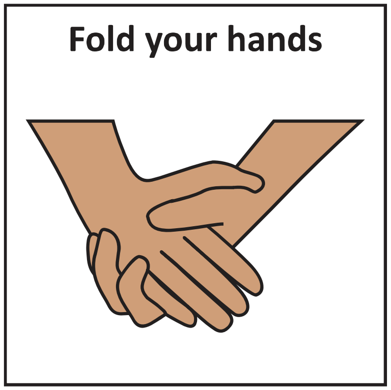

Private

Private Parts

Public places are where other people can see me. **Private** means away from other people, like in my bedroom or bathroom with the door closed. Everyone has **private** parts of their body. I can tell what parts of my body are **private** because I cover them with my underwear. I don't touch my private parts in public where other people can see me. I don't ever put my hands inside my pants in public. I can help myself remember not to touch by putting my hands by my side, crossing my arms, or folding my hands. Sometimes I need to touch my private parts, like when I itch or my underwear is uncomfortable. I can ask to go to the bathroom. When I am alone in my bedroom or bathroom, I can touch my private parts.







But It Feels Good!

Everyone has private parts of their body. I can tell what parts of my body are private because I cover them with my underwear. I don't touch my private parts in public where other people can see me. When I am alone in my bedroom or bathroom with the door shut, I can touch my private parts. When I touch my private parts, sometimes it feels good. Some people like how it feels when they touch their own private parts. It's okay to touch my private parts when I am alone. Sometimes touching my private parts can be messy. I will clean my hands and private parts when I am done. I will not talk about touching my private parts with others. If I have questions or if touching hurts, I will ask my _________ (insert doctor or trusted adult's name.)

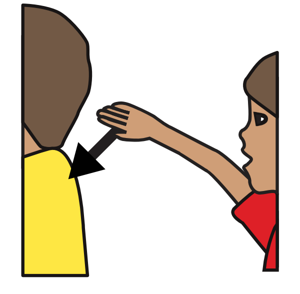
To Touch or Not to Touch, That is the Question!

When I am with my friends and family, it's usually okay to touch them and for them to touch me on the arm, back, shoulders, or hands. These are "Go" areas of the body. For example, I can give high-fives, pat them on the back, or touch them on the arm to get their attention. It's not okay for me to touch other people on parts of their body covered by underwear, such as their buttocks, breasts, penis, or vagina. It's not okay for anyone (but my doctor/parent/_______)* to touch me on parts of my body covered by my underwear either. These are private parts of the body and are "Stop" areas. If someone touches me in my private area, I should say "STOP" or "NO" and tell my Mom, Dad, or teachers. Sometimes my Mom, Dad, _______ (insert name of trusted adult) and my doctor will need to see my private areas to help me stay clean and healthy. If I don't want them to see my private areas, I can ask them for privacy.

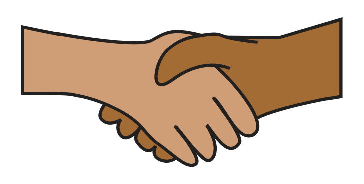
* May need to alter to include caregivers or medical professionals who need to assist with daily living skills or perform needed medical procedures.

High five

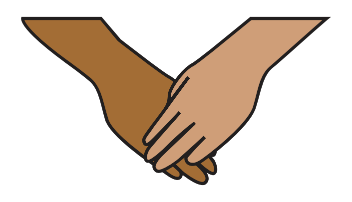
Pats on the back



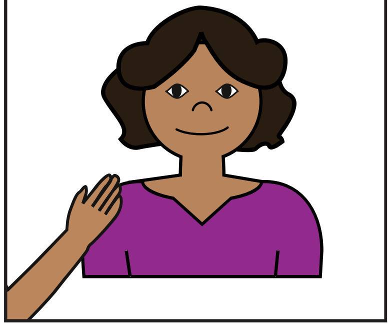
Shaking hands



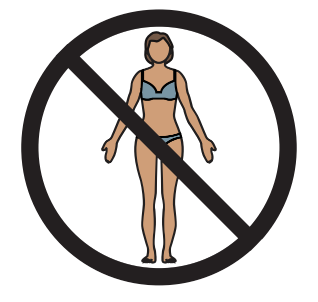
Holding hands



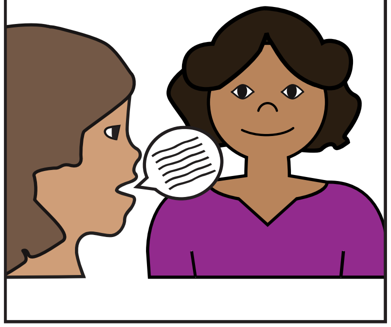
Touch shoulder



Swimsuit



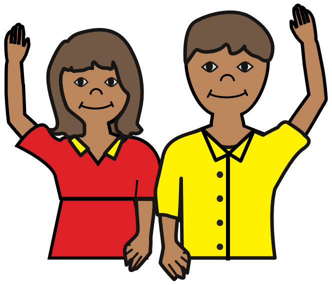
Talk to mom



Family, Friends, and Others

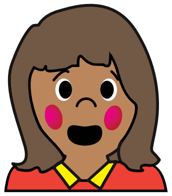
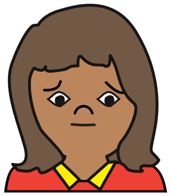
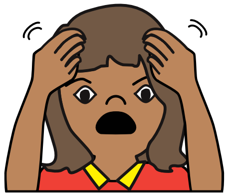
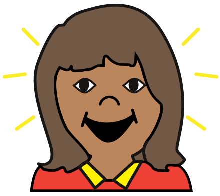
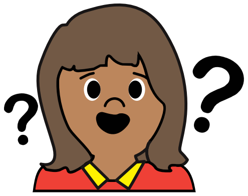
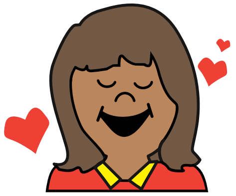
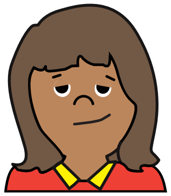
Using a sorting game to explain relationships can help your child understand what type of behavior is appropriate for different types of relationships. For example, strangers are in the far column, and your child can see that it is okay to wave or shake hands with them. Behaviors that are in the first row are for romantic partners and spouses. Family and friends fall in between. Your family can decide what behaviors should be included in each box. You may want to take pictures of people to illustrate each group.

Practice. Take it with you on outings and use it to help your child understand how to greet someone. For example, get out the chart when your child sees someone they know from school and show them what behaviors are okay to use to say hello.

Married or dating	Family	Friends	Others & strangers
Kiss 	Hug 	High five 	Wave 

Moods and Feelings – Emotions Visuals

These picture cards show different feelings and facial expressions. You can use these cards to a) label how your daughter is feeling and b) help her tell you how she feels. For example, if she seems happy, show her the "Happy" card while you label that feeling ("You seem happy today"). She can learn to give you the card to tell you how she feels, too.

Sad 	Depressed 	Embarrassed 	Angry 	Shocked 
Disappointed 	Hurt 	Confused 	Frustrated 	Excited 
Happy 	Relaxed 	Curious 	Love 	Proud 
Lazy 	Ready to work 	Tired 	Grumpy 	

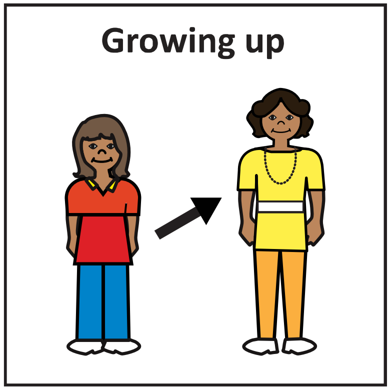
Moods and Feelings – Diary

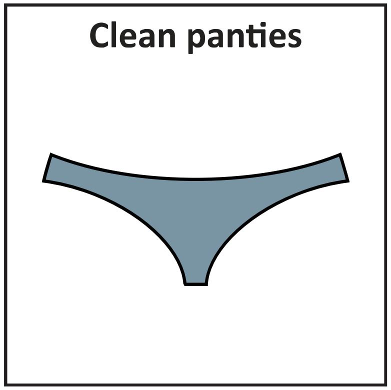
Keep track of your daughter's mood and behavior using a diary like this one. We have filled out the first line as an example. You can take this diary sheet to your daughter's next medical visit and talk about your concerns.

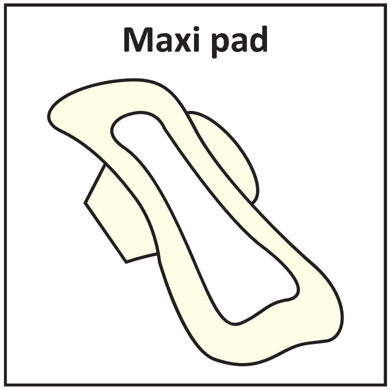
Date	Hours of sleep	Appetite	Behavior	Medications/ Supplements
1-8-2012	8-10 hrs, up with nightmare 11-4	Skipped breakfast		

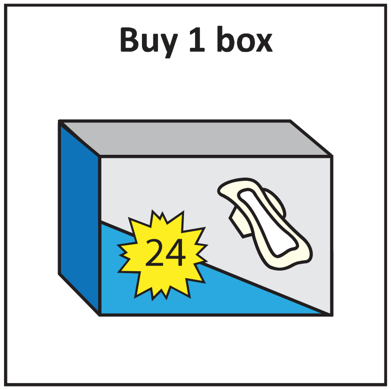
My Period

Soon I will get a period like my ________(e.g., aunt, mom, big sister). This means I am growing up. Other girls my age are starting their periods too. When I get a period, blood will come from my vagina. This is okay. I'm not hurt! My period may come every month. Periods are messy and can get on underwear and pants. I will use a pad in my underwear so the blood won't get on my pants. The pad may feel weird at first when I use it, but it will help keep my pants clean from the blood. I will keep my pad on. When the pad smells or becomes full of blood after ___ hours, I will change the pad in the bathroom. I will take off my dirty pad and wrap it in toilet paper. I will throw it away in the trash can. I will not flush it down the toilet. When I throw away my dirty pad I need to put on a new pad. Sometimes my stomach may hurt when I have my period. I will tell my mom or dad or the school nurse. My parents will be proud of me for taking care of my period and changing my pads.



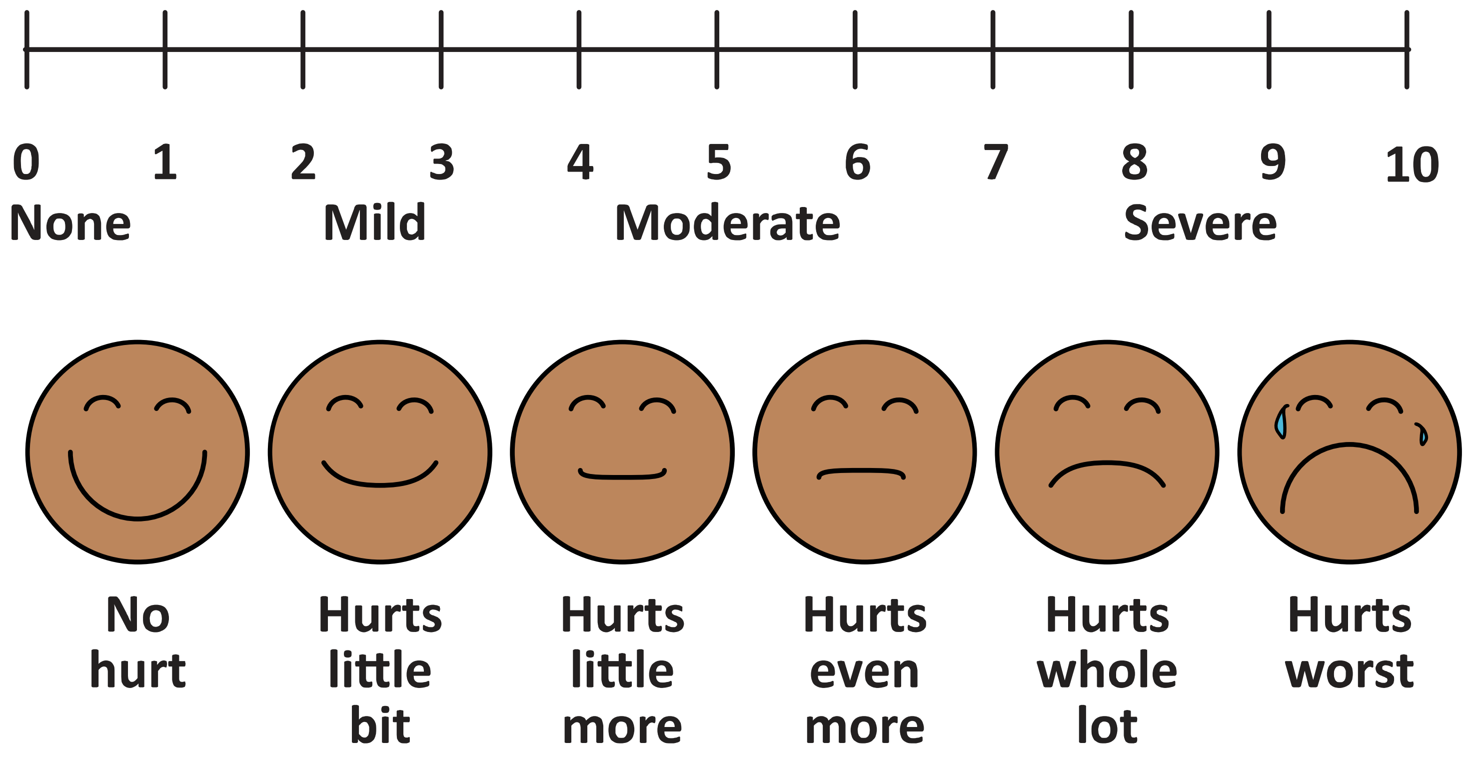






Teaching About Periods – Pain Scale

During her period, your daughter may feel tired and moody. Her stomach may swell or cramp. Using a pain scale like this can help her tell you how much she hurts or feels uncomfortable.



Instructions:

1. Print a color copy (3 pages total).
2. Cut along the dotted lines to make individual picture cards.
3. Punch a hole in the circles in the top left.
4. Use the numbers to order the picture cards. If you are using pads without wings, omit cards 8-10.
5. Place the picture cards on a ring to keep the schedule organized.
6. To show your child what a dirty pad looks like, you can use red food coloring or a marker to dye a pad at home. You can even take a picture and add it to this visual schedule.
7. This visual schedule is portable! It can go in a backpack, purse, or hygiene kit.
8. You can also put velcro on the back of each picture and make a velcro board.

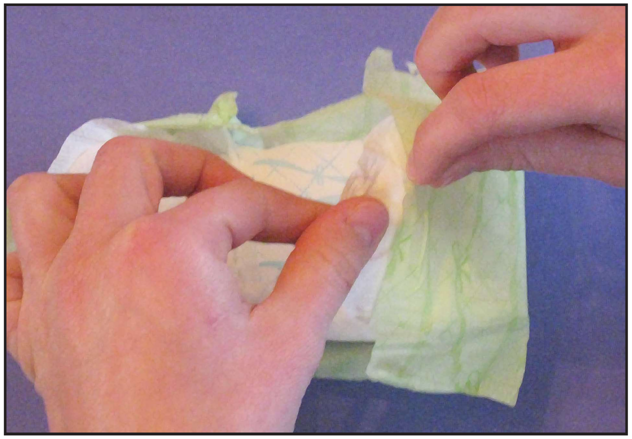
● #1

How to Use My Pad

● #2

Open wrapper.

● #3



Take pad out of wrapper.

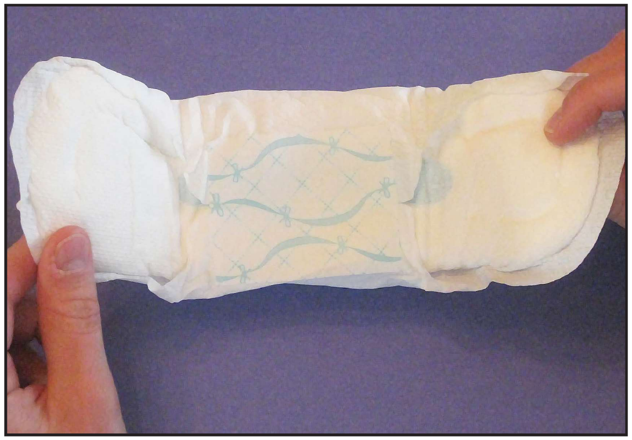
● #4

Open up panties.

● #5

Take off sticker.

● #6



Unfold pad.

● #7

Press pad into panties.

● #8

Peel off sticker.

● #9

Fold wing around panties.

● #10

Press wings on panties.

Instructions:

1. Print a color copy (3 pages total).
2. Cut along the dotted lines to make individual picture cards.
3. Punch a hole in the circles in the top left.
4. Use the numbers to order the picture cards. If you are using pads without wings, omit cards 8-10.
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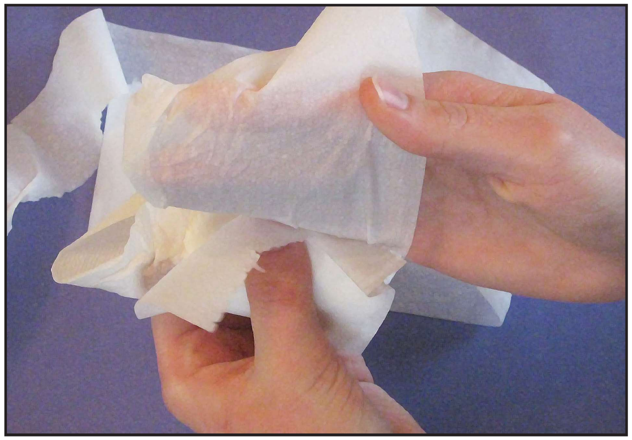
7. This visual schedule is portable! It can go in a backpack, purse, or hygiene kit.
8. You can also put velcro on the back of each picture and make a velcro board.

● #11

How to Throw Away My Pad

● #12



Fold dirty pad in toilet paper.

● #13

Throw pad in trash can.

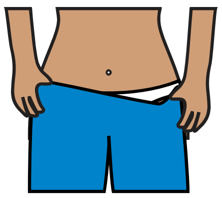
● #14

Wash hands.

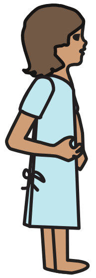
Teaching About the Female Exam

Show your daughter a picture schedule of what will happen at the exam. You can cross pictures off as the visit happens to show your daughter what comes next and how much of the visit is left.

Take off clothes



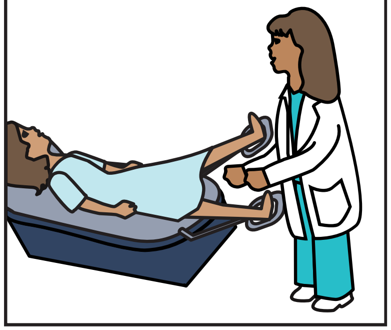
Put on gown



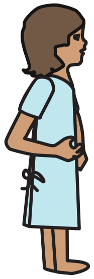
Lay on table

Put feet in stirrups

Dr checks your body

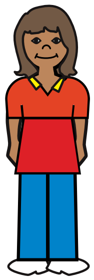


Stand up

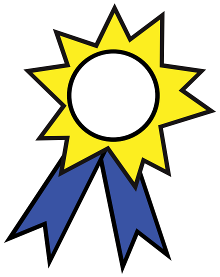


Take off gown

Put on clothes



Reward



This publication was developed and written by Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) long-term trainees Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; Doctor of Audiology student, Elizabeth Harland; Cong Van Tran, PhD; and LEND faculty members Jennifer Bowers, RN, MSN, CPNP, Pediatric Nurse Practitioner, Division of Developmental Medicine; and Cassandra Newsom, PsyD, Assistant Professor of Pediatrics, Division of Developmental Medicine, Director of Psychological Education, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. It was edited, designed, and produced by the Communications and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) with the support of the Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). We are grateful for review and suggestions by many, including faculty of TRIAD and members of Autism Tennessee.

This publication may be distributed as is or, at no cost, may be individualized as an electronic file for your production and dissemination so that it includes your organization and its most frequent referrals. For revision information, please contact courtney.taylor@vanderbilt.edu, (615) 322-5658, (866) 936-8852.

This publication was made possible by Grant No. T73MC00050 from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS. Cover photo and illustrations top of page 1 ©istockphoto.com 06/2013

VANDERBILT KENNEDY CENTER
LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

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LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Cuerpos sanos – Anexo

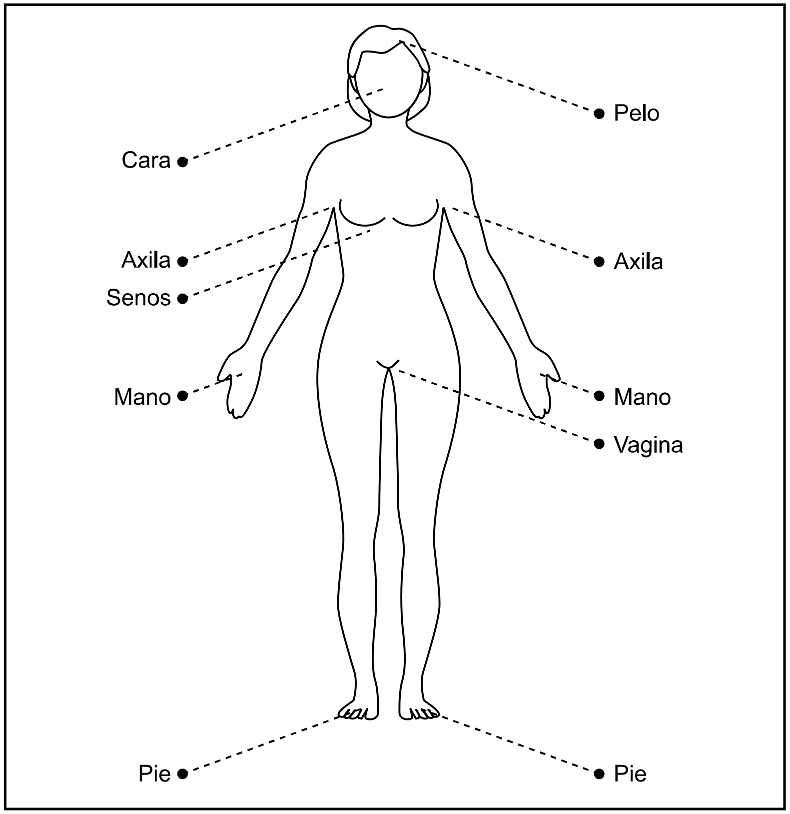
Para niñas

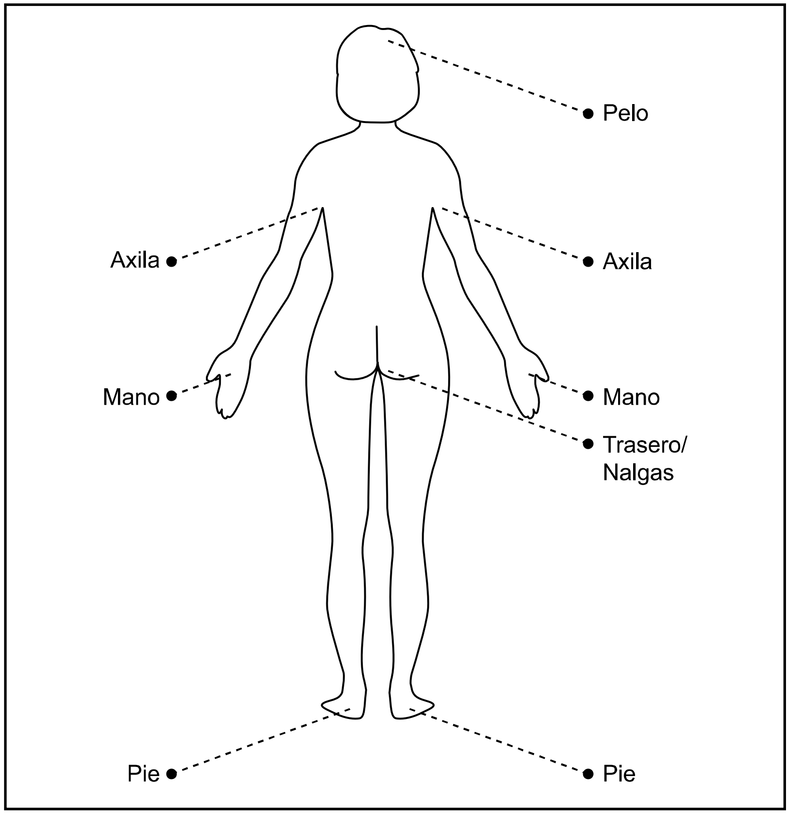
Un juego de herramientas con información y recursos que se pueden descargar de:
kc.vanderbilt.edu/HealthyBodies

Una guía para padres sobre la pubertad en niñas con discapacidades

Las partes del cuerpo – Apoyos visuales

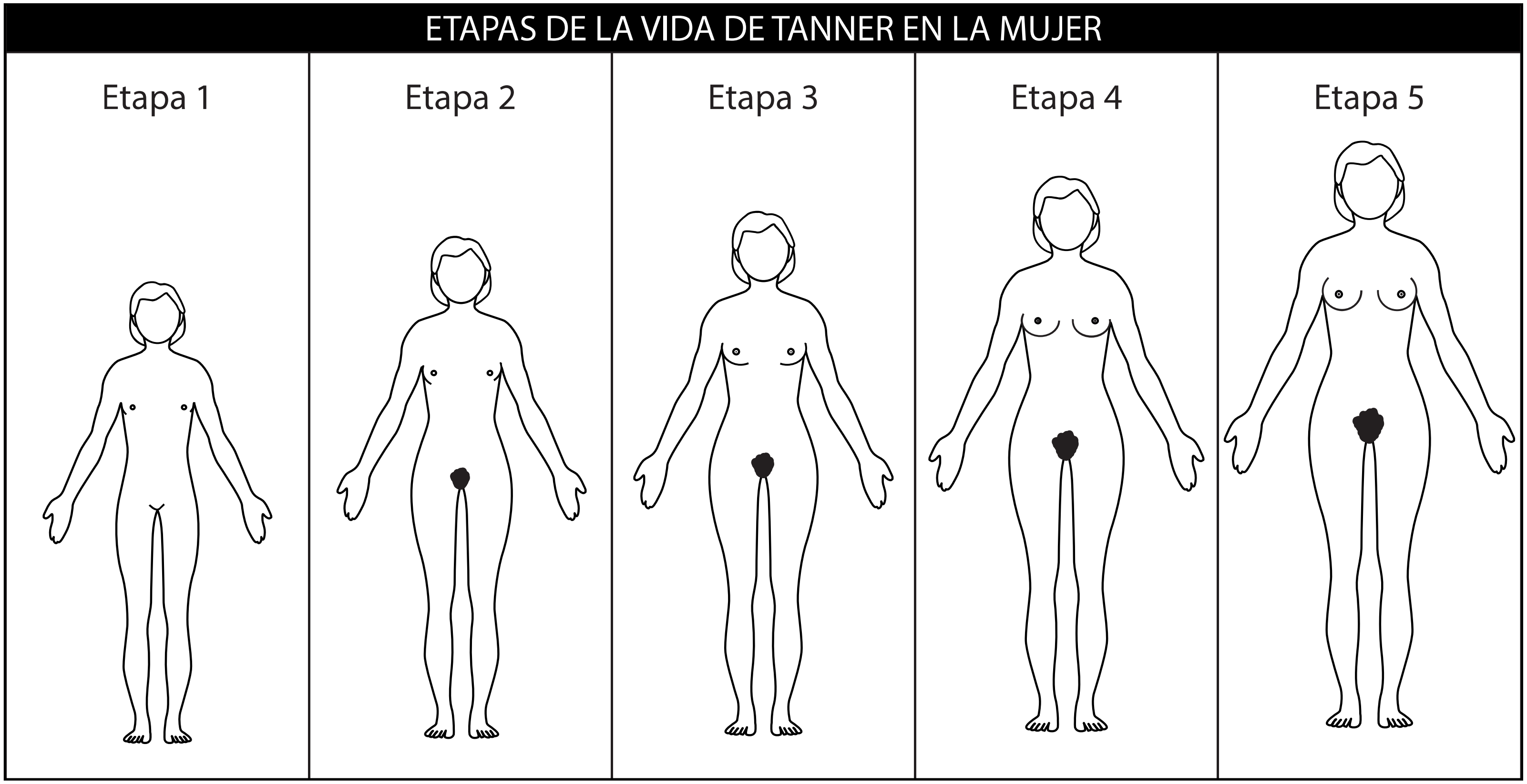
Use estos dibujos para que la niña aprenda los nombres de las partes del cuerpo. Después de enseñárselos, puede cubrir los nombres y jugar a que su hija le diga los nombres de las partes. También puede hacer tarjetitas con los nombres y que su hija coloque las tarjetitas sobre el dibujo.





Las partes del cuerpo – Apoyos visuales

Las Etapas de Tanner pueden mostrarle los cambios que verá en sus senos y cómo le crecerá el vello.



Tablero Primero-Después – Plantilla en blanco

Para motivar a su hija a hacer cosas que quizá le cuesten trabajo o que no le agraden, como hacer ejercicio, trate de usar apoyos visuales como un Tablero Primero-Después. Ponga la actividad que le gusta poco en el recuadro de Primero y la actividad de recompensa en Después. Por ejemplo, “Primero ejercicio” seguido de “Después videojuegos”. Puede usar dibujos, o si su hija sabe leer, palabras. Puede enmicar o laminar las tarjetas y pegar los dibujos con velcro, o usar una pizarra blanca con plumones o marcadores que se pueden borrar.

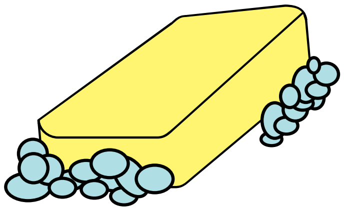
RECUERDE: Siempre ponga la actividad más divertida en el espacio de Después. Eso le muestra a la niña lo que ganará por su esfuerzo.

Primero	Después

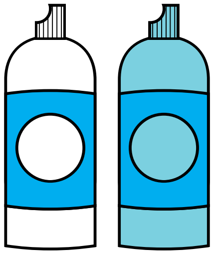
Primero	Después

Fomentar el aseo personal – Imágenes de artículos para el aseo

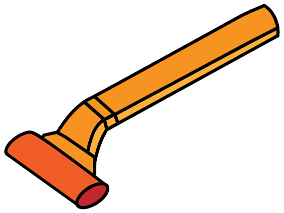
Jabón



Champú/ Acondicionador

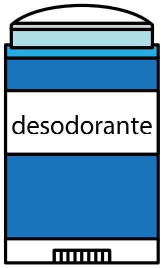


Afeitadora

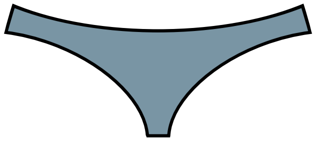


Crema de rasurar

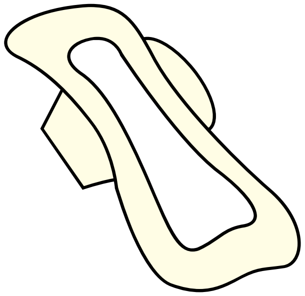
Desodorante



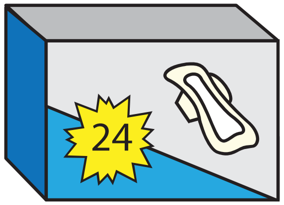
Calzón limpio



Toalla femenina

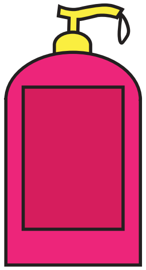


Caja de toallas femeninas



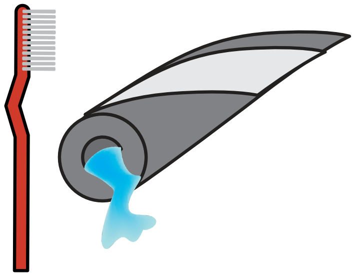
Toallitas húmedas

Crema

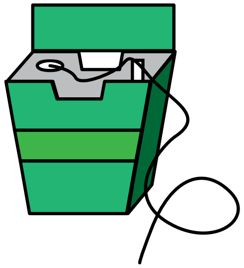


Cepillo de pelo

Cepillo y pasta dental

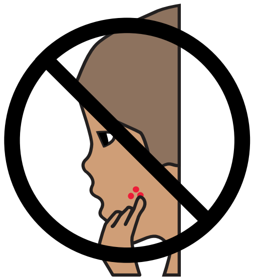


Hilo dental



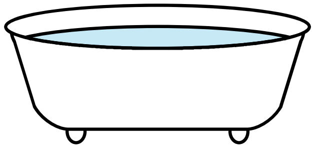
Tomar medicina

No tocarse los granos

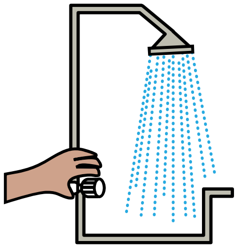


Fomentar el aseo personal – Imágenes de los pasos para bañarse

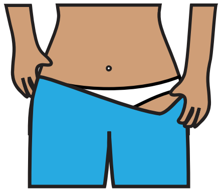
Llenar la tina con agua caliente



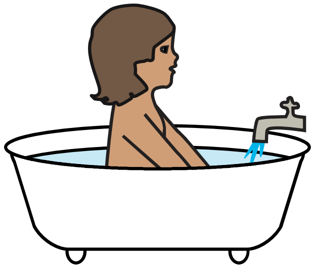
Abrir la llave de la ducha



Quitarse la ropa



Meterse en la tina



Meterse en la ducha

Lavarse todo el cuerpo

Quitarse el jabón

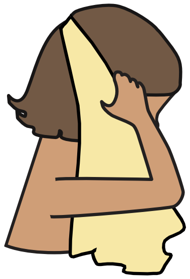
Ponerse champú en la mano

Lavarse el pelo

Enjuagarse el pelo

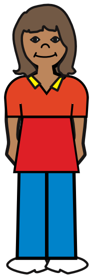
Cerrar la llave del agua

Secarse con la toalla

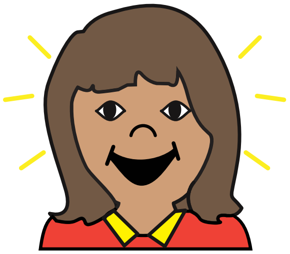


Ponerse desodorante

Ponerse ropa limpia



Lo hice muy bien



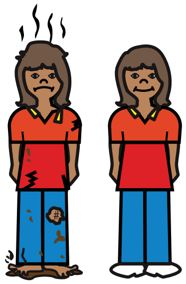
Anexo

Fomentar el aseo personal – Historia

¿Qué es ese olor?

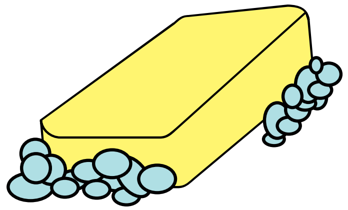
Estoy creciendo y mi cuerpo está cambiando. Me está saliendo pelo en las axilas y en las partes íntimas. A veces mis axilas y mis partes íntimas huelen mal. Ese olor se llama olor corporal. A la gente no le gusta el olor corporal. Si yo huelo mal, la gente no va a querer estar cerca de mí. Yo me puedo quitar el olor corporal si me lavo todos los días el pelo, las axilas, las partes íntimas y los pies con agua y jabón. Después de lavarme, me puedo poner desodorante en las axilas; con el desodorante me huelen bien y están secas. Yo me voy a poner desodorante todas las mañanas para no oler mal. Me gusta oler bien. Si huelo bien mis padres, amigos y maestros estarán contentos también.

Sucio - Limpio



Lavarse el pelo

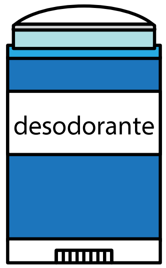
Jabón



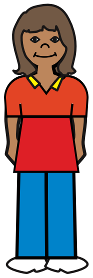
Lavarse todo el cuerpo

Ponerse desodorante

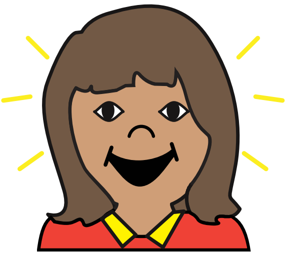
Desodorante



Ponerse ropa limpia



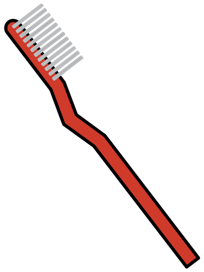
Oler bien



Anexo

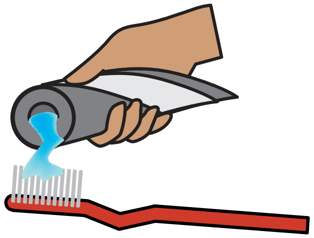
Fomentar al aseo personal – Imágenes de los pasos para cepillarse los dientes

Cepillo de dientes

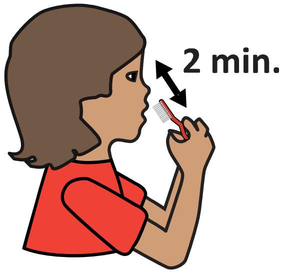


Pasta dental

Apretar para que salga la pasta



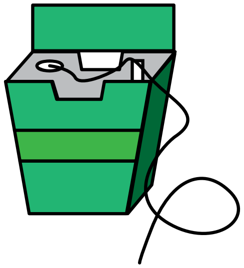
Cepillarse los dientes



Escupir en el lavabo

Enjuagarse con agua

Hilo dental



En público o en privado – Tabla para clasificar, plantilla en blanco

Usando dibujos, puede enseñar a su hija los comportamientos que son aceptables en sitios públicos y las cosas que se deben hacer solo en privado. La siguiente actividad puede ayudarla a clasificar las cosas que se hacen en público o en privado. Puede usar los dibujos de las páginas siguientes o hacer sus propios dibujos.

Cuando su hija entienda qué significa en público y en privado, usted también podrá usar las tarjetas de “En público” y “En privado” como un apoyo visual para ayudarla a recordar. Por ejemplo, si se mete el dedo en la nariz, muéstrele la tarjeta de “En privado” y dígale que vaya a un sitio privado para hacer eso.

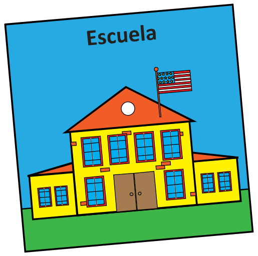
Estos dibujos o apoyos visuales también se pueden usar para preparar a su hija cuando va a un lugar público, como un restaurante.

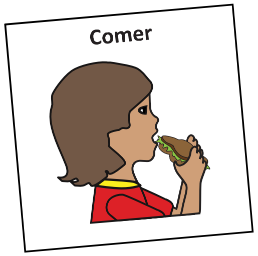
En público

En privado

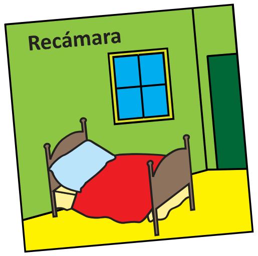
En público o en privado – Tabla para clasificar

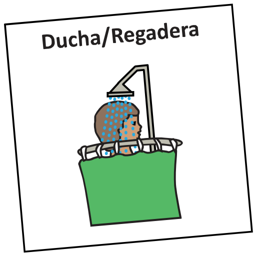
En público





En privado

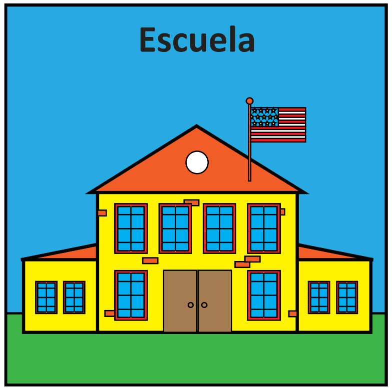




Comportamientos en público o en privado – Imágenes

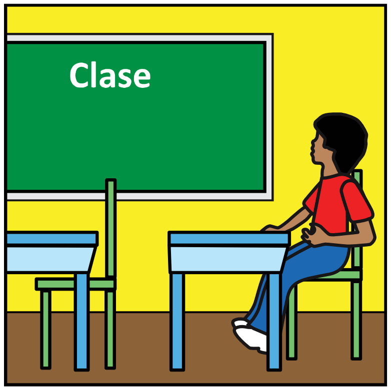

En público


En privado

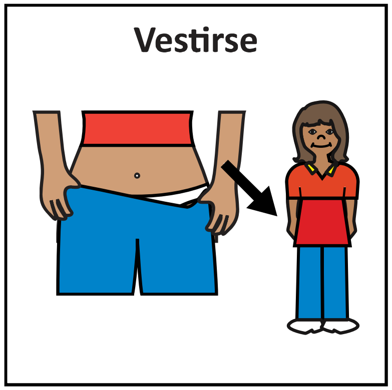

Escuela


Supermercado


Templo/Iglesia


Clase

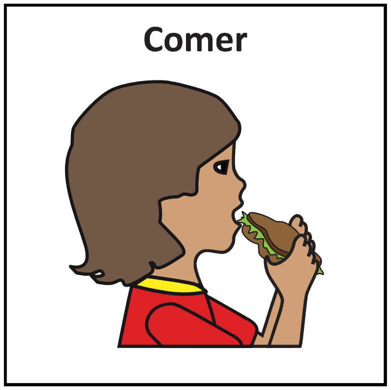

Restaurante


Vestirse


Hablar con un amigo

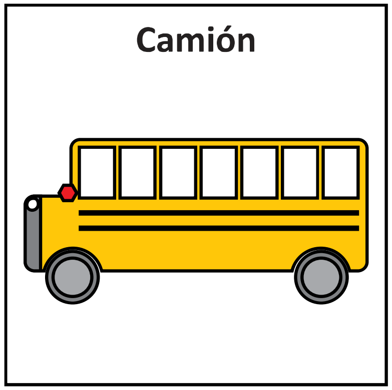

Decir palabrotas


Bailar


Comer


Tocarse las partes íntimas

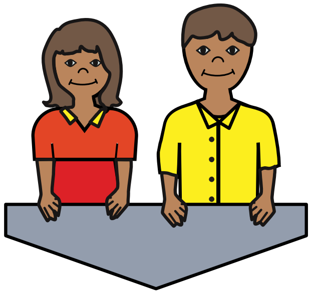

Ducha/Regadera


Camión

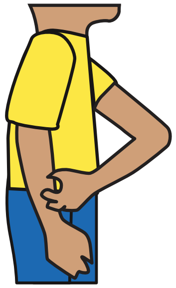
Comportamientos en público o en privado – Imágenes

Expulsar gases

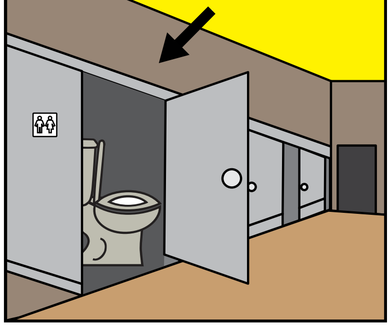
Manos en la mesa



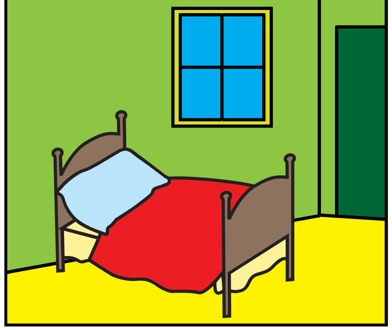
Rascarse un brazo



Excusado

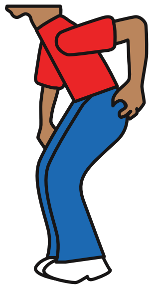


Recámara

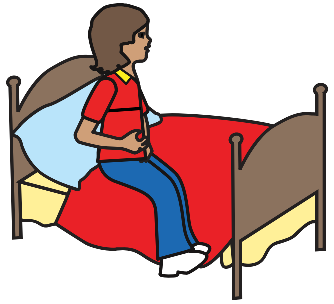


Cuarto de baño

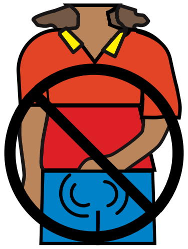
Rascarse el trasero



Sola



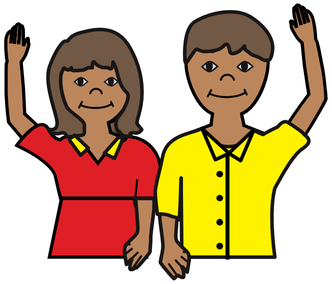
No tocarse las partes



Lavarse las manos

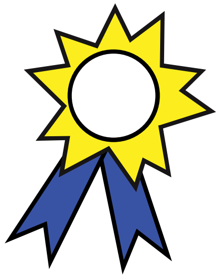
Jugar a la pelota

Saludar



Recompensa

Premio

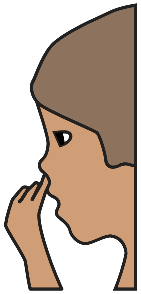


Actividad especial

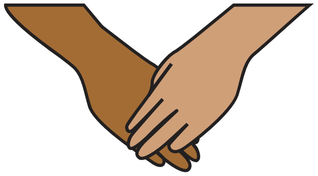
Comportamientos en público o en privado – Imágenes

Golpecitos en la espalda

Meter dedo en la nariz



Agarrarse las manos



¡Chócala!

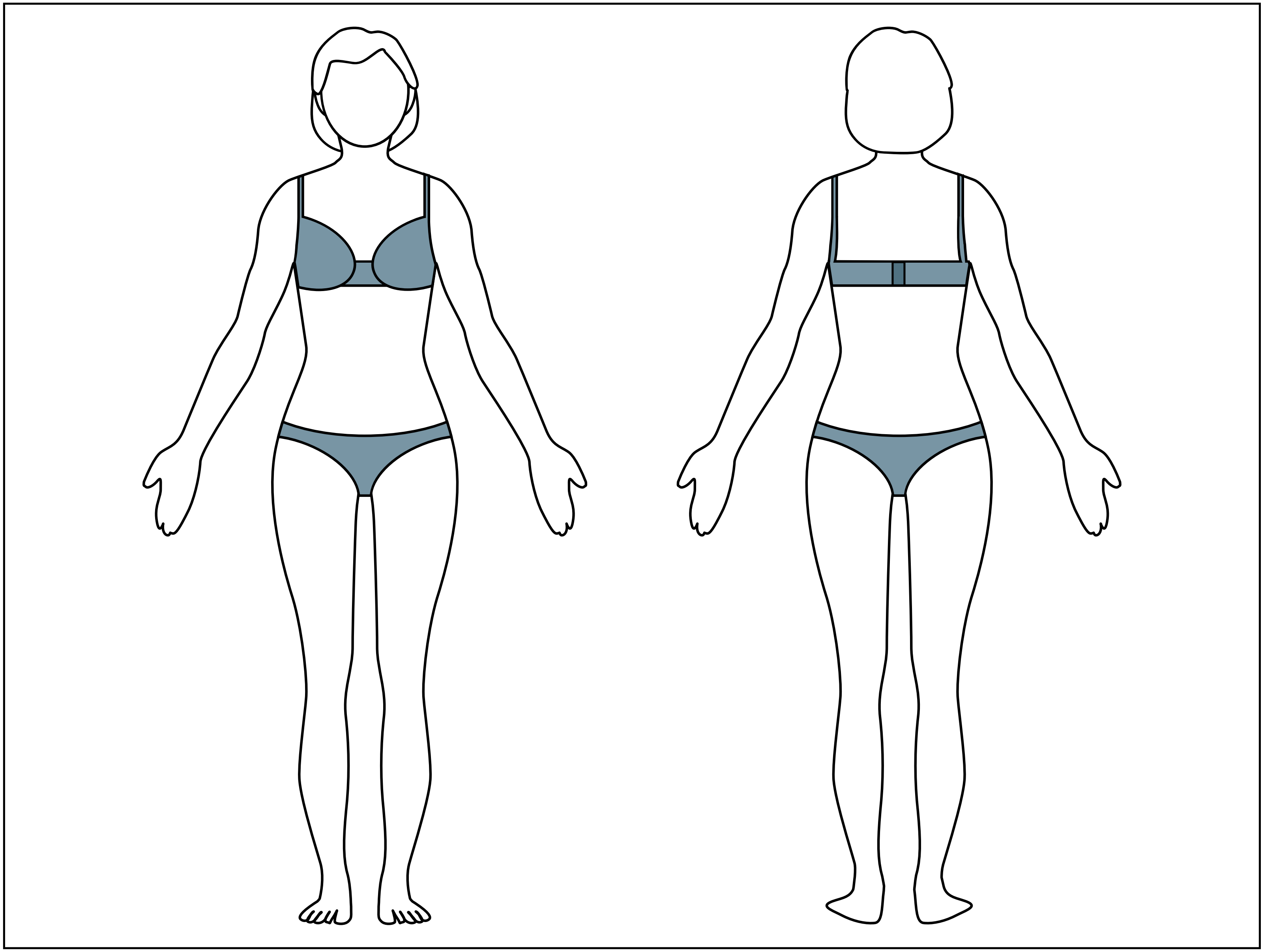
Abrazar

Besar

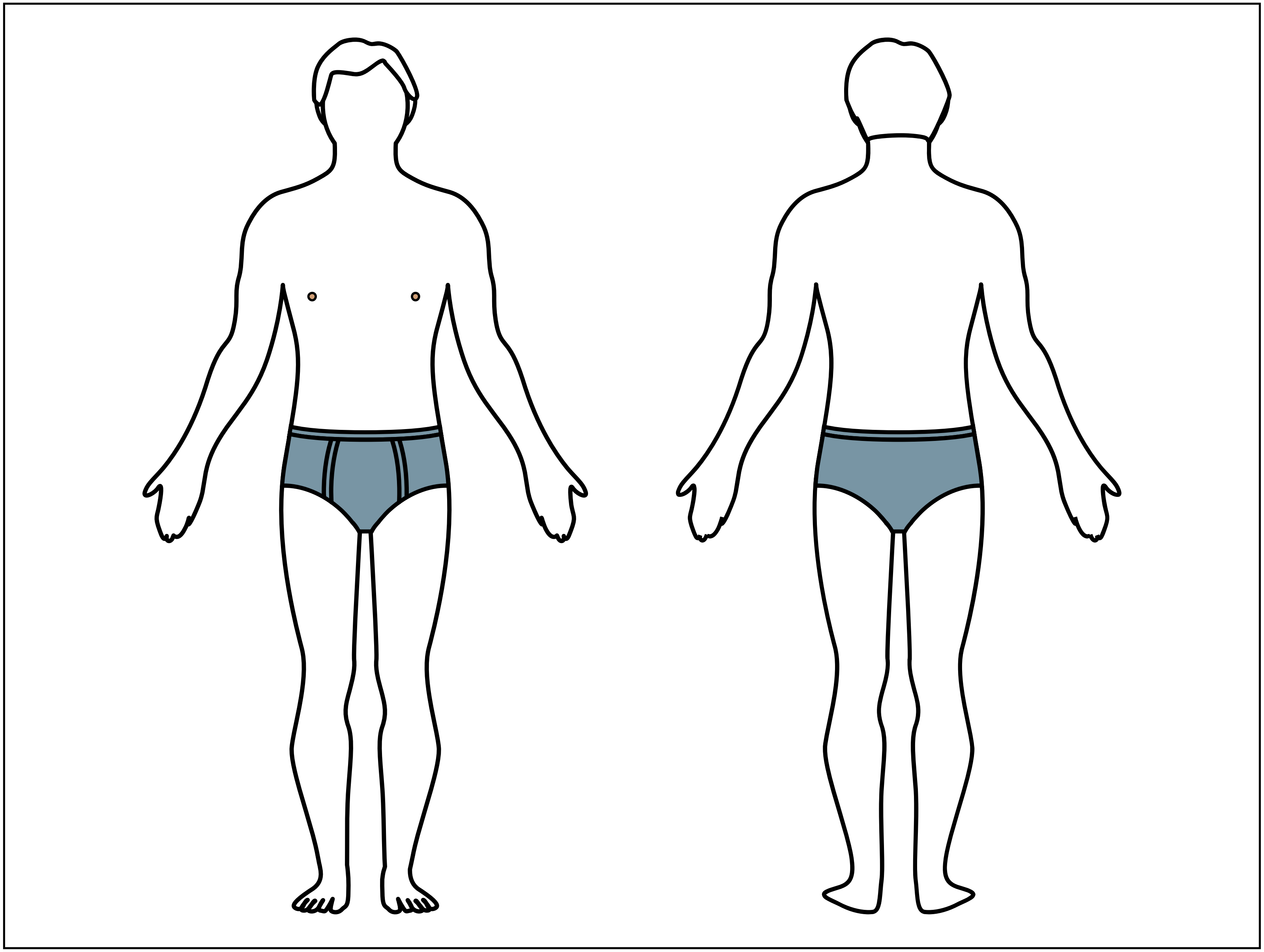
Partes íntimas - Apoyos visuales

Con estas figuras, enseñe a su hija dónde pude tocar a otras personas y dónde está bien que la toquen a ella. Apunte a una parte del cuerpo y pregunte: “¿Se puede tocar?”. Si es que sí, ponga un círculo verde en esa parte del cuerpo, “Adelante”. Si esa parte del cuerpo no se puede tocar, ponga un círculo rojo de “Alto”.

Por ejemplo, su hija debe poner un círculo verde en la mano, pero otro rojo en el trasero. Luego puede usar la misma actividad para “¿Dónde me puede tocar la gente?”.



Partes íntimas - Apoyos visuales



Comportamientos en público o en privado – Historia

Meterse el dedo en la nariz se hace en privado

A veces puede que quiera meterme el dedo en la nariz en privado. Solo me meteré el dedo en la nariz cuando tenga algo dentro y no pueda hacerlo salir sonándome la nariz. Meterse el dedo en la nariz puede esparcir gérmenes. Cuando me meto el dedo en la nariz o me sueno, debo usar un pañuelo de papel. Tengo que lavarme las manos después de meterme el dedo en la nariz. A la gente no le gusta verme con el dedo en la nariz. Cuando tengo que meterme el dedo en la nariz, voy a un sitio en privado, como el cuarto de baño, con la puerta cerrada. No voy a meterme el dedo en la nariz enfrente de otras personas, ni hablar con la gente sobre meterme el dedo en la nariz.


Meter dedo en la nariz


Sonarse la nariz


Pañuelo de papel


Lavarse las manos


Excusado


En privado

Comportamientos en público o en privado – Historia

Partes íntimas

En público significa que estoy en un sitio donde la gente me ve.

En privado es cuando no me ve nadie, como en mi recámara o en el baño con la puerta cerrada.

Todos tenemos partes íntimas en el cuerpo. Son las que se cubren con la ropa interior. No me toco las partes íntimas en público donde otros me pueden ver. Tampoco me meto las manos por dentro del pantalón cuando estoy en público. Para recordar esto, puedo poner las manos a los lados, meterlas en los bolsillos, cruzar los brazos o agarrarme las manos. A veces si me pica algo o si el calzón me molesta, puedo preguntar si puedo ir al baño. Cuando estoy sola, en mi cuarto o en el baño, puedo tocarme las partes íntimas.


En público


En privado


Brasier y calzón sobre las partes íntimas


No tocarse las partes


Los brazos a los lados


Agarrarse las manos


Rascarse el trasero


Cuarto de baño


Tengo que tocar

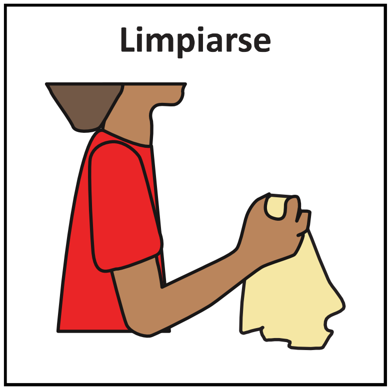

Recámara


Sola

Comportamientos en público o en privado – Historia

¡Pero me gusta!

Todos tenemos partes íntimas en el cuerpo. Yo sé cuáles son las partes íntimas porque las tapa la ropa interior. No me toco las partes íntimas en público donde otros me pueden ver. Cuando estoy sola en mi recámara o en el baño con la puerta cerrada, puedo tocarme las partes íntimas. Cuando me toco las partes íntimas, a veces me gusta. A algunas personas les gusta tocar sus propias partes íntimas. Está bien tocarme cuando estoy sola. A veces al tocarme las partes íntimas termino ensuciándome. Entonces me lavaré las manos y las partes íntimas cuando termine. Yo no le hablaré a nadie sobre tocarme las partes íntimas. Si tengo preguntas o si me duele al tocarme, le preguntaré a mi __________ (ponga el nombre del doctor o una persona adulta de confianza).



Anexo

Comportamientos en público o en privado – Historia

Tocar o no tocar, ¡esa es la cuestión!

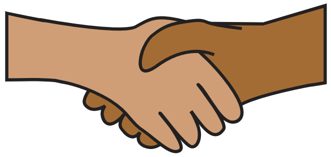
Cuando estoy con mi familia y amigos, normalmente está bien tocarles y que me toquen el brazo, la espalda, los hombros o las manos. Estas áreas del cuerpo están permitidas, “Adelante”. Por ejemplo, puedo chocar las manos con ellos, darles palmaditas en la espalda o tocarles el brazo para que me presten atención. No está bien tocar a otras personas en las partes que van cubiertas con la ropa interior, como el trasero, los senos, el pene o la vagina. No está bien que nadie (excepto mi doctor/madre o padre/ _______)* me toque a mí en las partes del cuerpo que van cubiertas con la ropa interior. Estas son las partes íntimas del cuerpo y son áreas donde hay que hacer “Alto”. Si alguien me toca en la zona íntima, yo debo decir “PARA” o “ALTO” o “NO” y decirle a mi mamá, mi papá, _______ (escriba el nombre de una persona adulta de confianza) y mi doctor querrán ver mis partes íntimas para ayudarme a estar sana y limpia. Si no quiero que miren mis partes íntimas, puedo pedirles privacidad.

* Puede cambiar el texto si tiene que incluir cuidadores o profesionales que la asisten con las necesidades diarias o al realizar procedimientos médicos.

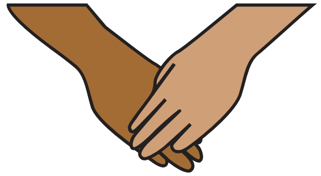
¡Chócala!

Golpecitos en la espalda

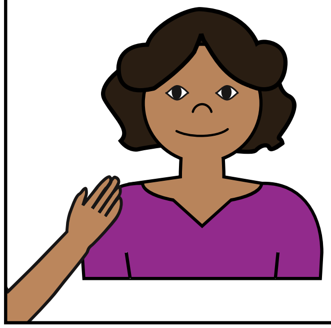
Estrechar la mano



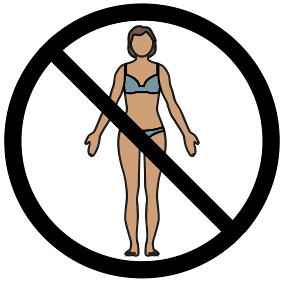
Agarrarse las manos



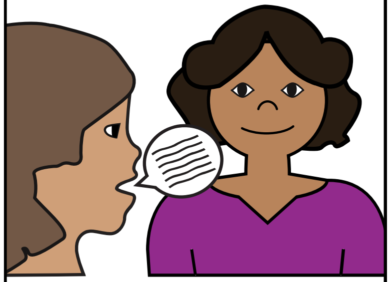
Tocar el hombro



Traje de baño



Hablar con mamá

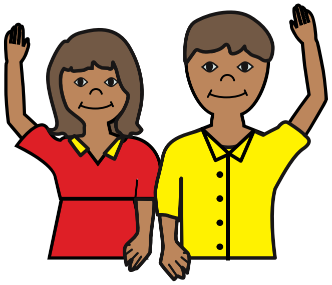


Comportamientos en público o en privado – Historia

Familia, amigos y otros

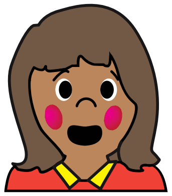
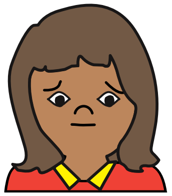
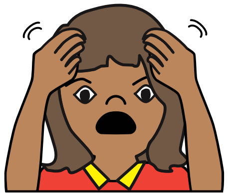
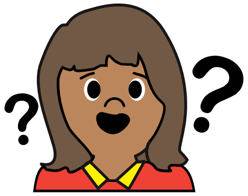
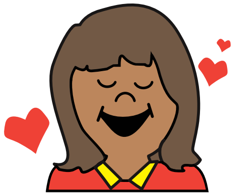
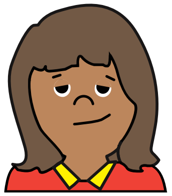
Un juego de clasificar puede ayudar a explicar las relaciones a su hija de manera que entienda el tipo de comportamiento que es apropiado para los distintos tipos de relaciones. Por ejemplo, los desconocidos están en la última columna, y su hija puede ver que está bien saludarlos o estrecharles la mano. Los comportamientos de la primera columna son para los novios o esposos. La familia y amigos están entre estos dos. Su familia puede decidir qué comportamientos deben incluirse en cada recuadro. Quizá quiera tomar fotos de personas como ejemplo de cada grupo.

Práctica. Lleve este juego cuando salga y úselo para enseñar a su hija cómo saludar a la gente. Por ejemplo saque el diagrama cuando su hija se encuentra a alguien de la escuela para mostrarle qué comportamiento está bien para decir hola

Casados o novios	Familia	Amigos	Otros y desconocidos
Besar 	**Abrazar** 	**¡Chócala!** 	**Saludar** 

Humor y sentimientos – Tarjetas de emociones

Estas tarjetas muestran las distintas emociones y expresiones faciales. Pueden usarse estas tarjetas para: a) Darle nombre a la manera en la que se siente su hija y b) ayudar a decirle a ella cómo se siente usted. Por ejemplo, si ella está contenta, muestre la tarjeta que dice “Contenta” al tiempo que le dice: “Hoy parece que estás contenta”. Ella puede aprender a darle a usted la tarjeta para decir cómo se siente, también.

Triste 	**Deprimida** 	**Avergonzada** 	**Enojada** 	**Sorprendida** 
Decepcionada 	**Dolida** 	**Confundida** 	**Frustrada** 	**Ilusionada** 
Contenta 	**Relajada** 	**Curiosa** 	**Amorosa** 	**Orgullosa** 
Perezosa 	**Lista para trabajar** 	**Cansada** 	**Gruñona** 	

Humor y sentimientos – Diario

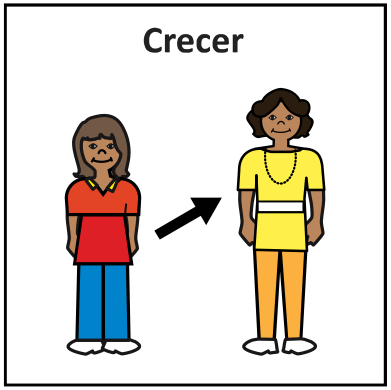
Puede anotar el estado de humor y comportamientos de su hija en una tabla-diario como esta. Hemos escrito en la primera línea para que vea un ejemplo. Puede llevar esta hoja a la próxima visita médica que tenga para hablar sobre lo que le preocupa.

Fecha	Horas de sueño	Apetito	Comportamiento	Medicinas/ Suplementos
1-8-2012	8-10 hrs, despertó con pesadilla 11-4	No desayunó		

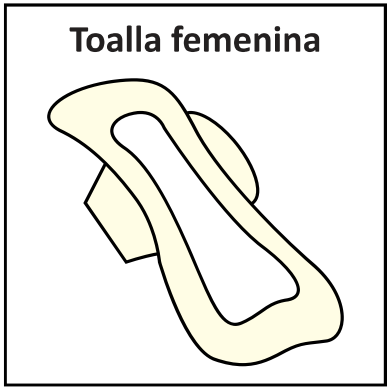
Enseñar sobre el periodo – Historia

Mi periodo

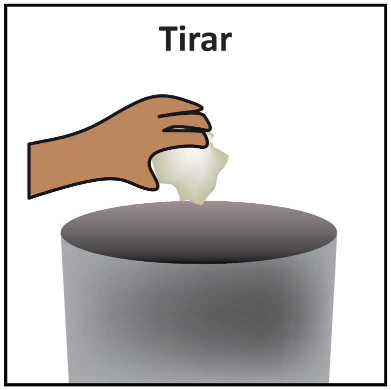
Pronto voy a tener el periodo como mi ________ (p. ej., tía, mamá, hermana mayor). Esto es porque estoy creciendo. Otras niñas de mi edad también empiezan a tener el periodo. Cuando tengo el periodo, me sale sangre de la vagina. Esto no es malo, ¡no estoy enferma, ni me he lastimado! Puedo tener el periodo cada mes. Cuando estoy en el periodo puede que se me ensucie el calzón o el pantalón. Voy a ponerme una toalla femenina en la ropa interior para que no se manchen los pantalones de sangre. La toalla femenina se siente rara al principio, pero me ayuda a tener los pantalones limpios. Cuando la toalla femenina huele mal o se llena de sangre después de ___ horas, me cambiaré de toalla femenina en el cuarto de baño. Me quito la toalla sucia y la envuelvo con papel higiénico. Luego tiro la toalla sucia en la basura. No la pongo en el inodoro. Después de tirar la toalla femenina en la basura, tengo que ponerme otra limpia. A veces me duele la pancita cuando tengo el periodo. Se lo diré a mi mamá, a mi papá o a la enfermera de la escuela. Mis padres estarán orgullosos de mí, por asearme en el periodo y cambiarme la toalla femenina yo sola.


Crecer

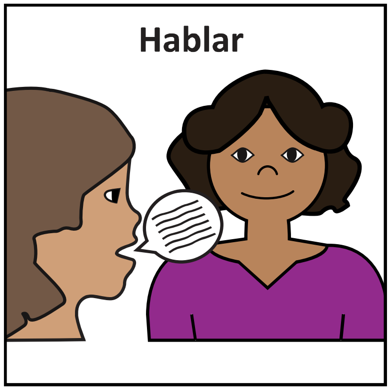

Calzón limpio


Toalla femenina


Cuarto de baño


Tirar


Hablar con el doctor

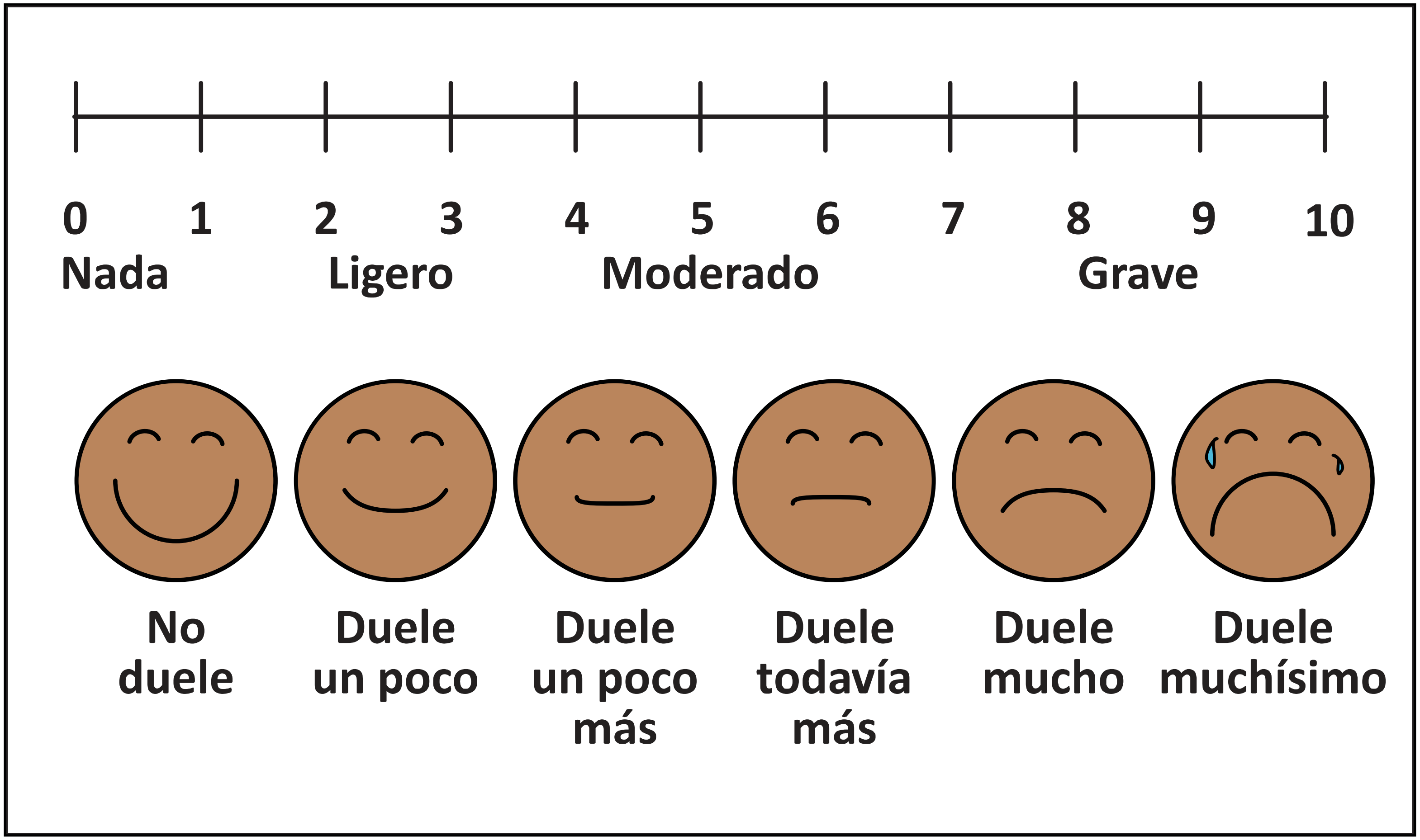

Hablar


Comprar 1 caja

Enseñar sobre el periodo – Escala del dolor

Durante su periodo, su hija puede sentirse cansada y tener cambios de humor. Puede tener hinchazón en el vientre o dolores en la espalda.

Usar una escala del dolor como esta puede ayudarla a comunicar el nivel de dolor o incomodidad que siente.



Instrucciones:

1. Imprima una copia en color (3 páginas en total).
2. Corte a lo largo de la línea punteada para tener tarjetas con fotos individuales.
3. Haga un agujero en la esquina de arriba a la izquierda.
4. Numere las tarjetas para ordenarlas. Si usa toallas sin alas, no use las tarjetas 8-10.
5. Una las tarjetas con una anilla para que la guía o agenda esté en orden.
6. Para mostrar a su hija cómo se ve una toalla sucia, puede poner colorante rojo para alimentos o un marcador para manchar una toalla en casa. Puede tomar una foto y ponerla en la agenda visual.
7. ¡Esta agenda visual no es fija! Puede llevar la guía o agenda siempre consigo en la mochila, el bolso o el estuche de aseo.
8. También se puede poner velcro en la parte de atrás de las tarjetas y ponerlas en forma de agenda en una carpeta.

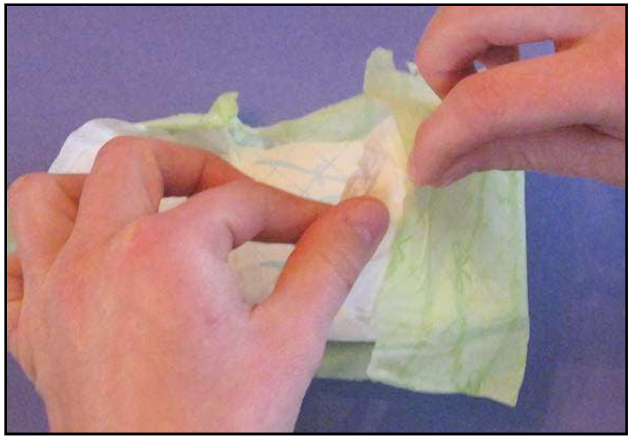
#1

Cómo usar mi toalla femenina

#2

Desenvolver.

#3



Sacarla de la envoltura.

#4

Estirar el calzón.

● #5

Despegar.

● #6

Estirar la toalla.

● #7

Presionar en el calzón.

● #8

Despegar un lado.

● #9

Doblar el ala sobre el calzón.

● #10

Doblar el ala sobre el calzón.

Instrucciones:

1. Imprima una copia en color (3 páginas en total).
2. Corte a lo largo de la línea punteada para tener tarjetas con fotos individuales.
3. Haga un agujero en la esquina de arriba a la izquierda.
4. Numere las tarjetas para ordenarlas. Si usa toallas sin alas, no use las tarjetas 8-10.
5. Una las tarjetas con una anilla para que la guía o agenda esté en orden.
6. Para mostrar a su hija cómo se ve una toalla sucia, puede poner colorante rojo para alimentos o un marcador para manchar una toalla en casa. Puede tomar una foto y ponerla en la agenda visual.
7. ¡Esta agenda visual no es fija! La puede llevar siempre en la mochila, el bolso o el estuche de aseo.
8. También se puede poner velcro en la parte de atrás de las tarjetas y ponerlas en forma de agenda en una carpeta.

● #11

Cómo tirar mi toalla femenina

● #12

Envolver la toalla sucia con papel higiénico.

● #13

Tirar la toalla en la basura.

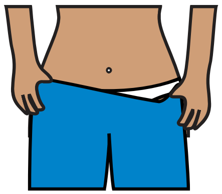
● #14

Lavarse las manos.

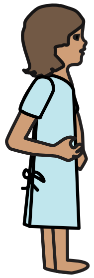
Enseñar sobre el examen femenino

Muestre a su hija una guía o agenda de lo que pasará cuando vaya a su examen. Puede tachar los dibujos a medida que van completando ese paso para que ella vea lo que viene después y cuánto le queda para terminar la visita.

Quitarse la ropa



Ponerse la bata

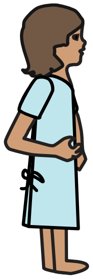


Acostarse en la camilla

Poner los pies a los lados

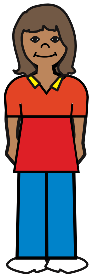
Doctor te toca el cuerpo

Levantarse

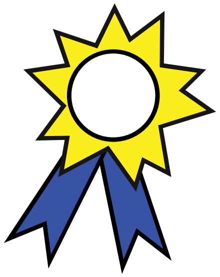


Quitarse la bata

Vestirse



Premio



Esta publicación fue desarrollada y escrita por los experimentados investigadores en práctica de Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND): Amy Weitlauf, PhD; Stormi White, PsyD; Olivia Yancey, MDE; Caitlin Nicholl Rissler, MSN; estudiante de doctorado de Audiología, Elizabeth Harland; Cong Van Tran, PhD; y los profesores de LEND Jennifer Bowers, RN, MSN, CPNP, Enfermera Pediátrica de Práctica Avanzada, División de Medicina del Desarrollo y Cassandra Newsom, PsyD, Profesora Auxiliar de Pediatría, División de Medicina del Desarrollo, Directora de Educación Psicológica, Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)/Vanderbilt Kennedy Center. Fue editada, diseñada y producida por el personal de Diseño Gráfico y Difusión del Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Kylie Beck, BA; Jan Rosemergy, PhD; Courtney Taylor, MDiv) el apoyo de Vanderbilt LEND (Pam Grau, BS; Evon Lee, PhD; Terri Urbano, RN, MPH, PhD). Les agradecemos la revisión y sugerencias a numerosos miembros del personal de TRIAD y de Autism Society of Middle Tennessee.

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Esta publicación fue posible, en parte, gracias al siguiente financiamiento: Grant N.° T73MC00050 de Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Sus contenidos son la responsabilidad única de los autores y no representan necesariamente las posturas oficiales del MCHB, HRSA, HHS. Foto de la portada e ilustraciones en la parte superior de la pág. 1. ©istockphoto.com. 12/2014.

VANDERBILT KENNEDY CENTER
LEND–LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

New Jersey Centers for Independent Living
Contact Information

Atlantic County ***Total Living Center, Inc.*** The Courtyard Suite B-8 707 White Horse Pike Absecon, NJ 08201 V (609) 645-9547 TTY (609) 645-9593 Fax (609) 813-2318 ***MaryBeth Luby, Transition Specialist*** marybeth@tlcenter.org	**Cape May, Cumberland, and Salem Counties** ***Tri-County Independent Living Center*** 120 North High Street #12 Millville, NJ 08332 V (856) 327- 5177 TTY (856) 327- 5328 Fax (856) 470- 8171 **Cape May Office:** V (609) 463- 4747 E-Mail: tcilc@aol.com
Bergen County ***Heightened Independence & Progress*** 131 Main Street Suite – 120 Hackensack, NJ 07601 V (201) 996-9100 TTY (201) 996-9424 Fax (201) 996-9422 *Andy Skea, Transition Specialist* askea.ber@hipcil.org	**Essex and Passaic Counties** ***Center for Independent Living*** 66 Mount Prospect Avenue Suite C1 Clifton, NJ 07013 V (973) 470- 8090 TTY (973) 470- 2521 Fax (973) 470- 8171 *Barbara Schank, Transition Specialist* bschank@dial-cil.org
Burlington County ***Resources for Independent Living (RIL)*** 351 High Street Suite 103 Burlington, NJ 08016 V (609) 747-7745 TTY (609) 747- 1875 Fax (609) 747-1870 *Joe Zesski, Transition Specialist* jzesski@rilnj.org	**Newark Office:** **C/O NJ DVR** 990 Broad Street, 2nd Floor Newark, NJ 07102 V (973) 470- 8090 TTY (973) 470- 2521 Fax (973) 648- 2598
Camden City ***Camden City Independent Living Center*** 2600 Mt. Ephraim Avenue Suite 413 Camden, NJ 08104 V (856) 966- 0800 TTY (856) 966- 0830 Fax (856) 966- 0832 E-Mail: ccilc@bellatlantic.net	**Gloucester and Camden Counties** ***Center for Independent Living of South Jersey*** 1200 North Delsea Drive Plaza 47, Suite 6 Westville, NJ 08093 V (856) 853-6490 TTY (856) 853- 7602 Fax (856) 853- 1466 *William Love, Transition Specialist* *Cilsj.transition@verizon.net*

Hudson County
Heightened Independence & Progress
26 Journal Square, Suite 602
Jersey City, NJ 07306
V (201) 533- 4407
TTY (201) 533-4409
Fax (201) 533- 4421
Marian Padilla, Transition Specialist
Mpadilla.hud@hipcil.org

Hunterdon Satellite Office:
4 Walter Foran Blvd.
Suite 410
Flemington, NJ 08822
V (908) 782- 1055
TTY (908) 782- 1081
Fax (908) 782- 6025
Pamela Vernon, Transition Specialist
Pamela.vernon@pcil.org

Hunterdon and Mercer Counties
Progressive Center for Independent Living
1262 Whitehorse Hamilton Square Road
Madison Corporate Center
Building A, Suite 102
Hamilton, NJ 08690
V (609) 581-4500
TTY (609) 581-4550
Fax (609) 581-4555
Renee Pfaff, Transition Specialist
Renee.pfaff@pcil.org

Middlesex, Somerset, and Union Counties
Alliance for Disabled in Action
629 Amboy Avenue, lower level
Edison, NJ 08837
V (732) 738- 4388
TTY (732) 738- 9644
Fax (732) 738- 4416
Carole Tonks, Transition Specialist
spniewski@adacil.org

Monmouth and Ocean Counties
MOCEANS Center for Independent Living
279 Broadway, 2nd floor
Long Branch, NJ 07740
V (732) 571- 4884
TTY (732) 571- 4878
Fax (732) 571- 4003
E-Mail: moceans@moceans.org
Contact: Ms. Joanne M. Jones, Executive Director
Sue Pniewsky, Transition Specialist
Orrie.moceans@verizon.net

Morris, Sussex, and Warren Counties
DAWN Center for Independent Living, Inc.
30 Broad Street
Unit #5
Denville, NJ 07834
V (973) 625- 1940
TTY (973) 625- 1932
Fax (973) 625- 1942
Sean Hardy, Transition Specialist
shardy@dawncil.org

New Jersey Department of Human Services
DIVISION OF DEVELOPMENTAL DISABILITIES
www.nj.gov/humanservices/ddd

State of New Jersey
DHS
Department of Human Services

DDD Housing Assistance: Frequently Asked Questions

Will the Division of Developmental Disabilities offer housing assistance in the Fee-for-Service system?

While “room and board” is not a Medicaid eligible service, the Division of Developmental Disabilities (DDD) recognizes that housing is an important resource for any individual. DDD is pleased to be able to provide rental subsidies to eligible individuals who have been enrolled in or transitioned into the Fee-for-Service system, to help cover the cost of housing, *as annual budget allocations allow*.

DDD-funded rental subsidies will be administered by the **Supportive Housing Connection** (SHC), which is a partnership between the NJ Housing and Mortgage Finance Agency and the NJ Department of Human Services (DHS). Subsidies will be issued through an **SHC housing voucher**.

Who can apply for an SHC housing voucher?

To apply for an SHC housing voucher an individual must:

- Meet the functional criteria for DDD eligibility
- Have current and active Medicaid
- Have a current NJ Comprehensive Assessment Tool (NJ CAT): **www.nj.gov/humanservices/ddd/resources/njcat.html**
- Have an assigned Support Coordinator

SUPPORTIVE HOUSING CONNECTION
A PARTNERSHIP BETWEEN NJHMFA & NJDHS

Applicants who may qualify for an SHC housing voucher include:

- Individuals with existing housing instability
- Individuals receiving or planning to receive services from the Supports Program
- Individuals enrolled on the Community Care Waiver (CCW) who are self-directing their services in an unlicensed residential setting
- Individuals on the CCW Waiting List who have been reached in the current fiscal year initiative

What type of housing does an SHC housing voucher cover?

In most cases, SHC housing vouchers will be provided for one-bedroom rental units. If an individual will be living with other individuals, an SHC housing voucher may be approved for a rental unit with more than one bedroom. The SHC will conduct initial, annual, and any other needed unit inspections.

An SHC housing voucher will subsidize rental units that are at or below Fair Market Rent (FMR), as established annually by the NJ Department of Community Affairs (DCA).

- Rental units that are not licensed through DHS will be inspected by SHC and must meet and maintain Housing Quality Standards established by the United States Department of Housing and Urban Development.
- Rental units licensed through DHS will be inspected by the DHS Office of Licensing and must meet and maintain standards identified in N.J.A.C. 10:44A – *Standards for Community Residences for Individuals with Developmental Disabilities:* **www.state.nj.us/humanservices/ool/documents/10_44A_eff_4_18_05.pdf**

Will the SHC housing voucher pay the individual's entire monthly rent?

The SHC housing voucher will not pay the entire monthly rent. An individual who receives an SHC housing voucher will be required to pay 30% of his/her gross income (Including SSI benefit, SSD benefit if applicable, and employment wages) directly to the landlord. The SHC will pay the remainder of the monthly rent amount directly to the landlord.

Will the SHC housing voucher pay for needed services and supports?

The SHC housing voucher provides rental assistance only and does not provide funding for disability-related services and supports. Before applying for a housing voucher, it is important that an individual work with his/her Support Coordinator to ensure that his/her budget can fund needed services and supports within the desired rental unit.

How can an individual apply for an SHC housing voucher?

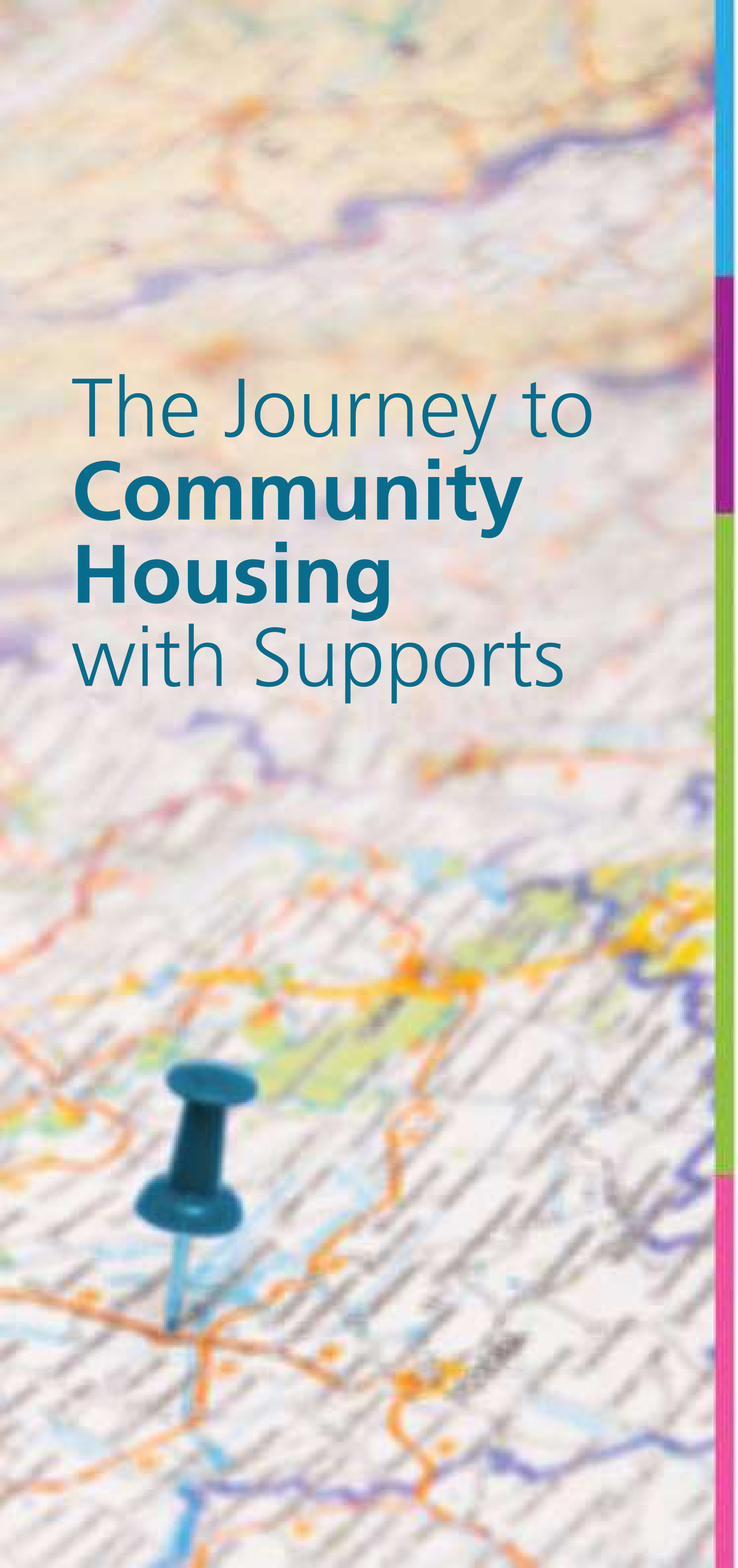
An individual who is interested in applying for an SHC housing voucher should talk with his/her Support Coordinator. The Support Coordinator will then take the following steps (referenced forms can be located at **www.nj.gov/humanservices/ddd/resources/community/**:

- The Support Coordinator will complete and submit the **Housing Voucher Eligibility Determination Form** to DDD
- If the request is approved, the Support Coordinator will be provided the **Tenant Information Form** and will be directed to complete and submit it to DDD within 5 business days
- Once Tenant Information Form is received by DDD, the individual will be referred to the **Supportive Housing Connection (SHC)**

Individuals approved for an SHC housing voucher will be contacted by a **DDD Housing Subsidy Specialist**, who will explain next steps in the process.

PLEASE NOTE: When an individual applies for and accepts an SHC housing voucher, it is important that he/she understand the rules and requirements, which are included in the DDD Housing Assistance Policy and the DDD Rental Subsidy Agreement, found here: **www.nj.gov/humanservices/ddd/resources/community/**.

For more information, please contact 732.968.4222 and ask to speak with someone in the DDD Housing Subsidy Unit.



The Journey to **Community Housing** with Supports

A Road Map for Individuals and Their Families in New Jersey

SHA
Supportive Housing Association
of New Jersey

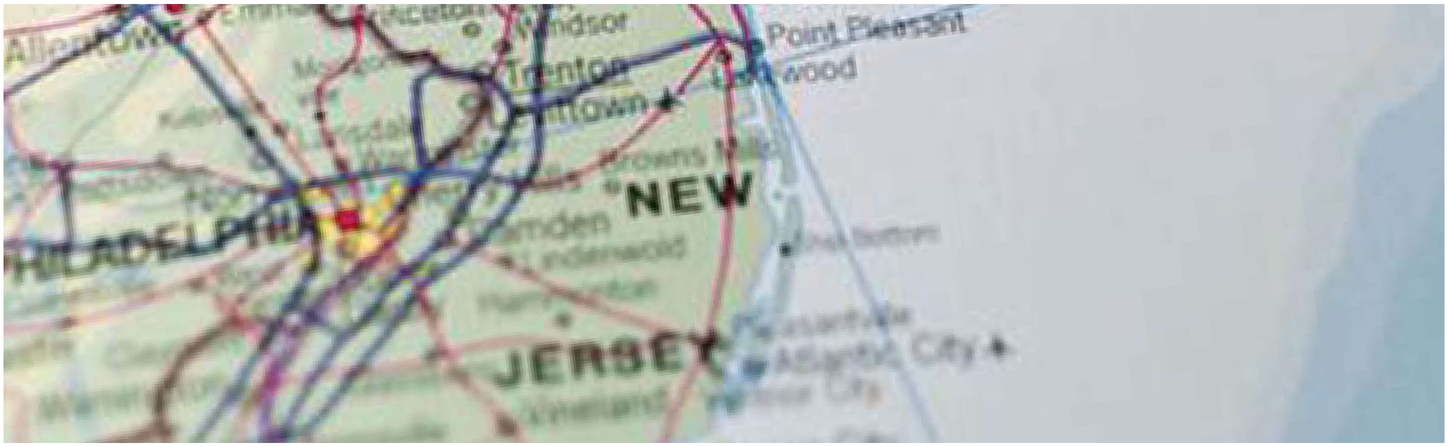
www.shanj.org

The Supportive Housing Association of New Jersey (SHA) is a statewide, nonprofit membership organization, founded in 1998, whose mission is to promote and maintain a strong supportive housing industry in New Jersey serving people with special needs. SHA engages in education, advocacy and networking for and on behalf of its over 100 members.

Autism™
NEW JERSEY
The Power of Connection

www.autismnj.org

Autism New Jersey is a nonprofit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families, and the professionals who support them. Through awareness, credible information, education, and public policy initiatives, Autism New Jersey leads the way to lifelong individualized services provided with skill and compassion. We recognize the autism community's many contributions to society and work to enhance their resilience, abilities and quality of life.



Dear Readers:

Welcome! This housing guide, entitled *The Journey to Community Housing with Support: A Road Map for Individuals and Their Families In New Jersey,* has been designed specifically for individuals with disabilities and their families, providing information, advice and guidance about community housing and supports. Funded by the New Jersey Council on Developmental Disabilities, it is written to inspire individuals with intellectual/developmental disabilities and their families about the possibilities. Navigating the many complex systems, each with detailed regulations, is challenging. This document can assist you or your loved one in finding your way. This guide recognizes the obstacles associated with securing housing and supports. There is a need for additional affordable housing units, rental subsidies, mainstream resources and funding for supportive services.

This housing guide should be read in keeping with its title, as a journey toward establishing a home that enables you or your loved one to live as independently as possible. Written for the layperson, the guide summarizes housing models through the experiences of individuals and families, providing suggestions for your unique housing needs. We must be candid: there are many barriers, and creative thinking, planning, perseverance and advocacy are required.

While much of the information is specific to New Jersey and individuals with developmental disabilities, housing with supportive services encompasses many common features. The funding streams, opportunities and obstacles described can benefit people with other special housing needs and those from other states. The content also has value for providers, public officials and advocates.

We are grateful to many people who contributed to the development of this important resource. The New Jersey Council on Developmental Disabilities recognized the need for this guide, offered critical input, and generously provided grant funding for its development and dissemination. Grant partner, Autism New Jersey, offered substantial conceptual and practical contributions to the text based on their publication entitled, *New Jersey Housing Resource Guide for Adults with Autism Spectrum Disorders* (2009) and their community's experiences to date. Many professionals and state officials provided their expertise, and we are grateful for their input. Deborah Wehrlen, consultant to this project, invested countless hours researching and writing this guide. She translated complex subject matter into understandable prose. Most importantly, we appreciate the individuals and their families who candidly shared their personal journeys so that others could benefit from their experiences.

As part of your journey I encourage you to familiarize yourself with the many SHA members - developers and supportive services providers - who offer community housing with supports. For more information visit www.shanj.org/members/members-directory.

On behalf of the Supportive Housing Association of NJ, I wish you a successful journey. This booklet will continue to evolve in its content and presentation; therefore, I encourage you to contact us with feedback, recommendations and additional ideas.

There is no place like home!

Gail Levinson

Gail Levinson Executive Director
Supportive Housing Association of NJ (SHA)

www.shanj.org

Acknowledgements

The Supportive Housing Association of New Jersey expresses its deepest gratitude to the New Jersey Council on Developmental Disabilities for the grant funding to develop *The Journey to Community Housing with Supports: A Road Map for Individuals and Their Families in New Jersey.*

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Please refer to online companion file for *The Journey to Community Housing with Supports: A Road Map for Individuals and Their Families in New Jersey* to easily access live links and additional resources. www.autismnj.org/Housing/SHAGuide

March 2016; First Edition • Supportive Housing Association of NJ • (SHA) 908.931.1131 • www.shanj.org

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Navigating the Systems

Systems of support for long-term care are changing. In the past, individuals' options were limited to placements in group homes or supervised apartments. While these residential settings continue to exist for those with more intensive support needs, options have and will continue to expand. Today, housing and services are being separated or "unbundled." Individuals, working with individual budgets, select providers and direct the services that they choose. Increasingly individuals with disabilities, by themselves or through their guardians, are controlling their own housing options and services and living in more community-integrated settings. This is called supportive housing.

There is a tremendous need for residential support as well as housing that is affordable. It is likely that funding for these expenses will come from multiple sources. Given the limitations of government resources, individuals with disabilities need to access mainstream resources that are available to anyone with low income in order to live within their budgets. These mainstream resources, described in the guide, include such things as rental subsidies, food stamps and utility assistance.

In most states, including New Jersey, there is no entitlement to residential services. States establish the number of people that they will serve based upon available state appropriations and available federal funding. Regulations define the means to access and maintain such benefits.

Supportive housing involves interconnected elements. There must be a readily available supply of affordable housing units. Funds, usually from several government sources, provide the individual with the supports necessary, based upon the person's level of need. The individual's personal income from social security and earnings pays for room and board, which may be supplemented by rental assistance or some form of housing subsidy.

Many housing models exist and some are described in this guide. Through person-centered planning, the person designs where and with whom he or she wants to live. Working within the scope of an individual budget, it may be a challenge to use the available dollars to cover all of the expenses. The person can select multiple providers or a single entity to address all of one's needs. For some, technological advances can supplement for assistance previously supplied by direct support personnel. Note: The authors did not vet the quality of service delivery in each of the models described. All individual names and some details about their lives have been altered to protect their privacy. The authors of this guide made every effort to accurately and completely describe appropriate residential arrangements and services for individuals with a broad range of abilities and needs. We have strived to capture this range in the examples of models and description of individuals in their homes. The intensity of staff support can vary within each model.

Multiple funding sources are also described. Each funding source has its own eligibility criteria and regulations. However, services in some models described may not be eligible for public funding, if determined by the state to be congregate in nature or at variance with state or federal regulations. The systems of funding are in transition and corresponding regulations are changing. To obtain the most current information, check the internet links provided.

With an understanding of these requirements and some "out of the box" thinking, you can develop an individualized plan to fit within the funding structure. We hope that you use this guide to find models and elements of these models that may be a match for you or your loved one. We welcome your feedback to improve future editions of this guide.

We hope that this guide will help individuals and their families as they navigate the road to supported living. Sometimes traveling to a new place can be scary as well as enjoyable. We hope this guide will help you and your loved one to find your way.

Note: This guide provides information best known at the time of publication. Much system change is in process and consequently regulations are changing. Refer to the websites for the most up-to-date information.

A Brief History of **Supportive Housing**

For almost 40 years, residential services provided in the community have been the preferred residential option rather than living within large institutional settings. The trends have increasingly supported smaller and more personalized settings while living as independently as possible with assistance. In 1999, the U.S. Supreme Court affirmed in the Olmstead v. L.C decision that as established in the Americans with Disabilities Act (ADA), people could not be required to live in institutional settings if a less restrictive alternative could meet their needs.

According to the University of Colorado's State of the States in Developmental Disabilities Project, New Jersey was one of six states in the country operating the largest number of state-run institutions (Braddock, 2013). The Research and Training Center of Community Living at the University of Minnesota has several publications that review the research studies regarding individuals with intellectual/developmental disabilities (I/DD) living meaningful lives in their communities. In New Jersey, educational efforts prepare individuals leaving institutional settings for community living by talking with peers who have successfully completed such transitions. New Jersey has made progress to increase opportunities to live in communities and reduce the number of people living in state-operated developmental centers and psychiatric hospitals.

This is a welcome trend from both quality of life and financial perspectives. A research brief on costs and outcomes of community services for individuals with intellectual and developmental disabilities revealed that the cost of institutional care far exceeds that of supplying similar supports within community settings (Stancliffe & Lakin, 2004). States typically spend significantly more money supporting institutions and community residences than they provide to family support services. Yet, most individuals receiving services live in their family home. Fortunately, a shift is underway across the country to provide families with more funding and the flexibility to utilize resources as they see fit. Individuals and their families, given more control through individual-directed services with individual budgets, are better satisfied with the services that they receive (Lakin et al., 2003).

THE IMPACT OF THE 1999 OLMSTEAD SUPREME COURT DECISION

In a landmark interpretation of the Americans with Disabilities Act (ADA), the Supreme Court decided that people with disabilities have a right to receive care in the most integrated setting. Unnecessary institutionalization violates the ADA. Every state is implementing plans to meet the mandates of this Olmstead decision. People living in developmental centers who choose to leave are transitioning into community placements.

A lawsuit settlement between Disability Rights New Jersey and the NJ Department of Human Services mandates that anyone who meets the Olmstead criteria (initially estimated to be 600 residents) must move from the state's (then) seven institutional facilities into integrated settings by 2017 to comply with the Supreme Court's decision. For more information visit www.nj.gov/humanservices/ddd/programs/olmstead/oipac.html. The Centers for Medicaid and Medicare Services (CMS) permit states to re-direct funding for institutional care to serve people in the most integrated settings in the community through the process of a "waiver." To date, the state has transitioned individuals from developmental centers each year into homes in the community thereby meeting the state's legal obligation. For more information visit www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/DRNJ%20v.%20Velez%20II%20-%20Settlement%20Agreement.pdf.

Housing Options with Innovative Elements

When asked about residential models, one progressive state official said, "We have 568 people and 568 models." This statement articulates the obvious fact that each person is unique. "No one size fits all." An individual's dreams are realized in various ways. The personally designed models depicted in this guide may or may not precisely meet someone else's needs. The purpose of describing these varied concepts in housing and supports is to inspire others to consider these ideas and redesign them to meet their own specific desires and circumstances. New Jersey is continuing on its journey to implement innovative models in housing and services.

Supportive Living Models

This guide provides an array of housing models and supports utilized by people with disabilities. Many of the models contain best practice elements of **supportive housing,** a philosophy that calls for permanent, affordable housing for people with disabilities in communities of their choice. **Supportive housing** advocates that everyone is entitled to a safe, decent place to live and should receive the services unique to their needs that will help them to live as independently and as self sufficiently as possible. Housing should promote the development of relationships among people with and without disabilities.

There should also be a separation between the provision of housing and services. People should be able to move and not lose their service provider. Similarly, someone should be able to change his or her service provider and not be required to move. The landlord should not also be someone's social worker. The individual has control of his/her housing through a landlord/tenant lease with the property owner. Skilled providers in various areas, including case management, care coordination, job coaching, crisis management, acquiring skills in daily living and much more, deliver these social services. The individual chooses the service provider to deliver supports flexibly and according to one's unique needs. Supportive housing operates in a variety of settings, in different constellations and may include apartments, houses, townhouses, condominiums, shared housing as well as (more rarely) home ownership. Some supportive housing exists in affordable housing projects that are integrated with non-disabled individuals and families.

Supportive housing is an approach to community living that is receiving much attention and implementation nationwide, including in New Jersey. Other housing models are also delineated in this guide as part of the continuum of housing options. These settings generally provide more congregate housing or housing intentionally created exclusively for people with disabilities. While these models are not considered supportive housing, they continue to be used by persons with disabilities, and are described herein.

Group homes serving more than four or six individuals and campus style housing that offers apartment/condos exclusively for individuals with disabilities may be considered institutional in nature and individuals may not be able to use their Medicaid budgets for services in these types of settings. For more information visit www.shanj.org/about/about-supportive-housing.

YOUR DESTINATION/ MANY ROADS CAN TAKE YOU THERE

The map key: terminology

Agency-directed services -
The individual selects an agency that is responsible for supplying residential or vocational programs, such as a group home placement.

Congregate housing refers to living situations where a group of unrelated individuals with disabilities live together, such as in a group home.

Integrated housing refers to the opportunity to live in typical mainstream settings with opportunities to interact with people who do not have disabilities.

Bundled and unbundled services refer to how services are delivered. With bundled services a package of supports are provided by one service provider usually through a program such as a group home. With unbundled services, a person obtains individually selected supports and services from one or more service providers. For example, one provider may supply individual supports while another agency delivers transportation. As systems are changing, most services will be unbundled and paid for through a fee for that service.

Support Coordination is a funded service that assists individuals in gaining access to needed program and state plan services, as well as needed medical, social, educational and other services. All individuals who are eligible and wish to access Division-funded services must either select or be assigned to a **Support Coordination Agency** (SCA).
For more information visit www.state.nj.us/humanservices/ddd/services/support_coordination.html.

INTEGRATED SUPPORTED HOUSING/REVERSE INTEGRATION

In this concept, the housing developer achieves integration by designating some of the rental units for people with disabilities and the majority of the units for those who do not have disabilities, or through reversing a congregate design by slowly integrating non-disabled households into the complex.

Hope House Foundation and Hope House Residential Corporation - Integrated Supported Housing

"Hope House Foundation provides supported living services to adults with intellectual or developmental disabilities exclusively in their own homes or apartments — regardless of how complex their disabilities may be." Hope House Foundation in Virginia converted all of their group homes and relocated everyone into apartments of their own. In some instances, individuals purchased condominiums or small homes of their own. Most tenants live in larger apartment complexes. Lynne Seagle, the executive director, believes that the 125 people that they support prefer living in their own place. "Having a roommate does not necessarily mean that a person is not lonely, especially if the person does not get to choose their roommate." The essential ingredient of this organization involves "community connectors" or unpaid folks socializing with individuals who have disabilities. The agency assists the person they are supporting to establish these relationships.

This organization found difficulty locating affordable housing in communities where people wanted to live. Not all property owners would accept rental assistance (vouchers). Hope House Foundation established Hope House Residential Corporation to develop housing and manage the properties. This corporation raises funds to purchase apartment complexes. They rent some of the apartments to tenants with disabilities but most of the people living there do not have special needs. This ensures that everyone with supported services lives integrated lives within typical communities. The rental incomes received exceed the property owner's expenses. These profits subsidize the living expenses of residents who need such assistance. Because the property owner and service provider are separate entities, the tenants can select a different service provider without having to move from their apartment. Conversely, they have the option to move to a different location and keep their supportive service provider. For more information visit www.hope-house.org.

After settling into his new home, Phil reports "For the first time in my life, I have friends."

Individual-Directed Supports Model: Mary's Home

Mary lives in an affordable apartment complex in a barrier-free apartment. In this particular public housing complex, the residents must be 55 years of age or older. Mary financially qualifies for residency with income from Social Security. With a State Rental Assistance Program (SRAP) voucher, Mary contributes 30% of her income and the voucher subsidizes the balance of her fair market rent. With the remainder of her Social Security check, Mary pays for her food, utilities, clothes and recreation. She also is eligible for food stamps and energy assistance benefits that help to stretch her limited income.

A Medicaid waiver funds her supported services that consist mostly of staff supports. With the assistance of a Support Coordinator, Mary selected a provider agency. She interviewed and chose the direct support professionals referred by the agency. These workers provide needed services including physical assistance with transferring from her wheelchair, bathing, dressing, cooking, housekeeping, shopping, budgeting, taking her medications and finding her way about town. Mary's staff supports her for several hours each day and are on-call in the event of an emergency.

Mary has her own one-bedroom apartment with a fully accessible bathroom, kitchen, dining area, and living room. She does not like to cook. She mostly uses the microwave. The local church delivers Meals on Wheels with a hot dinner, a sandwich and snacks each day. On Sunday mornings, Mary's neighbor drives her to church and then they go out for breakfast.

The county offers a transportation service to medical appointments, recreation and shopping. A van from the complex also supplies transportation to the local shopping plaza twice a week. She holds a membership and enjoys swimming at the YMCA swimming pool, when she has free time. Mary attends the community Senior Center for recreation during the day. Within the apartment building, there is a fitness center, computers, and laundry. Some of the neighbors started a social club and asked Mary to join. This social group convenes twice a week to play cards or games in the community room. They also plan outings to the movies, shows and community events.

When home alone, Mary wears a personal security system alert button. There is also an emergency call button in her bathroom. In the event of an emergency, Mary can access help quickly through these monitoring systems.

HOUSING SEPARATED FROM SUPPORTS

Ideally, a person receives supportive services from a provider agency and holds a lease from another entity. This concept ensures that the person can change where he lives but keep his service provider or conversely, can change his service provider but continue to live in his home.

FAIR MARKET RATE (FMR) is the published rental rate established by the U.S. Department of Housing and Urban Development (HUD) and used for determining the monthly rent charged in an affordable housing unit. For more information visit www.huduser.org/portal/datasets/fmr.html.

STATE RENTAL ASSISTANCE PROGRAM (SRAP) or federal **SECTION 8 HOUSING CHOICE VOUCHERS** are government-subsidized programs that provide rental assistance. Typically, tenants pay 30% of their income towards the cost of the Fair Market Rent and the voucher supplements the difference. An annual certification of income is required to verify that the person's annual income meets the threshold for rental assistance. People obtain vouchers that are used to pay their rent (tenant-based rental assistance) while other vouchers are attached to the apartment unit (called project-based vouchers). You can apply for rental assistance through local public housing authorities in towns, county or state offices. For more information visit www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/pha/contacts/nj.

According to the Supportive Housing Association of NJ data, in 2013 long wait lists exist because there are insufficient rental assistance vouchers available. In New Jersey, over 120,000 adults are recipients of SSI benefits for disabilities while only approximately 40,000 people of very low income with disabilities receive some type of federal or state housing assistance.

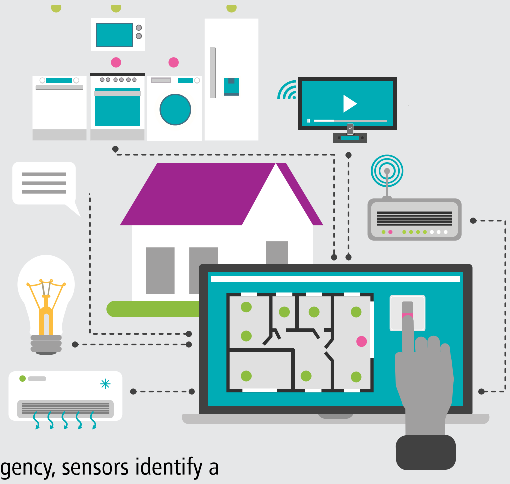
With **INDIVIDUAL-DIRECTED SUPPORTS,** a person exercises more control to manage and direct the supports that they receive. He or she chooses the desired services and who will provide them. A support coordinator assists in planning and securing services. People who self-direct assume more responsibility for independently managing these services. The individual selects one or more providers to serve their needs, based upon a plan and individual budget. Most often, the person has the ability to hire and discharge their direct support professionals. A fiscal intermediary manages the funds and may assume responsibility for paying salaries and administering benefits as the "employer of record."

In **SUPERVISED APARTMENTS,** an individual lives alone or with a roommate in an apartment with staff available to them on the premises for up to 24 hours a day.

Clustered Supervised Apartments within a Housing Complex Model: Gary's Home

With funds from the Low-Income Housing Tax Credit Program, a housing developer constructed 64 apartments. Within this building, four apartments adjoin with interior doors between the four living units. The state inspects and licenses each apartment as a community residence. Recently, Gary has been coping with medical issues related to his advancing age and cerebral palsy. His health is fragile and he needs staff present with him throughout the day and night. His individual budget from the waiver was not sufficient to fund all these staffing hours. Sharing the staff supports with his three friends has made this affordable. Gary loves having his own apartment with a kitchen, living room, bedroom and bath. When he feels like it, Gary socializes with his three housemates watching movies or cooking meals together. Direct support professionals are available during the day and one staff overnight. The staff move freely between the four apartments attending to each person as needed.

Gary enjoys all of the amenities of living within a garden apartment complex, including having friends and neighbors who do not have disabilities. By sharing the expenses with three other people, Gary can live more independently and afford the services that he requires.



SMART HOMES AND TECHNOLOGY

Depending upon the level of need, a person may prefer receiving services on demand in the event of a medical need or emergency. Remote monitoring can identify when staff intervention is needed. The resident can push a button to call for help. In the event of an emergency, sensors identify a problem so that staff can respond to the need. This technology can be programmed so that the person does not have to ask for help.

A person may have difficulties performing certain tasks. Many low to high technological devices are readily available to assist a person to live more independently. These assistive devices can overcome barriers that deter a person from living on their own. Simple apps on a smart phone possess unlimited possibilities for controlling the environment. Pre-programmed devices can automatically provide schedule information and prompts. Simple machines alert and dispense medications at designated intervals. If a dose is missed, these systems contact a designated person by telephone to follow up. Monitors signal an alert when someone falls, has a seizure, is in the bathroom too long or the front door opens. Emergency call buttons, computers or video cameras provide communication in the event of an urgent situation. Programs operate environmental controls such as lights or thermostats from computers or cell phones. Sensors detect when a stove is unattended and automatically shut it off. There are endless technological solutions that can be incorporated into a home to overcome barriers, reduce reliance upon personal aides, increase independence and keep people safe.

Many simple assistive devices are purchased inexpensively. Systems that are more complex may be costly. If medically necessary, some items are paid by medical insurance. Technology that promotes independence may be funded through the NJ Comprehensive Medicaid Waiver. Lending libraries exist so the person can test the equipment before purchasing.

The Faison Residence in Richmond, Virginia, is an inclusive community of 45 apartments with 30% of the units designated for those with special needs. Affiliated with The Faison Center for Excellence, the residence incorporated smart home technology into the construction to benefit all of the occupants. For more information visit www.faisonresidence.net. At the renter's request, remote monitoring by staff is available. Homelink Technologies consulted on the state of the art design.

Go to www.disabilities.temple.edu/tech or www.homelinktechnologies.com for sources for technological or adaptive devices that assist independence. The Assistive Technology Center in New Jersey has a lending library that can be accessed at www.assistivetechnologycenter.org.

Shared Living

SHARED LIVING means that a few unrelated people, with or without disabilities, share their resources to live in one home. This model works best when the person with special needs holds the lease and chooses who the housemates will be. Housemates might receive remuneration in exchange for providing supportive services. Often, long-term relationships develop among the people who share their home and their lives.

Agencies such as HomeSharing Inc. provide services to screen and match people interested in sharing responsibilities and expenses of a home. For more information visit www.HomeSharing.org. These matching services are available in some but not all counties in New Jersey. In this model, social workers reach out to home providers (home owners with extra room and a willingness to share common space in return for payment toward household expenses), and home seekers (persons of very low income who are in need of a place to live and cannot afford independent housing), to provide match making opportunities.

CIRCLES OF SUPPORT is a group of people chosen by an individual to help achieve valued outcomes. This group meets regularly and assists the person in making decisions and taking charge of his/her own life.

Shared Living Model: Dan’s Home

Dan enjoys structure and a consistent routine. Adjusting to change makes him uncomfortable. For many years, Dan lived in a group home with six other men with disabilities. Some of the behaviors of the other residents upset Dan. There were many disruptions including a continuous rotation of new staff members. Dan’s parents dreamed of a better life for Dan. They researched an alternative arrangement for Dan called “shared living.”

Dan and his family began meeting and planning with a Circle of Support which included his brother, family members and friends. They engaged a provider agency with experience in administering shared living to join the discussions. With the help of the agency, they found a compatible housemate. This person, Todd, receives hourly wages and a portion goes to his share of the rent for the home that he now shares with Dan. With his parents’ assistance, Dan leased an apartment with two bedrooms and two bathrooms for himself and Todd. Todd assists Dan weekdays from 3pm-7am. Dan typically sleeps through the night but Todd is there if he needs help. Dan and Todd share some finances to purchase groceries, utilities and such. Todd helps Dan with his spending and medications. Weekdays from 7am-3pm, another staff person supports him. She assists while Dan volunteers at the local food pantry, attends the gym and enjoys a busy social life.

Two other people spend alternating weekends with Dan and sleep over, so Todd has most weekends free. Before any of the staff began working with Dan, each spent significant time with him at his family home getting to know his daily routine, likes and dislikes.

Dan’s parents and sibling are very involved with Dan and his new lifestyle. Initially, they met as a Circle of Support every two weeks until everyone adjusted to the new living arrangements. Now meetings are once a month. Dan and his parents interviewed the potential housemate and staff to ensure that they were the right fit for Dan. The provider agency employs the staff but Dan hires and fires them.

Dan enjoys having four people who know him well caring for him. They understand his ways of communicating. They minimize disruptions and respond to changes in his moods. Dan’s preferences are important to them. Dan likes not having to compete with anyone for his staff’s attention. Dan keeps a lively social life that involves his housemates, family, and friends. They enjoy many activities together. Since Todd does not have family living close by, he spends holidays with Dan and his family. These two young men are becoming very close friends. It is hopeful that Todd will be a part of Dan’s life for many years to come.

Shared Living with Technological Supports Model: Lenora's Home

Lenora shares her condominium with two women who also are deaf. They assist Lenora to live as independently as possible despite her multiple disabilities and intensive support needs. Although not everyone with a disability prefers to live with others who do, Lenora enjoys sharing her home with housemates who can communicate with her in sign language. To accommodate hearing impairments, they installed additional equipment such as smoke alarms with flashing lights. Lenora's bed shakes if smoke triggers the alarm. The phone and television display the words being spoken.

Shared Living with Live-in Supports Model: Eve's Home

Eve sustained a traumatic brain injury as the result of an automobile accident. She lived for three years in a nursing home where she received therapy as well as total physical and nursing care. Her dream was to return to live in her own home. With determination, she worked through intensive physical, occupational and speech therapy to regain some of the abilities that she lost because of her head injury. A team helped Eve plan for the services needed to live in her own home and funded her transition through the I Choose Home NJ program. For more information visit www.ichoosehome.nj.gov.

Through this program and with Medicaid waiver funding, Eve could live more independently in the community. To accommodate her motorized wheelchair, adaptations were made including ramps and bathroom modifications. Because of memory deficits and physical disabilities, Eve could not live alone. Eve hired Olga to live with her. Olga attends to Eve's care needs and household responsibilities. Eve and Olga share companionship with each other and they have developed a close bond.

SHARED LIVING ALSO KNOWN AS HOME SHARING

As more people find managing the finances of home ownership a challenge, home sharing has gained popularity. Some homeowners have a spare room to rent. An owner may struggle to afford the costs of taxes and property maintenance. Others find it difficult to manage the responsibilities to upkeep a home. They may need assistance with household maintenance tasks. They may be looking for companionship. Those seeking home sharing opportunities may be looking for an affordable place to live and have much to offer as a housemate. Shared living matches these people and their needs.

Agencies exist to match seekers with home providers who are interested in sharing their home or apartment as well as the expenses and responsibilities. These agencies conduct screening and background checks of the occupants. For more information visit www.homesharing.org. On their own or with the assistance of an agency, the home sharers can sign formal agreements delineating the responsibilities of each party. A model contract for shared living is available at www.ancor.org/resources/best-practices.

Potentially, this housing option meets many needs through these matches. For example, a person with I/DD may lease an apartment and want to share expenses with someone who can assist with supports. An elderly homeowner might welcome an able-bodied person with I/DD to assist with household duties. There are endless possibilities. With the assistance of an agency, a more formal prescribed process facilitates this match. For more information visit www.nationalsharedhousing.org.

A Guide for Shared Living specifically for people with disabilities is available at: www.nasddds.org/publications/nasddds-titles-for-purchase/shared-living-guide.

Home Sharing Model: Tracy's Home

For seven years, Tracy has been living in her own home. She rents her house from her parents. Her mom and dad renovated a lovely ranch-style home just for her. Tracy's parents are responsible for maintenance, upkeep of the property, insurance and property taxes. Tracy's dad is a contractor so he knew how to handle all of the construction and repairs. The barrier-free design of the floor plan anticipated that Tracy was becoming less mobile and relying more upon using a wheelchair. Tracy lives in her hometown in the same neighborhood as her sisters and parents.

Prior to living in her own home, Tracy lived in a group home. Due to her increased medical care needs, her parents decided it would be best to purchase a home and have Tracy as the tenant. Her DDD support budget is now used to provide services to her in her own home. Her mom says, "All the stars and the planets were aligned for us." Mom's vision and determination were largely responsible for making this dream become a reality. Tracy's parents called upon key family members, a pro bono consultant, the executive director of the service provider agency, state workers and even the local senator for advice and support. It took two years of planning and negotiating, but their perseverance paid off.

Tracy, with her parents' assistance, selected a housemate to share this home. It took a few tries before the right match was made. For the past four years, her housemate, Stacy, has also been her best friend. They chose a service provider who had experience supporting people who wanted to make their own decisions. This agency provides the staff to help these two women live as independently as they can. Tracy and Stacy, along with their parents and the provider agency, discuss any matters that arise that directly affect the ongoing care and happiness of these women. These decisions are always made in the best interest of Tracy and Stacy. Tracy is a person of few words. However, she is very capable of communicating what she likes or dislikes without conversation. Her parents serve as her spokesperson.

Tracy's mom says that this model and the way in which it operates may not be for everyone. Tracy's parents and sisters are very involved in her life. They oversee the supportive services that she is receiving and advocate on her behalf whenever needed. They help with support. Tracy's dad has the building expertise to maintain the property. Not everyone can do this but some pieces of this type of self-determined housing may work for others just the same.

To ensure continuity, the family has made provisions for a succession plan. When Tracy's parents can no longer contribute their time and resources, Tracy's sisters have agreed to take charge. Legal documents have been prepared so that the home will continue to be a home for those with special housing needs, whenever Tracy no longer needs this home.

Support Families, Teaching Family Homes or Host Homes

A **SUPPORT FAMILY** is a family who is recruited, trained, monitored by a provider agency, and paid to supply long-term care in their home for a person with a disability. Sometimes extended family members provide a support family through kinship care. In other instances, people are recruited who are willing to integrate the person with a disability into their family.

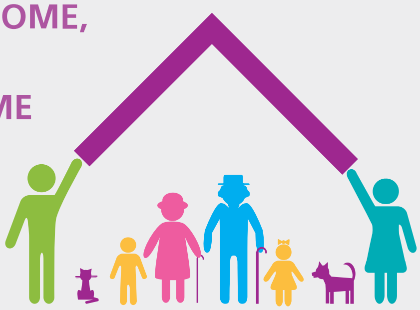
Distinguished from traditional foster care, a Support Family can share parental responsibilities with relatives. The person and their family interview and choose their Support Family. Most often, the person's relatives maintain a strong role in their family member's life. The concept promotes the development of a strong bond between the individual with a disability and the family they join. Support families tend to be long-term in duration.

The Support Family receives training, supervision, respite and assistance from a social services agency that supervises the services. The Mentor Network supplies professional staff in their teaching family homes. In some states like Texas, Support Homes can be funded by a Medicaid waiver to supply wrap-around supports to individuals with intensive medical and behavioral care needs. Pennsylvania calls this model Lifesharing. In New Hampshire, Enhanced Family Care is their most commonly used model. Literature supports that individuals with disabilities, particularly children, respond well in family rather than institutional care. Relatives, birth families and adoptive families can share responsibilities through this family-based alternative. For more information visit www.everychildtexas.org.

In New Jersey, a licensed

- **COMMUNITY CARE RESIDENCE,**
- **TEACHING FAMILY HOME,**
- **HOST HOME OR**
- **FOSTER FAMILY HOME**

is where an individual lives as part of the family of a caregiver who provides training and assistance for that person.



Support Family Model: Dennis' Home

Before her passing, Dennis' mom made plans with her best friend, Mary, to look after Dennis. Dennis knew Mary and her husband well for many years. He now lives within their home and shares in all family activities. He participates in all the extended family holidays and events. A special needs trust left by his mom supplies money to support Dennis while preserving his eligibility for SSI benefits, Medicaid and other public entitlements.

An agency provides supervision, training and support so that Mary can best care for Dennis.

> **"Build networks of support for yourself and your family member. You can learn so much from others. Many are willing to help if you invite them in."**

Group Homes

Group homes or community residences are small homes shared by residents who receive services from an agency that provides on-site staff 24 hours a day. A provider agency operates a licensed group home, typically serving four to six residents with disabilities.

Group Home Model for John

John loves the group home where he has lived for 10 years. Three other men in the home have become his friends. John likes the camaraderie. He also likes having peers with whom he can socialize. They share household responsibilities, take turns cooking, and enjoy eating several meals together each week. Sometimes they quarrel about things but most of the time John likes their companionship. When John prefers time to himself, his own bedroom offers the privacy that he wants. John has many interests. He bowls on a team each week with friends from work.

John grew up in the town where the group home is located. He stops by the local firehouse on Saturday mornings. He knows many neighbors and shopkeepers. John visits the library frequently to learn about local history. He is conversant about the U.S Presidents who summered at the Jersey shore. John's reading ability is limited so a library volunteer reads the reference books to him.

John has intensive support needs and requires assistance with everyday activities. For example, staff are available throughout the day and night to assist him with basic skills of daily living like toileting, bathing and dressing. Frequently, his medical needs become more acute. A nurse visits him on a daily basis. In extreme wintery weather or when ill, John's mobility is limited. In these instances, he particularly appreciates the staff support that he receives and enjoys the company of his housemates.

Intensive Specialized Group Homes

Individuals with significant medical, intellectual, behavioral or psychiatric needs may require intensive staff supports throughout their day. One model to meet these needs could be an intensive treatment group home with professional supports such as nursing, behavior analysis, counseling and therapies.

Intensive Specialized Group Home Model: Walter's Home

Walter lived in an apartment with supportive services. He was reclusive, angry and isolated. When support staff arrived, Walter demonstrated aggression towards them. He became aggressive by throwing rocks. Since the program was not equipped for these types of challenges, the staff would respond by leaving without an in-person visit. As a result of being left on his own and without the appropriate support structure, his life consisted of microwave foods and non-stop television. His inconsistent personal care created a serious health concern. He barely slept and paced the house throughout the night. He stopped taking his psychotropic medications and began to decompensate. His family felt helpless as a result of his disruptive behaviors. Because of this, they also were not able to visit him for several years. They located an agency that specialized in serving individuals with complex medical and behavioral challenges. Walter visited their group home and agreed to move there.

The agency prepared for Walter's needs by providing structure and consistency. The agency developed a program with additional clinical support to assist with his transition. They anticipated this to be an extremely challenging transition, since Walter was not accustomed to having this type of structure in his daily routine. Walter adjusted quickly and responded well beyond anyone's expectations. The successful transition led to a very quick, but systematic fading of the enhanced supports and allowing him to generalize into the existing program. With healthy meals and meaningful vocational and recreational activities, Walter felt better. His sleep patterns returned to normal. Walter became close friends with one of his housemates. They both enjoy NBA basketball and attend some of the 76er's home games.

The agency operates three homes serving individuals with similar support needs. They cluster their homes within a five-mile radius so that supportive medical, clinical and supervisory personnel can be shared among the residents. Utilizing Applied Behavior Analysis (ABA), all staff receive extensive training on the principles and practices of ethical and effective behavior support. To figure out why Walter acted this way, staff carefully defined and recorded the frequency, intensity, and duration of his challenging behavior as well as what occurred right before and after the behavior under the direct supervision of a Board Certified Behavior Analyst (BCBA). Then the team generated hypothesis statements regarding the purposes the behavior served for Walter and the likelihood of the behavior occurring or not occurring during various situations. These hypotheses served as the basis of the behavior intervention plan that outlined skills to teach Walter how to meet his own needs and get along with others in more adaptive ways. Staff were trained on the plan's implementation and consistently followed it to prevent and minimize challenging behaviors. Staff's adherence to the behavior plan kept everyone safe and taught Walter more adaptive behavior.

As the behavior program proved to be effective, the agency nurse communicated with his physician to review and adjust his medications with the goal of reducing them as much as possible. A medical practitioner and a psychiatrist consulted with a team of professionals regarding a comprehensive treatment plan maximizing the effectiveness of the behavior program while minimizing the use of medications that could result in more long-term detrimental effects.

Technology in a home permits the clinical staff to observe the person as they interact with staff and residents. When a resident engages in a challenging behavior, the behavior analyst can support the individual and staff during the incident through a remote monitoring system from any location, while not providing undue attention to the episode.

Walter continued to make progress as a result of ongoing behavioral assessment and the use of technology during transitions. Previously, staff noted Walter engaged in aggressive behavior during changes in his routine, especially when they intervened. Following direct observation, the behavior analysts taught the staff how to use antecedent-based interventions such as structuring Walter's daily activities, teaching him how to handle transitions appropriately, and teaching him how to use a watch to signal upcoming changes. These interventions have drastically reduced his aggression and increased his independence in maintaining his own schedule. Walter is eating healthy meals and participating in his daily hygiene routines. He has more opportunities for recreation and socializing with family and friends.

To learn more about Applied Behavior Analysis as a treatment visit www.autismnj.org or www.asatonline.org.

“Housing First” Concept

The supportive housing movement had its roots in addressing the needs of the seriously mentally ill, chronically homeless population by recognizing lease-based housing and supportive services as separate but of equal importance. A person’s basic needs must be met so that someone living in vulnerable circumstances can find stability while living in the community. The Housing First model was adopted pertaining to those who are chronically homeless. Implementation of the concept provides permanent housing as quickly as possible, rather than requiring individuals to successfully advance through various levels of care.

The continuation in housing is not contingent upon participation in rehabilitation. Service providers offer but do not require enrollment in services to assist the person. Because those living without housing for many years have multiple challenges, they are often afraid of commitment and difficult to engage. The model does not restrict eligibility due to behavior challenges and allows individuals to move into housing regardless of active addictions and other behavioral impediments. Slowly over time, with the stability in their housing, these individuals are enrolled in a variety of behavioral and health care services that are rehabilitative and promote wellness.

Data compiled over the years has demonstrated the success of Housing First in various communities. Not only have a majority of chronically homeless adults become stable in their housing, states employing this model have saved significant public dollars formerly spent on emergency care, institutionalization, homeless shelters and prisons.

FOR ADDITIONAL INFORMATION ABOUT HOUSING FIRST GO TO

www.endhomelessness.org/pages/housing_first

www.csh.org/toolkit/supportive-housing-quality-toolkit/housing-and-property-management/housing-first-model

www.endhomelessness.org/blog/entry/data-points-housing-first-decreases-re-offending-among-homeless-individuals#.VQTLmmTF90w

“Housing First” Model: Doug’s Home

Doug suffers with post-traumatic stress disorder and dulls his pain through alcohol. Over the years, he has frequently been homeless. A mental health agency reached out to Doug and connected him to much needed services. With a housing voucher, Doug now can afford to rent a small apartment. He attends a medical clinic for health care. Food stamps and the local food pantry supply him with groceries. Members of the local church provide warm clothes and household necessities. He formed a deep attachment to a rescued dog that now shares his apartment. They look after each other. Doug still has a dependence upon alcohol. He finds comfort, however, that he will not be evicted from his home because of his lack of sobriety. Having a stable home is a big first step toward recovery for Doug.

Supportive Housing Model

Supportive Housing Model: Cynthia's Home

Cynthia spent many years in unstable living circumstances and high cost treatment centers including the state psychiatric hospital and shelter services. She has been homeless and lived with her parents intermittently during difficult times. Cynthia was diagnosed with serious mental illness and addictions since her late twenties. Due to her illness, Cynthia spent years in unstable housing and lived on the streets.

Cynthia received a rental voucher from the Department of Human Services and promptly leased a one-bedroom apartment. She has resided there since 2008. Once her housing situation became stable, Cynthia discovered her talent and passion for art. She supplements her income modestly as an artist. Her income consists primarily of SSI benefits. Cynthia pays 30% of her income towards her rent and the voucher subsidizes the balance of the fair market rent.

Cynthia attends Alcoholics Anonymous meetings to keep sober and avoid drugs. She has reestablished her relationship with her mom and stepdad, who provide ongoing emotional support and guidance. She maintains contact with a therapist and utilizes services in the mental health system. Although she continues to experience symptoms of mental illness, her stable housing, participation in therapeutic mental health services and strong natural support system have assisted Cynthia to lead a happy life.

BOARD AND CARE HOMES OR SINGLE ROOM OCCUPANCY LIVING ARRANGEMENTS are licensed in New Jersey by the Department of Community Affairs. A facility rents individual rooms and supplies three meals per day. Some facilities, Residential Healthcare Facilities, provide additional supportive services and physical care. For more information visit www.nj.gov/dca/divisions/codes/offices/roomingboarding.html.

While concern has been expressed by the substandard conditions in many rooming (room only, no meals provided) and boarding homes, families and individuals can research homes that are smaller and provide a nurturing environment. The Montclair Inn, for example, is a 21 bedroom boarding home with common space for tenants, owned and operated by a non-profit organization. The home is located within walking distance of the local town with access to transportation, shopping, jobs and socialization. Seniors and some individuals with disabilities live in the home. For more information visit www.themontclairinn.org.

COLLEGE CAMPUS - LIVING IN THE DORMS

Some young adults with intellectual and developmental disabilities, mental illness and other special needs are attending colleges and living on campus. According to research studies, adults with intellectual disabilities have the lowest rate of post-secondary education, career preparation and employment of all other disability groups (Newman et al., 2011). Opportunities exist for people with disabilities, including those with intellectual disabilities, to attend flexible college programs with supports. Peer mentors are available to assist students in their adjustment to college life. Readily available apps on smart phones and tablets help a student to record lectures, dictate essays, take notes, complete assignments and organize coursework. Colleges offer classes for credit and not-for-credit. Numerous colleges provide on-campus living experiences as well. Besides the educational benefits, the value of a college experience includes preparation for employment, inclusion with peers, and independent living experiences. Only 23% of students with I/DD, however, go on to post-secondary education (Grigal, Hart, & Migliore, 2011).

Most programs educate students between the ages of 18 and 25 during or after their graduation from high school. Fees for these educational studies vary. Students can apply for scholarships, grants and work/study. In some instances, tuition can be waived for students of low-income. Funding for supports, including transportation, books, technology and individual supports, might be supplied through Medicaid waiver services. In some instances, the Division of Vocational Rehabilitation may fund a college education. Similarly, a school district might approve post-secondary education through a teenager's educational entitlement. For more information visit www.thinkcollege.net.

College Campus Experience for Nicky

Nicky walked with her high school class for graduation but continued her educational entitlement in the local college. She lived on campus, learned, and adjusted to college life with supports. She made friends and enjoyed all the social and academic aspects of attending college. A fellow college student served as a mentor. Tutors helped with academics. She took courses in public speaking, drama, writing and math. In a drama class, Nicky role-played and learned how to interact in various interpersonal situations. Nicky used her smart phone to record classes so she could listen to them later and have someone assist her in taking notes. Tutoring was also available when course work was difficult. She dictated into her computer to write essays. Nicky enjoyed the experience of living away from home while attending classes in college.

Living with Family and Receiving In-Home Supports

Living with Family and Receiving In-Home Supports means that a person with a disability receives supportive services delivered within his or her own home while living with family members. Services can include such things as personal care assistance, respite, positive behavioral supports, crisis intervention and tutoring.

Living with Family and In-Home Supports Model: Adam and Dave's Home

Adam and Dave are brothers who live with their parents. With diagnoses on the autism spectrum, these young men are unable to verbalize their preferences. Adam responds to pain by inflicting injury to himself. Dave cries uncontrollably but cannot vocalize what makes him sad. Often, they are unable to find relief from frustrations without others intervening on their behalf. Because of the difficulties that they experience, their parents believe that the best life for their two children is to continue living within the family home. Judging by their demeanors, it appears that Adam and Dave are very happy with their lives, as well.

There have been many challenging events over the years. Dave seeks harmony by his own definition. With a keen sense of hearing, certain words or loud noises provoke Dave. If a situation occurs, Dave wants to resolve it expeditiously. In such instances, Dave paces and shows agitation. If unchecked, he can be aggressive toward other people. He just wants them to stop the behavior that he finds disruptive. Failure to sustain this structured environment quickly disintegrates into a commotion that can escalate into a crisis. Following a traumatic event, both Adam and Dave regress from the progress that they have achieved.

At six feet tall, Adam does not comprehend his own strength. He likes his routine and hates interruptions of his favorite activities. Adam experiences grand mal seizures that can be life threatening. Adam cannot communicate where he feels pain. When in discomfort, Adam injures himself. Adam required hospitalization for several months when his self-injurious behavior threatened his own health and safety. Understanding what Adam communicates through his actions is a key to keeping him safe.

Adam and Dave's parents have wondered, at times, how long they can continue to care for their sons in their family home. Their children do well at home with a structured routine and a consistent approach to their behavioral challenges. They utilize funding from the Community Care Waiver to pay for in-home staff support and therapeutic services. Five staff people supply eight hours of support every day for each of the brothers. Adam has some significant medical conditions and qualifies for additional personal care assistance through the Personal Preference Program (PPP), a state plan service (see page 31.) All caregivers are chosen for their compatibility with Adam and Dave. Being close in age to their staff companions, they share common interests. Dave and Adam have grown to trust these new people in their lives.

Their parents and caregivers receive intensive training in positive behavioral supports. A Board Certified Behavior Analyst (BCBA) developed individualized behavioral support plans for each brother. After careful observation, the plans identify the antecedents that trigger maladaptive behaviors, the target behavior and the consequences that reinforce these behaviors. These plans describe how their caregivers can minimize the likelihood of the target behavior occurring and how to respond instead of react should the target behavior occur. As often as possible, their parents and caregivers write down how often and under what conditions the target behavior occurs. Then, the BCBA continuously analyzes the data and updates the plans to increase their effectiveness. The implementation of these systematic and dynamic plans minimizes dangerous behavior and helps Adam and Dave maintain existing skills while learning new appropriate skills.

Staff must be very attentive. When Dave encounters someone who does not understand his ways, it can trigger an aggressive response. Caregivers must immediately respond by diverting Dave's attention and using a calming phrase to prevent an altercation. When needed, staff members know how to de-escalate the situation as well as utilize crisis intervention measures.

With the success of these methods, Dave enjoys daily outings in the local neighborhood. With his support worker, he goes each day to the gym to exercise. They shop for groceries and his companion assists him in preparing his own meal daily. Dave goes to the park, the library, the petting zoo, and local events. He loves dining out once a week. Dave works a few hours at a local business to complete clerical tasks by stuffing envelopes and making copies. He also volunteers at the animal shelter. Dave leads a very active life within his community.

Adam loves technology. He plays video games, listens to music and uses a computer tablet proficiently. Being more introverted, Adam struggles to stop using his electronics and engage in integrated activities. His worker uses effective strategies that promote Adam's cooperation when he needs to change his routine. He has a well-prepared plan that identifies the triggers and the interventions to promote Adam's continued safety. For instance, staff makes certain that Adam's hands are busy at all times. When he is holding something, he is less likely to bite his hands. Adam likes to walk through his neighborhood while listening to music. He visits the park and enjoys the activities that it offers.

Their home has many safeguards designed for their protection. Adam and Dave do not recognize danger or know how to respond. Since Dave only sleeps about 4 to 6 hours per night, the family has devices on their exterior doors to alert his parents when he leaves the house. The experience of glass breaking intrigues Dave. Consequently, nothing in the house is made of glass. Even the windows contain plexi-glass. Adam elopes and attempts to jump out of the car while it is running. The car is equipped with childproof locks, and Adam is transported with two people in the car to ensure that he remains in his seat while the car is in motion.

Living within their family home with supports, Adam and Dave have achieved a high quality of life with fewer disruptions. Their family attributes this success to the great stability accomplished by only a few well-trained people giving support. They have the security of living with their loving parents in the comfort of their family home. For as long as they are able and their children continue to thrive, their parents have made a commitment to keep their sons at home with them.

Accessory Apartments and Tiny House Movement

ACCESSORY APARTMENTS are living units that are added or created within a single-family home. Sometimes called a "mother/daughter home," relatives live in close proximity yet have their own private space.

Available in some states, **ELDER COTTAGE HOUSING OPPORTUNITIES (ECHO)** units are small modular cottages. These accessory units can be installed adjacent to a caregiver's house for people who are elderly or have disabilities. This type of housing is best located on larger parcels of land and may require local zoning approvals.

Accessory Apartment Model: William's Home

William lived with his parents but wanted more freedom. His family converted their two-car garage into an efficiency apartment with a barrier-free bathroom for him. He obtains 30 hours per week of personal care attendant services from a state plan service called the Personal Preference Program to assist him with some activities of daily living like dressing and bathing. During the daytime hours, he has day habilitation services from DDD. His family is steps away from him, if he needs additional help, especially during the overnight hours. On overnights and weekends, family and friends provide him with support.

TINY HOUSE MOVEMENT

The concept of tiny houses is growing nationally and internationally. As shown on HGTV and A&E Network's Tiny House Nation, people interested in a simpler lifestyle without financial burdens are downsizing. Small communities are being established internationally. For more information visit www.smallhousesociety.net.

Such compact housing can be developed more cost effectively than traditional housing. The living space of 100 to 300 square feet is comparable to the size of a shed up to a single car garage. It can be built on wheels for portability. Similarly, small houses are between 400 and 1700 square feet.

In some instances, shipping containers have been re-purposed into small housing units. The durable material of these containers lends themselves to modular construction. These units interlock so more than one container can be connected into a larger living space. The internet supplies many creative interior and exterior designs for this cost effective re-purposing. For more information visit www.homedsgn.com/2014/04/14/22-modern-shipping-container-homes-around-the-world. This micro house idea is applicable for someone seeking inexpensive housing.

Numerous floor plan designs are readily available on the internet. Construction is efficient and sustainable while being attentive to the environment by using natural, health conscious materials. Some units are self-sufficient using propane gas and holding tanks. Optional solar roof panels provide low cost energy. Local utilities' hookup connections can also be made when available.

Zoning ordinances may not specifically apply to small house dwellings and will have to be addressed on a local level.

International and American Intentional Community Models

Intentional Communities are founded upon shared values.
People with disabilities live together with families or caregivers
in homes, campuses or villages in a community setting.

L'Arche Model

Jean Vanier founded the L'Arche Movement in Paris as an alternative to institutions by inviting two people with intellectual disabilities to live in his home in 1964. Today, there is an international federation of over 140 communities in 40 countries subscribing to common values. These faith-based communities adhere to the same founding principle that everyone has equal value. Communal life involves sharing experiences within a "stable, life-giving home environment." Members within L'Arche homes include people with and without disabilities who develop long-term mutually interdependent relationships. Everyone contributes to the home by sharing responsibilities. This worldwide movement received the 2014 Notre Dame Award for International Human Development and Solidarity. For more information visit www.larcheusa.org.

Camphill Village Model

Camphill Village was established more than 50 years ago in Europe based upon the insights of anthroposophy, the spiritual scientific understanding of human beings. Family homes include individuals with developmental disabilities and co-workers who "eat, pray, sing, work, and celebrate together." Co-workers receive no salary demonstrating that everyone exists on an equal plane. All community members care for each other and the earth. Work involves artistic endeavors, farming and crafts as well as household responsibilities. Since 1961, Camphill Village has operated more than eleven communities within the United States and Canada. For more information visit www.camphillvillage.org. Recently, Camphill established a similar assisted living concept for elder care.

Note: As of this writing, the New Jersey Department of Human Services will not permit individuals to use Medicaid Home and Community- Based Services (HCBS) Waiver funding while living in congregate settings such as intentional communities, farmsteads or gated communities.

Community Cooperatives

Community Cooperatives include people living and working together in a community setting such as a farm or ranch.

Community Cooperatives Model: Phil's Home

Phil loves nature and the outdoors. He lives on a seven-acre farm. Students from the local community college, as well as five other young adults with abilities similar to Phil, live together. They all share responsibilities within the home such as cooking and cleaning and supporting one another. People without disabilities live in the huge farmhouse, as well.

Collectively, they cultivate a large organic garden and raise chickens and goats. They eat healthy whole foods from their crops. With hard work and fresh air, they sleep well at night. When not farming, they create soap from the goat's milk. Birdhouses and picture frames are constructed from repurposed wood. Some people enjoy weaving and make beautiful scarves. On weekends, they sell these products at the local farmer's market. The income generated from the sales helps Phil to pay his living expenses.

The farmhouse is a place of much activity. A local instructor teaches yoga classes. A masseuse provides free massages once a week. On Sunday afternoons, the residents host "high tea" for anyone from the community. They serve an elegant tea with finger sandwiches to the guests in their formal living room. Donations help to offset household expenses.

Interacting with strangers is sometimes difficult for Phil. These public events supply opportunities to become more comfortable in social settings. People are available to Phil when he is faced with a challenge. If it is not a good day for Phil, his housemates can help him through it or cover his responsibilities when necessary.

Phil leads an active social life. He attends classes at the local community college and participates in campus activities. Each week, he volunteers at a local restaurant where everyone pays for their food based upon what they can afford. High school seniors come over to the farmhouse on Friday evenings for pizza, ping-pong and camaraderie.

Phil's mom obtained grants to purchase, renovate and establish housing on the farm. Rent is charged and paid from each person's Social Security income. Phil chooses to work on the farm and earns additional income.

> **"Someone can get lonely even with many people around them. They need to develop real friendships and become active members of their community."**

Secure Communities

The term Gated or Secure Communities could be used to describe large complexes with security features designed exclusively for people with disabilities. For example, one project describes itself as a "Unique Residential Lifestyle" featuring 97 affordable "apartment-style" rentals only for individuals with developmental disabilities. The complex offers one or two-bedroom accessible units with amenities such as a swimming pool and community center. Security features include on-call emergency assistance, community security cameras and on site security patrols.

In one such community, some tenants obtain rental assistance vouchers that subsidize the rent of $550 per month. A projected budget of $1,200 per month includes rent, utilities, food, clothing and personal spending money. The tenant can purchase supportive services including live-in staff, personal assistance, emergency support, employment and recreational services.
For more information visit www.arcjacksonville.org/village-on-hodges-planned-community.

While there may be cost efficiencies in larger settings, the Centers for Medicaid and Medicare Services resist approval of funding for group living if it secludes tenants with disabilities. When considering a congregate model, opportunities for the integration of people into the non-disabled community must be incorporated into the design.

Funding **Sources**

Medicaid's Home and Community Based Services (HCBS) Waivers

The **Medicaid HCBS Waivers** pay for services and supports necessary for eligible individuals with I/DD to live in the community and avoid institutional care. State appropriations, supplemented with federal Medicaid dollars, fund these waivers.

The federal government's Centers for Medicare and Medicaid Services (CMS) permit each state to create waivers that fund specific services. In New Jersey for instance, a Community Care Waiver (CCW) could pay for individual supports and supported employment/day habilitation as well as other services. Sometimes these are provided in a program like a group home or an adult day program. For others, an individual may select specific services and contract with providers to receive them.

In New Jersey's CCW as well as the Supports Program through the NJ Comprehensive Medicaid Waiver, individuals must be eligible for DDD services, be assessed to need a certain level of care as well as secure and maintain Medicaid eligibility.

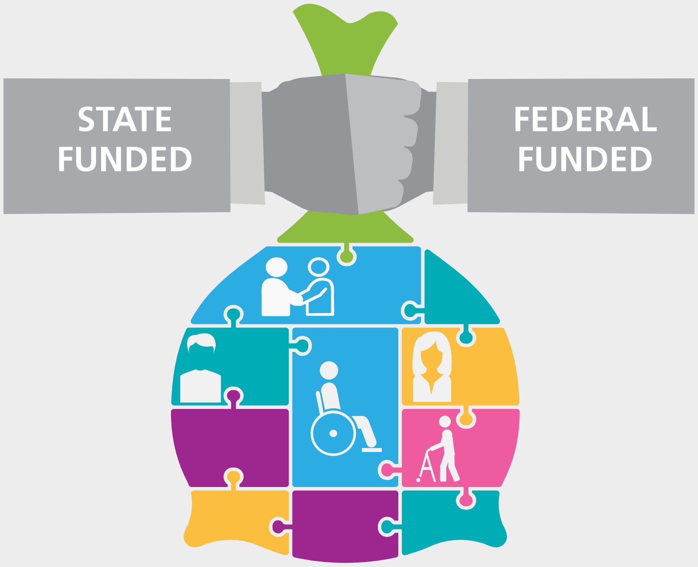
For example persons, eligible for the CCW in New Jersey live with significant intellectual and developmental disabilities as determined by functional assessments and meet the need for an institutional level of care. Individuals not receiving the CCW but eligible for DDD services may be provided a budget that can be used to purchase individualized supportive services as well as day habilitation/employment services. This Supports Program is not intended to fund extensive support needs.

Governmental agencies administer services appropriated by the state. In addition, state dollars combined with federal Medicaid funding supply supports and services through Home and Community Based Services (HCBS) Waivers.

For more information on
ACCESSING SERVICES,
see the flow chart on page 32.

Each waiver has specific eligibility requirements for the finite number of beneficiaries to be served with the state's appropriated funding. Some waivers are available for pre-determined, renewable periods while others are ongoing in their duration. The intent of a waiver is to prevent the need for placement in an institutional setting or support a person who is re-entering the community after a period of institutionalization. Medicaid regulations require that a person can be enrolled in only one waiver program. Someone may, however, be enrolled in one waiver while on a waiting list for another.

> **"It is so essential that your family member maintains eligibility for their Social Security and Medicaid benefits if they want to obtain state funded services."**



MEDICAID IS A SOCIAL HEALTH CARE PROGRAM FOR FAMILIES AND INDIVIDUALS WITH LOW INCOME AND LIMITED RESOURCES.

It is jointly funded by the state and federal governments and managed by the states. Medicaid is a key entitlement that will provide both physical health care and supports to people of low income living with disabilities, including I/DD. Eligibility for Medicaid can be obtained through several doors. Perhaps most common is through Social Security's Supplemental Security Income (SSI) program, which provides cash and Medicaid benefits to eligible seniors and people with disabilities. Community Medicaid and the Disabled Adult Child Social Security benefit (DAC) also provide Medicaid options.

For more information on Social Security go to www.ssa.gov. Medicaid also funds state plan benefits and long-term care.

The Centers for Medicaid and Medicare Services (CMS) issued an information bulletin (June 2015) regarding Coverage of Housing-Related Activities and Services for Individuals with Disabilities. While Medicaid cannot be used to fund rent or utilities, the bulletin does describe some flexible options including one-time only needs such as security deposits and furniture purchase as well as transition services to assist individuals with housing stability.
For more information visit www.medicaid.gov/federal-policy-guidance/downloads/CIB-06-26-2015.pdf.

The New Jersey Department of Human Services

NJ Department of Human Services (DHS)
Division of Developmental Disabilities (DDD)

WHAT IS THE NJ DIVISION OF DEVELOPMENTAL DISABILITIES (DDD)?

The Division of Developmental Disabilities (DDD), within the NJ Department of Human Services, is a leading provider of community services for individuals with intellectual/developmental disabilities (I/DD). DDD funds all residential services and supports for adults with intellectual and developmental disabilities (I/DD) within New Jersey through Medicaid funded services. The majority of those served by DDD live at home with their families, may receive supports in their own homes or in unlicensed settings, and may receive supportive services including day habilitation or employment. A smaller number of individuals receive funding to live within licensed community residences, independent and supportive living apartments.

There are limited community-based residential supports for eligible individuals in emergent need of housing or incapable of living with family. The law requires that DDD services be designed to maximize developmental potential and shall be provided in a manner which is least restrictive of each person’s personal liberty (N.J.S.A. 30:6D-9). DDD can assign people to waiting lists for the waiver when services are not immediately available.

For Medicaid and DDD eligible recipients who have been assessed to be in need, DDD has regulations to serve a person more quickly in an emergency. Service options depend upon the available resources. It is important that individuals have an understanding of DDD’s most current regulations particularly those related to an emergency. For more information, go to www.nj.gov/humanservices/ddd/news/publications/divisioncirculars.html.

Circumstances may change where individuals urgently need residential services before reaching the top of the Community Care Waiver waiting list. If an emergency exists, it is up to the family to bring the situation to the attention of DDD. This state agency will determine, if an individual’s circumstances meet their criteria of an emergency. If it does, the person will be moved to the top of the list to receive services. If there is disagreement about whether an emergency exists, whether services offered meets the emergency standard, or whether the long-term supports are adequate, the consumer can appeal DDD’s determination.

Parents often ask, “What happens when I can no longer care for my adult child?”

WHO IS ELIGIBLE TO APPLY FOR DDD SERVICES?

Adults age 21 and older can be eligible to receive services under DDD when they meet the functional criteria of developmental disabilities, are legal residents of the US and NJ, and are eligible for Medicaid. The definition of I/DD is as follows:

- Diagnosis of a physical or mental impairment including but not limited to autism, intellectual disability, cerebral palsy, epilepsy, spina bifida or neurological impairment;
- A severe and chronic disability must manifest before the person reached age 22 and is expected to be lifelong; and
- Difficulties in at least three areas of life activities including self-care, learning, mobility, decision-making, and communication including receptive and expressive language, economic self-sufficiency, and independent living.

SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a federal program that provides monthly cash payments to eligible children and adults in need. In New Jersey, individuals who are determined eligible for SSI are also eligible for Medicaid.

IF MEDICAID IS REQUIRED TO OBTAIN SERVICES, HOW DOES SOMEONE APPLY FOR THESE BENEFITS?

To receive Medicaid funded waiver services, a person must be eligible and maintain eligibility for Medicaid benefits. There are four common ways for a person with a disability to obtain Medicaid. The most common is through receiving Supplemental Security Income or SSI, which includes Medicaid benefits. The other three ways are 1) Disabled Adult Child (DAC) Status, 2) Community Medicaid, and 3) New Jersey Workability.

For more information about applying for Social Security and Medicaid, go to www.state.nj.us/humanservices/ddd/services/medicaideligibility.html.

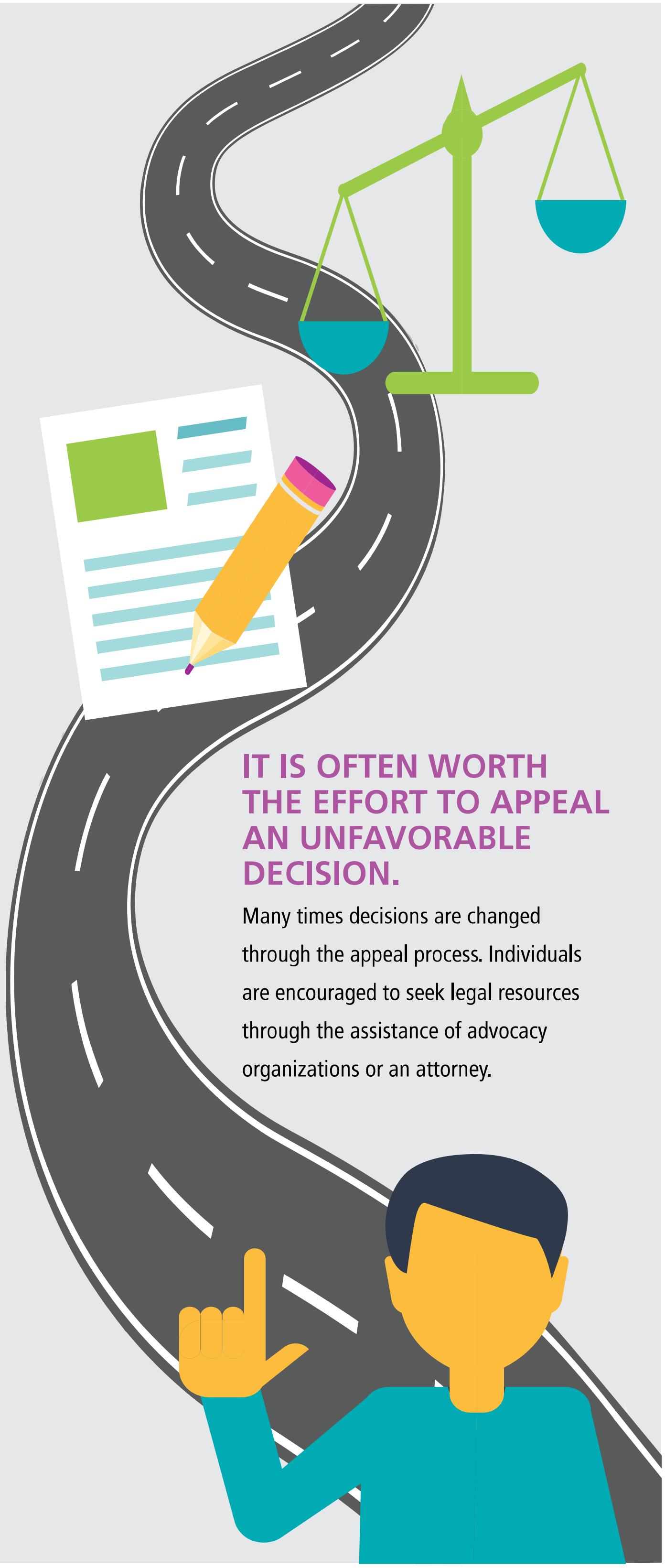
HOW DOES SOMEONE APPLY FOR DDD ELIGIBILITY?

To begin the process, a person can file an application for services at the local DDD office. For the DDD Intake Package Application go to www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/Intake%20Package%201-30-14.pdf.

An intake worker will interview the person and his/her family and gather the information needed to determine eligibility for DDD services. Necessary documentation includes information about the person's functional abilities, Social Security card, Medicaid eligibility and diagnosis of a disability. In addition, DDD will request written permission to obtain school records, psychological test reports and medical records that assist in determining eligibility. Once all of the necessary information is assembled, DDD will review and send a decision in writing about eligibility. Receiving services depends upon the availability of waiver funding and is not an entitlement. If denied eligibility, the decision can be appealed.

WHAT IS THE PROCESS TO APPEAL A DECISION, IF DENIED ELIGIBILITY?

In most instances, when a government agency makes a decision to deny a service, the person affected is entitled to appeal the denial of that decision. The notice of denial should include information about how to file an appeal. In DDD, the person will have the opportunity to attempt to resolve the dispute at a settlement conference. If the settlement conference is unsuccessful, the appeal will be referred to the Office of Administrative Law for a hearing before a judge.



IT IS OFTEN WORTH THE EFFORT TO APPEAL AN UNFAVORABLE DECISION.

Many times decisions are changed through the appeal process. Individuals are encouraged to seek legal resources through the assistance of advocacy organizations or an attorney.

What services can be funded through Medicaid waivers?

A wide variety of services and supports can be funded through a Medicaid waiver through hiring of staff from approved provider agencies or self-hires (self directed employees). Each waiver has its own regulations and service definitions. For a full explanation, these waivers can be found on the internet.

Go to www.nj.gov/humanservices/ddd/programs/supports_program.html for information about the Supports Program and the related policy manual.

Go to www.nj.gov/humanservices/ddd/services/ccw/index.html for information about the Community Care Waiver (CCW).

WHAT ARE THE MEDICAID WAIVERS IN NEW JERSEY?

There are a few waivers administered by different entities of state government. Each has different eligibility criteria and a menu of supports.

COMMUNITY CARE WAIVER (CCW) ADMINISTERED BY DDD

New Jersey's Division of Developmental Disabilities administers the Medicaid **Community Care Waiver (CCW)** to pay for specific services that are needed so individuals with I/DD can live in the community. The CCW is reserved for people who require the most intensive levels of support. This Medicaid waiver funds most licensed residential programs and supported living services to those with I/DD. For more information visit www.nj.gov/humanservices/ddd/home/. These services can be obtained through one or more service providers selected by the individual.

For a fact sheet on CCW go to www.nj.gov/humanservices/ddd/documents/Documents%20for%20Web/CCW%20Renewal%20FAQs.

SUPPORTS PROGRAM ADMINISTERED BY DDD

Through the newly established Supports Program adults with I/DD, who live with their families or in a non-licensed setting, can access Division-funded supports from a list of eligible services. For more information visit www.state.nj.us/humanservices/ddd/programs/supports_program.html. Such services are generally individual-directed with a menu of options accessed through the assistance of a Support Coordinator.

IS THERE A WAITING LIST FOR WAIVER SERVICES?

Yes, most waivers have a waiting list. For instance, a waiting list exists to receive more comprehensive services through DDD's Community Care Waiver (CCW). A person may also be eligible for other waivers that exist such as the Managed Long Term Services and Supports (MLTSS) described below. After an assessment is completed, a person may qualify for these intensive supports. If services are not available, a person may be assigned to a waiting list for waiver services. Services are distributed based upon funding initiatives, available resources and/or the assessment of a person's level of care needs.

DDD's Community Care Waiver is the most comprehensive source of funding for residential supports or services, and there is a lengthy wait for these services.

The Supports Program is another means of obtaining limited supports while living at home with family or in your own home. Previously, many people placed their name on the waiting list as soon as they were eligible and waited for a group home or supervised apartment placement. Today, eligibility for Medicaid is a pre-requisite for obtaining any services from DDD. Individuals must have Medicaid and meet an institutional level of care to qualify for these intensive long-term supports. Individuals wait for waiver funding to obtain individual support services in their own home, in their family home or in a licensed community residence. In circumstances where DDD determines that a Medicaid recipient's circumstances meet the criteria of an emergency, the individual may receive services regardless of their position on the waiting list. For more information go to www.state.nj.us/humanservices/ddd/services/ccw/ccwwl.html.

> **"Look out for and help those who don't have the time, money and resources to manage for themselves."**

THE NEW JERSEY COMPREHENSIVE ASSESSMENT TOOL (NJCAT) is the assessment tool used by the New Jersey Division of Developmental Disabilities (DDD) to determine the abilities and needs of a person with intellectual/developmental disabilities (I/DD) in many areas including medical, behavioral and self-care needs. States use such instruments to document a person's level of service need, determine the individual budget to fund supports and promote fairness in the funding process. The assessment is an important document measuring a person's abilities at a particular moment in time. It substantiates the individual's need for assistance and supports. The assessment determines the commensurate funding that may be available for services and supports. Inconsistency among reporters' descriptions of a person's abilities can affect the accuracy of the assessment. Consequently, the assessment should be completed by those who know the person well. Ideally, the assessment should be done collaboratively involving the individual, if able, the family, and the service provider(s). If the results of the assessment do not seem to match with the individual's level of need or if the level of need has changed, re-assessment can be requested through the Intake Director in DDD's Community Services Office serving the region in which the individual resides. For a short video describing the assessment process, go to www.youtube.com/watch?v=nluCSo5kFWk&feature=youtu.be.

INDIVIDUAL BUDGET - a sum of funding that may be available for a person with I/DD based upon an assessment of their needs and abilities.

FEE FOR SERVICE - The state is adopting a change in the way services are paid to providers. Rather than annual contracts from the state, providers bill Medicaid directly after services have been delivered to individuals. This is called fee-for-service.

MANAGED LONG TERM SERVICES AND SUPPORTS (MLTSS) PROGRAM ADMINISTERED BY DMAHS

New Jersey residents with Medicaid, who are living in institutions or nursing homes for more than 90 days, may qualify for this program under the Managed Long Term Services and Supports (MLTSS) program within the NJ Comprehensive Medicaid Waiver. The person must meet financial criteria and be assessed to require a "nursing home level of care." Services are planned so that the person has a smooth and successful transition moving back into a home of their own. A person requiring too little or conversely too much support may not qualify for the program.

An interdisciplinary team works with the person to develop an individualized plan of care based upon his/her needs. Funding for in-home services might include home health aides, adult day care, transportation, behavioral health care and meal delivery. Personal income such as Social Security benefits must pay for living expenses and housing.

Go to www.nj.gov/humanservices/dmahs/home/mltss.html for information regarding the MLTSS Waiver.

NJ Department of Human Services Division of Medical Assistance and Health Services (NJDMAHS)

The Division of Medical Assistance and Health Services (DMAHS) administers the state- and federally-funded Medicaid and NJ FamilyCare programs for certain groups of low-to-moderate income adults and children.

MLTSS or Managed Long Term Services and Supports refers to the coordination of the waivers for people with higher levels of medical care needs administered through the Division of Medical Assistance and Health Services. The **NJ Comprehensive Medicaid Waiver** encompasses four previous waivers called Global Options for Long-Term Care (GO); AIDS Community Care Alternatives Program (ACCAP); Community Resources for People with Disabilities (CRPD); and, Traumatic Brain Injury (TBI) Waiver that now operate within one managed care system.

These Medicaid funded long-term care and home and community-based services are overseen by Managed Care Organizations (MCO). An MCO is also known as Health Management Organization (HMO). They approve and coordinate all community-based services as well as acute and primary health care. People who qualify for a nursing home level of care must meet the clinical and financial guidelines for MLTSS. Funding is determined based upon an assessment and person-centered planning.

These comprehensive supports could be provided in-home, in an assisted living facility, in community residential services, or in a nursing home as long as the person meets the standard of care for this waiver. A person cannot receive MLTSS and DDD services at same time.

State Plan Services

WHAT ARE THE “STATE PLAN SERVICES” IN NEW JERSEY?

State Plan Services are those services that the state supplies to its beneficiaries. Any Medicaid recipient, who meets the specific eligibility criteria for a state plan service, is entitled to receive it. Such services may include dental services, various therapies, personal care assistance and such. No waiting lists exist for state plan services. The MCO/HMO however must assess and approve that there is a medical necessity for the services and they will determine the number of hours that an individual can receive.

NJ Department of Human Services Division of Disability Services (DDS)

The Division of Disability Services (DDS) serves as a single point of entry for people seeking disabilities related information and referral. DDS administers services that support people with different types of disabilities to live more independently in the community.

PERSONAL PREFERENCE PROGRAM (PPP)

Personal Preference Program (PPP), a State Plan Service is administered under the auspices of the NJ Division of Disability Services, PPP is a state plan service that can be utilized separately or in combination with waiver services. The PPP permits Medicaid recipients more choice in obtaining Personal Care Assistance (PCA) services. Personal Care Assistants perform non-emergency, health related tasks to assist with activities of daily living (ADLs) such as bathing, dressing, meal preparation, and light housekeeping. These tasks must be essential to maintain a person’s health and comfort. Individuals can contact their MCO to start the enrollment process. For more information go to www.nj.gov/humanservices/dds/services/ppp/index.html.

Given a monthly cash allowance, individuals work within a budget to hire Personal Care Assistants directly or through an agency. Individuals with intellectual disabilities can identify a representative to assist with making decisions to implement the plan. PPP also includes Fiscal Management (FM) services to help individuals with the financial aspects of the program. The Fiscal Management handles all payroll responsibilities for participants and acts as a bookkeeping service.

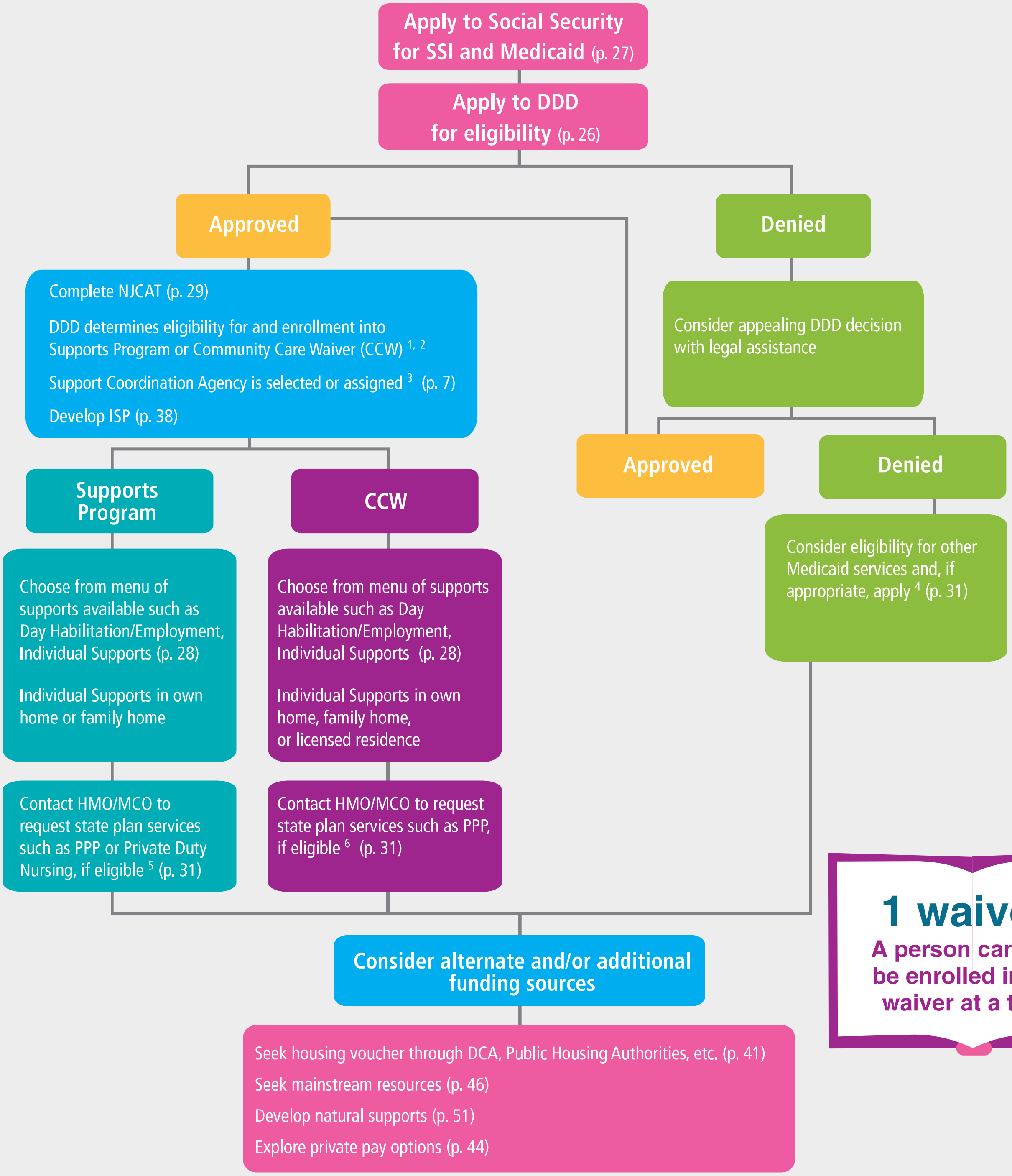
The PPP requires greater individual responsibility while providing more control, flexibility and choice over the services received. PPP also pays for environmental modifications, equipment, appliances or technology that enhance independence.

Regarding eligibility, a person must have Medicaid, qualify for needing Personal Care Assistant Services (PCA) for at least six months and be able to self-direct services or choose a representative who can act on their behalf.

PERSONAL ASSISTANCE SERVICE PROGRAM (PASP)

Personal Assistance Service Program (PASP) is another state plan service that supplies up to 40 hours per calendar week of personal care assistant services to support adults with disabilities going to work or school. Additional hours of services may be approved on a case-by-case basis, based upon exceptional circumstances. Individuals are responsible for directing their own services that can include assistance with activities of daily living like bathing and dressing as well as housekeeping, cooking, shopping and using transportation. For more information visit www.nj.gov/humanservices/dds/projects/pasp/.

FUNDING FOR LONG-TERM CARE



Apply to Social Security for SSI and Medicaid (p. 27)

Apply to DDD for eligibility (p. 26)

Approved

Complete NJCAT (p. 29)

DDD determines eligibility for and enrollment into Supports Program or Community Care Waiver (CCW) [1, 2]

Support Coordination Agency is selected or assigned [3] (p. 7)

Develop ISP (p. 38)

Supports Program

Choose from menu of supports available such as Day Habilitation/Employment, Individual Supports (p. 28)

Individual Supports in own home or family home

Contact HMO/MCO to request state plan services such as PPP or Private Duty Nursing, if eligible [5] (p. 31)

CCW

Choose from menu of supports available such as Day Habilitation/Employment, Individual Supports (p. 28)

Individual Supports in own home, family home, or licensed residence

Contact HMO/MCO to request state plan services such as PPP, if eligible [6] (p. 31)

Denied

Consider appealing DDD decision with legal assistance

Approved

Denied

Consider eligibility for other Medicaid services and, if appropriate, apply [4] (p. 31)

Consider alternate and/or additional funding sources

Seek housing voucher through DCA, Public Housing Authorities, etc. (p. 41)

Seek mainstream resources (p. 46)

Develop natural supports (p. 51)

Explore private pay options (p. 44)

1 waiver

A person can only be enrolled in one waiver at a time.

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[1] Currently, capacity for CCW enrollment exceeds the demand. Unless there is an emergency, there may be a multi-year wait before accessing services through the CCW.

[2] Individuals who are eligible for the CCW may access the Supports Program while waiting for CCW services (p. 31).

[3] Some individuals may still be working with case managers. Going forward, virtually all individuals will eventually transition to Support Coordination Agencies.

[4] If a nursing home level of care is met, Managed Long-term Services and Supports (MLTSS) waiver or state plan services may be an option. For more information (p. 30 and 31).

[5] No state plan service(s) can be used that are duplicative of services received on the Supports Program.

[6] No state plan service(s) can be used that are duplicative of services received on the CCW.

NJ Statewide Transition Plan (STP)

CMS "FINAL RULE" AND NJ STATEWIDE TRANSITION PLAN

What does the CMS "Final Rule" say about integration?

In January 2014, the Centers for Medicaid and Medicare Services (CMS) issued guidance to the states that administer Home and Community Based Services (HCBS) Waivers. Funded community-based services must also be provided in the most integrated settings appropriate to the needs of the person. Settings that tend to isolate people from the broader community may not be eligible for federal funding, if they violate the ADA mandates. For more information visit www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf. The following are excluded settings for Medicaid Home and Community Based Services.

- Nursing homes
- Intermediate Care Facilities (ICF)
- Institutes for Mental Diseases (IMD)
- Hospitals

According to CMS, large long-term care settings such as gated or secure communities, farmsteads, disability specific or intentional communities or residential schools might not be eligible for Medicaid funding. Even smaller group homes are subject to a higher level of scrutiny to demonstrate that people have autonomy as well as integration within these settings. The residents served in specialized housing must have opportunities to access the benefits of community living while living in the most integrated settings. Day habilitation programs must meet these requirements, as well. States must implement a transition plan indicating how such programs within the state will become compliant with these regulations.

Go to www.HCBSAdvocacy.org for state-specific information about this transition planning process.

NJ Statewide Transition Plan (STP)

As of the writing of this guide, the Department of Human Services submitted its Statewide Transition Plan (STP) to comport with the CMS Final Rule regarding Home and Community Based Settings (HCBS) and is awaiting approval.

What is the STP?

New Jersey's plan declares that, "HCBS settings must provide opportunities for individuals to: seek employment and work in a competitive and integrated environment; engage in community life and control personal resources with the same access to the community as people not receiving Medicaid HCBS. The setting must promote individual initiative, autonomy, and independence in making life choices."
For more information visit www.state.nj.us/humanservices/dmahs/info/hcbs_trans.html.

All individuals receiving HCBS waiver services must have full access to the benefits of community living like others without disabilities and have the opportunity for choice, privacy, community integration, landlord tenant protections and the ability to select supportive services based on individual needs.

What are some of the implications of the STP for housing?

DDD has made a tangible commitment to diversify housing options for individuals with developmental disabilities and expand community-based options. For new settings, the STP limits the number of individuals with disabilities who can live together and discourages certain settings.

- A maximum of four people can live in a community residence or six people in certain circumstances (such as when the residents require certain specialized services).
- No more than 25% of housing units can be set aside for people receiving HCBS waiver funding in a housing complex.
- Multiple programs cannot be co-located (a waiver of this prohibition may be granted based on clinical need).
- Gated or secure communities as well as residential schools are discouraged from consideration as home and community based and must be subject to a heightened scrutiny process to secure CMS approval for individuals using HCBS funds.

All settings, existing and new, must comply with the HCBS Final Rule. The site-specific assessments to be conducted by DDD will determine whether each existing setting complies with the HCBS Final Rule. For existing sites, the size of the site, in and of itself, will not be the sole determinant of compliance with the Final Rule.

What is the status of the STP?

When the NJ Department of Human Services (DHS) requested public comment on the draft STP, more than 1,000 stakeholders commented. Hundreds of families requested more flexibility for individuals with special needs to choose settings that exceeded these limitations. DHS revised the STP to assess existing settings for compliance but maintained the quantitative limits mentioned above for future settings in its final draft submitted to CMS. As of this writing, CMS approval is pending.

The state has until 2019 to bring all HBCS waiver funded services such as CCW, MLTSS and the Supports Program into full compliance, and DHS has taken substantial measures to implement the policies in the STP as submitted in preparation for this deadline.

The NJ Department of Human Services will likely adopt regulations incorporating these policies as requirements. Thus, when considering housing and vocational options to be funded by Medicaid waivers, one should be well informed of the current state requirements and any changes that may have occurred since the writing of this publication.

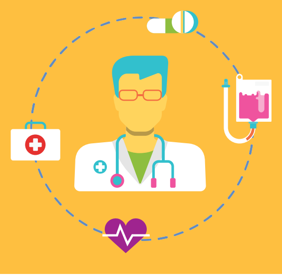
To learn more about the New Jersey Statewide Transition Plan go to www.state.nj.us/humanservices/dmahs/info/hcbs_trans.html.

MORE ABOUT THE CMS "FINAL RULE:" MANDATE ON INTEGRATION

Beth Miller of The News Journal reported that some people see a group home "as a sequestered environment, exactly the kind of thing the nation is trying to leave behind as it promotes community-based life for all. Others see such options as a welcome, sustainable alternative for those who may need support but still want a place of their own." The Centers for Medicare and Medicaid Services (CMS) released guidance regarding its final rule concerning isolation in institutional settings and describing what federal funds will support in the future. Each state receiving HCBS waiver funding must submit and implement a transition plan by 2019 that identifies how the state will bring all of its waiver-funded services into compliance. Miller states that CMS is "steering everything toward independence, choice, and community integration. Anything that looks or functions similar to an institution will have to prove it is no such thing to be eligible for future home and community-based funding. The new rules reflect the mandates of the Americans with Disabilities Act (1990) and the subsequent 1999 U.S. Supreme Court ruling known as Olmstead, which said that people with disabilities have the right to full access to the benefits of community living and the opportunity to receive services in the most integrated setting appropriate." For more information visit www.delawareonline.com/story/news/local/2014/10/31/conference-focus-innovative-neighborhoods/18234271.

MEDICALLY ORIENTED SUPPORTS

HEALTH HOME



Health Home refers to how medical, behavioral and mental health issues are all interconnected when implementing a robust plan of care. A health home addresses all issues concurrently in the context of health and wellness. The various medical practitioners work in coordination with all interdisciplinary team members to develop a comprehensive treatment plan for the person with special needs. Health Homes are Medicaid reimbursable and have been piloted in New Jersey in several counties. For more information visit www.npaonline.org/website/article.asp?id=12.

SKILLED NURSING

Skilled Nursing Care or Nursing Homes are licensed facilities regulated by the state's Department of Health. They provide skilled nursing for those who require intense medical care. Such facilities provide 24 hour per day nursing care to frail or medically complex residents on a long or short-term basis. Individuals with disabilities require a Pre-Admission Screening and Resident Review (PASRR) prior to entering a Medicaid certified nursing facility to determine the appropriateness and identify any in-home or community placement alternatives. MLTSS must be approved for long-term care by the MCO/HMO.

ASSISTED LIVING

Assisted living serves adults who are elderly or have disabilities and do not require skilled nursing care. These facilities provide a combination of personal supports, assistance with activities of daily living and health care. Residents are encouraged to maintain as much independence as possible, pursue personal interests and sustain relationships with family, neighbors and friends. The individual must be approved for MLTSS and can only receive services from one waiver at a time.

Supports vary depending upon a person's needs, desires and the amenities offered at each location. Typically, services include **staff assistance, meals, transportation, housekeeping, medication administration, nursing and medical care as well as social and recreational activities.** Costs and insurance reimbursements vary according to the facilities. The New Jersey Department of Health licenses and inspects assisted living facilities.

Note: Assisted Living cannot be funded through a New Jersey Department of Human Services Home and Community Based Services Waiver.

Other Governmental Agencies

Other governmental agencies **within the New Jersey Department of Human Services (DHS)** may have resources that a person with a disability may access. If a person has a developmental disability with a secondary condition such as blindness, deafness, mental illness, are aging or have a physical or medical disability, other agencies may have services from which the individual can benefit.

NJ Commission for the Blind and Visually Impaired (CBVI)

CBVI provides a wide range of educational services, vocational rehabilitation services as well as independent living services for New Jersey residents of all ages who live with blindness or visual impairment. CBVI also offers a number of special programs that address specific needs of people with this disability. Depending on family income, some people who apply are required to pay a share of the cost of programs or services.

NJ Division of Deaf and Hard of Hearing (DDHH)

DDHH serves New Jersey residents who are deaf or hard of hearing by providing advocacy, employment and vocational opportunities and by assisting with a wide variety of social, legal, medical, educational and recreational issues. DDHH administers New Jersey's primary sign language interpreter referral service, provides assistance through an information and referral hotline and publishes a monthly newsletter. DDHH distributes text telephone equipment and voice carryover phones to assist individuals in their daily activities.

NJ Division of Aging Services

Program of All-Inclusive Care for the Elderly (PACE) is a Medicare funded program for frail individuals ages 55 and older that supplies comprehensive medical and social services in a community-based center and in the person's home to avoid the need for nursing home care. The PACE® model is based upon the belief that elderly individuals with chronic health conditions are better served in the community whenever possible. An interdisciplinary team of professionals meets regularly with each participant to plan to address his/her needs. Services may include primary medical, dental, and nursing care; prescription medications; adult day health care; in-home personal care services; nutrition services; transportation; and in-patient and nursing home care if needed.

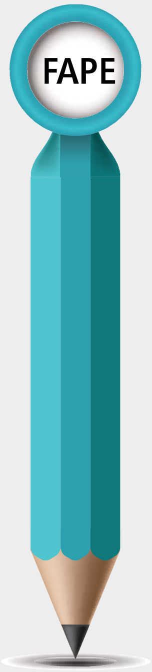
There are limited geographic areas where PACE is available. Participants must reside in the service area of a PACE organization to be enrolled in this service The elderly person attends the PACE Center a few times each week where they can receive medical care, rehabilitation, social activities and dining. Medicaid, Medicare or private payment can pay for these services.

NJ Division of Mental Health and Addiction Services (DMHAS)

DMHAS provides public mental health services to individuals with serious mental illness and addictions through provider agencies statewide. As part of a settlement agreement with Disability Rights New Jersey, this Division has been developing more supportive housing arrangements generally with a combination of housing vouchers and access to supportive services. Individuals with greater needs may be discharged from state psychiatric hospitals into supervised apartments and group homes referred to as "legacy homes." Services will be funded through the Community Support Services Rehabilitation Program delivered by community provider agencies statewide. Rental assistance vouchers will be administered and managed by the Supported Housing Connection for eligible individuals.

Many other social service organizations recognize that having the security of a safe place to live is crucial to a person recovering from a mental illness. Individuals with mental health conditions need a full array of supports in order to seek recovery. In addition to locating affordable housing and supportive services, people need employment, education, health and wellness, transportation and medication supervision. Periodically, individuals experiencing de-compensation may need additional supports such as food preparation, medication administration, and housekeeping. The intensity of a person's needs dictates the level of supports that they require at any given time. DMHAS serves people with serious mental illness and addictions; however, there are programs and services addressing co-occurring diagnosis for persons with both developmental disabilities and mental illness.

Self-help and family support groups such as the National Alliance on Mental Illness supply information, education and advocacy www.naminj.org.



WHAT SERVICES ARE AVAILABLE FOR CHILDREN?

All children, including children with a disability, are entitled by law to a Free Appropriate Public Education that is designed to meet their individual needs. In some instances when a child's educational needs cannot be met within a local school setting, the local educational agency funds a placement within a residential school to meet the child's educational needs. Educational entitlement ends after the school year following the person's 21st birthday. For the New Jersey Department of Education's *Parental Rights in Special Education* booklet go to

www.state.nj.us/education/specialed/form/prise/prise.pdf.

At the age of 18, an individual or guardian can apply to DDD to be determined eligible for DDD services as an adult. The Department of Children and Families is responsible to provide all direct services (residential, in-home, behavioral, family support, etc.) until age 21 and has their own requirements for eligibility and service delivery.

EMPLOYMENT

Employment is another important way to increase income and afford independent housing. In April of 2012, Governor Christie announced that New Jersey would be the 14th state to adopt the "Employment First" initiative. The Employment First initiative requires state government to eliminate barriers or practices that prevent persons with physical, developmental, and mental disabilities from being employed and is intended to increase the employment opportunities available to persons with disabilities. Both the New Jersey Department of Labor and Workforce Development and the Department of Human Services are tasked with implementing the goals of the Employment First initiative and encouraging private sector employers to improve their efforts to hire persons with disabilities.

Competitive employment after high school is the first and preferred activity for everyone, including people with disabilities. Vocational services such as career counseling, job training and losing their benefits, New Jersey's Medicaid Buy-in Program, NJ WorkAbility, and the Social Security Administration's Work Incentive programs allow individuals with disabilities to earn more income and still keep their Medicaid benefits. For an overview of the Social Security Administration's Work Incentives, as they pertain to both SSI and SSDI cash and healthcare benefits go to www.nj.gov/humanservices/ddd/documents/section_1619b_factsheet.pdf.

Assuring Quality

The purpose of this housing guide is to describe traditional and innovative ways in which to receive housing and residential supports. Individuals and guardians make many more choices and decisions regarding how they or their loved ones receive services. It is important to know the options that exist and continuously evaluate service delivery quality.

The size and location of the home can affect isolation. It is important to consider elements that influence the quality of life. Do I feel safe and have access to the services I need? Do I have caring people nearby? How many will be living together? Who signs the lease? Is the service provider also the property owner? What happens if I am not happy with a staff member? Who hires/fires the staff? What opportunities exist to interact with people who do not have disabilities? These components are important in deciding what model works best.

These factors alone are not sufficient to determine satisfaction. There are elements of quality that must be evaluated by each person and extend beyond these individual features. For some, living in their own scattered site apartment is an ideal situation. For others, it might be lonely, if there are not enough opportunities to have meaningful interactions with friends. For others, living with friends in a small communal setting can be very satisfying, particularly if they can choose their housemates. If choices are available, the individual and his family or advocates should research the options to decide which types of supports and settings best suit him/her.

Having a stable service provider that respects self-direction and choice is very important. The CMS Final Rule on Home and Community-Based Services (HCBS) listed factors that could lead to isolation. This list intentionally consists of settings that include more individuals with disabilities than the population as a whole. The intention behind this position is so that "HCBS programs provide full access to the benefits of community living and offer services in the most integrated settings." For more information visit www.state.nj.us/humanservices/dmahs/info/hcbs_trans.html. CMS and the NJ Department of Human Services will not fund services that do not comply with these requirements. Choice and community integration are values held dear by people within the disability community and one essential means of measuring quality. Ultimately, each person must decide what he/she prefers and evaluate the quality based upon his/her own criteria. Resources are available to assist individuals and their families to identify quality indicators in residential services. For example, you can contact Autism New Jersey's Helpline 800.4.AUTISM or information@autismnj.org for a list of quality indicators in residential settings. Several toolkits and resources are also available and referenced in the Appendix.

Not all residential settings require a license. There are advantages and disadvantages of licensing. In a provider operated setting, the oversight by a state license offers some basic assurance of quality as well as recourse, if dissatisfied. Some individuals feel it is an imposition to meet the many tedious requirements of having a licensing inspection of their living quarters. To assess quality, individuals and their families must determine what factors are important to them, assess what they are receiving and advocate for improvements that are needed. Each person measures quality of life objectively and subjectively based upon one's own perspective. What factors/questions/services are important to you and your loved one? Through a Person Centered Planning process, each person develops an Individualized Service Plan (ISP) that identifies his or her goals and objectives. This document can serve as a basis upon which to evaluate quality of life.

> **"Recharge your batteries by taking care of yourself. Don't be too proud to ask others for help."**

Finding
Affordable Housing

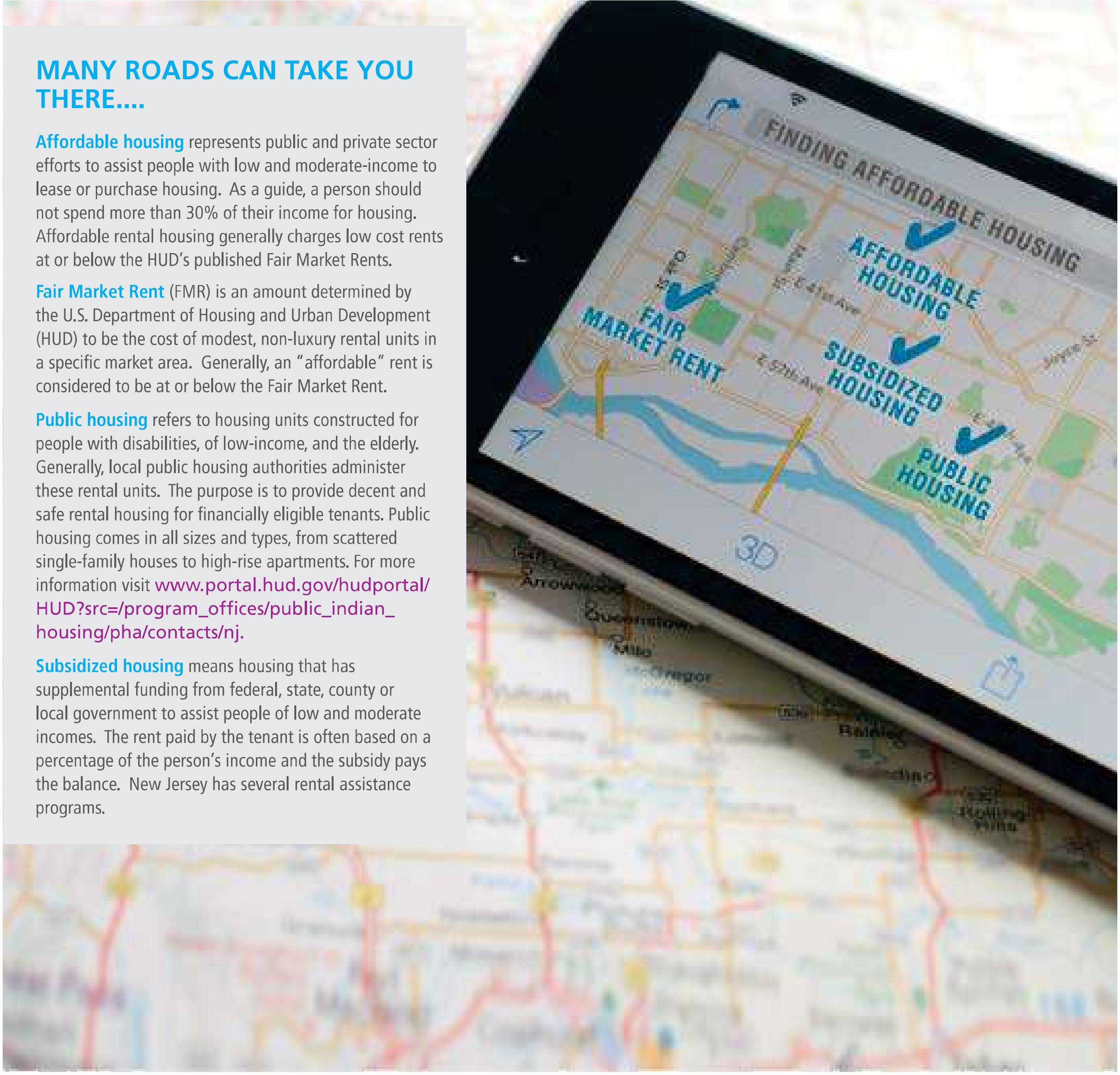
MANY ROADS CAN TAKE YOU THERE....

Affordable housing represents public and private sector efforts to assist people with low and moderate-income to lease or purchase housing. As a guide, a person should not spend more than 30% of their income for housing. Affordable rental housing generally charges low cost rents at or below the HUD's published Fair Market Rents.

Fair Market Rent (FMR) is an amount determined by the U.S. Department of Housing and Urban Development (HUD) to be the cost of modest, non-luxury rental units in a specific market area. Generally, an "affordable" rent is considered to be at or below the Fair Market Rent.

Public housing refers to housing units constructed for people with disabilities, of low-income, and the elderly. Generally, local public housing authorities administer these rental units. The purpose is to provide decent and safe rental housing for financially eligible tenants. Public housing comes in all sizes and types, from scattered single-family houses to high-rise apartments. For more information visit www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/pha/contacts/nj.

Subsidized housing means housing that has supplemental funding from federal, state, county or local government to assist people of low and moderate incomes. The rent paid by the tenant is often based on a percentage of the person's income and the subsidy pays the balance. New Jersey has several rental assistance programs.



Rental Subsidies

Many programs exist to help people with limited income secure affordable housing. Housing vouchers, for instance, provide a supplement so that the person does not spend more than 30% of his/her income on rent. The U.S. Department of Housing and Urban Development (HUD) publishes Fair Market Rents for each county. Tenants pay a portion of their income (typically 30% to 40% of the household's adjusted monthly income) and the voucher pays the balance of the rent directly to the property owner.

These rental assistance programs are available with federal and state funds often called HUD's federal **Housing Choice Voucher** (Section 8) or **State Rental Assistance Program** (SRAP). The state's Department of Community Affairs, county social services offices and local housing authorities administer these vouchers. Vacancies and opportunities fill quickly; households can only apply for housing assistance when there is an open waiting list.

The rentals of new subsidized housing units and the process to apply are advertised in the local newspapers. Such complexes offer affordable rental rates and may have some project-based subsidies available. Applications are accepted, and then waiting lists are created. An applicant must submit income verification to document that everyone living in the household meets the financial eligibility guidelines.

The application asks if the person has a disability. This includes people with mental illness and intellectual and developmental disabilities. Frequently, preference is given to people with special needs such as veterans, the elderly or someone with a disability. A person can be on several waiting lists simultaneously.

Some affordable housing projects have vouchers assigned to the apartment called "project-based rental assistance." When the person moves, they lose the subsidy. Alternatively, "tenant-based vouchers" are assigned to the tenant and can move with the person to any place with a Fair Market Rent that they choose to rent. Vouchers may be time limited. Most are renewable.

Obtaining a rental assistance voucher can be a significant step toward achieving affordable housing and independent living. Securing a voucher is a complicated, time-consuming process but worth the effort. Eligibility is determined by the public housing authority based upon the number of people in the household, the annual gross income, available assets, citizenship status and criminal background.

TENANT-BASED RENTAL ASSISTANCE

SEARCH

People use tenant-based rental assistance to secure affordable, decent, safe, and sanitary housing in single-family homes, condominiums, townhouses or apartments. The recipients of this subsidy locate their own rental housing and sign a lease with the property owner. Both parties are required to meet the terms of that lease. The landlord must also sign an agreement accepting the terms of the voucher program. The rents must be determined reasonable as compared to rental rates in that community.

AGREE

The landlord must agree to the terms of the program that includes meeting basic health and safety standards and submitting to an inspection of the property. The Public Housing Authority (PHA) pays the rental subsidy directly to the property owner. Tenants pay their share of the rent directly to the landlord.

ELIGIBILITY

The PHA determines eligibility for a voucher based upon the family size, annual household gross income, assets and citizenship status. The tenant must also report changes to income and household membership.
If determined no longer eligible, the family could lose its subsidy.

Federal Housing Choice Vouchers and NJ State Rental Assistance Program (NJ SRAP)

People with disabilities may also receive a preference or priority consideration in obtaining a housing voucher based upon their disability. When contacting the NJ Department of Community Affairs, the county, or the local public housing authority about rental assistance, also ask about "set-aside" opportunities. These are vouchers reserved for people with disabilities. It is advantageous for a person to apply and have their name placed on multiple waiting lists for low-income housing and rental subsidies.

Periodically contact the **NJ Department of Community Affairs (DCA) Customer Services at 609.292.4080** to see if any waiting lists are open.

To locate the agency in each county, usually called the **Board of Social Services**, go to www.nj.gov/humanservices/dfd/programs/njsnap/cwa/.

Public Housing Authorities, also referred to as **Public Housing Agencies**, are designated entities that manage public housing units in a certain geographic area. Go to **Public Housing Agency** to locate low-income housing options in each county or municipality. For a list of New Jersey's public housing entities go to www.hud.gov/offices/pih/pha/contacts/states/nj.cfm.

HUD publishes a **Fact Sheet on Housing Choice Vouchers** at www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet.

To locate HUD **Housing Choice Voucher** (Section 8) housing inventory go to www.portal.hud.gov/hudportal/HUD?src=/states/new_jersey.

For more information on The New Jersey Housing and Mortgage Finance Agency's (HMFA) Supportive Housing Programs, contact: 609.278.7629 or visit www.NJhousing.gov.

VOUCHER

If a voucher is not readily available, the person/family is placed on a waiting list. When the waiting list becomes too long, the PHA can decide to close the waiting list until additional vouchers become available. The PHA can also determine local preferences favoring certain groups of people to receive vouchers. For instance, the PHA could decide to give preference to people who are homeless, displaced or currently paying more that 50% of their income toward rent. These eligible people could be determined to receive priority to receive available vouchers ahead of others on the waiting list. It is not unusual to be on a waiting list for several years.

Housing Choice Voucher Fact Sheet www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet.

LIST

Once a name is added to a waiting list, it is important to notify the PHA of any changes in address and household composition. When the person's name gets to the top of the waiting list, it is imperative to complete all of the paperwork in a timely manner.

Affordable Housing Funded by Tax Credits

The Federal **Low-Income Housing Tax Credit** program provides tax incentives to housing developers to establish affordable rental units for people who meet established income criteria. Subsidized or affordable housing is available within these complexes. New tax credit funded housing projects publicize their application process in local newspapers. Existing housing complexes maintain waiting lists to fill vacancies. HUD maintains an inventory of tax credit housing at www.huduser.org/DATASETS/lihtc.html. People interested in obtaining affordable housing within one of these complexes can locate such housing in the towns where they want to live and apply. In addition, further opportunities to find rental housing are listed below.

Rental Resources

HOUSING RESOURCE CENTER (HRC)

The New Jersey Housing Resource Center (HRC), located on the web at www.NJHRC.gov is a free service for people searching for affordable housing and property owners looking to lease housing. The HRC website, created by the NJ Housing and Mortgage Finance Agency (HMFA), provides a central location for people to search for accessible and affordable housing that is for rent or sale in New Jersey. People without Internet access may call the bilingual toll-free number 877.428.8844 for help in using this service.

SUPPORTIVE HOUSING CONNECTION (SHC)

The **Supportive Housing Connection** is a partnership between the New Jersey Housing and Mortgage Finance Agency (HMFA) and the New Jersey Department of Human Services (DHS), formed to administer DHS rental subsidies to individuals served by DHS. This entity provides unit referrals, administers DHS rental subsidies, inspects rental units and responds to inquiries regarding disputes with property owners. For more information visit www.njhousing.gov/dca/hmfa/rentals/shc/index.html or www.state.nj.us/humanservices/providers/housing.

The Supportive Housing Connection will provide:

- Landlord outreach and training
- Rental and other housing assistance
- Unit referrals and inspections
- Resident inquiry resolution services

Ownership Resources for Individuals with Disabilities

Programs exist to help people with disabilities buy and maintain their own homes. There are national, state and local programs that offer mortgage assistance and other types of housing aid to help better serve people with disabilities. Local banks and housing counseling organizations can provide guidance and information about buying a home. In some instances, families purchase a home for their adult child with a disability to operate as a group home or home sharing. Cooperative arrangements have also been made for a few families to own the group home.

Home ownership can be costly and include unexpected expenditures for repairs. The advantages and disadvantages must be weighed carefully before making a decision to buy a home. **Freddie Mac** publishes a fact sheet on home ownership vs. renting. They suggest that if someone intends to build equity, stays in the home at least four years and has funds for ongoing maintenance/home improvements, home ownership has financial advantages. The buyer must have a source of steady income, a favorable credit rating and a down payment in order to finance a mortgage on the property. For more information visit www.freddiemac.com/homeownership/rent_or_buy/right_for_you.html.

There are several programs to assist people with low incomes to purchase, renovate or refinance a home of their own with minimum down payments, subsidies and/or low interest mortgages. The Housing Mortgage Finance Agency or your local bank may have special mortgage rates for first-time homebuyers. With home ownership come additional responsibilities and financial expenses. These factors must be considered carefully when contemplating the purchase of a home.

PROGRAMS FOR HOME BUYERS - NEW JERSEY HOUSING AND MORTGAGE FINANCE AGENCY (HMFA)

Buying a house is a big step with a rewarding outcome – a home to call your own. **The New Jersey Housing and Mortgage Finance Agency** (HMFA) promotes affordable homeownership and housing opportunities for New Jersey residents.

The Homeward Bound Program provides for a 30-year loan at a fixed interest rate and no points. The program is open to first-time homebuyers, trade up and trade down borrowers. The home must be the borrower's primary residence or a two-to-four unit dwelling in which one unit will be the borrower's primary residence and the remaining unit(s) may be rented.

The Smart Start Program provides down payment and closing cost loans of up to 4% of the first mortgage amount to qualified First-Time Homebuyer Program borrowers and certain Homeward Bound Program borrowers.

- Further information on purchasing a home through one of HMFA's homebuyer programs and brochures on the home buying process also can be requested by calling 1.800.NJ.HOUSE (1.800.654.6873) or visit www.njhousing.gov.

Refinancing For Home Owners through New Jersey Housing and Mortgage Finance Agency

The Stay At Home Program provides for the refinancing on an existing single family home that has been and will continue to be used as the borrower's primary residence or a two-to-four unit dwelling in which one unit has been and will continue to be the borrower's primary residence and the remaining unit(s) may be rented. The loan will be for a term of 30-years, at a fixed interest rate.

- Further information on purchasing a home through one of HMFA's homeownership programs can be requested by calling 800.NJ.HOUSE (654.6873) or visit www.njhousing.gov.

HMFA publishes a guide to buying a home at www.state.nj.us/dca/hmfa/homeownership/owners/refinance.

Financial Qualifications and Leasing

A principle of Supportive Housing contends that the person with a special need or his/her guardian must have control over their housing. This is achieved most effectively through the signing of a lease. With control comes responsibility. The lease is a legal agreement that must be read and understood before signing. Residents should anticipate and plan contingencies when their roommates must change.

Landlords may require that tenants demonstrate their financial ability with a positive credit and rental history. In affordable housing, these standards may be waived. Agencies and services exist to assist tenants with these issues.

Housing Counseling Agencies

The U.S. Department of Housing and Urban Development (HUD) approves local agencies that can provide housing and financial counseling for those seeking affordable housing. These organizations supply various services such as money management counseling, financial literacy training, credit counseling, foreclosure avoidance and assistance locating affordable rental properties. For more information visit www.hud.gov/offices/hsg/sfh/hcc/fc/index.cfm?&webListAction=search&searchstate=NJ&filterSvc=dfc.

Credit Information / Credit Repair

For more information on credit and credit repair contact New Jersey Division of Individual Affairs at www.njconsumeraffairs.gov/News/Consumer%20Briefs/credit-reports-and-credit-repair.pdf or call toll free 888.656.6225.

Using Private Resources

INDIVIDUAL DEVELOPMENT ACCOUNTS (IDA)

In order to save money that may be used to support housing, the **Individual Development Accounts Program** may help. Individual Development Accounts (IDAs) are matched savings accounts designed to help families of low income and low wealth to accumulate assets of a few thousand dollars to fund investments in their education, homeownership and small business ownership.

SPECIAL NEEDS TRUSTS

Special Needs Trusts allow funds to be saved for the individual with a disability without jeopardizing government means-tested benefits and in some instances providing additional options for an individual with a disability to secure housing.

The purpose of these trusts is to allow the individual to have funds available to him/her without jeopardizing government means-tested benefits. Regardless of the type of special needs trusts established, the funds must be used for the sole benefit of the individual with a disability and in a way which does not jeopardize benefits. Therefore, if the individual is receiving SSI and/or Medicaid, then funds in a Special Needs Trust cannot be used for food, clothing or shelter because any funds used for these purposes are deemed to be "income" and could potentially jeopardize SSI and Medicaid eligibility.

Regulations and laws change, so legal advice must be obtained at the time of establishing trusts and reviewed periodically thereafter.

ACHIEVING A BETTER LIFE EXPERIENCE (ABLE) ACT

The **ABLE Act** establishes an additional way to save funds for an individual with a disability without jeopardizing some government means-tested benefits. The ABLE Act was passed by Congress in late 2014. In addition to the federal passage of the bill (NJ approved 1/11/2016 P.L.2015,c.185), each state must pass legislation to authorize its guidelines for ABLE Act provisions to be effective in that state. These regulations will more clearly define the benefits and limitation of ABLE accounts.

An ABLE account must be established for the benefit of an individual with a disability that manifests itself before age 26. The funds must belong to the individual or their parents, family, or friends. Funds in an ABLE account grow tax-free and funds used from an ABLE account are not taxed so long as they are used for qualified expenses including housing, education, transportation, healthcare, employment supports, therapies, and other similar expenses.

It is imperative that families create a comprehensive plan to prepare for the future of an individual with a disability. When establishing an estate plan for a person with special needs, it is advisable to seek the advice of an attorney or financial advisor who has specific expertise in this area of the law.

National Disability Institute: For more information about The ABLE Act visit autismnj.org or www.realeconomicimpact.org/news/?id=460.

Quality Monitoring of Housing

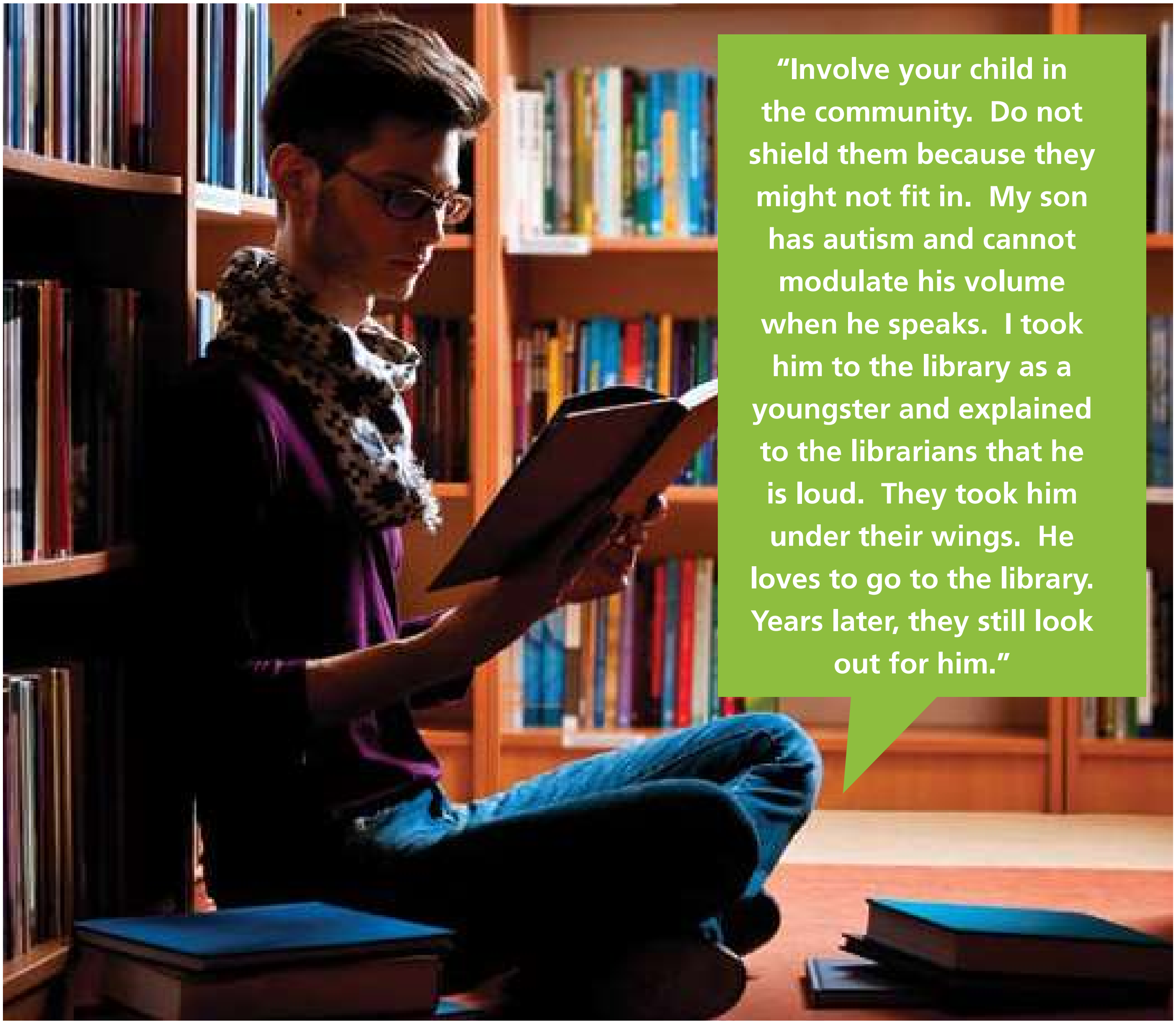
Quality Monitoring

The U.S. Department of Housing and Urban Development (HUD) has identified "13 key aspects of housing quality, performance requirements, and acceptability criteria" when evaluating the quality of housing that they use during an inspection. A checklist is available online. HUD or their designee performs such inspections to ensure basic housing quality standards (HQS) are met.

The Supportive Housing Connection is responsible for making these inspections in DDD and DMHAS funded housing units. For more information visit www.portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/hqs.

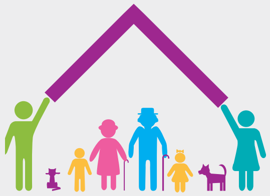
HOUSING DISCRIMINATION

For information on the rights of people with disabilities in housing go to www.portal.hud.gov/hudportal/HUD?src=/program_offices/fair_housing_equal_opp/disabilities/inhousing.



> **"Involve your child in the community. Do not shield them because they might not fit in. My son has autism and cannot modulate his volume when he speaks. I took him to the library as a youngster and explained to the librarians that he is loud. They took him under their wings. He loves to go to the library. Years later, they still look out for him."**

Mainstream Resources



MAINSTREAM RESOURCES, such as those that support individuals with disabilities, the elderly or those of low income, may be of assistance. Research is required to identify the eligibility criteria for each service. Here is a brief description and contacts for governmental agencies. Non-profit organizations, such as Autism New Jersey, The Arc of New Jersey, United Way and others can assist with information and referral. See the Appendix for contact information.

Local Municipal and County Services

Most counties and some towns offer assistance to people who are elderly or have a disability regarding transportation, money management, income tax preparation, telephone reassurance calls, meals on wheels, food pantries, recreational activities, accessibility, home modifications and more. Contact the County Board of Social Services, the Office on Aging and Disability Services and your local municipality. The county offices will be aware of other programs or services that can be of assistance. Some towns and counties have funds to assist in getting started in a new home by funding a security deposit, purchasing food or household supplies, etc. The local Public Housing Authorities manage the rental of affordable housing units and rental assistance within their local communities.

Some programs designed for people of low income can also provide assistance for the person with a disability to live independently and stretch a limited budget. Generally, when people with a disability reach the age of 18, their personal income, not the family income, is considered when applying for financial assistance. Eligibility for these programs requires research but may be well worth the effort. This section includes some options to consider.

FUNDING FOR LIVING EXPENSES

Social Security Administration

- **800.772.1213**
- **800.325.0778 TTY**
- www.socialsecurity.gov
- www.state.nj.us/humanservices/ddd/services/medicaideligibility.html

The Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs pay benefits to adults with disabilities (after their 18th birthday) who have limited income and resources. In New Jersey, a person with SSI automatically receives NJ Medicaid benefits. Maintaining Medicaid eligibility is essential for individuals with intellectual or developmental disabilities to secure waiver-funded services.

PRESCRIPTION ASSISTANCE

Pharmaceutical Assistance for the Aged and Disabled (PAAD)

- **800.792.9745**
- www.state.nj.us/humanservices/doas/services/paad

PAAD is a program that assists eligible New Jersey residents to pay for their prescription medicines with a co-pay of $5.00 for each covered prescription. Enrollment in this program provides access to additional benefits. (Note that individuals on Medicaid cannot receive this assistance.)

Senior Gold Prescription Discount Program (Senior Gold)

- **800.792.9745**
- www.state.nj.us/humanservices/doas/home/seniorgolddetail.html

Senior Gold is a New Jersey funded prescription program for people over age 65 or receiving Social Security Disability Insurance (SSDI) who meet income eligibility requirements. (Note that individuals on Medicaid cannot receive this assistance.)

SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (SNAP)

Formerly known as Food Stamps Program

- **800.687.9512**

The **NJ Supplemental Nutrition Assistance Program (SNAP),** formerly known as the **Food Stamps Program**, issues monthly benefits that can be redeemed at local food stores to purchase groceries. A person can apply through the county's Board of Social Services or by completing an application online at www.nj.gov/humanservices/dfd/programs/njsnap/apply.

Eligibility is determined based upon several factors such as income, household size, resources, etc. There is an online tool to assist in determining eligibility. For more information about SNAP and other local benefits, contact your County Welfare Agency or Board of Social Services who determine eligibility for Food Stamps. See www.nj.gov/humanservices/dfd/programs/njsnap/cwa for the phone numbers of the county offices.

> **"Don't pamper them because they have a disability. We think we are protecting them but we are not. We need to teach them what they need to know to be on their own."**

UTILITY ASSISTANCE

- www.bpu.state.nj.us/bpu/assistance/programs
- www.nj211.org

Weatherization Assistance Program

- **609.292.6140**

This program works with community-based agencies to help seniors, residents with disabilities and low-income households to weatherize their homes to improve heating system efficiency, conserve energy and decrease utility bills. The program also provides funds to pay heating bills under emergency circumstances.

Home Energy Assistance (HEA) Program

- **800.510.3102**
- www.nj.gov/dca

Home Energy Assistance helps pay home energy bills for households with limited income.
This program provides heating, cooling and emergency energy assistance to eligible applicants.

LIHEAP Energy Assistance Program

- www.acf.hhs.gov/programs/liheap

LIHEAP is a federally funded program to help eligible residents of low-income in New Jersey meet their home heating and/or cooling needs.

> **"There are no entitlements after my kid graduates from high school. I cannot rely entirely upon DDD funded programs being available to meet all of his needs. I have become an expert on the rules of the government programs and knowledgeable about the community resources that are available."**

New Jersey Statewide Heating Assistance and Referral for Energy Services (NJSHARES)

- **866.657.4273**
- www.njshares.org

NJSHARES is a nonprofit corporation organized to assist New Jersey residents who are in need of temporary help in paying their energy, water and telephone bills. NJSHARES administers assistance programs for several companies including NJ Natural Gas, JCP&L, American Water Company, United Water and Verizon.

New Jersey Natural Gas Gift of Warmth

- **800.221.0051**
- www.customerservice@njng.com

Funded through NJ Natural Gas, **Gift of Warmth** assists customers who are unable to afford their natural gas heating bills.

Verizon Telephone Company
Verizon's Communications Lifeline and Linkup America

- **866.452.4623**
- www.njshares.org/otherPrograms/communications-lifeline.asp

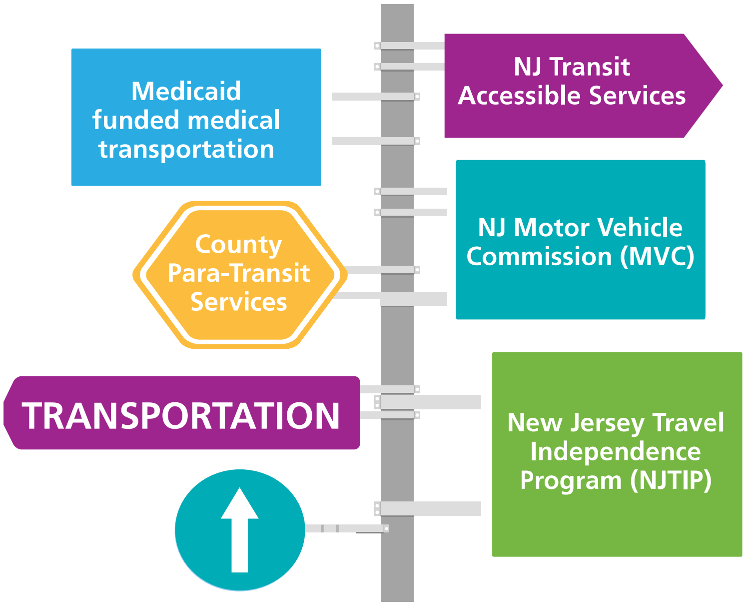
Discounted telephone service is available from Verizon Telephone Company through its **Linkup America Program** for seniors and people receiving Social Security benefits. Verizon Communications makes residential telephone service more affordable in its service area in New Jersey by offering Communications Lifeline and Linkup America services for qualified customers of low- income. If a person receives SSI benefits or qualifies for PADD, he/she meets the qualifications for this program as well.

Communications Lifeline provides a credit toward your monthly telephone bill including a full credit for Touch-Tone service. Communication Lifeline allows someone of fixed income to receive the discount by choosing Flat Rate Service, Moderate Use Message Rate Service or Low Use Message Rate Service Plans.

Mainstream resources, such as those that support individuals with disabilities, the elderly or those of low income, may be of assistance. Research is required to identify the eligibility criteria for each service. Non-profit organizations, such as Autism New Jersey, The Arc of New Jersey, United Way and others can assist with information and referral. See the Appendix for contact information.

TRANSPORTATION

Accessible public transportation and demand-response para-transit are two of the most pressing problems facing individuals with disabilities. Public transportation provides greater access to employment, education, medical care and a host of other services and activities to help people who do not drive to be active and productive members of their communities. Therefore, many individuals with disabilities need to be able to access public transportation. It is important to identify transportation mechanisms that are in place on a municipal, county and statewide level that will support individuals with disabilities to lead independent and full lives.



Medicaid funded medical transportation

is currently contracted through LogistiCare Medical Transportation at

- **For transportation reservations, call 1.866.527.9933**
- www.state.nj.us/humanservices/dmahs/home/logisticare.html

NJ Transit Accessible Services

NJ Transit is responsible for making public transportation in New Jersey accessible to people with disabilities. New Jersey Transit also administers the **Reduced Fare Program** for seniors and individuals with disabilities who use New Jersey Transit buses or trains. Access Link is New Jersey Transit's para-transit service. This curb-to-curb service is designed for individuals with disabilities who cannot use the local fixed route bus service.

County Para-Transit Services

- **800.955.2321 (TTY 800.955.6765)**
  between the hours of 8:30 a.m. and 5:00 p.m., Monday through Friday
- www.njtransit.com/tm/tm_servlet.srv?hdnPageAction=ParaTransitTo

Each county operates a **para-transit system** to serve seniors and residents with disabilities. Services vary by county and may be door to door or link the person to public transportation. These specialized transportation services charge a minimal fee. To utilize each county's para-transit bus system, individuals must complete an application process and provide advance notice to arrange for these transportation services.

NJ Motor Vehicle Commission (MVC)

- **888.486.3339 toll-free in NJ**
- **609.292.6500 (TTY 609.292.5120)**
- www.state.nj.us/mvc/About/Contact.htm

The New Jersey Motor Vehicle Commission (MVC) issues license plates and placards that are required to legally park in a designated parking space for a person with a handicap. These license plates and placards are issued free of charge and are useful for drivers or passengers with disabilities. Applications may be obtained by visiting any MVC location or calling the customer service number. For persons with temporary physical disabilities, temporary placards (valid for up to six months) are available through local police departments for a small fee.

The Motor Vehicle Commission also issues Non-Driver Photo ID cards to individuals who need a valid photo ID for the purpose of identification, but who are unable to drive. An applicant must appear in person at a MVC office with the required identification documents to obtain this card.

- www.state.nj.us/mvc/Licenses/NonDriverID.htm

New Jersey Travel Independence Program (NJTIP)

The mission of the New Jersey Travel Independence Program (NJTIP) is to increase the independence and self-sufficiency of people with disabilities, older adults and others by empowering them to use the public transit system safely and independently.

- www.vtc.rutgers.edu/njtip

EMERGENCY PREPAREDNESS

New Jersey Register Ready

- www13.state.nj.us/SpecialNeeds/Signin?ReturnUrl=/SpecialNeeds

REGISTER READY – Call 211 (toll free) is New Jersey's Special Needs Registry for disasters or other emergencies. NJ residents with special needs can call to register their special medical needs and/or functional needs information, so that emergency responders can better plan to serve them in a disaster or other emergency.

LEGAL SERVICES

Disability Rights New Jersey (DRNJ)

- www.drnj.org

Disability Rights New Jersey is a private, non-profit, individual-directed organization established to advocate for citizens of New Jersey with disabilities, promote public awareness, advise and assist in obtaining and protecting the rights of individuals with disabilities, and provide education, training and technical assistance.

Community Health Law Project (CHLP)

- www.chlp.org

CHLP is a legal services organization with regional offices in NJ providing civil legal representation to people of low income with disabilities.

Legal Services of New Jersey (LSNJ)

- www.lsnjlaw.org

LSNJ is a statewide legal services system which provides free legal assistance to low-income New Jerseyans for their civil legal problems.

American Bar Association To locate an attorney or for more information about American Bar Association go to:

- www.americanbar.org/aba.html

NATURAL SUPPORTS

"Natural Supports" means personal relationships developed that enhance the quality of life for people. Natural supports include, but are not limited to, family relationships, friendships and associations with fellow students or employees in regular classrooms and work places as well as associations developed though participation in clubs, organizations, and other civic activities.

People with disabilities should develop relationships with the people and places around them that define their community. When creating a housing plan, the person with a disability should include participation within his or her natural supports environment. Professional staffing and assistance, while necessary in many areas, should not be the sole experience for consumers on a day-to-day basis.

- www.dds.ca.gov/Publications/docs/Natural_Supports.pdf

Employment Policy

Employment is also a part of the natural support system and an important way for a person to achieve self-sufficiency. For more information go to

- www.dol.gov/odep

Housing Development

An adequate supply of safe, decent, accessible housing for people with disabilities is a critical part of the whole. This section describes the many resources that are utilized by housing developers to acquire, construct and/or rehabilitate housing for people of low income.

Funding is available to develop affordable housing for individuals with disabilities. Some families join together informally to support and formally to sponsor housing projects. For housing development, there are multiple sources for low-cost loans and grants. Federal, state, county and municipal governmental agencies administer several programs. Private foundations, investors, banks and lending institutions support the development of bricks and mortar projects as well. Each source has its own set of rigorous regulations.

Most often, funding is awarded competitively after the review of various project documents submitted with the funding application. The project sponsor assumes the risk that development fees advanced may not be reimbursed. The housing development process is complicated, time consuming and not for the faint of heart. Teaming with an experienced consultant and/or developer is highly recommended. The following is a very brief description of funding sources and programs for housing development.

The **development costs** include all expenses incurred prior to construction such as architectural, engineering and legal fees. **Carrying charges** comprise building permits, insurances, property taxes and expenses incurred prior to and during construction. A contract for sale or similar legal document constitutes **evidence of site control** indicating that the developer has possession of the property once the project is funded.

A budget, referred to as a **Pro-Forma**, delineates the costs and sources of funding for the capital expenses to acquire, construct or renovate the housing. **Funders** require a credible description of income and expenses to justify that the rents can support the facility's operations. A **social services** plan explains what services will be available and how they will be funded.

FEDERAL FUNDING

Federal Department of Housing and Urban Development (HUD)

Region II
Jacob K. Javits Federal Building
26 Federal Plaza
New York, NY 10278

212.264.8000

The Federal Department of Housing and Urban Development (HUD) is the primary federal agency promoting housing opportunities for people of low and moderate incomes. HUD administers several programs directly to not-for-profit and for-profit housing developers, and indirectly through state, local public housing authorities, counties, as well as Housing and Mortgage Finance Agencies to support the creation of affordable housing for people with special needs.

With federal dollars, HUD funds various initiatives such as the **Community Development Block Grants**, and **HOME** funds. They publish a **Notice of Funding Availability (NOFA)** to announce the regulations and application processes. Further information about HUD programs can be located at www.hud.gov.

HOME Program

Under the **HOME Program,** HUD allocates funds to eligible state, county and municipal governments to expand the supply of affordable rental housing for families with low-income. HOME funds can only be matched with non-federal funding resources. Participating jurisdictions award HOME funds to meet the community needs as described in their consolidated plans. Generally, funds are utilized for rental assistance or acquisition, rehabilitation and new construction of housing.

Community Development Block Grants (CDBG) provide federal funding to municipalities to help with economic development, housing rehabilitation and neighborhood revitalization. Some municipalities pool their resources and administer the funding through a county consortium.

HUD Section 811 Program for people with disabilities provides rental assistance to subsidize the difference between the Fair Market Rent and the amount the residents can afford.

STATE FUNDING

NJ Department of Community Affairs (DCA) Division of Housing and Community Resources

609.633.6302

Within the NJ Department of Community Affairs, the **Division of Housing and Community Resources'** mission is to strengthen and revitalize communities through the delivery of affordable housing, supportive services and the provision of financial and technical assistance to communities, local government and community-based organizations. The Department of Community Affairs oversees several federal and state funded programs that promote affordable housing for families with low income, women, persons with disabilities and aged persons. Through its Division of Housing and Community Resources, DCA administers programs for rental assistance, housing rehabilitation, relocation assistance, family self-sufficiency, emergency shelter grants and homelessness prevention, Community Services Block Grant and weatherization programs. The Division assists local groups to sponsor housing through programs that preserve, rehabilitate and expand the housing supply for families of low and moderate income.

New Jersey Housing and Mortgage Finance Agency-Division of Special Needs

The **New Jersey Housing and Mortgage Finance Agency (HMFA)** administers financing and supports programs for service-enriched housing development for people with special needs. They also provide technical assistance and coordination with developers and other state agencies. The agency works to improve housing opportunities for some of New Jersey's most vulnerable residents, including people with developmental disabilities, mental health concerns, the homeless, elderly, people with HIV/AIDS and other under-served communities.

Special Needs Housing Partnership Loan Program (SNHPLP) is collaboration between HMFA, DCA, and DHS/DDD to provide financing to create permanent supportive housing and community residences for individuals with developmental disabilities.

Loan funds may be used for the acquisition, construction and rehabilitation of existing three to four-bedroom homes. The program matches with a municipality's commitment of funds from its Affordable Housing Trust Funds (AHTF). This allows municipalities to leverage their trust funds with the SNHPLP to create much needed affordable housing for special needs populations.

One of the fundamental reasons the SNHPLP was developed was to meet the demands of the state's Olmstead Settlement Agreement. The SNHPLP specifically targets affordable housing opportunities for individuals with developmental disabilities who are leaving state developmental centers, returning home from out-of-state placements, and who need independent housing in the community.

The **Special Needs Housing Trust Fund (SNHTF)** was signed into law in New Jersey in 2005 (P.L. 2005, c. 163) to provide capital financing to create permanent supportive housing and community residences for individuals with special needs. The Trust Fund provides capital financing in the form of loans, grants, and other financial vehicles and investments to eligible non-profit and for-profit developers. Project costs include the acquisition of property, rehabilitation, new construction, or conversion of building(s) into rental apartments/units as well as community residences for people with special needs. Funding for rent, operating subsidies and supportive services must be financed by other sources and is not available from the Trust Fund. The Trust Fund, established as a revolving loan program, has been fully utilized. As loans are repaid, funds will become available again for new projects. Advocates are working to urging public officials to replenish the Trust Fund for additional housing development.

Federal Low Income Housing Tax Credit Program (LIHTC Program)

The Housing and Mortgage Finance Agency (HMFA) administers the federal **Low Income Housing Tax Credit Program (LIHTC)** on behalf of the state. The program provides a dollar-for-dollar reduction in federal tax liability and acts as a catalyst to attract private investment into the affordable housing market. Since its inception in 1986, the federal Low Income Housing Tax Credit (LIHTC) program has helped produce more than 40,000 affordable housing opportunities in New Jersey.

This program has long been considered one of the most successful and efficient federal housing programs ever created to provide the private market with an incentive to invest in the creation or rehabilitation of quality affordable rental housing that enhances the character of our neighborhoods.

HMFA is continuously working to adapt the program's rules in New Jersey to reflect the state's current housing policies and priorities through its Qualified Allocation Plan (QAP). The QAP details the selection criteria and application requirements for both the 9% and the 4% tax credits. Substantial revisions were made to the QAP in 2013 including prioritizing the need to provide permanent supportive housing to the homeless and individuals with developmental disabilities following the Olmstead Settlement Agreement.

For additional information about HMFA's Programs, contact NJHMFA at 609.278.7521 or www.NJhousing.gov.

> **"Just as I saved money for college for my other kids, I started when my son was young to save for his future. I bought life insurance when I was young, and it was affordable. I also set up a special needs trust in my will. "**

OTHER SOURCES OF FUNDING

Federal Home Loan Bank (FHLB)

The FHLB funds the Affordable Housing Program (AHP) that directs member banks to collaborate with developers to utilize this funding in conjunction with other programs such as the LIHTC and CDBG to develop housing for low-income populations. In addition, the Community Investment Program (CIP) provides funding to member banks to be used for long-term projects that create low-income housing.

Community Reinvestment Act (CRA)

Federal law requires that commercial banks have a continuing obligation to assist the credit needs of the local communities that they serve. This law requires evaluation of these financial institutions in meeting the community needs including low- and moderate-income neighborhoods. Often local banks assist housing development through grants or loans www.federalreserve.gov/communitydev/cra_about.htm.

Affordable Housing Trust Funds, Council on Affordable Housing (COAH) and the Mount Laurel Decision - The *Mount Laurel Doctrine* prohibits housing discrimination against the poor by the state and municipalities. In 1975, New Jersey's litigation was one of the first court cases of its type in the nation. It is widely regarded as one of the most significant civil rights cases in the United States. In direct response to this litigation, the New Jersey Legislature enacted the Fair Housing Act in 1985. This created the Council on Affordable Housing (COAH) to assess the statewide need for affordable housing, allocate that need on a municipal fair share basis, and to review and approve municipal housing plans that develop housing for people of low and moderate income. After a series of legal challenges by the NJ Fair Share Housing Center (www.fairsharehousing.org) the courts determined that COAH was not properly executing its responsibilities and that towns must use the trial courts to get their housing plans approved. In addition, it was determined that **municipal affordable housing trust funds** are to be spent on affordable housing development. These funds are accumulated at the municipal level through an assessment of a developer's fee when building permits are issued. Families should reach out to their mayors and local housing officials to ask about the municipal housing plans and encourage municipalities to use trust fund dollars now and in the future, along with their zoning powers, to provide affordable housing for people with special needs.

Advocacy

There are many challenges associated with securing supportive housing. New Jersey needs additional resources. The numbers speak for themselves. According to 2013 data, in New Jersey there are approximately 120,000 adults or adult households receiving Social Security's Supplemental Security Income (SSI) benefits for disabilities and receiving less than $800 per month. Of that total, approximately 40,000 receive housing assistance from the federal or state government in the form of housing units or housing vouchers. Furthermore, these numbers do not reflect people in institutions, prisons and homeless shelters, as well as those living with aging parents, and are a sobering reminder of the many thousands of New Jerseyans living with disabilities on very low incomes in need of independent, safe, decent housing with supports.

The surest way to expand opportunities in housing and services for people with disabilities is through good old fashioned advocacy. Families, individuals and providers should regularly communicate with lawmakers to request that resources for support services, affordable housing development, rental vouchers or other subsidies be available for people on very low incomes. Please use the SHA or other disability advocacy organizations' websites to become aware of federal and state advocacy initiatives. Feel free to contact these organizations to learn more about the most urgent initiatives. You can sign on to help support petition drives, contact public officials and write letters to the editor of local media publications on these issues. Your voice in Trenton and Washington DC is essential to a effective supportive housing industry. The Supportive Housing Association calls for assertiveness, networking and advocacy to achieve these objectives. Our collective and coordinated efforts can create change.

> **"The surest way to expand opportunities in housing and services for people with disabilities is through good old fashioned advocacy."**

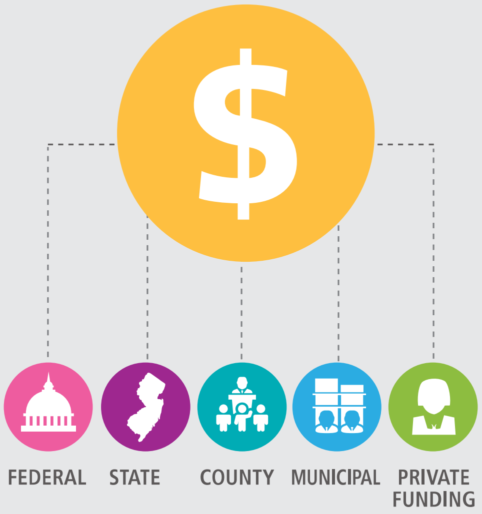
Conclusion

We hope the guide encourages creative thoughts about how people can live more independently despite low incomes, how families can contribute without jeopardizing a loved one's public entitlements, and the importance of full or part-time employment for those able to work so they can better afford a more robust lifestyle. Resources, both housing and services, exist; finding them and using them productively is what we hope you will achieve, now and in the future, as you use the information compiled for you in these chapters.

To secure supported housing for her daughter, one mom describing her journey said, "It is like traveling to the Wild, Wild West." In many ways, she has been blazing the trails where maps were unavailable. Resources are scarce. Rules and regulations are abundant and cumbersome. The outcome for her daughter will ultimately be worth the effort.

We are grateful for all who have shared their experiences and hope that this Housing Resource Guide helps you identify and secure these critical resources to find a place you or your loved one can call home.

FUNDING FOR THE CREATION OF SUPPORTIVE HOUSING



Given the high cost of housing, funding to support the creation of supportive housing generally comes from multiple sources. These sources may include a mix of federal, state, county, municipal and private funding sources. Individuals and parents have joined in large and small groups to establish their own non-profit organizations to sponsor the development of housing units for people with disabilities.

Understanding the intricacies of government funding to creating housing involves a great deal of research. This brief review does not depict the whole range of opportunities. New funding sources are introduced and the regulations are frequently revised. There is much to learn before embarking on housing development. A good place to start is by joining a trade organization such as the Supportive Housing Association (SHA) and collaborating with experienced housing developers.

About the Author

DEBORAH WEHRLEN

While there were many contributing writers for the Housing Resource Guide, Deborah Wehrlen served as the primary author. Deborah Wehrlen has over forty years of experience in establishing innovative residential supports and developing affordable housing in New Jersey. Prior to establishing her consulting business in 2002, Deborah Wehrlen was the director of the New Jersey Division of Developmental Disabilities (DDD). In this policy-making position, she advanced efforts to develop in home supports, fund deinstitutionalization and downsize the state operated developmental centers.

Deborah Wehrlen was also employed as the residential director and then the executive director with The Arc of Monmouth, establishing housing for over 85 people. Currently as a consultant in DTW Consulting Group LLC, Deborah Wehrlen has worked with several organizations to obtain funding, implement supported housing and residential supports for persons with disabilities needing permanent supported housing. She has secured millions of dollars of capital and operating funds from various governmental funding sources, grants, capital campaigns and private foundations. During her entire career, Deborah Wehrlen has strongly advocated for quality services and best practices to support individuals with developmental disabilities and their families.

Further Acknowledgements

The following individuals providing ongoing advice and management to the development and finalization of this guide:

- Gail Levinson, Executive Director, SHA
- Ed Murphy, Director of Operations, SHA
- Suzanne Buchanan, Psy.D., BCBA-D, Executive Director, Autism New Jersey
- Jessica Barkosky, Manager of Communications & Marketing, Autism New Jersey
- Deborah Charette, Coordinator of Public Policy, Autism New Jersey
- Amy Smith, Director of Information Services, Autism New Jersey

We would like to thank the many stakeholders including the NJ Council on Developmental Disabilities, The Arc of New Jersey, Disability Rights New Jersey, the NJ Department of Human Services, the New Jersey Housing & Mortgage Finance Agency and several parents and consumers for their review and feedback on the guide before its final publication.

We also express appreciation to Maria Fischer, Esq., a partner in the firm of Hinkle, Fingles, Prior & Fischer, P.C., Attorneys at Law, who contributed considerable information regarding legal and regulatory issues within this guide.

Thank you to Joan Migton for her attention to detail by providing copy editing.

Finally, thanks are due to members of the SHA Family and Consumer Housing Workgroup whose voices gave rise to this publication.

State agencies, organizations and individuals reviewing the guide have provided much appreciated feedback but have not endorsed its content.

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Appendix

ADDITIONAL RESOURCES

Affordable Housing Resources

- **NJ Housing and Mortgage Finance Agency (HMFA)** *(For help with mortgages and housing resources)*
  800.NJ.HOUSE
  609.278.7400
  www.nj.gov/dca/hmfa
- **NJ Guide to Affordable Housing by County** www.state.nj.us/dca/divisions/codes/publications/developments
- **HUD: US Department of Housing & Urban Development** *(Rent Information)*
  www.portal.hud.gov/hudportal/HUD?src=/states/new_jersey
- **NJ Public Housing Authorities for Section 8 and Public Housing**
  www.hud.gov/offices/pih/pha/contacts/states/nj.cfm

Affordable Housing Subsidies and Resources

- **Housing Choice Vouchers**
  www.state.nj.us/dca/divisions/codes/publications/developments.html
- **Housing Choice Voucher (Section 8) housing inventory** www.portal.hud.gov/hudportal/HUD?src=/states/new_jersey
- **HMFA's Housing Resource Center** www.NJHRC.gov
- **Supportive Housing Connection** www.state.nj.us/humanservices/providers/housing
- **Low Income Housing Tax Credit Locations** www.huduser.org/DATASETS/lihtc.html

Assistive Technology to Support Independence

Technology - Advances in technology offer many options for people to live with less dependence upon caregivers. Assistive Technology refers to any device to improve the functional capabilities of a person with a disability. These tools can be simple or complex.

- **Assistive Technology Advocacy Center (ATAC)** *Advancing Opportunities' Technology Lending Center (TLC) features a wide variety of assistive technology including computer access technology, communication devices, adapted toys and an impressive array of adaptive equipment used for daily living.*
  888.322.1918
  www.assistivetechnologycenter.org
- **Coleman Institute for Cognitive Disabilities** *University of Colorado*
  3825 Iris Ave., Suite 200, Boulder, Colorado 80301
  www.cu.edu/ColemanInstitute/agenda.html
- **RESNA**
  The Technical Assistance Project is a sponsored project of the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). RESNA continues to operate the Technical Assistance Project under a grant from the Rehabilitation Services Administration, U.S. Department of Education. The RESNA Technical Assistance Project Resource Guide provides information about assistive technology and home modifications. The guide covers definitions, laws and guidelines, initiatives from the Assistive Technology Act grantees, advocacy, financing, modification, and research resources, accreditations, online courses, and a bibliography. www.resna.org
- **Temple University** www.disabilities.temple.edu/tech
- **Your ReSource** *is a not-for-profit organization, affiliated with Goodwill Industries of Southern Jersey and Philadelphia that collects durable medical equipment and redistributes it to people in need.*
  8 Industry Court, Ewing, NJ 08638
  609.530.1513
  www.yourresourcenj.org
- **Home Link Technologies** *develop Smart home technology to promote independent living.*
  www.homelinktechnologies.com

Building Design to Support Independence

- **National Resource Center on Supportive Housing and Home Modification** www.homemods.org
- **Northeast ADA & IT Center** www.northeastada.org
- **TechConnections** www.techconnections.org

Building Design Information to Support Specific Needs

- **Making Homes that Work A Resource Guide for Families Living with Autism Spectrum Disorder + Co-occurring Behaviors** *George Braddock & John Rowell*
- **Developing Housing for the MS Community - Partnering with Developers to Create Housing Opportunities** *Ken Regan & Candice Baldwin*
- **Moving Out: A Family Guide to Residential Planning for Adults with Disabilities** *Dafna Krouk-Gordon & Barbara D. Jackins*
- **Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders** *Urban Land Institute Arizona, Southwest Arizona Research and Resources Center & Arizona State University*
- **Renovating Dwellings for Basic Access: A Guide for Construction Professionals**
  www.silcga.org/wordpress/wp-content/uploads/2015/01/Renov-Tool-revised.pdf
  www.iacc.hhs.gov/events/2011/091511/homes_that_work_091511.pdf

Developmental Disability Agencies that are Federally Mandated

- **Disability Rights New Jersey (DRNJ)** www.drnj.org
- **New Jersey Council on Developmental Disabilities** www.njcdd.org
- **The Elizabeth M. Boggs Center on Developmental Disabilities** www.rwjms.rutgers.edu/boggscenter

Disability Specific Organizations

- **Arc of New Jersey:** www.arcnj.org
- **Asperger Autism Spectrum Education Network (ASPEN):** www.aspennj.org
- **Autism New Jersey:** www.autismnj.org
- **Autism Speaks:** www.autismspeaks.org
- **Brain Injury Alliance of New Jersey:** www.bianj.org
- **Cerebral Palsy of North Jersey:** www.cpnj.org
- **Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD):** www.chadd.org
- **Cystic Fibrosis Foundation:** www.cff.org
- **Epilepsy Foundation of New Jersey:** www.efnj.com
- **Family Support Center of New Jersey:** www.FSCNJ.org
- **Learning Disability Association:** www.ldanj.org/
- **Mental Health Association in New Jersey:** www.mhanj.org
- **Muscular Dystrophy Association:** www.mda.org
- **National Multiple Sclerosis Society:** www.nationalmssociety.org
- **National Alliance on Mental Illness of New Jersey:** www.naminj.org
- **New Jersey Association of the Deaf:** www.deafnjad.org
- **Spina Bifida Resource Network:** www.spinabifidaassociation.org

Employment

- **New Jersey Department of Labor, Division of Vocational Rehabilitation (DVR)**
  www.jobs4jersey.com/jobs4jersey/jobseekers/disable/
- **NJWINS** - *The Family Resource Network's*
  New Jersey Work Incentives Network Support (NJWINS) *program assists Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries to start, continue or increase work efforts while maintaining benefits for as long as they are needed.* www.njwins.org

Home Sharing

- www.nasddds.org/publications/nasddds-titles-for-purchase/shared-living-guide
- www.ancor.org/resources/best-practices
- www.nationalsharedhousing.org
- www.homesharing.org

Housing First

- www.endhomelessness.org/pages/housing_first
- www.csh.org/toolkit/supportive-housing-quality-toolkit/housing-and-property-management/housing-first-model
- www.endhomelessness.org/blog/entry/data-points-housing-first-decreases-re-offending-among-homeless-individuals#.VQTLmmTF90w

Information and Referral Sources

- **Autism New Jersey** *is the largest statewide network of parents and professionals dedicated to improving lives of individuals with autism spectrum disorders.* 800.4.AUTISM www.autismnj.org
- **NJ Department of Human Services**
  Division of Disability Services (DDS)
  888.285.3036
  609.292.7800 TDD 609.292.1210
  www.state.nj.us/humanservices/dds
- **The Division of Disability Services (DDS)** *serves as a resource for all people seeking disability-related information in New Jersey. Information and Referral Specialists are available to confidentially discuss issues and provide information, assist with problem solving and refer to appropriate agencies or services. Annually, they publish NJ Resources, a guidebook on service delivery.*
  www.nj.gov/humanservices/dds/documents/RD%2015.Web.pdf
- **New Jersey Aging and Disability Resource Connection** www.adrcnj.org/
  ADRC provides information and assistance to older persons, adults with physical disabilities, caregivers and professionals looking for services or programs.
- **Centers for Independent Living** *are community-based, individual-driven organizations that provide information and referral, peer counseling, skills training, advocacy and a variety of services based on individual needs.*
  www.state.nj.us/humanservices/dds/home/cntrindlivindex.html
- **211 for Information and Referral** www.211.org
  877.652.1148
  Spearheaded by The United Way, 211 is an easy-to-remember telephone number to connect people regarding community services and referral agencies in local communities nationally. 2-1-1 is a growing national model for information and referral. NJ 2-1-1 can help you find resources in the community for utility assistance, housing, social services, vocational training programs, senior services, medical insurance, and more.
- **New Jersey Helps** *Connects people to various forms of assistance, including housing, through the Department of Human Services and other NJ State partners:*
  www.njhelps.org

Information and Referral from County Resources

- **County Board of Social Services** www.nj.gov/humanservices/dfd/programs/njsnap/cwa/
- **County Office for People with Disabilities** www.state.nj.us/humanservices/dds/home/cntyofficeindex.html

Guardianship

- www.ganji.org/index.htm

Medicaid

- 800.356.1561 www.lwd.dol.state.nj.us/labor/roles/disable/ACDS_list.html

Medicare

- 800.MEDICARE
  800.633.4227
  www.nj.gov/humanservices/dmahs/clients/medicaid

Mental Health Supports

- **National Alliance on Mental Illness New Jersey (NAMI)** www.naminj.org
- **County Crisis Intervention** www.state.nj.us/humanservices/dmhas/resources/services/treatment/mh.html
- **NJ Mental Health Cares** www.njmentalhealthcares.org
  NJ Mental Health Cares has mental health professionals who can link a person to mental health information and referral services at
  866.202.HELP or TTY: 877.294.4356.
- **National Suicide prevention Lifeline** www.suicidepreventionlifeline.org
  1.800.273.TALK (8255)
- www.after55.com

Plan NJ

- www.plannj.org/019D31EE-009863F9.0/SPONSOR%20DIRECTORY%20%204-25-2014.pdf

Protection of Rights and Advocacy

- **Disability Rights New Jersey (DRNJ)** www.drnj.org
  210 South Broad Street, 3rd Floor, Trenton, NJ 08608
  609.292.9742 or 800.922.7233 (NJ Only)
  609.633.7106 TDD

Self-Advocacy

- **NJ Self-Advocacy Project:** www.arcnj.org

Senior Services

- **New Jersey Department of Human Services**
  In 2013, senior supports and services transferred from the Department of Health to the Department of Human Services. The Division of Aging Services constitutes a single point of entry and coordination of care to support people to continue living at home.
- **Division of Aging Services**
  12B Quakerbridge Plaza, P.O. Box 715, Mercerville, NJ 08625-0715 www.state.nj.us/humanservices/doas/home

Shared Living

- **A model contract for Shared Living is available at** www.ancor.org/resources/best-practices
- **A Guide for Shared Living is available at**
  www.nasddds.org/publications/nasddds-titles-for-purchase/shared-living-guide

Special Educational Resources

- **New Jersey Coalition for Inclusive Education:** www.njcie.net
- **New Jersey Department of Education:** www.state.nj.us/education
- **Statewide Parent Advocacy Network:** www.spannj.org
- **IDEAL Group - free Assistive Technology applications for students** www.onlineconferencingsystems.com/ at.htm
- **NJ Department of Education's** *Parental Rights in Special Education* **booklet**
  www.state.nj.us/education/specialed/form/prise/prise.pdf

Statewide Agencies and Resources

NJ Department of Human Services

- **Department of Human Services (DHS)** www.state.nj.us/humanservices
- **Division of Developmental Disabilities (DDD)** 800.832.9173 www.state.nj.us/humanservices/ddd/home
- **Commission for the Blind and Visually Impaired (CBVI)** www.nj.gov/humanservices/cbvi/home
- **Division of the Deaf and Hard of Hearing** www.nj.gov/humanservices/ddhh/home
- **Division of Mental Health and Addiction Services (DMHAS)**
  www.state.nj.us/humanservices/dmhas/resources/servicestreatment/mh.html
- **Division of Family Development (DFD)** www.state.nj.us/humanservices/dfd/home
- **Division of Disability Services (DDS)** 11A Quaker Bridge Plaza Mercerville NJ
  Telephone: 888.285.3036
  TDD: 609.631.4366
  www.nj.gov/humanservices/dds/home/index.html

NJ Department of Community Affairs

- **Department of Community Affairs** www.state.nj.us/dca
- **Division of Housing** www.state.nj.us/dca/divisions/dhcr

NJ Waiver Programs and State Plan Services

- **I Choose Home NJ (MLTSS)**
  www.nj.gov/humanservices/ddd/documents/Documents%20for%20Web/MFP_OP_FINAL8.8.2012.pdf
- **Community Care Waiver**
  www.nj.gov/humanservices/ddd/documents/Documents%20for%20Web/CCW%20Renewal%20FAQs.pdf
- **Personal Assistance Service Program (PASP)** www.nj.gov/humanservices/dds/projects/pasp
- **Personal Preference Program** www.state.nj.us/humanservices/dds/services/ppp
- **Supports Program** www.state.nj.us/humanservices/ddd/programs/supports_program.html

Advocacy and Professional Organizations

- **Alliance for the Betterment of Citizens with Disabilities (ABCD)** www.abcdnj.org
- **Autism New Jersey** www.autismnj.org
- **Corporation for Supportive Housing** *is a national nonprofit organization and community development financial institution that helps communities to create permanent housing with services to prevent and end homelessness.* www.chs.org
- **Fair Share Housing Center** www.fairsharehousing.org/
- **Housing and Community Development Network of NJ (HCDDNJ)** www.hcdnnj.org
- **New Jersey Association of Community Providers, Inc. (NJACP)** www.njacp.org
- **Statewide Parent Advocacy Network (SPAN)** www.spannj.org
- **Supportive Housing Association (SHA)** *a statewide non-profit organization working for the establishment of a strong supportive housing industry in New Jersey serving persons with disabilities* www.shanj.org
- **The Arc of New Jersey** www.arcnj.org

Toolkit Resources and Checklists Readiness Guides

- **Ready? Get Set. Go! Guide to Independence**
  Health checklists developed as part of a framework for transition planning to help youth and their families begin preparations for adulthood at an early age by setting goals and making plans for all levels of development.
  www.nhfv.org/wp-content/uploads/2014/11/Ready-Set-Go-Final-10-2014.pdf

- **Neighbors-** *International publishes several helpful booklets for individuals on independence entitled You and Your Budgets, You and Your Home, Living Your Own Life, You and Your Personal Assistants*
  www.neighbours-international.com/our-books.html

- **The Boggs Center on Developmental Disabilities-** *Getting the Community Life You Want*
  www.rwjms.rutgers.edu/boggscenter/products/GettingtheCommunityLifeYouWant.html

- **Autism Speaks publishes the** *Housing and Residential Supports Tool Kit*
  www.autismspeaks.org/sites/default/files/housing_tool_kit_web2.pdf

- **CSH Toolkit on quality**
  www.chs.org/wp- content/uploads/2013/07/CSH_Dimensions_of_Quality_Supportive_Housing_guidebook.pdf

- *The* **Minnesota Governor's Council on Developmental Disabilities** *publishes a booklet with housing checklists for individuals at* www.mn.gov/mnddc/extra/publications/choice/Its_My_Choice.pdf.

- *The* **Florida Developmental Disabilities Council** *publishes a curriculum assisting people with disabilities who want to find a home of their own* at www.fddc.org/sites/default/files/file/publications/APlaceCurriculum.pdf

- *The* **Florida Developmental Disabilities Council** *publishes a guide to Practical Information About Buying or Renting a Home at*
  www.fddc.org/sites/default/files/file/publications/FindingAHome.pdf

The websites included in the Appendix are shared for informational purposes only. Endorsement should not be implied.

Stop and Ask for Directions

1. GATHER INFORMATION

- Learn the rules and regulations of the services delivery and housing systems.
- Join advocacy and/or support groups to network and obtain information.

2. APPLY FOR SERVICES FROM A VARIETY OF SOURCES

- Apply and maintain eligibility for Social Security and Medicaid benefits.
- Apply for waiver services with the state agency to which you are eligible (such as Division of Developmental Disabilities).
- Locate and apply for Supportive Services and other resources from generic and mainstream sources. For example, apply for food stamps, energy assistance, PADD, meals on wheels and such that can supplement your budget.
- Apply for housing subsidies like Section 8 vouchers and vouchers through the State Rental Assistance Program (SRAP) by contacting public housing authorities and provider agencies. While often these are in short supply, there are multiple places to obtain vouchers or be on a waiting list to obtain one.

3. EXPLORE VARIOUS HOUSING OPTIONS

- Research housing and supportive service options and plan for the best models to suit your needs.
- Are there people with whom you can share resources?
- Determine what supports are needed and where to access them. Assess how many supports are available from friends and family. Seek additional supports from relatives, neighbors, and community connections.
- Decide where and with whom you would like to live based upon access to family/ friends, job/daytime activities, transportation, and needed services.

4. DEVELOP INDEPENDENT LIVING SKILLS

- Learn how to deal with safety and emergency responses such as using the telephone, calling 911, basic first aid responses and how to respond in a fire.
- Use technology like cell phones, GPS, iPods, computers, Skype, Face Time and emergency call buttons.
- Develop independent living skills like meal preparation, taking medications, being independent for hygiene and grooming and/or other ways to meet these needs such as meals on wheels, microwave cooking and electronic reminders for medication administration.

SHA

Supportive Housing Association
of New Jersey

www.shanj.org

908.931.1131 • 185 Valley Street • South Orange, NJ 07079

Community Paratransit Contact Information

Atlantic County Transportation	(609) 645-5910	www.aclink.org
Bergen County Transportation	(201) 368-5955	www.co.bergen.nj.us
Camden and Burlington Sen-Han Transit	(856) 456-3344	www.co.camden.nj.us
Cape May Fare Free Transportation	(609) 889-3700	www.co.cape-may.nj.us
Cumberland Area Transit System	(856) 691-7799	www.co.cumberland.nj.us
Essex County Office On Aging	(973) 618-1280	www.essex-countynj.org
Gloucester County Division of Transportation	(856) 686-8355	www.co.gloucester.nj.us
Hudson County TRANSCEND	(201) 369-4320	www.hudsoncountynj.org
Hunterdon County, The Link	(800) 842-0531 (Voice & TT)	www.co.hunterdon.nj.us
Mercer T.R.A.D.E	(609) 530-1971 (Voice & TT) (609) 275-2929 (Princeton Area only)	www.mercercounty.org
Middlesex County Transportation, AWTS	(800) 221-3520	www.co.middlesex.nj.us
Monmouth County SCAT	(732) 431-6480	www.co.monmouth.nj.us
Morris County (Excluding Jefferson, Kinnelon, Butler, Riverdale, Pequannock, Lincoln Park)	(973) 829-8103	www.co.morris.nj.us
Jefferson	(973) 208-6123	
Kinnelon, Butler, Riverdale, Pequannock, Lincoln Park	(973) 835-8885	
Ocean County Ocean Ride	(877) 929-2082 or (732) 736-8989	www.co.ocean.nj.us
Passaic County Paratransit (excluding Paterson, Clifton, West Milford and city of Passaic)	(973) 305-5756 or -5757 or -5758	www.passaiccountynj.org
Paterson	(973) 881-0058	

Community Paratransit Contact Information

Clifton	(973) 470-2235	
West Milford	(973) 728-2863	
Passaic	(973) 365-5754	
Salem County Transportation	(856) 339-8622	www.salemcountynj.gov
Somerset County Transportation	(908) 231-7115 (800) 246-0547	www.co.somerset.nj.us
Sussex County Transportation	(973) 579-0480	www.sussex.nj.us
Union County Transportation	(908) 241-8300	www.ucnj.org
Warren County Transportation	(908) 454-4044 (866) 594-4044	www.co.warren.nj.us

LogistiCare Reservations

1-866-527-9933

LogistiCare
“Where’s My Ride?”

1-866-527-9934

LogistiCare Delivers Transportation Management that Works. LogistiCare is the nation’s leading manager of medical transportation programs for government agencies, managed care organizations, self-funded insurers, hospitals, transit authorities and school boards. The company currently manages more than 1,000 transportation providers and coordinates more than 18 million trips for more than 6 million people each year.

LogistiCare®

LogistiCare Solutions, LLC

How to Access Non-Emergency Medical Transportation (NEMT)

for

NJ Family Care/Medicaid Clients

Frequently Asked Questions

Q. Who can receive a ride to medical appointments?

A. Rides to medical appointments are for people who are on Medicaid/NJ Family Care and have no other way to get a ride. Your medical problem should not be an emergency.
<u>If you have an emergency call 911.</u>

Q. When should I call to ask for a ride?

A. Call at least **2 business days** before you need a ride to your medical appointment. If you do not call at least **2 business days** before, you may not be able to get a ride.

You can only get a ride with less than 2 days' notice for special medical trips, such as when a person is being released from the hospital or if the appointment is considered to be urgent by your doctor. The number to call is **1-866-527-9933.**

Q. Who decides what time I will be picked up for my ride?

A. LogistiCare will determine the pick-up time based on how long it takes to get you to your medical appointment on time.

Q. Who decides what kind of ride I will get?

A. LogistiCare will ask you about your health and walking ability. Your answers will help us decide what kind of vehicle will be used for your ride.

Q. Who can call to ask for a ride?

A. You, someone in your family, or a person who takes care of you can call for your ride.

Q. How do I get rides for trips that I need to take on a regular schedule, like to dialysis?

A. Tell a LogistiCare customer service person what you need. They will call your medical office and ask them to send us a form that says you need regular rides. We will make sure that you get rides until you or your medical office tells us that you don't need them anymore.

Q. Can I ask for a specific transportation company I prefer to give me a ride?

A. Whenever we can, we will be happy to send the company you prefer for your ride.

Q. What if my ride is late?

A. If your ride is more than 15 minutes late from the pick-up time, you should call the LogistiCare **"Where's My Ride?"** line at **1-866-527-9934**. We will do everything we can to help you.

Q. What if I want to complain about my ride or another part of the service?

A. If you have a problem with your ride or service, call us at **1-866-527-9934**.

How to
Get a Ride

The kinds of rides we provide are:

- For people who can walk without another person's help. (Essex and Hudson Counties only.) If you live in any other county you will need to contact your local county board of social services.
- For people who need assistance walking or are in a wheelchair.
- For people who need a stretcher (not an emergency).

Call 1-866-527-9933 to get a ride to your medical appointment

Remember:

- All rides must be for a medical reason like a doctor appointment or dialysis.
- You must ask for a ride at least **2 business days** before you need it.
- Please have the following ready when you call for a ride:
  - Your NJ FamilyCare/Medicaid ID number
  - Your pick-up address and zip code
  - Name, phone number and address of medical provider
  - Appointment time and date
  - Special transportation needs
- Please be ready and waiting at least **15 minutes** before your ride is scheduled.

Reservaciones de LogistiCare

1-866-527-9933

LogistiCare
"¿Dónde está mi transporte?"

1-866-527-9934

LogistiCare brinda un manejo de transporte que sí funciona. LogistiCare es el principal administrador de programas de transporte médico de la nación que brinda servicios a entidades gubernamentales, organizaciones de atención administrada, entidades auto-aseguradas, hospitales, autoridades viales y concejos escolares. Actualmente, la compañía administra más de 1,000 proveedores de servicios de transporte y coordina más de 18 millones de viajes para más de 6 millones de personas cada año.

LogistiCare

LogistiCare Solutions, LLC

Cómo acceder transporte médico en casos que no son de emergencia (NEMT, siglas en inglés)

para

Clientes de NJ Family Care/Medicaid

Preguntas frecuentes

P. ¿Quién puede obtener transporte a las citas médicas?

R. El transporte a las citas médicas es para personas que tienen Medicaid/NJ Family Care y que carecen de otra manera de ir a sus citas. Su problema médico no debe ser una emergencia.

<u>Si tiene una emergencia, llame al 911.</u>

P. ¿Cuándo debo llamar para solicitar transporte?

R. Llame por lo menos **2 días hábiles** antes de su cita médica. Si no llama por lo menos **2 días hábiles** antes, quizá no pueda obtener transporte.

Si llama menos de dos días antes, sólo puede obtener transporte para viajes médicos especiales, como cuando le dan de alta del hospital o si su médico considera que la cita médica es urgente. Llame al número **1-866-527-9933.**

P. ¿Quién decide a qué hora me recogerán?

R. LogistiCare determinará la hora según el tiempo necesario para que llegue a tiempo a su cita médica.

P. ¿Quién decide qué tipo de transporte obtendré?

R. LogistiCare le preguntará sobre su salud y capacidad para caminar. Sus respuestas nos ayudarán a decidir qué tipo de vehículo se usará para transportarle.

P. ¿Quién puede solicitar el transporte?

R. Usted, uno de sus familiares o una persona que le cuida puede llamar para solicitar transporte.

P. ¿Cómo solicito transporte para viajes que tengo que hacer con regularidad, como a diálisis?

R. Informe a la persona de servicio de LogistiCare lo que necesite. Esa persona llamará al consultorio de su médico y solicitará que nos envíen un formulario indicando que usted necesita transporte con regularidad. Nos aseguraremos de que tenga transporte hasta que usted o el consultorio de su médico nos informe que ya no lo necesita.

P. ¿Puedo solicitar que alguna compañía de transporte que prefiera me brinde el transporte?

R. Siempre que podamos, con gusto enviaremos a la compañía que usted prefiera para su transporte.

P. ¿Qué hago si mi transporte se demora?

R. Si su transporte se demora más de 15 minutos de la hora en que deben recogerle, debe llamar a la línea **"¿Dónde está mi transporte?"** de LogistiCare al **1-866-527-9934**. Haremos todo lo posible para asistirle.

P. ¿Qué hago si deseo quejarme sobre el transporte u otro aspecto del servicio?

R. Si tiene algún problema con su transporte o servicio, llámenos al **1-866-527-9934.**

Cómo obtener transporte

Los tipos de transporte que brindamos son:

- Para personas que pueden caminar sin la ayuda de otra persona. (Sólo en los Condados Essex y Hudson.) Si vive en cualquier otro condado, necesitará comunicarse con la junta local de servicios sociales del condado.
- Para personas que necesitan ayuda para caminar o que están en silla de ruedas.
- Para personas que necesitan una camilla (debe ser en casos que no son de emergencia).

Llame al 1-866-527-9933 para obtener transporte a su cita médica

Recuerde:

- Todos los viajes deben tener motivos médicos, como una cita con su médico o diálisis.
- Debe solicitar el transporte por lo menos **2 días hábiles** antes de que lo necesite.
- Por favor tenga lo siguiente a la mano cuando llame a solicitar transporte:
  - Su número de identificación de NJ FamilyCare/Medicaid
  - La dirección y código postal de onde le recogerán
  - Nombre, número telefónico y dirección del proveedor médico
  - Hora y fecha de la cita
  - Necesidades especiales de transporte
- Por favor esté listo y esperando al menos **15 minutos** antes de la hora de llegada programada de su transporte.

Transition Tool Kit

For Families on the Journey from Adolescence to Adulthood

AUTISM SPEAKS® FAMILY SERVICES

AUTISM SPEAKS®

It's time to listen.

The Transition Tool Kit is designed to assist families of individuals with autism on the journey from adolescence to adulthood.

ACKNOWLEDGEMENTS

Autism Speaks would like to extend special thanks to the Parent Advisory Committee for the time and effort that they put into reviewing the Transition Tool Kit.

PARENT ADVISORY COMMITTEE

Dan Aronson
Liz Bell
Sallie Bernard
Michele Pierce Burns
Liane Carter
Marc Carter
Claire Dees
Susan Logan Evensen
Kathy Mannion
Denise Resnik
Laura Shumaker
Frank Turner
Jennifer Zarrilli

PROFESSIONAL ADVISORY COMMITTEE

Dan Baker, Ph.D.
Director, Community Positive Behavior Support,
Transition and Supported Employment Projects
Associate Professor of Pediatrics
Boggs Center on Developmental Disabilities
Robert Wood Johnson Medical School, UMDNJ

Jan Blacher, Ph.D.
Founding Director, SEARCH Family Autism Resource Center
Distinguished Professor of Education,
UC Presidential Chair
Graduate School of Education,
University of California, Riverside

Susan L. Connors, M.D.
Instructor, Harvard Medical School
Assistant Physician, MassGeneral Hospital for Children
Lurie Family Autism Center/LADDERS

Janet Farmer, Ph.D., ABPP
Professor and Director of Academic Programs
Thompson Center for Autism & Neurodevelopmental Disorders
University of Missouri

Peter Gerhardt, Ed.D.
Founding Chair of the Scientific Council,
Organization for Autism Research

Jeri Kendle
Social Enterprise Strategist, Former President
Southwest Autism Research and Resource Center (SARRC)

Robin Martin Marsh, Ph.D./NCSP
Senior Continuing Education Coordinator
Thompson Center for Autism & Neurodevelopmental Disorders
University of Missouri-Columbia

Caroline I. Magyar, Ph.D.
Associate Professor of Pediatrics
University of Rochester Medical Center

Shana Nichols, Ph.D.
Owner/Director,
ASPIRE Center for Learning and Development

Diane Osaki, OTR

Valerie Paradiz, Ph.D.
Director, Valerie Paradiz LLC
Director, Autistic Global Initiative
Parent and self-advocate

Mary Ann Powers, Ph.D., BCBA-D
Senior Behavior Analyst
Coryell Autism Center

Stephen Shore, Ed.D.
Assistant Professor of Education
Adelphi University

Paul Wehman, Ph.D.
Chairman, Division of Research, Department of Physical Medicine and Rehabilitation
Director, Autism Center for Excellence
Director, Rehabilitation Research and training Center
Virginia Commonwealth University

Nicole Weidenbaum, M.S.Ed., SAS
Executive Director
Nassau Suffolk Services for Autism (NSSA)

FAMILY SERVICES COMMITTEE

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Parent

Sallie Bernard*
Parent
Executive Director, SafeMinds

Cuong Do*
Parent

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Licensed Psychologist, Developmental Assessment & Intervention Center

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Parent

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Parent

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Founding Attorney, Mayerson & Associates

Kevin Murray*
Parent

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Autism Consultant

Danny Openden, Ph.D., BCBA-D
President and CEO, Southwest Autism Research and Resource Center (SARRC)

Valerie Paradiz, Ph.D.
Director, Valerie Paradiz LLC
Director, Autistic Global Initiative
Parent and Self-advocate

Lori Rickles
Parent

Stuart Savitz
Parent

Paul Shattuck, M.S., M.S.S.W., Ph.D.
Leader, AJ Drexel Autism Institute Research Program Area on Life Course Outcomes

Stephen Shore, Ed.D.
Assistant Professor, Special Education, Adelphi University

Michelle Smigel
Parent

*Autism Speaks Board Member
**Chairperson – Autism Speaks Board of Directors
Parent – Indicates Parent of a Child with Autism

We wish to express our appreciation and gratitude to all of the adolescents and young adults with autism spectrum disorders and their families for their perseverance and inspiration.

Autism Speaks thanks the following supporters whose generous contributions helped to fund Version 1.0 of the Transition Tool Kit in 2011:

- Bank of America

- NYSE Euronext Foundation

- MassMutual Financial Group

- The Karma Foundation

- Susan Logan Evensen and Peter Evensen

- Jenny and Joe Zarrilli

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Introduction

The future can often seem uncertain for a young adult with autism. It may be hard for you to imagine your child out in the world, or what he or she will do once the school bus is no longer arriving each morning. Some parents find the thought of the transition process overwhelming. Many families have spent years researching, negotiating and advocating for services and supports to maximize their child's potential during his or her school years. And the thought of doing this again with a whole new system can seem daunting.

> To ease your fears and help you start developing your child's transition plan, you have come to the right place!

As overwhelmed as you might be, try to be positive when thinking about the future. Take a look back and think about all of the strides that your child has made so far, and how much you have learned along the way. One lesson you may have learned over and over is the importance of being proactive.

Keep in mind, too, that many others have traveled this road before you, and lots of information and resources have been developed to help you along the way. Additionally, experts in the field have researched and investigated the process and we have compiled a great deal of this information and many of these resources into this guide. The best news is that autism awareness is continuing to generate more opportunities for growth in the transition process, which can lead to more opportunities for young adults with autism like your child!

> The guiding principle that we used in developing this kit is that all individuals with autism, regardless of the level of support needed, should be able to live a life filled with purpose, dignity, choices and happiness.

As parents and caregivers, we all want our children (those living with or without autism) to be happy and to live fulfilling lives. It is important to remember that what constitutes happiness or fulfillment for a person is specific to that individual. All young adults living with autism have their own unique strengths and challenges, as well as their own specific likes and dislikes. So what may be an appropriate or desired employment, housing, postsecondary education or community involvement option for one individual may not be the right fit for someone else.

This kit will provide you with suggestions and options for you to consider as you set out on this journey toward finding your child's own unique path to adulthood.

With the importance of finding your child's own specific path in mind, the development of self-advocacy and independent living skills is highlighted throughout this kit. We have broken the kit down into different sections. At the end of the kit, we have provided resources specific to each section. Since the transition process is different in each state, we have also developed timelines for each state, with state agency information that may be helpful to you throughout this process.

When it comes to transition planning, it can be helpful to start thinking about the future as early as possible. Some parents even start the transition conversation with their child's school by age 12 or 13. And while it is never too early to think about the future of your child, if your child is older and close to finishing high school or aging out of the school system, rest assured that it is also never too late!

It can also help to work backwards. Think about where you see your child in the future based on his or her strengths, challenges, abilities and preferences. What type of job will he or she have? Where will he or she live? The transition plan should be developed and then adjusted through the years with these ultimate goals in mind. Where do you see your child in ten years? To get there, where do you see him or her in five years? Two years? Six months? Working backwards can help you stay on track and take the necessary steps now to get to the future you and your child dream of.

Remember that all roads do not lead to the same place. The path will be different for each family, but the goal remains the same: that your young adult with autism will lead a fulfilling and happy adult life. With some planning and collaborative efforts with your child, family members, educators and other professionals involved in his or her life, you will succeed in accomplishing this goal!

Happy reading!

Self-Advocacy

The most important place to start the transition process is with your child who is now or will soon be an adolescent or young adult. His or her hopes, dreams and desires should drive the process.

Some individuals with autism can verbally communicate their goals and ideas for their adult lives. These conversations should serve as starting points to develop their transition plans.

Some adolescents may not be developmentally ready to tackle the transition process. Others may be unable to express their wants and needs for the coming years due to limited communication skills. This is particularly challenging for families, as many want to provide their adolescent with the life that he or she wants.

Remember that transition planning is not a single conversation, but rather a process that will evolve over time.

The transition process will take time. It is important that you work with your adolescent to provide the communication, self-help and self-advocacy skills that he or she needs in order to be an active participant in the process.

What is Self-Advocacy?

For most of your child's life, you have probably been doing the advocating – making decisions for him or her and making sure your child has gotten what he or she needs, wants and deserves. However, as individuals with autism age, they will need to learn to advocate for themselves to the best of their ability. Helping adolescents with autism to develop a sense of self will aid in the transition process and will develop a skill that will benefit them throughout their lives.

> **Self-advocacy plays a vital role in nearly every aspect of life…**
> The more self-aware people on the spectrum become, the more they can be players in advocating for their own comfort, happiness and well-being.
>
> - Valerie Paradiz, Ph.D.,
> *The Integrated Self-Advocacy Curriculum*

Self-advocacy involves speaking up for yourself, asking for what you need, negotiating for yourself, knowing your rights and responsibilities and using the resources that are available to you. It is never too early to begin to teach self-advocacy skills. Learning to ask for help is another step in developing self-advocacy skills. In order to do this, the individual must be able to identify that there is an obstacle or difficulty, and then seek out assistance to have the issue resolved.

Disclosure

It is important to note that part of self-advocacy may involve disclosure. Therefore, it is important that an adolescent be told that he or she has autism. Be sure to share with your child or adolescent that autism has provided him or her with strengths, as well as certain challenges. Each person will react differently, but many individuals with autism have shared that they were relieved to know that there is a label for what may make things more difficult. These individuals realized that their challenges are not due to any fault of their own, but only because their brains work differently. It may be helpful for the individual to join a support or social skills group for those with similar abilities. You may be able to find groups in your area in the Autism Speaks Resource Guide at **AutismSpeaks.org/resource-guide**.

Matthew is a 15-year-old boy with autism and limited verbal skills.

Matthew and his family frequently go to the local ice cream shop. Matthew's dad worked with him to teach him to order his own ice cream. Matthew was fairly competent at doing this, and so his dad suggested that he go into the shop by himself and order. Matthew's dad would watch through the store front window. Matthew went in with his money and ordered his ice cream. When Matthew came out of the store, he was unhappy because he didn't get the mint chocolate chip ice cream that he had asked for. Matthew's dad guided him through his options. They identified three options: Matthew could get very upset because he didn't get the ice cream flavor that he wanted and have no ice cream; he could eat the ice cream that he got; or he could go back into the store and let the server know that he had asked for mint chocolate chip. Matthew decided to go back into the store. Before Matthew went in, his dad helped him practice what he needed to say. Matthew was very nervous, but he went back into the shop. He showed the server the ice cream he got and he told him that he wanted mint chocolate chip. The server apologized for the error and gave Matthew the mint chocolate chip that he had wanted. Matthew was so happy to have his mint chocolate chip ice cream, and his dad was very pleased with Matthew's new found self-advocacy skills.

How Do We Teach Self-Advocacy Skills?

Self-advocacy should be taught throughout a person's lifetime. It can start in small ways by teaching an individual to make choices. Gradually, more advanced skills such as those involving negotiations and disclosure should be added to the curriculum if appropriate. Teaching self-advocacy skills will be a process and it will take time to acquire these skills.

It is important to teach your child or adolescent about the decision-making process, i.e. clearly defining the decision, weighing pros and cons and learning from each choice for next time. Start with decisions as simple as what clothes to wear each day. You can eventually build up to decisions about making his or her own schedule, all the way up to decisions like what therapists to work with and what topics should be discussed at an IEP meeting.

There are several tools that are available to help you and your child think about what he or she wants and build the skills necessary to communicate his or her desires for the future. See the Resource section of this tool kit for more information.

Person-Centered Planning

As mentioned, the development of the transition plan should be driven by your child's desires, preferences, strengths and challenges. This is the theory behind person-centered planning.

The process usually starts with an initial team meeting to identify opportunities for the focus person to participate in the community, find employment or postsecondary education and live as independently as possible. To the best of his or her ability, your child should play a central role in the meeting. He or she should even choose who to invite to this meeting – this might be family members, friends, teachers, therapists, etc. The process will provide you and your adolescent with a vision for his or her future and some specific steps to get there. Team members are responsible for implementing the strategies discussed in planning meetings. It is best to prepare your child as much as possible for these meetings so he or she is able to participate as much as possible.

More information about person-centered planning can be found on the PACER Center website and individuals and families can get assistance with person-centered planning by contacting their local University Center on Excellence in Developmental Disabilities or Parent Training and Information Center.

There are several person-centered planning tools available to families. Below is information about two tools that families have found helpful.

PATH: Planning Alternative Tomorrows with Hope

PATH is a person-centered planning and goal-setting tool used to map out a vision of a desirable future for the individual. This tool helps families to think about the future and then work backwards to determine the steps necessary to achieve that future.

PATH, developed by Jack Pearpoint, John O'Brien and Marsha Forest, starts with identifying the individual's "dream" and creating a portrait for the future he or she desires. Based on this ultimate vision, the team then thinks about the goals for 1-2 years ahead, followed by the next few months and continuing to the present. The team next determines the immediate steps that should be taken to achieve that long-term vision.

PATH resources can be found at inclusion.com/path.html.

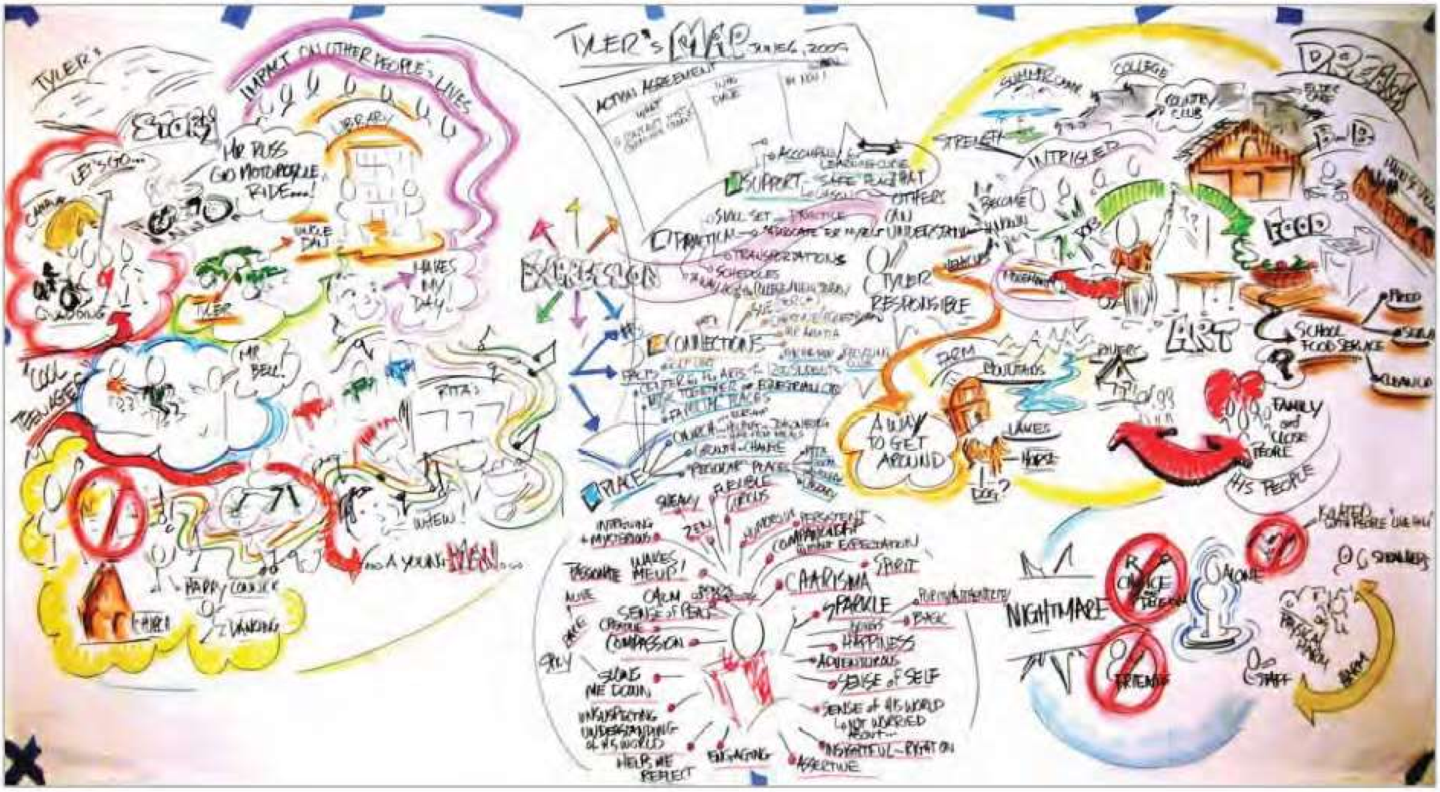
MAPS: Making Action Plans

MAPS is a collaborative action planning process used to help an individual create a plan for his or her own life. During the meeting, the team develops a MAP to serve as the compass that points in the direction of a positive future for the individual with autism. Some essential elements of a MAP meeting include a personal and informal atmosphere, the presence and participation of the focus person and the key actors in his or her life, the discussion of key issues and the development of a concrete plan of action to begin right away.

There are eight questions that should be covered by the facilitator in the MAPS meeting, divided into 2 parts:

PART I

1) **What is a MAP?**
2) **What is the person's story?**
3) **What is your dream?**
4) **What is your nightmare?**



This is an example of map planning.

PART II

5) Who is the person?

6) What are the person's talents, gifts and strengths?

7) What are the person's likes and needs?

8) What is the plan of action?

The answers to these questions should drive the development of a MAP for the individual. Above is an example of the MAP of an adolescent with autism: MAPS information and resources can be found at **inclusion.com/maps.html**.

Conclusion

So when thinking about all aspects of transition planning, keep in mind that teaching your child to advocate for him or herself can make a big difference in helping him or her to secure the supports and services needed to live the life that he or she wants and deserves. It may seem overwhelming to you to think about teaching these important skills, but remember that you can start very small and build upon these skills gradually and to the best of your child's ability. Even just teaching your child that he or she has the right to make or contribute to decisions big and small can go a long way. You may not think your child has the ability to make decisions for him or herself, but remember that even though it may not be easy to communicate them, your child has thoughts and feelings just like any other young adult who wants to shape his or her own future.

Start small, start early and you can succeed in providing your child with a life of happiness and dignity.

Developing Independent Living Skills

In addition to self-advocacy skills, teaching your child skills that will foster his or her independence on the journey to adulthood is also of utmost importance. As autism is a spectrum disorder, every individual is different, and as a result, the independent living skills that will be taught, as well as the pace at which they are taught, will vary significantly across the spectrum. For example, one young adult with autism may ultimately be able to live on his or her own with very little, if any, outside support, while another may require supports and services 24 hours a day, 7 days a week.

As with self-advocacy, starting to develop independence skills to the best of your child's ability at a young age will make a difference in terms of the ease of this transition period. Building these skills little by little is an effective way to teach skills you may not have thought your child would need one day.

Teaching your child independent living skills - home living, personal care, etc. - can be easier said than done, especially if he or she is accustomed to having things done for him or her. You may be rushed, your child may be fighting you every step of the way, you may be too exhausted, but teaching life skills early on is an important part of raising a child with autism.

Ten Ways to Build Independence

This list from Autism Speaks Autism Response Team member Emily Mulligan provides information on how you can help your child increase his or her independence at home, at school and in the community. By introducing these skills early and building block by block, you can help your loved one with autism gain the tools that will allow him or her to be more independent throughout his or her life.

1. Strengthen Communication

If your child struggles with spoken language, a critical step for increasing independence is strengthening his or her ability to communicate by building skills and providing tools to help express preferences, desires and feelings. Consider introducing Alternative/Augmentative Communication (AAC) and visual supports. Common types of AAC include picture exchange communication systems (PECS), speech output devices (such as DynaVox, iPad, etc.) and sign language.

2. Introduce a Visual Schedule

Using a visual schedule with your child can help the transition from activity to activity with less prompting. Review each item on the schedule with your child and then remind him or her to check the schedule before every transition. Over time, he or she will be able to complete this task with increasing independence, practice decision making and pursue the activities that interest him or her. You can learn more about using visual supports by downloading the **ATN/AIR-P Visual Supports and Autism Spectrum Disorder Tool Kit.**

3. Work on Self-Care Skills

This is a good age to introduce self-care activities into your child's routine. Brushing teeth, combing hair and other activities of daily living (ADLs) are important life skills, and introducing them as early as possible can allow your child to master them down the line. Make sure to include these things on your child's schedule so he or she gets used to having them as part of the daily routine.

4. Teach Your Child to Ask for a Break

Make sure your child has a way to request a break – add a "Break" button on his or her communication device, a picture in his or her PECS book, etc. Identify an area that is quiet where your child can go when feeling overwhelmed. Alternatively, consider offering headphones or other tools to help regulate sensory input. Although it may seem like a simple thing, knowing how to ask for a break can allow your child to regain control over him or herself and his or her environment.

5. Work on Household Chores

Having children complete household chores can teach them responsibility, get them involved in family routines and impart useful skills to take with them as they get older. If you think your child may have trouble understanding how to complete a whole chore, you can consider using a task analysis. This is a method that involves breaking down large tasks into smaller steps. Be sure to model the steps yourself or provide prompts if your child has trouble at first! Also, try using **My Job Chart**: a great tool to help both kids and adults learn to complete tasks and manage time.

6. Practice Money Skills

Learning how to use money is a very important skill that can help your child become independent when out and about in the community. No matter what abilities your child currently has, there are ways that he or she can begin to learn money skills. At school, consider adding money skills to your child's IEP and when you are with your child in a store or supermarket, allow him and her to hand over the money to the cashier. Step by step, you can teach each part of this process. Your child can then begin using these skills in different settings in the community.

7. Teach Community Safety Skills

Safety is a big concern for many families, especially as children become more independent. Teach and practice travel training including pedestrian safety, identifying signs and other important safety markers; and becoming familiar with public transportation. The **GET Going pocket guide** has many useful tips to help individuals with autism navigate public transportation. Consider having your child carry an ID card which can be very helpful to provide his or her name, a brief explanation of his or her diagnosis, and a contact person. You can find examples of ID cards and other great safety materials.

8. Build Leisure Skills

Being able to engage in independent leisure and recreation is something that will serve your child well throughout his or her life. Many people with autism have special interests in one or two subjects; it can help to translate those interests into age appropriate recreational activities. The **Autism Speaks Resource Guide** contains activities that your child can get involved with in your community; including team sports, swim lessons, martial arts, music groups and more. For more information about participation in youth and community organizations, see the **Autism Speaks Leading the Way: Autism-Friendly Youth Organizations guide**.

9. Teach Self-Care during Adolescence

Entering adolescence and beginning puberty can bring many changes for a teen with autism, so this is an important time to introduce many hygiene and self-care skills. Getting your teens into the habit of self-care will set them up for success and allow them to become much more independent as they approach adulthood. Visual aids can be really useful to help your teen complete his or her personal hygiene routine each day. Consider making a checklist of activities to help your child keep track of what to do and post it in the bathroom. This can include items such as showering, washing face, putting on deodorant and brushing hair. To stay organized, you can put together a hygiene "kit" to keep everything your teen needs in one place.

10. Work on Vocational Skills

Starting at age 14, your child should have some vocational skills included on his or her IEP. Make a list of his or her strengths, skills and interests and use them to guide the type of vocational activities that are included as objectives. This is also a time to start planning for the future. Consider all of the ways up to this point that you have been fostering your child's independence: communication abilities, self-care, interests and activities and goals for the future. The **Community-based Skills Assessment** (CSA) can help you evaluate your child's current skills and abilities to create an individualized transition plan.

Teaching Daily Living Skills

A 2015 study funded by Autism Speaks and Foundation of Hope, presented at the International Meeting for Autism Research (IMFAR), found that the single most important predictor of positive outcomes in adulthood is the mastery of self-care skills such as bathing, dressing, cleaning and cooking. According to the researchers who tracked children with autism into middle adulthood, these skills prove more important than language, intellectual ability or the severity of autism symptoms when it comes to maintaining employment and achieving life satisfaction.

> **We can't necessarily change IQ or symptom severity, but we can teach daily living skills.**
>
> *Laura Kling, lead researcher, University of North Carolina's TEACCH Autism Program*

One tip for teaching independence skills like self-care is to think of the specific skill you'd like your child to learn and work backwards so that you can break down lessons piece by piece and eventually build to your goal. For example, if you are teaching your child to bathe on his or her own, you can teach him or her step-by-step, gradually lowering your involvement in the process:

1. **Identify when a shower is necessary.**
2. **Turn on the shower.**
3. **Find the desired water temperature.**
4. **Use soap to wash arms, legs and stomach.**
5. **Use soap to wash underarms and private parts thoroughly.**
6. **Wet and use shampoo to wash hair.**
7. **Rinse off soap and shampoo until no more bubbles.**
8. **Turn off the shower.**
9. **Dry off with towel.**
10. **Get dressed.**

Be sure to reinforce your child with positive feedback once he or she masters each step. Motivation is critical to learning and as your child becomes familiar and more competent with new skills, confidence, interest and motivation will increase. Keep in mind that each step might take a long time, some more than others, but the ultimate goal remains the same – to teach your child appropriate self-care and hygiene, an important skill as he or she ages into young adulthood.

Conclusion

Whether your child will move on to postsecondary education, live in a group home or continue to live with you and your family, independence skills are important for individuals with autism of all ages and abilities. You may look at your child and think that the challenges he or she faces will keep him or her from learning any skills that foster independence. At times along the way, you may feel frustrated with the progress or lack thereof, but keep trying and little by little, your child will learn some of these skills. Celebrate the little things and don't dwell on the bumps in the road.

> Be patient. Remember, the transition to adulthood, and teaching the skills that go along with it, is a marathon, not a sprint!

Planning for Transition

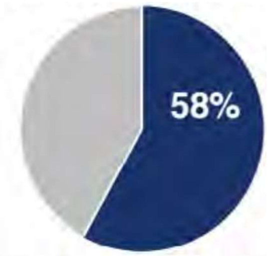
When thinking about the transition process, a great place to start is by consulting with your child's school. Whether it is a school counselor, school psychologist, teacher, case manager or school administrator, a school professional with experience can be very helpful in getting the ball rolling when it comes to planning for the transition to adulthood.

As you have hopefully learned throughout your child's school years, the Individuals with Disabilities Education Act (IDEA) mandates a public education for all eligible children ages 3 through 21 (in most states) and makes the schools responsible for providing the supports and services that will allow this to happen.

It is important to recognize that one of the goals of IDEA is for students to be prepared for employment and independent living.

As you may also know, IDEA requirements are facilitated through the Individualized Education Program (IEP) process. The IEP process must include transition planning services for all special education students at age 16. Ideally, this should begin a few years before that. The funding and services available through IDEA are not available once the student has received a high school diploma or aged out of the school system, so it is important to take advantage of these services when they are available.

Federal law requires schools to have a transition plan for every special education student exiting high school.



of youth with autism had a transition plan by the required age according to their teachers.

Source: National Autism Indicators Report Transition into Young Adulthood. AJ. Drexel Autism Institute, Drexel University.

Transition Planning and the IEP

As outlined in Section 300.43 of IDEA, transition services means a coordinated set of activities for a child that…

1. **Is designed to be within a results-oriented process that is focused on improving the academic and functional achievement of the child to facilitate the child's movement from school to post-school activities, including:**
   - Postsecondary education
   - Vocational education
   - Integrated employment (including supported employment)
   - Continuing and adult education
   - Adult services
   - Independent living or
   - Community participation

2. **Is based on the individual child's needs, taking into account the child's strengths, preferences and interests; and includes:**
   - Instruction
   - Related services
   - Community experiences
   - The development of employment and other post-school adult living objectives
   - If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation

The transition process will continue to evolve, as the transition plan is a work in progress that should be monitored several times a year. You and your adolescent will continue to learn and grow during this process, and you will need to adjust your plan accordingly.

Getting Started: Preparing for the Transition IEP Meeting

As far in advance of the first meeting as possible, you should talk with your adolescent about what he or she may want to do in the future. While out in the community, you can identify different jobs or activities that may be of interest to him or her. It is important to remember that the future may seem like a scary topic for adolescents with autism to discuss and they may not be ready. Some families have shared that they scheduled a specific day of the week and a specific time to discuss future plans with their young adult. This helped provide structure and a time limit on a sensitive subject. It also provided some time for the young adult to prepare for what he or she was going to share during these sessions.

If you have completed a person-centered plan, or if you would like to implement a person-centered approach, the best time to do this is before the transition IEP meeting. The information generated from the person-centered plan should be shared with the transition IEP team prior to the meeting. There are also several tools available to help prepare for the meeting – two such tools are *It's My Choice*, a transition workbook from the Minnesota Governor's Council on Developmental Disabilities; and Chapter 3 of *Keeping It Real* on the Elizabeth M. Boggs Center on Developmental Disabilities website. Both can be found in the resource section of this kit.

> **Life for all adults, autistic or not,** is very much about this ongoing process of identifying and making adjustments when they need to be made. Every person with autism has a path; making the adjustments is the journey.
>
> *– Valerie Paradiz, Ph.D.*

Assessments

In preparation for the meeting, your school district may also conduct several assessments that should be shared with you and your adolescent in advance. Some of the assessments are outlined below:

Level I Assessment:

- Parents, students and teachers all complete a questionnaire to help them focus on the student's long term career goals
- Helps explore possible areas of interest that can be used in the transition plan
- Should be updated yearly

Level II Assessments:

- Parents, students and teachers provide feedback as to a student's skills and aptitudes when compared to his or her peers
- Can often help pinpoint areas where further skills can be developed

Level III Assessments:

- Student tries out different areas of work in different settings with the proper supports in place (situational assessment)
- Allowed students to get some hands-on work experience and see what they enjoy and in what fields they excel
- Staff on hand assesses the student's response to each environment
- For students who do not perform well on tests or thrive in testing environments

The Community-based Skills Assessment, developed for Autism Speaks through a contract with Virginia Commonwealth University's Rehabilitation Research and Training Center, can help you and your child's team develop a comprehensive personalized transition plan by assessing his or her current skill levels and abilities beginning at age 12 and continuing into adulthood. An app for the CSA is coming soon! Learn more at **autismspeaks.org/csa**.

Preparing Your Adolescent for the Transition Meeting

The transition meeting is a perfect place for your child to work on his or her self-advocacy skills. Making sure that he or she is involved in the transition process is a great way for your child to learn how to express his or her thoughts and feelings about future plans. Topics you may want to review with your child before the meeting include his or her autism, entitlements and ideas for accommodations to help provide the greatest support possible. Make sure he or she understands what an IEP is and what the purpose of the meeting is to the best of his or her ability. For those with limited verbal ability, pictures or written statements may be helpful.

> **Just as with every other subject, it is important to develop a lesson plan and anticipate questions and concerns that students may have as they work on applying their strengths and challenges to create their own customized education.**
>
> - Stephen Shore, Ed.D., *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum*

Just as when transitioning to any other new activity, prepare your child in advance of the IEP meeting and describe its purpose. His or her involvement can take place on a sliding scale of responsibility. Initially and/or for students at a lower cognitive or developmental stage, familiarizing your child with the purpose of an IEP can be sufficient and all that can reasonably be expected. The range of involvement might include the following:

- **The teacher brings the student to the IEP meeting for a brief period of time, encouraging interactions with some or all of the team members. This introduction may be as short as a few minutes where the student just says "hi" to one or two IEP team members or helps pass out materials.**
- **The student prepares a short statement that he or she distributes or reads aloud to the IEP team, indicating strengths and difficulties in school.**

- **After obtaining data from IEP team members prior to the meeting, the student writes sections of the IEP for modification and approval at the meeting.**
- **The student co-presents as an equal member of the IEP team.**
- **The student leads the IEP meeting with support from his or her primary teacher.**

The Transition Meeting

Since your school district is responsible for coordinating transition services for your adolescent, you may want to partner with the school district in advance of the meeting to make sure that any outside agencies or individuals that can offer resources have been invited. As you can imagine, it takes a fair amount of time to coordinate with those who may need to attend the meeting, so you may want to work with your school advisors to start the process as early as possible.

The transition IEP meeting can involve a wide array of people, including:

- **The student (as appropriate)**
- **Parents or guardians**
- **Teachers (special and general education)**
- **School administrators**
- **Related service providers such as speech therapists, behavioral consultants, etc.**
- **Representatives of outside agencies that may provide support to reach post-transition goals such as the state Division of Vocational Rehabilitation**
- **Other individuals who can support your child**

You may feel overwhelmed sitting at a table with all of these people making recommendations about your child's future. Remember, nothing is "written in stone" and the plan continues to be a work in progress. Goals are set in order to move forward and with a proper plan, your child will reach new vistas.

During the meeting, it is important to respect your adolescent's wishes and needs and encourage others to do so as well. Try to model appropriate behavior by addressing questions about your child to your child. If your child is having trouble answering a question, provide visual supports or choices to further encourage him or her to be an active participant in the meeting.

Many parents want to highlight their child's successes, while downplaying struggles. In believing that your adolescent has mastered a skill that may not be possible independently, you are doing him or her a disservice. A mastered skill needs to be done correctly from beginning to end, without prompts or support. This is an important point to keep in mind.

Be prepared to discuss a wide variety of topics at your transition meetings – planning for adulthood requires a focus on employment, housing, community living, postsecondary education, independence and more. Lots of factors go into creating a life that allows your child to be as independent and fulfilled as possible.

Steps for Creating a Transition Plan

Several steps have been outlined that will be important in developing a transition plan:

1. **Describe the student's strengths and present levels of academic achievement and functional performance.**
2. **Develop measurable postsecondary goals based upon the student's strengths and challenges.**
3. **Develop corresponding IEP goals that will enable the student to meet his or her post-secondary goals.**
4. **Describe the transition services needed to help the student achieve his or her desired post-school goals.**

> **Once we started the transition process,** I looked at Stacey's education with a different focus. Although academics are important, I needed to work with her to make choices as to the best possible use of her high school time. Was it more important for her to identify the predicate of the sentence, or to respond when a peer spoke to her? My husband and I started to think about Stacey's education by asking the question "is this a skill or information that she will use when she leaves school?"
>
> *– Jeannette, Mom of Stacey, age 14*

In addition to stating the goals, the transition plan should include logistical information on how the plan will be implemented and monitored, such as: a timeline for achieving goals, responsible people or agencies to help, clarification of how roles will be coordinated and a plan for identifying post-graduation services and supports, including methods to obtain funding to access these.

If you are not in agreement with the transition services proposed, you can try to reach an acceptable agreement with the school district. If this is not possible, you and your family have the right to go to mediation or an impartial hearing.

Diploma Options

As you plan for transition, it is very important to understand the different types of diplomas available to individuals with disabilities in the public school system. Some learners with autism will be able to receive a general high school diploma, while others may work toward an IEP or Occupational Diploma or certificate. The list below outlines some of the different types of diplomas and what opportunities they may provide for postsecondary education. Remember that each state has different options and guidelines for diplomas, so be sure to check in with your school administrators:

High School Diploma: This diploma is awarded to students who have passed required courses and exams in a number of subjects. It is generally accepted for admission everywhere: two- and four-year colleges as well as military and trade schools.

General Education Development (GED) Diploma: This diploma is awarded to students who have passed the GED exam. It is generally accepted by military, trade schools and some junior/community colleges (which sometimes require additional qualifications).

IEP/Local Diploma or Certificate of Completion: This diploma is awarded to students who have reached the goals on their Individualized Education Programs. It is not accepted for admission to any postsecondary degree program without other testing or certification.

Conclusion

Again, long-term transition planning is an ongoing process that reflects the continuing development and changing needs of your adolescent. Given that the process starts in the early to mid-teen years, there needs to be a great deal of flexibility in the plan. Your adolescent will continue to grow and learn throughout his or her remaining school years and beyond, so the plan needs to be flexible and at times altered to meet his or her changing needs and goals.

> **Once the actual plan is completed by the team,** it is a living, evolving document that should be reviewed and updated several times a year to ensure it reflects and meets all of your young adult's needs and adequate progress is being made to that end. By creating a document with outcome-oriented goals that can be measured, you can more efficiently and effectively monitor your young adult's progress.
>
> - *Life's Journey through Autism, A Guide for Transition to Adulthood* from the Organization for Autism Research

Evidence Based Predictors for Post-School Success

Ohio Employment First Transition Framework Evidence Based Predictors Tool

ohioemploymentfirst.org

Predictor One: Collaborative Networks for Student Support

Research shows that youth benefit from having a support network. Both 'formal' (agency based) networks and 'informal' (friends, family, community members) networks enhanced youth success.

Predictor Two: Individualized Career Development

Career Development refers to the process used by an individual to form a work identity. It is ongoing and spans a lifetime. Individualized career development means that the strategies, supports and services are selected to align with how the youth learns and also provides access to careers that reflect the youth's preferences, interests and skills.

Predictor Three: Authentic Community Based Work Experience

During the high school years, participation in real life work experiences that closely resemble adult environments has been identified as a high predictor of successful adult outcomes.

Predictor Four: Social and Social-Emotional Instruction and Skills

Social competencies are critical to successful participation in the adult community life. Employers report that inability to meet the social expectations of the community and workplace remains as a top reason why employees (disabled or not) lose their jobs.

Predictor Five: Academic, Vocational, Occupational Education and Preparation

Youth with disabilities require a well-designed, coordinated, and unique education and preparation program. The program requires aspects of academic preparation as well as vocational/ occupational preparation

Predictor Six: Supporting Parental Involvement and Expectations

Parent, guardian or other caretaker participation is essential to an individual's ongoing success. Involvement means parents/families/guardian are active and knowledgeable participants in all aspects of transition planning. Parental impact also encompasses the expectation of the family.

Predictor Seven: Self-Determination, Independent Living Skills Instruction and Skill Building

A successful adult reflects self-management and direction, often referred to as Self-Determination. Many skills can support the development of self-determination such as the ability to make choices, solve problems, set goals, evaluate options, and take initiative to reach goals, and accept the consequences of actions.

Predictor Eight: Inclusive Practices and Programs

Participation in inclusive settings during the school years provides opportunities to prepare for integration into the adult community. Inclusive practices refer to engagement and participation, not simply access to an environment.

ohioemploymentfirst.org/up_doc/Evidence_Based_Predictors_for_Post_school_Success3_25_15.pdf

Legal Matters to Consider When Planning for the Future

You may have subconsciously avoided the topic of long-term planning for a long time. This is not unusual. You may suddenly feel that you are back to the beginning stages of accepting the diagnosis. It can help to remind yourself that with planning, you will begin to feel much better about what lies ahead!

There are changes when a person with autism reaches the age of majority, which is 18 years old in most states. Parents no longer have the legal rights to which they were entitled throughout their child's youth. This can include accessing confidential health information and school records.

It can be difficult to take the first steps in planning for your child's future. By taking action early on, you can help protect your child's future well-being and rest a bit easier.

Before your child reaches the age of majority, we suggest that you consult with professionals: attorneys, financial planners and others who can help you make critical decisions about your child's future.

Many of these topics involve state-administered programs, and each state sets its own guidelines. You will want to check with your state agencies for guidance.

When planning for the transition to adulthood, there are several important legal matters to think about, including health insurance laws, special needs trusts and more. This section provides an overview of these topics. More information can be found on the Autism Speaks website.

Health Insurance

Obviously a key component to think about for your child as he or she becomes an adult is health insurance. One of the most significant changes in healthcare law that came from the Affordable Care Act of 2010 is that insurers must now cover dependents on a parent or guardian's plan up to age 26, no longer age 18. Insurers cannot deny or restrict coverage based on certain factors about the child's status. To learn whether your plan or policy offers dependent coverage, check the plan materials or ask your insurer or employer.

Another significant change under the Affordable Care Act is that insurers can no longer deny coverage for pre-existing conditions, even if you have been refused coverage in the past. A diagnosis of autism has been treated as a pre-existing condition in many states and under the new law, this will not affect your child's access to health insurance.

The Affordable Care Act also allows states to choose whether to expand their Medicaid programs to low-income adults, many of whom have never been eligible for coverage before. The new law allows states to expand Medicaid coverage to most adults with incomes up to 138 percent of the poverty level. You can learn more about these options and enroll in

Medicaid at **healthcare.gov**. In addition, the Children's Health Insurance Program (CHIP) provides low-cost health coverage to families that earn too much money to qualify for Medicaid. Each state offers CHIP coverage. To learn if your child is eligible for CHIP, you can visit **insurekidsnow.gov**.

Guardianship

In the eyes of the law, even a person with a significant developmental, cognitive or mental health disability is legally permitted to make decisions on his or her own behalf at the age of majority. The only way parents can continue making decisions for their child is to become his or her legal guardian. There are a few options to consider:

Guardianship is a court-ordered arrangement in which one person is given the legal authority to make decisions on behalf of another person whom the court has deemed to be "incapacitated". The guardian's decision-making authority extends to all areas specified by the court.

There are two types of guardians. A **limited guardian** can make decisions in only some specific areas, such as medical care. This may be appropriate if the person with autism can make some decisions on his or her own. A **general guardian** has broad control and decision-making authority over the individual. This may be appropriate if the person has a significant intellectual disability or mental illness and, as a result, is unable to meaningfully participate in important decisions that affect him or her.

With **conservatorship**, a conservator manages the finances (income and assets) of a person with a disability. A conservator has no authority to make personal decisions (medical, educational, etc.) for the person whose funds he or she is managing.

With a **Power of Attorney** (POA), your child will need to appoint you as the authority to make decisions on his or her behalf under agreed upon terms in the legal document. Unlike guardianship, with a Power of Attorney, courts are not involved and the arrangement is often simpler and easier to change. The individual maintains more control over decisions than with a guardianship arrangement and as a result, this option is more common among more independent individuals.

Deciding Whether Guardianship is Necessary

For parents, the decision to seek guardianship can be difficult. You need to protect your son or daughter with autism, but there may be some areas where he or she can make sound decisions.

Fortunately, legal guardianship is not an "all or nothing" proposition. It is possible to carve out some areas where your child can retain important decision-making rights and control of his or her own life. When considering how much authority you need – and how much independence your son or daughter should retain – you should begin with an assessment of the different areas in which your son or daughter may need assistance.

The below list covers some of those areas – for each area, assess whether he or she can do the following:

Medical

- Seek medical care when he or she is sick or injured
- Weigh the risks and benefits of any particular medical procedure that is being proposed
- Understand the need for routine medical care
- Understand that even if a medical procedure is painful or unpleasant, it may still be necessary
- Assess whether a particular medication is desirable, even though it may have unpleasant side effects
- Provide accurate information about his or her medical condition
- Follow medical advice

Education

- Grasp the essentials of his or her learning problems and understand the services needed to learn effectively
- Advocate for him or herself to obtain necessary education services

Finances

- Understand money basics, including the purpose of money, how to count money and how to make change
- Safeguard his or her money so that it is not lost or stolen
- Budget money so that some funds are available to pay expenses at the end of the month

Vocational/Adult Services

- Apply for services from the Department of Disability Services, Department of Mental Health or other agency that serves people with disabilities
- Access necessary services and supports such as job training, employment support or a day habilitation program
- Negotiate with the agency overseeing his or her care to obtain the best possible services

Living Arrangements

- Provide for his or her own physical care and well-being such as purchasing proper food, clothing and shelter
- Live harmoniously in a group setting, respecting others' needs for quiet, privacy and cleanliness

Legal and Decision-making

- Understand the implications of signing documents
- Make sound decisions in important areas such as living arrangements, school and work

Self-care and Safety

- Understand personal safety skills, such as staying out of dangerous areas, not talking to strangers and keeping doors locked
- Know how to summon help in an emergency such as a fire or accident
- Have basic safety skills such as being careful around fires, stoves, candles, etc.

Communication

- Communicate effectively (verbally or by other means)
- Understand that he or she has choices and be able to express them

Even if your son or daughter needs help with any of the above items, you should also consider whether or he or she could be assisted by any means short of guardianship. For example, sometimes a person who needs help to make medical decisions can appoint a health care agent to act on his or her behalf. A person who receives government benefits such as Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) can have a representative payee manage them.

Obtaining Guardianship

To obtain guardianship, an attorney is not legally required, but you may want to consider hiring one with expertise in this area. Each family is unique in that there are many significant choices and decisions to be made in the process and an attorney can help you with those. You can search for an attorney in your area by visiting the Autism Speaks Resource Guide at **autismspeaks.org/resource-guide**.

Conservatorship

Conservatorships must be filed in the Probate Court of Superior Court, in the courthouse where the proposed individual resides based on zip code. Most courthouses use Judicial Counsel forms and local court-required forms. Conservatorship is a lifelong process. The conservator must comply with the court for the lifetime of the individual.

Special Needs Trusts

The information below comes from Autism Speaks' Legal Guide provided by the law firm Goodwin Procter LLP:

A Special Needs Trust is a trust to hold assets for a special needs beneficiary. Such trusts can be used for an individual receiving public benefits, such as SSI or Medicaid, in order to supplement his or her income without impacting eligibility to receive benefits.

A Special Needs Trust can ensure that money will be available for your child throughout his or her lifetime and that such money will not impact his or her access to means-tested benefits. The trustee, often the parent, is designated to manage the trust for the benefit of the child.

There are generally two kinds of Special Needs Trusts:

(1) A Third Party Special Needs Trust is designed to hold property provided by someone other than the special needs beneficiary. A parent, custodial or non-custodial, or anyone else can put money in a trust for the benefit of the individual.

(2) A Self-Settled Special Needs Trust is designed to hold property belonging to the individual.

Does your child need a Special Needs Trust? Here are some things to consider when answering this question:

- Diagnosis is not required.
- Consider whether or not your adult child can manage his or her contracts and finances, and resist fraud and undue influence.
- Consider hiring a lawyer. There are many important choices and decisions to be made in the process.
- The Special Needs Trust needs to stand alone from any other living trust your family may have.
- The trust is irrevocable in your child's name once funded. But the trust owns the assets, not the child.

Support Programs

The Social Security Administration (SSA) has two kinds of benefits for people with disabilities over the age of 18: Supplemental Security Income (SSI) and Social Security Disability Insurance/Disabled Adult Child Benefits (SSDI). In order for your child to qualify for these programs, he or she must meet the Social Security Administration's definition of disabled.

The SSA's definition of disability is: the inability to engage in any substantial gainful activity by reason of medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. (There is an actual number that is used to measure substantial gainful activity and it varies by year.)

SSA will review whether your child's disability is on a list of conditions that are considered "severe" and if the disability would prevent him or her from working for a year or more.

Not all children who receive special education services may be considered disabled under the SSA definition. Even if your family is receiving SSI for your child when he or she is under the age of 18, you will need to go through a redetermination process to maintain his or her SSI benefits as an adult.

To determine if your child meets the criteria, you must submit his or her detailed medical records, along with a list of all current medications, as well as all doctors, hospitals, clinics and specialists that he or she has visited. In addition, he or she will be asked to go through an examination paid for by the SSA. This process can take several months.

Social Security Income (SSI)

SSI is available to people whose disabilities prevent them from gainful employment. In order to be eligible, your child must not have greater than $2,000 in countable resources and must have a limited monthly income.

At age 18, your family's income and resources are not counted, even if your child continues to live at home. The amount of benefits is determined by a number of factors, including where your child lives and what other income he or she may have.

Social Security Disability Insurance (SSDI)

SSDI provides income supplements to people who are restricted in their ability to be employed because of a disability. Unlike SSI, this benefit is available regardless of the individual's income and resources.

Anyone whose disability developed prior to age 22, and whose parent or guardian is either deceased or getting Social Security retirement or disability benefits, may qualify for a form of insurance called Disabled Adult Child Benefits.

Representative Payee

The SSA appoints an administrator called a representative-payee (rep-payee) for all beneficiaries who are incapable of managing their own SSI or SSDI benefits. If you are seeking to become the rep-payee for your child's benefits, you must file an application in person with the SSA. You can be established as a rep-payee without gaining guardianship over your child. If he or she does not have income or resources aside from the Social Security benefits, you may prefer to avoid guardianship appointment and pursue the simpler rep-payee process instead.

It is important that careful records be kept of your child's monthly income and that it be reported on time to the SSA. A copy of everything you send to the SSA should be kept.

Appealing Decisions

If the SSA rejects your child's application for SSI or SSDI benefits, or it simply reduces benefits, you can take several steps to reverse the decision. There are four levels of the appeals process, described below. Beneficiaries have 60 days to file an appeal at each level of the appeal process:

Reconsideration: You may ask for your child's case to be reviewed by the person who originally decided it.

Appeals Hearing: If you are denied benefits again in reconsideration, you can request a hearing before an Administrative Law Judge who will listen to testimony and review any additional documents that may help your child's case. At this hearing, you have the right to bring a representative.

Appeals Council Review: You have the right to appeal the decision of the Administrative Law Judge to the Appeals Council which will review your file but not hear new testimony.

Federal Court: If the Appeals Council rejects your application, you may then file an appeal in the U.S. court system.

Medicaid Benefits

Individuals who qualify for SSI are eligible to receive Medicaid, which pays for a wide array of services for people with disabilities and provides government-funded health insurance for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports.

Medicaid Eligibility:

Categorical: Persons who fit in a specific category for whom federal law permits coverage (age 65 or above, blind, disabled, etc.)

Financial: Persons whose income and assets do not exceed the state threshold

Home and Community-Based Waiver Services

In the past, Medicaid funding was limited to those who live in certain types of facilities. But now, through the use of Medicaid Home and Community-Based Waivers, people with autism and other disabilities can use these funds more flexibly. Waiver services are an option available to states to provide integrated community-based long term care services and supports to qualified Medicaid recipients. The programs "waive" some of the rules of Medicaid to serve children and adults otherwise requiring an institutional level of care who can instead be served at home or in the community.

These programs may provide a combination of both traditional medical services (dental services, skilled nursing services) and non-medical services (respite, case management, environmental modifications, etc.). Family members and friends may be providers of waiver services if they meet the specified provider qualifications.

Each state set its own guidelines.

All states operate HCBS programs for people with developmental disabilities (some states also have specific HCBS waivers for people with autism). Services in HCBS waivers vary across waivers and states but may include respite, employment supports, residential services (e.g. group homes, supported living, etc.), family support and many other community supports. The state Medicaid agency or the state Developmental Disabilities agency is usually responsible for the operation, eligibility and enrollment into these programs – individuals interested in waiver services should contact these agencies to find out about enrolling and/or placing their name on the waiting list.

Other Legal Considerations

- Obtain a state identification card or driver's license from the Bureau of Motor Vehicles.
- Register for Selective Services. (Note that all males, regardless of disability, must register for Selective Service at age 18. They may register at the post office or online at sss.gov.)
- Register to vote.
- Explore options for transportation, including driver's training.

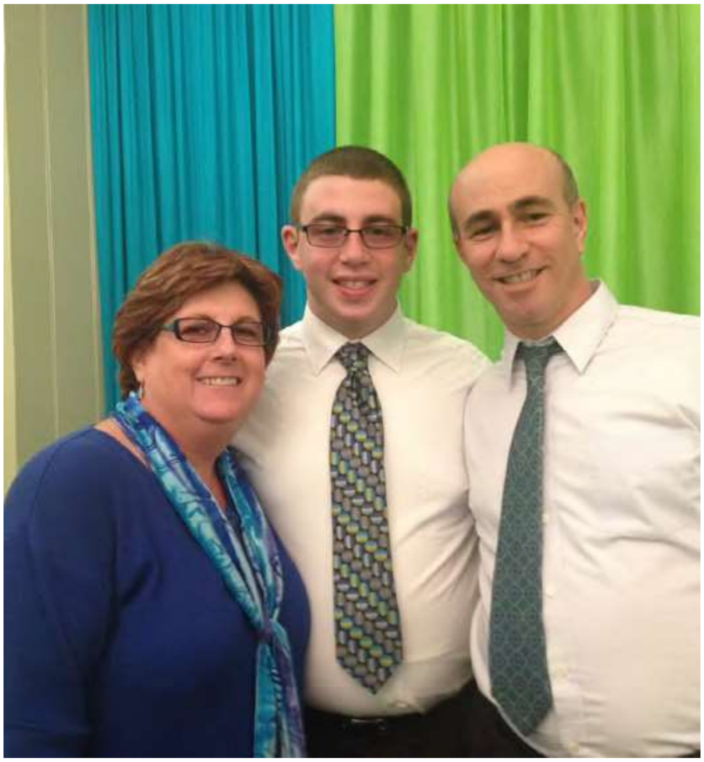
Achieving a Better Life Experience (ABLE) Act of 2014

The Achieving a Better Life Experience (ABLE) Act, passed by Congress and signed by President Obama in December 2014, allows people with disabilities and their families to set up a special savings account for disability-related expenses, similar to the current 529 education savings plans that help families save for college.

Earnings on an ABLE account are not taxed and account funds are generally not considered for the SSI program, Medicaid and other federal means-tested benefits, which generally cap (usually at $2,000) the amount an individual with a disability may save. An eligible individual is someone who becomes disabled before age 26 and (1) receives SSDI or SSI; or (2) files a disability certification under IRS rules.

Expenses made for the benefit of a disabled individual include education, housing, transportation, employment training and support; assistive technology and personal support services; health, prevention, and wellness; financial management and administrative services; legal fees; expenses for oversight and monitoring; funeral and burial expenses; and any other expenses approved under regulations.
It is important to keep in mind that individual states may regulate ABLE accounts differently.

You can learn more about the ABLE Act and check on its status in your state at autismspeaks.org/advocacy/federal/able.



The Letter of Intent

A Letter of Intent is a document written by you (the parent or guardian) or other family member that describes your son or daughter's history, current status and your hopes for his or her future.

You might want to start the letter now and add to it as years go by, updating it when information about your child changes. It is also a good idea to involve your child when writing the letter, so that the letter truly "presents" and represents your child, to the best of his or her ability. The letter is then ready at any moment to be used by all the individuals who will be involved in caring for your son or daughter, should you become ill or disabled yourself, or when you should pass away.

The letter is not a legal document, but it can provide the courts and others with insight and knowledge about the best possible care for your child.

Conclusion

As you can see, there are many factors to consider when thinking about long-term planning for your child's future. This information may seem overwhelming, but if you start early, you will feel better prepared for the time when he or she transitions into the world of adulthood. Determining finances, benefits and decision-making, or even starting the conversation about these important issues when your child is still young, can help ensure the correct services and supports are in place in advance. Keep in mind you have successfully navigated your child through the special education system and other childhood-related issues, now it is time for step two.

And with effort and work, you can be sure your child will be equally supported and provided for as an adult!

Community Living

As you plan for the transition to adulthood, it is important to remember that integration into the community is a key component of happiness and independence in the lives of adults with autism. You may want to think early on about introducing your child to members of the community. As your child grows older, you and his or her educators may need to become creative in your efforts to create opportunities for social interactions.

Whether your child has contact with the bagger at the grocery store or the crossing guard outside his or her school, these regular interactions are the foundation for being part of the community. This is just the beginning. Community ties can be developed at different times on different levels.

Adults with autism can be active participants in all areas of community life, including social and recreational activities, just like their peers.

There is truly something for everyone. It may just take a bit more effort to find what your young adult with autism is looking for and what social opportunities will provide him or her with the greatest amount of happiness.

Picking the Right Activities

There are a number of programs available that vary from athletic to creative, one-on-one instruction to full inclusion, recreational to competitive. Some things you may want to think about:

What are your child's likes and dislikes?

What makes your child tick or motivates him or her?

What are your goals for your child with this activity? (e.g. to socialize, learn how to play, develop a hobby, strengthen an existing skill, etc.)

What are your child's challenges?

Does your child have behavior problems that may prevent him or her from participating in certain activities?

Does your child need a one-on-one aide to participate?

Answering these question will help you and your child decide on which activities will make him or her the happiest and which will help most with integration into the community.

Community Activities

There are many opportunities for individuals with autism in most communities. These may include:

- **Public/private facilities: pools, parks, YMCAs, fitness clubs, programs at local universities**
- **Exercise and sports**
- **Hobbies, games, arts and crafts**
- **Social events**
- **Youth groups or religious community activities**
- **Special Olympics**

Title II of the American with Disabilities Act (ADA) prohibits discrimination against individuals with disabilities by any state or local government agency. An additional source of activities can be found by contacting local government agencies, such as the parks and recreation department in your city.

Prepare your child for participation in these activities with social stories, schedules, behaviors to expect, etc. In some cases, it may be helpful to have an aide who knows your child to go with him or her to the sessions in order to ensure that participation in the activity is a success. In addition, before you register for an activity, it is important that you speak to the activity leader about your child's positive attributes, as well as his or her challenges. If necessary, ask if you can bring him or her on a trial basis and arrange the most practical time.

For a list of recreational opportunities in your area, search the Autism Speaks Resource Guide at **autismspeaks.org/resource-guide**. You can also search the Autism Speaks Grants database for recreational programs Autism Speaks has funded for young adults near you at **science.grants.autismspeaks.org/search**.

Below is an example of a community life experience by Robyn Schneider, mother of Alex and Jamie, two young men with autism. Robyn is the author of *Silent Running: Our Family's Journey to the Finish Line with Autism.*

He's 16 years old, tall, slim and handsome. A year ago he started running, and now he runs a mile in 6 minutes and 30 seconds, competes in races all over Long Island, has won trophies and awards, and in a recent race finished 90th out of 1183 runners. He's my son Alex and he has autism.

Alex and his twin brother Jamie, who also has autism and runs an 8:30 mile, run in competitive mainstream races throughout Long Island. They are able to do this with the help and dedication of the Rolling Thunder Running Club, where experienced runners volunteer their time providing one-to-one support to special needs kids in races all over the country.

When they first started, their coaches held their hands while running with them, not sure what to expect as both Alex and Jamie have limited language and self-injurious behavior that can oftentimes be unpredictable. Soon the coaches were able to let go and run with them side by side. Now, in just a little over one year, Alex and Jamie have run in 15 races all over Long Island. Their first race was a 5K (3.1 miles) and Alex finished in 27:45, Jamie in 31:24. Now, for the same 5K race, Alex finishes in 20:53 and Jamie in 25:35. They have also begun to increase their distance running in 10K races (6.2 miles). In the last 10K, Alex finished in 43:28 and Jamie in 55:35. They have both placed in several races, including first and second place! Their trophies and race photos have begun to clutter our home and it's wonderful. They have even been featured in the New York Times and the Greater LI Running Club Magazine!

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Kids with autism have many skills that we often never know exist. The best part of our new discovery is that Alex and Jamie are running with typically developing kids and adults, together. As we watch and cheer and wait with nervous anticipation until they cross the finish line each time, we are so excited and proud to see them with all the other runners and realize their abilities to succeed in this wonderful outdoor sport. Best of all are the ear to ear smiles on both of their faces; they really love to run! Now we are planning our own race to increase awareness of autism and to benefit Eden II's Genesis School, a program exclusively for individuals with autism, where Alex and Jamie have attended since its inception in 1995.

We have lived through many tough times through the years, but there's one thing that we've learned and that's to keep exploring the inner talents and skills that our kids possess. A year ago we had no idea that Alex and Jamie could run so fast. Now, come this September, the boys will be included in their high school cross country team. Inclusion in their own district high school was so far beyond our expectations. We never dreamed of this happening! The greatest joy I have as a parent is to see how happy our boys are. As parents of boys who are predominantly non-verbal, it has always been a challenge to assess their likes and dislikes. But happily, we accept their beautiful smiles that warm our hearts. For us, these are better than any words could describe.

If you have a child with autism or you know someone who does, keep on exploring and never stop dreaming! You never know what they can do; if only they're given the chance they deserve!

Travel Training

The issue of transportation is an important part of allowing your child to integrate into the community. In order to be able to gain more independence and greater access to the community, travel training is very important. Travel training should begin at an early age to get your child as prepared as possible for community life.

You should be aware that travel training is available to your child and can be part of his or her transition IEP. In addition, your state office of vocational rehabilitation can help with training your child to travel to work. Postsecondary programs often have a travel curriculum as well.

Travel training is a proactive tool that will play a big role in establishing more independence for your child. Some individuals with autism may be quite savvy about reading maps, but they may have no idea how to ask how much a ticket costs. Others might know everything about trains but have trouble with the hustle and bustle of a train or subway station.

For many travel training programs, there is a prerequisite skill of being able to cross the street safely. Your child may be a pro at riding the train, but often a skill that seems as basic as crossing the street can be difficult, especially for those with autism who struggle with understanding danger. Make sure you start to teach your child this skill as early as possible. Knowing he or she has mastered this skill will make you feel more at ease when your child is out in the community.

A comprehensive approach to training is helpful because there are most often many components involved when traveling from one place to another. It is important to think about all of these factors that go into taking public transportation. Teach your child what to do in an emergency in all travel-related settings. Let him or her know what to do when lost or confused. Be sure to teach your child that there are often delays in some public transportation systems, and that traffic might affect the time it takes to get somewhere.

You may want to start small, like a weekly trip to the train station, and slowly build up to riding the train to a desired destination. The earlier you can start with these small steps, the easier it will be for your child to navigate life in the community as he or she enters adulthood.

Safety

Safety is a very real concern for all parents, but especially parents of children and adolescents with autism. Your child may be seeking more independence and as a parent, you want to foster this growth. But you may also be concerned about the many risks associated with him or her being out in the world. It is important that safety is taught to adolescents with autism as part of the skills that they will need to enhance their independence.

Some basic skills to consider include the ability to:

Identify strangers

Identify community members who can offer assistance

Ask for help

Know what to do when he or she gets lost

Communicate name, address, phone number and emergency contact person – either verbally or with a card

Use a cell phone, to both call and text

Identify public versus private spaces

Navigate your neighborhood, downtown and surrounding area safely

Wandering

A 2012 study from the Interactive Autism Network found that 49% of children with autism are prone to wandering from safety. And unfortunately, many children do not grow out of this tendency as they enter adulthood. You may have heard some of the tragic stories in the news that result after an individual on the spectrum wanders from his or her home, school or the company of loved ones. Teaching the skills necessary to prevent wandering incidents at a young age will help maintain your child's safety once he or she is out in the community.

If your child has a tendency to wander, it is critical to address this issue in his or her IEP. Be sure to carefully document all wandering-related incidents so you can identify the triggers and eliminate them as much as possible. You can also practice safety skills out in the community and teach your child what to do if he or she gets lost.

Unfortunately, the leading cause of death among individuals with autism after wandering is drowning. It is critical that your child not only knows how to swim, but understands the importance of water safety. Autism Speaks provides grants to swim programs to award scholarships for swimming and water safety lessons for financially disadvantaged individuals with autism. See if there is a program near you at **autismspeaks.org/family-services/grants/swimming**.

There are also many safety products available that can help prevent wandering and respond to wandering incidents. These include locating devices, which you can use to make sure you can locate your child if he or she goes missing. There are a number of these devices available with a wide variety of features. Many people with autism carry ID cards that they can show first responders or members of the community to let them know about their autism diagnosis and may include contact information as well. You can also share this information with neighbors and other members of your community so they can keep an eye out for your child and help get him or her home if he or she wanders from safety. Find these and other safety products on the Autism Speaks website at **autismspeaks.org/family-services/resource-library/safety-products**.

Interacting with First Responders

Another important skill to teach individuals with autism to help maintain their safety in the community is how to interact with first responders. It is estimated that children and adults with autism are seven times more likely to have interactions with first responders than their typical peers. To make sure these interactions are safe and effective, it is critical to teach your child about first responders, and if possible, to teach your local first responders about your child and others with autism.

It is important that your child knows how to identify first responders and understands that these men and women are there to keep the community safe so that he or she feels comfortable approaching them if a situations arises. It might help to bring your child down to the local police station to introduce him or her to the policemen and women there so that if they meet when there is a safety issue in the community, both parties will be able to reach a safe and effective solution as soon as possible.

Providing first responders with key information before an incident occurs may improve response. You may want to develop informational handouts that contain all pertinent information to circulate to first responders, as well as family, neighbors, friends and co-workers. This might contain information about your child's challenges, other medical conditions, the most effective ways to communicate with him or her, favorite attractions where he or she might be found and more. Autism Speaks offers safety trainings as well as first responder trainings and has a wide variety of resources for both families and first responders. Find them at **autismspeaks.org/safety**.

Preventing Abuse

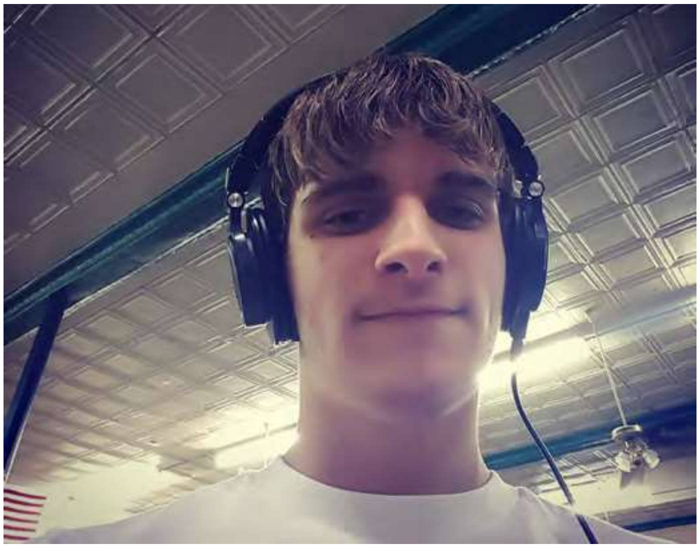
Sadly, individuals with disabilities are far more likely to be victims of abuse of all types than their typical peers. Many abuse cases are never reported because the individual may not be aware that another's actions are constituting abuse, may not be able to communicate the abuse to his or her parents or may feel ashamed and not want to share the information. It is important to teach individuals with autism from an early age what is appropriate versus inappropriate treatment by others so they can easily identify when they are being abused, emotionally, physically, sexually, etc. Make sure your child understands that abuse comes in many forms and can identify the red flags and feel comfortable telling you if suspicions arise that he or she might be a victim of abuse.

In terms of sexual abuse, an important factor in preventing it is teaching your child about sexuality and the difference between public and private places and between "okay" and "not okay" touches. While many children learn about sexuality through movies, magazines or gossip at school, children with autism often need to be taught more explicitly about issues related to sex and puberty, especially because they are more likely to be sexually abused. Teach your child very concretely about boundaries and personal safety, and make sure he or she feels empowered to make decisions about his or her own body. It is important that your child understands that saying "no!" is okay when he or she feels scared or threatened by someone else.

Educate yourself on how to identify warning signs and how to report it if you suspect abuse or neglect. It is important to trust your instincts! If you have a suspicious or uneasy feeling about the way your child is being treated in the community, speak up. Encourage your child to share his or her feelings with you and keep the lines of communication constantly open so he or she can more easily report if something is wrong. Learn more about sexuality education in the Health section of this tool kit.

It is important to note that abuse is most often committed by people known to the child (a family member, staffer, respite care provider, etc.). Shockingly, research suggests that 97 to 99 percent of abusers are known and trusted by the victim. Make sure you evaluate the relationships your child has with the people in his or her life and be on the lookout for warning signs. When teaching your child about boundaries, make sure you emphasize how there are different boundaries for different people – for example, your sister can hug you but an aide at your school should not; only Mom, Dad and Dr. Smith are allowed to see your private parts.

As with so many other topics in this kit, self-advocacy skills play a role in preventing your child from becoming a victim. If he or she is able to "speak up" or express his or her feelings in the best way possible when an uncomfortable situation arises, your child will be less vulnerable to abuse. Start teaching your child as early as possible about the dangers of abuse and helping him or her build the skills necessary to keep it from happening. Learn more at **autismspeaks.org/family-services/autism-safety-project/abuse**.



Conclusion

It is essential to keep in mind that community integration is a big part of life for all people and that your child with autism is no different. It may seem like a far off thought, but it is important to teach your child at a young age about the skills he or she will need to become a part of his or her community as a young adult and adult. Lessons like social skills, travel training, safety precautions and abuse prevention education can start small and build gradually over time. These skills take time to learn so keep in mind that patience is key! The better prepared that he or she is, the more likely it is that your child will one day thrive as a member of his or her community.

Employment and Other Options

For many of us, our job represents a big piece of who we are. As outlined in IDEA, one of the most important objectives of transition planning is to develop and implement a plan to secure employment. In order to do this, you and your young adult may want to consider activities that utilize his or her strengths, as well as activities that he or she likes to do. Information gathering, volunteer opportunities, internships, job sampling and job matching all play important roles in preparing a young adult for employment.

Preparation

While your child is still in high school, you may want to begin the process of learning and educating him or her about possible future careers. Go over the various types of jobs available with your child and start to make a list of those that might match his or her interests and strengths. Try to expose him or her to those specific career areas as much as possible, and continue to build upon the skills that will allow him or her to succeed in the workplace.

Work experience while your child is still in school is an important way to help you understand his or her strengths and challenges within different types of work. Examples of ways to explore careers while still in school include volunteer opportunities, internships and job sampling. There may even be opportunities at school to practice work – such as general office tasks, working in the school store or helping out at after school programs for younger children.

Experiences such as internships can often help with skill building, job training and eventually the job application process. Your child may be able to connect to a peer or mentor at the internship or volunteer site who can lend a hand if needed. For young adults with autism who have more significant challenges, job coaches can help them reach their full potential. A job coach will assist your child in obtaining a job and provide onsite support and assistance. Your school district may be able to help you find an agency that can supply a job coach.

It is also important to keep in mind when exploring career opportunities that your child may need to build up the endurance and stamina needed to complete his or her workday. It may be helpful to start with one hour per week and slowly build up to more hours on multiple days per week. You will know best what your child is able to do at work, but don't be afraid to gradually build his or her endurance until an adequate level is reached for him or her to accomplish career goals.

Types of Employment

There are many different employment options for individuals with autism. It is important to note that a young adult on the spectrum can go from one type of employment option to another over time.

Below is a list of several possible types of employment:

Competitive Employment: a full-time or part-time job with market wages and responsibilities; generally no long-term support is provided

Supported Employment: a competitive job where the individual receives ongoing support services while on the job; can be funded through state developmental disabilities or vocational rehabilitation agencies

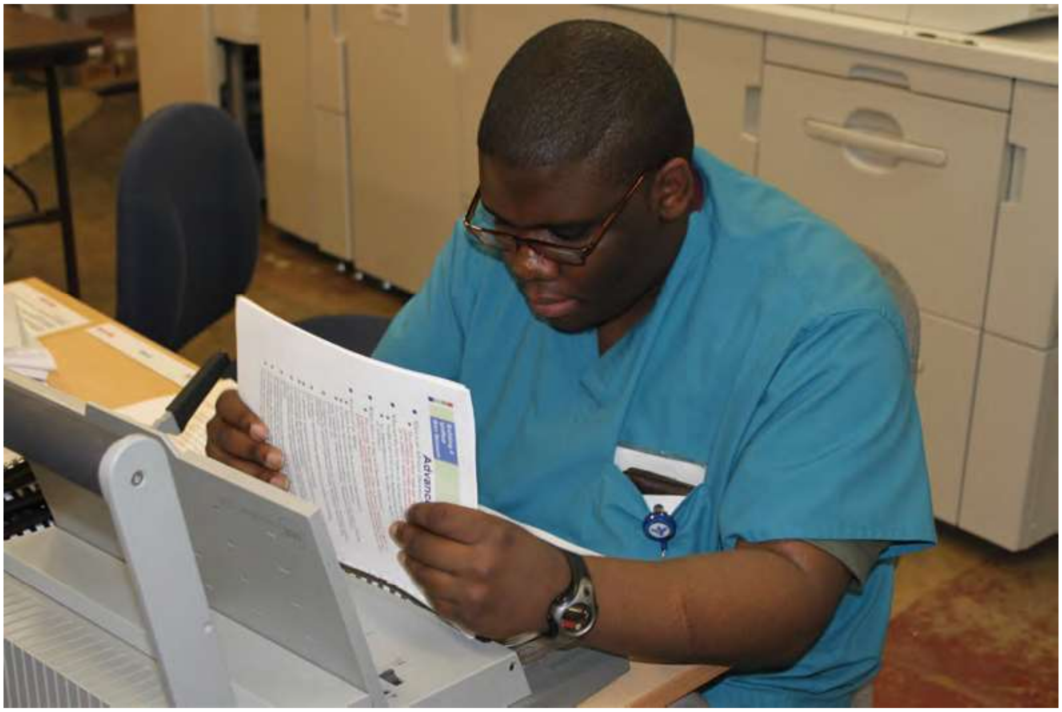
Customized Employment: a job in which the individual's strengths and abilities are used to develop a specific role uniquely created for the individual

Self-Employment: a job situation in which the individual's interests and strengths are matched to a product or resource that can allow him or her to make money, i.e. a bakery for those who love to cook; can increase the opportunity to tailor the work environment to the individual's needs

Sheltered Employment: a job setting where individuals with disabilities are not integrated with workers without disabilities; generally supported by a combination of federal and/or state funds; some argue that this system more often hinders the independence of people with autism in the community

Job Matching and Searching

Finding the best possible match is the most important component of securing successful employment. Sometimes even your child's passions or intense interests can be converted to a career. If your son is very interested in trains, maybe there is a job available at the local station. If your daughter loves to rearrange her closet in perfect order, bring her down to the local department store to see if they need help with restocking. Many individuals with autism have found great success pursuing their unique passions. For example, when Dr. Temple Grandin was a young girl, she became obsessed with cattle handling equipment at her aunt's ranch. Though that did seem different at the time, she was encouraged to pursue these interests and today she is the world's leading expert on the design of cattle handling facilities.



The information below regarding job matching is excerpted from *Life Journey through Autism: A Guide for Transition to Adulthood*, by the Organization for Autism Research:

Components of the Physical Job Match

- Hours of employment
- Acceptable noise levels at the job site
- Pay, leave and other benefits
- Acceptable activity levels
- Physical requirements of the job (e.g. lifting)
- Acceptable margin of error
- Production requirements

Components of the Social Job Match

- Acceptable level of interaction with coworkers
- Clear job expectations
- Grooming and hygiene requirements
- Demands on communication skills
- Personal space available
- Phone/vending machine/cafeteria
- Coworker training and support
- Community status

Workplace Skills

It is essential for young adults with autism to learn proper skills in the workplace, not just related to the job itself, but also social skills and rules of a work environment. Example of these skills include:

Initiating interactions with coworkers, as well as ending them

Understanding and respecting boundaries

Asking questions when help or clarification is needed

Being patient in situations that may be frustrating

Learning the best ways to respond when agitated, i.e. taking breaks in a quiet room or walking outside for fresh air

Maintaining proper hygiene

Knowing what topics are appropriate in the workplace and what should be kept private

Practice these skills at home and out in the community so your child is prepared for the workplace. Make sure he or she feels comfortable telling you in the best way possible if there are situations at work that might be improved with better understanding of these "soft" skills.

Remember that learning these skills will be an ongoing process and may take time. With practice and dedication, your child can and will succeed when the right fit is found!

Below is an excerpt from *Autism and the Transition to Adulthood* by Paul Wehman, Marcia Datlow Smith and Carol Schall.

Social Skills in the Community and the Workplace

Using Social Amenities: Phrases such as please, thank you and you're welcome are simple, short and easily taught.

Using Appropriate Greetings: Some students fail to greet or acknowledge others; others greet people over and over again. Teaching the appropriate use of greetings can be helpful.

Terminating Conversations: A common complaint of peers, supervisors and coworkers is that the worker or participant with autism walks away while being spoken to.

Accepting Correction: Many people do not like to receive correction or criticism, which can be especially upsetting to an individual with autism. Social skills training may need to focus on teaching the student exactly what to say and do when given correction.

Responding Assertively: People with autism can sometimes be taken advantage of. Social skills training may be required to teach them how to stop this from happening, for example, how to say, "Leave me alone" if someone is bothering them.

Accepting Suggestions: If a teacher or parent provides a suggestion, this can sometimes result in a refusal to take the suggestion, and can even serve as a trigger to acting out behavior. Providing the student with general instructions on the need to accept suggestions followed by the opportunity to practice this skill can be effective.

Asking for Help and Revealing a Problem: One of the most important social skills is to ask for help when it is needed. In either the work or school setting, social skills training can be used to teach individuals how to ask for help and how to talk to others about a problem.

Other Options

Some individuals with autism, especially at a young age, may not be ready for employment. You may feel that there aren't any options that seem to be the right fit for your child. That in no way means he or she has to be home all day. Other options to consider include:

Day Habilitation Programs

Day habilitation programs are person-centered programs that provide structured activities and specialized supports that will allow your child to participate in non-employment related activities in the community. These services can be provided almost anywhere in the community based on the desired skill being taught. Day programs are available for adults with disabilities who have exited the school system and may not be ready or able to participate in the workforce in an effective way. These structured programs focus on independent living skills and integration into the community.

Day Treatment Programs

These programs combine therapeutic treatment with daily life skills. This type of program is administered at a program site rather than in the community. Many day programs for individuals with autism and other disabilities are administered through your state's Department of Developmental Disabilities. Contact your local office for more information on the programs available in your area. It is important to note that many programs may have waiting lists, so start the process of getting on a list as soon as possible.

Brian Merring has never considered himself much of a cook. But there he was, dressed in kitchen whites at the helm of a professional-grade stove and armed with a spoon and a palette of tasty ingredients. Brian, who was diagnosed with autism at age six, has never held a job. He wasn't sure if he would be able to complete the task at hand – turn the raw flavors before him into retail-worthy soups – but he was willing to try. It was the experience that he craved, and that's exactly what the Southwest Autism Research & Resource Center (SARRC) served up with CulinaryWorks®, a program the organization launched through a partnership with notable Arizona chefs that offers adults with autism spectrum disorders hands on job training through the preparation, packaging, distribution and sale of classic soups. CulinaryWorks provides those with autism vital trade skills that can be translated into employment opportunities in the future that will allow them to live and work independently.

"It's about creating a quality of life and a sense of independence for our adults with autism," says Jeri Kendle, Vocational & Life Skills Academy director. "Our participants are trained in a variety of skills, with opportunities in bookkeeping, sales and cooking. We want to give these individuals valuable skills so they can find jobs, have meaningful experiences and build self-esteem."

Developing skills and working toward employment and independence is crucial for many in this program. Brian's parents, Mildred and Dr. Leroy Merring, want their son to have every advantage possible in the job market. Both worry about what will happen to their son when they are no longer around to take care of him. "He has never had a job, and we're not going to be here forever," Leroy Merring says. "This is the first program out there that does something for the future of people like Brian. And It's a relief that this program is now available." **For more information about SARRC, visit *autismcenter.org*.**

Additional Resources

Vocational Rehabilitation

Each state has a Vocational Rehabilitation (Voc Rehab or VR) agency that provides employment service supports to people with disabilities, including autism. VR agencies can give your child vocational assessments that lead up to the development of an Individual Plan for Employment (IPE). A variety of employment-related services can be provided under an IPE, including training, counseling, job placement and supported employment.

State Developmental Disability Agencies/Home and Community-Based Waivers

State and local Developmental Disabilities services operate under a variety of names across the country. Frequently the funding for these services comes through the Home and Community-Based Services Waivers (HCBS), which are made available through Medicaid. The requirements for gaining access to these services vary from state to state. Several employment services can be accessed through this funding source, including supported employment, case management services and counseling and treatment services. Reach out to your local agency or the Centers for Medicaid and Medicare Services (CMS) to see if your child is eligible for these waivers and if so, when you can get him or her on the wait list. You can find more information in the Legal Matters section of this kit.

Autism Speaks Employment Tool Kit

Autism Speaks has developed an Employment Tool Kit for young adults and adults with autism to help them find and maintain employment. This helpful guide covers a wide array of topics, including benefits and funding, various employment options, building a resume and cover letter, interviewing, accommodations and personal stories. Download the kit at **AutismSpeaks.org/Family-Services/Tool-Kits/Employment**.

Conclusion

As you know from your own life and those of your family members and friends, employment can play a vital role in the well-being of all people. It is important to keep in mind and let the world know that adults with autism can be positive contributors to the workplace when given the opportunity to display their strengths and abilities. Encourage employers to look past the communication and other such challenges your child might face, and see the skills that will allow him or her to succeed in a specific job. Start helping your child identify his or her greatest strengths and interests from an early age so you can start a list of some employment ideas for his or her future. Job sampling, internships, volunteer opportunities and more can help you see what type of work your child can do and enjoys. With a little research, assessment and advocacy, you and your child can help find a job, training opportunity or day program that works!

Postsecondary Educational Opportunities

There are many opportunities for education when your child leaves the school system or graduates from high school, including traditional two- and four-year colleges. Each model offers different levels of supports and types of services. In addition, in some models, students are integrated with students without disabilities, and others are kept separate. Some allow students to receive individualized services based on his or her vision and career goals.

Types of Postsecondary Education

Below is a list of some options for postsecondary education programs for individuals with autism.

Four-Year College

More and more four-year colleges and universities are providing support services for students with disabilities, including autism. However, you are encouraged to research these options and make sure that the supports offered meet the needs of your child. Self-advocacy skills are very important in postsecondary education because your child must know how to ask for necessary services and accommodations, such as housing supports, extended time on exams and access to assistive technology. Most schools have counselors and tutors available to help with this process. A good place to start is the school's office of disability services. It is important to note that some schools have autism-specific programs and others are more general for all students with some type of disability.

Cooperative Education

One option at some colleges and universities is cooperative education. In this type of program, your child would alternate between taking academic classes and working in the field of his or her choice. This can oftentimes be a good choice for students with autism, as it allows them to develop both academic and work skills at the same time. It also allows students to explore the fields that interest them and work on the soft skills they will need in the workplace after school ends. Be sure to reach out to colleges and universities or check their websites to see if this type of program is available.

Community College

Many community colleges have developed or are currently developing programs to meet the needs of young adults with developmental disabilities. Community colleges put more of an emphasis on the needs and goals of each student. For some students, the services provided can include necessary life skills like money management and problem solving. Others may focus on more traditional academic subjects and some may have a combination of both. A 2013 study, funded in part by Autism Speaks, found that community colleges may play a particularly important role in fostering transition into productive lives for individuals with autism. The study also found that graduation rates are higher when college students with autism start in a community college, especially those focused on technology, engineering or math.

Vocational/Technical/Trade Schools

Vocational or technical schools can provide your child with the opportunity to experience hands-on learning in a variety of fields. There are some programs that provide this training along with academic skills such as reading, writing and math. These programs also provide vocational experience such as internships and mentorships.

It has been reported that participating in vocational or technical classes during the last two years of high school, especially classes that offer occupational-specific instruction, is a successful transition strategy. It may be helpful to work with your school district to find out about programs in your area.

Life Skills Programs

There are many life skills programs available for people with autism that offer services to help your child live as independently as possible. These programs cover a wide array of skills – from basic skills like money management, shopping and transportation, to employment training skills in work settings. The programs also teach social skills and provide services such as recreational and leisure activities that will help integrate your child into his or her community, an important part of adult life.

504 Plans

Once you choose the right program, it is important to become familiar with the school's disability-related resources so that your young adult can be sure to advocate for the services and supports to which he or she is entitled.

IDEA requirements no longer apply when your child has left high school and is enrolled in an institution of higher education. However, Section 504 and the Americans with Disabilities Act (ADA) are civil rights laws that help protect individuals with disabilities including autism from discrimination in school, work and public accommodations. Section 504 applies to any school that gets federal funding. Students with disabilities cannot be denied appropriate services or supports that may be necessary to meet their needs, or that would be available to students without disabilities.

In order to be eligible for Section 504 protections, your child has to have a physical or mental impairment that *substantially limits* one or more major life activity, as well as a history of this impairment in a major life area. Reasonable accommodations can include audio books, readers or note-takers, access to the instructor's notes, extended time for assignments and tests, preferential seating and other similar supports.

Keep in mind that Section 504 does NOT require an institution to compose a written plan, but most places will do this. In order for your child to receive accommodations, he or she or an advocate must request them. Remember that the level of supports, as well as their efficiency and effectiveness, varies from school to school, so be sure to do as much research as possible.

Learn more about Section 504, IDEA and the general responsibilities of a public school from the National Association of School Psychologists by **clicking here** or using the link in the resources section of this kit.

Differences between High School and College

The following chart, adapted from Kay McVey, Faculty Development Specialist, PROJECT Connect, at Henderson State University, provides a clear illustration of the differences between high school and college:

HIGH SCHOOL	COLLEGE
All students have the right to an education.	College education is a privilege, not a right.
Protections include Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act, Americans with Disabilities Act.	Protections include Section 504 of the Rehabilitation Act, Americans with Disabilities Act; IDEA no longer applies.
School district designs Individualized Education Program (IEP).	Student is responsible for providing documentation that establishs verification of learning or other type of disablility.
School district ensures that the IEP is implemented.	Student indentifies his or her needs in collaboration with his or her counselor.
Teacher functions as advocate.	Student is responsible for his or her own progress.
Fundamental alterations to program of study are made.	Fundamental alterations of programs are not allowed - classroom accommodations may not alter the fundamental nature of a course or impose an undue burden on an instruction/institution.
Personal services are provided (e.g., aide) - success is more of a right.	Personal services are the student's responsibility - only the opportunity to succeed is provided.
Transportation to and from school is provided.	Transportation to and from school is NOT provided.
Parent or guardian is the primary advocate - students learn ways to become their own advocate.	Students are expected to be their own advocates to the best of their ablitiy

When preparing your child for college, below are some important points for you to remember:

In order to apply for or attend college, your child will need to obtain a high school diploma or a General Education Diploma (GED). An IEP diploma will not be recognized by institutions of higher education.

Make sure that all standardized tests have been taken. Some colleges will require these for admission. If you think your child may need extra support taking these tests, oftentimes accommodations can be arranged.

Find out if colleges that your child may be interested in require IQ or achievement test scores to receive accommodations under Section 504.

Assess if your child needs any remedial classes before going on to college. Some students do this at college, others spend an extra year in high school. Summer courses may be an option at a college in your area.

Work closely with your child's guidance counselor to begin to explore available options. One option is dual enrollment, when a student who is still officially in high school is also taking one or more classes at a college for credit. This allows your child to begin to get used to the college setting, life and workload while still in high school.

Discuss your child's postsecondary options with your local Division of Vocational Rehabilitation Services (DVRS). They may have funding available to help defray costs.

Choosing the Right School

Choosing the right school is important for any student's happiness and success, but often especially for students with autism. There are many factors to consider and questions to ask when exploring post-secondary education options. *The Autism Transition Guide: Planning the Journey from School to Adult Life* by Carolyn Bruey and Mary Beth Urban offers the following advice:

- Talk to the guidance counselor at your school.
- Attend local college fairs and ask about disability support services.
- Ask your child's teachers where some of their past students have attended college.
- Ask other parents of students with ASD.
- Consult local autism organizations to see listings of colleges that offer supports.
- Make sure to arrange visits to any potential schools where you can speak to staff and students. The school may also be able to connect you to other students with ASD and their families.
- Investigate if the school has the proper supports and services available for your child to have the most successful and rewarding experience possible.
- Keep in mind that there are many different types of institutions that your child could possibly attend. These include vocational school, community college, technical institutes, state schools, liberal art schools and also the variation of two-year versus four-year programs.
- Factors that come into play when selecting a college can also include location and finances.
- Students and their parents should not hesitate to visit the selected college and the one they will eventually attend as many times as they need to in order to familiarize themselves with the college.

Self-Advocacy in Postsecondary Education

Postsecondary education is the one of the best opportunities for your child to advocate for him or herself. College counselors are more readily willing to listen when the student, not the parent, approaches them. You may want to remind your young adult that his or her "voice" will make a difference. You may also want to help him or her make a list of his or her most significant concerns about colleges or other postsecondary programs. Young adults should be encouraged to share these concerns with their advisors. Creating a solid support system may lower the chances of future problems.

Because the mandatory supports available in high school are no longer available, it is far more important to advocate for services and supports in postsecondary education. Rather than receiving them automatically, it is now up to your child to ask for what he or she needs in all situations, both academic and social. Aside from the necessary services, there will be other areas in which your child needs to communicate and advocate for him or herself – including knowing when and how to disclose his or her autism diagnosis, understanding his or her rights and asking for assistance when necessary.

Once again, it is never too early to start teaching self-advocacy skills. The more prepared your child is to advocate for him or herself in postsecondary programs, the more supports he or she will receive and the more successful and effective the program will be as a result.

Expert Advice for Parents

Barbara Kite, M.Ed., Assistant Director of the PACE program at National Louis University, offered Autism Speaks six tips to share with parents regarding preparing for postsecondary education:

1. Plan Ahead – It is never too early to learn about the different kinds of programing available for your child.

2. Know Your Goals – What is it you want for your child? Independence? A four-year degree? A job?

3. Go and Look – Be sure to visit the programs that you are interested in. There is a good chance that what you THINK the program is in actuality may be quite different.

4. Ask Questions! – Not all programs are what they appear to be.

5. Think About Cost – Unless you are going to use government programs, the price of postsecondary programs can be high. You may have to be creative when it comes to financing your child's postsecondary experience.

6. Make A List – Think about what environment you want your child in. Do you see him or her at a community college? Or going away from home? Does he or she need a program that offers academic support? Consider whatever YOU learned by osmosis is what you need someone to teach to your child.

Autism Speaks Postsecondary Educational Opportunities Guide

In 2013, Autism Speaks released the Postsecondary Educational Opportunities Guide, a tool written for young adults with autism to help them and their families explore the different opportunities and learning environments after leaving high school. Sections include: Preparing for Postsecondary Education, Obtaining Services and Asking for Accommodations, Peer-to-Peer Advice, Life on Campus and more. Download this tool kit at **autismspeaks.org/family-services/tool-kits/postsecondary**.

Conclusion

When your child graduates from high school or ages out of the special education system, it is important to continue to educate him or her, whether it's at a college, a local day therapy program, in your home, or anywhere in between. The more your child continues to learn, the more opportunities that will become available to him or her at work, out in the community or in other local programs. Be sure to research and explore the postsecondary education options available to your child from an early age so you can decide together what might be the best fit.

Housing and Residential Supports

One of the most difficult parts of the transition process is finding the right residential option for your child's future. Coordinating choices for the physical home, as well as the necessary support services can be complicated, often leaving families unsure of where to start. The information below, along with the **Autism Speaks Housing and Residential Supports Tool Kit,** can help assist you and your family in planning for the future in the areas of housing and community living.

There are different options to choose from, but several hurdles to get over before your child is settled in the right place. The most important thing is to build the skills necessary for him or her to live as independently as possible as an adult. And remember - start early!

Where Do I Begin?

It is critical to be proactive when it comes to choosing the right residential option. Think first about what is best for your child as an individual based on his or her needs, abilities, strengths, challenges, etc. Some important questions to ask might be:

Where would your child thrive?

Where would he or she be happiest?

Where would he or she feel safest?

What type of setting would best help him or her achieve an independent and successful future?

What supports does he or she need and what types of options can best provide those supports?

What setting can help your child expand upon his or her strengths and abilities?

Many of these questions can be answered through the person-centered planning process which can help families and individuals with autism identify the right types of residential and support services based on the individual's goals and needs. More information about person-centered planning can be found in the Self-Advocacy section of this kit.

A great place to start is with your school district. They can help or tell you where you can go to get help. Check in with other families you know who have a family member with autism or other developmental disability. If you don't know any personally, you can most likely find some families through support groups or local autism organizations. To find out about options in your area, contact state and local agencies to speak about residential options.

This is hard work and will take time, but it is critical to uncover all possible options in your community and the surrounding area. The hard work will be worth it in the long run.

Once you find some good options, ASK LOTS OF QUESTIONS! Below are some you may want to consider when looking into a specific option or speaking to a housing agency:

What type of housing models do you offer?

How long have you been providing residential services?

What type of training does your staff receive to work with an adult with autism?

What level of support does the staff provide to the adults with autism? Is support available 24 hours a day?

Can I speak with other families who are using your service?

How do the residents spend their time during the day and on weekends?

How close is the local community and how often do you access community resources?

Who provides transportation during the week and on weekends?

How close are hospitals?

What is done in a medical and/or behavioral emergency?

What is done to support medical and/or behavioral needs?

What type of training do staff receive?

It is important when researching residential placement for your child, that you keep him or her as involved in the process as possible. Allow your child to contribute to the discussion in the best way he or she knows how. Though some young adults with autism may not be able to decide on their own what type of housing they'd like to live in for their future, do your best to keep your child's preferences and strengths in mind. This is likely one of the most important decisions your family will make, so it is critical to make sure everyone is on the same page and that an outcome is reached that everyone can be happy about, especially your child.

Most residential service providers that receive public support, including all providers that receive Medicaid, are regulated by state agencies. For Medicaid providers, the state agency conducts routine monitoring – often referred to as "survey and certification." Before choosing to use any provider, ask to see the latest monitoring, survey or licensure reports conducted by the state. You can also contact the state regulatory agency to find out if any complaints of abuse and neglect have been filed against a provider or if the provider has violated any licensure or regulatory standard.

Models for Residential Support

There are many different community-based residential service options. Some of these options combine housing and support services, while others allow the housing and support services to be purchased and arranged separately. As you read these descriptions, bear in mind that states may use different terms to describe similar models:

Supported Living offers services to individuals with disabilities who are able to live independently in a home or an apartment. The services, typically minimal in nature, are based on the individual's specific support needs and are provided by caregivers working under the direction of the individual.

Supervised Living (semi-independent living) offers more direct and intensive structured supports available 24 hours a day, if needed. The individual may live in a house or apartment, either alone or with others. Functional life skills such as banking, shopping, cooking and going to doctor appointments can be taught or supported by staff.

Group Home Living has been the traditional model for residential services for individuals with developmental disabilities. In a group home, several unrelated people (all of whom have a disability) live together with onsite staff who are present 24 hours a day, 7 days a week. Instruction focuses on independent living skills and community activities. The house is owned and operated by a provider agency that also employs and supervises the staff. Typically group homes have eight or fewer residents.

Group Living/Ownership (co-op) is similar to group home living, except that the house is owned by a group of families or individuals who have formed a cooperative agreement. Caregivers hired by the cooperative, in some cases, by an agency contracted by the cooperative, provide support services.

Teaching Family Model/Foster Home Living offers family-style living with support services available 24/7 by professional teaching parents, usually a married couple. The individual may be the only person with a disability living in the home or there may be others with or without disabilities.

Farmstead Communities provide residential supports and services for a number of individuals within the context of a working farm. These models generally combine residential living arrangements with agriculture science and community-based employment.

Assisted Living Facilities/Intermediate Care Facilities (ICF) provide assistance with personal care and activities of daily living such as bathing, grooming, dressing and more. In some states, ICF programs also provide medication assistance and/or reminders. Each ICF is responsible for providing active treatment, consistent training and health support. Assisted living communities differ from nursing homes in that they don't offer complex medical services.

Developmental Centers are large residential facilities clustered on a campus-like setting where residents have intensive needs related to their developmental disabilities. Most states no longer run large developmental centers and some states that do are looking to shift people to more community-based settings and will only place a person in a developmental center on an emergency basis.

Funding Options

It can be challenging and confusing to navigate the funding streams for housing for your young adult with autism. Below is some information about options and programs for you to look into when finding the right housing fit for your child:

Self-Funded Housing

Self-funded housing is purchased by the family and/or the individual using private money and/or public dollars. The funds are secured and directed by your child and family, not an outside agency.

When exploring ways to pay for housing, you should consider all resources available to you and your child, including:

Donations

Income

Grants

Foundations

Banks

Community Development Financial Institutions (CDFI)

Credit unions

Private insurance

Special Needs Trusts

Individual Development Accounts (IDAs)

Pooled trusts

Tax credits

Individuals with autism and other disabilities are often eligible to participate in state and federal programs designed to provide funding to build and renovate houses. It is important to know that each program has distinct guidelines and that programs can often vary by state.

Most public funding for projects will be contingent on your child's ability to pay for rent/mortgage and a social-service plan that addresses health and safety. There are many public programs that offer assistance to people with disabilities and others with low and limited income.

Below we have highlighted programs that are more frequently used for people with disabilities. For a more comprehensive review of federal programs, visit the United States Department of Housing and Urban Development's (HUD) website at **hud.gov**.

HUD Section 811 provides interest-free capital advances to nonprofit sponsors to develop rental housing for low-income persons with disabilities. HUD Section 911 Housing Choice Vouchers (HCV) are dispersed directly by HUD to persons with disabilities to spend on the housing option of their choosing.

Low Income Housing Tax Credit (LIHTC) allows qualified for-profit and nonprofit developers to apply on a state-by-state basis for federal tax credits that they can sell to investors and use the proceeds as equity for the development of apartment complexes for persons below 60% of area median income.

Home Program provides formula grants and loans to state and local participating jurisdictions to expand housing opportunities for low and moderate income individuals and households.

Community Development Block Grants (CDBG) are grants to jurisdictions that can be used to support affordable housing through land acquisition and infrastructure development.

Federal Resources

The HUD programs above provide funding for families or groups of families to purchase or rent their own apartment, condominium, house, etc. for their family member with autism. It is important to note, however, that very often costs for the physical home and costs for the services provided within the home are kept separate.

You should discuss funding options with the state agency responsible for serving adults with developmental disabilities. Below is a list of some federal entitlements that can help with residential support costs and other services. You can find more information in the Legal Matters section of this kit:

Medicaid Benefits

In most states, individuals who need residential support will need to be eligible for Medicaid, a program designed to pay for intensive services. Medicaid pays for a wide array of services for people with disabilities, including long-term services and supports. To be eligible for Medicaid, a person must fit in a specific category of coverage and meet income and assets requirements.

Home and Community-Based Waiver Services

Through the use of Medicaid Home and Community-Based Services (HCBS) Waivers, people with autism and other disabilities can use Medicaid funds more flexibly. Waiver services are an option available to states to provide integrated community-based long term care services and supports to qualified Medicaid recipients. These programs may provide a combination of both traditional medical services (dental services, skilled nursing services) and non-medical services (respite, case management, environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications. The exact type of residential support included in an HCBS waiver as well as who is eligible for the program varies within and across states.

Supplemental Security Income (SSI)

SSI is a federal program through the Social Security Administration that provides cash benefits directly to recipients. In order to receive SSI, an individual must be disabled and have a limited income, including a maximum asset limit of $2,000. In 40 states, individuals who qualify for SSI are automatically qualified for Medicaid. Learn more and determine if you qualify at **ssa.gov/ssi**.

Waiting Lists are Long – Plan Ahead!

Regardless of the funding mechanisms available, the most important thing when it comes to housing and residential supports is to plan ahead. Unfortunately, at this time there are many more people waiting for appropriate supported living settings than there are openings in these settings.

Although there are state-funded day services and/or vocational rehabilitation programs for young adults when they transition to adult life, many families are surprised to learn that there can be a waiting list of five, ten and even 15 years or more for residential services and supports that are funded with public dollars, specifically Medicaid HCBS waivers.

It is important to understand and monitor the waiting list in your state and stay vigilant in pursuit of accurate information. Begin planning as early as possible and take the time to research your state's funding structure for housing and supports to minimize waiting time.

Be sure to put your child's name on the HCBS waiver waiting list as soon as possible – it may be many years before he or she is offered services.

Conclusion

The thought of your child living outside your home at this point might seem very overwhelming. But regardless, it is never too early to start researching residential plans and the corresponding funding mechanisms, even if you aren't quite sure of when, if at all, you think might be the best time for the move. With diligent and proactive research and planning, you can help guarantee that whether his or her future home is down the hall from you, two blocks away or across the state border, your child will live in a place that will allow him or her to be as happy and as independent as possible.

Health

Ensuring and maintaining your child's health as he or she becomes an adult will be critical. It is important to understand and be on top of the changes that are happening for your child – physically, mentally and emotionally – as well as the shifts in many health-related policies, benefits and entitlements as he or she ages into adulthood.

Finding the Right Doctor

As children mature into young adults, pediatricians are no longer appropriate as their primary care physicians. It can be challenging to find a primary care physician who accepts insurance or Medicaid of adults with autism and more importantly, who understands young adults on the spectrum.

It is important that the primary care physician treats your child as an individual like every other patient, not just an individual with autism. Remember to advise the primary care physician to make sure that he or she doesn't see every health or behavior problem as a result of autism and understands your child as a whole person.

You should begin the search for a primary care physician early, though the transition doesn't usually occur until age 21. Start by asking your pediatrician for some names of doctors in the area who may be appropriate for your son or daughter. Ideally, there should be communication at the beginning between the pediatrician and the new doctor to ensure that everyone involved is fully informed of your child's state of health.

One of the most essential things to consider when selecting a doctor is that your child feels comfortable with him or her, as it is critical that your child is able to express any health-related feelings or concerns. This process is another important time for him or her to self-advocate.

> While little is known about the interaction of ASD and aging, it is generally accepted that adults with ASD
>
> 1) tend to be fairly poor self-reporters when it comes to health issues; and
>
> 2) as a group tend to be fairly sedentary.
>
> As such, concerns related to the long term health and wellness of adults with ASD should be at the forefront of any discussion of appropriate services.
>
> - *The Current State of Services for Adults with Autism,* prepared by Peter F. Gerhardt, Ed.D.

Mental Health

Unfortunately, mental health issues can complicate the transition process. The teenage years are already a time of turmoil and change and an adolescent with a mental health diagnosis can have a more difficult time managing the emotions that come along with these years.

Many individuals with autism are also diagnosed with mental health disorders like depression, anxiety and Obsessive Compulsive Disorder. Psychiatric diagnoses are not developmental disorders and often times they may not be visible during childhood.

This is often further complicated by the assumption that certain behaviors and emotions are connected to the individual's autism diagnosis, when the behavior may not be related to the diagnisis at all. It is important that your child's primary care physician is able to distinguish between the two so that he or she can treat these conditions and behaviors effectively.

If you suspect that your young adult may be suffering from a psychiatric disorder, you may want to speak with his or her doctor about a screening, which will consist of questionnaires that will indicate if your child needs further evaluation and/or interventions. Keep in mind that screening results are not a formal medical diagnosis. The results may indicate if a visit with a trained medical professional such as a psychiatrist is needed to make a diagnosis and develop a treatment plan.

Common psychiatric disorders among individuals with autism include anxiety, attention deficit hyperactivity disorder (ADHD), Obsessive Compulsive Disorder and depression. The Autism Speaks website contains detailed information about the signs and symptoms of each of these conditions, as well as effective ways to treat them.

A number of research studies have found that a significant percent of children with autism lack access to mental health services when they need them. Parents often have a stigma around mental health issues which unfortunately prevents their children from getting treatment and making progress. In addition, the mental health care system can be difficult to navigate. If you have trouble finding a psychiatrist for your child, look into mental health clinics that are staffed by social workers. Treatment for mental health issues is of vital importance, especially for individuals with autism, so it is critical to take the necessary steps to access these services so that your child has a better chance of living a life of purpose and dignity.

In addition, individuals with autism are more likely to have new onset seizures during puberty or after they have completed puberty than at any other time since before they entered school. While the likelihood is still not very high, if your child does experience a seizure, a neurologist can administer tests to determine the cause. Most seizure disorders can be managed with the right medication.

Personal Hygiene

Personal hygiene is an important life skill that all young adults with autism must understand no matter what level of support is needed. Skills such as bathing, using deodorant, brushing teeth, washing hands and shampooing hair are all important skills that need to be taught for young adults to become as independent as possible. While other young adults may wake up in the morning and have a set routine, your child may need more explicit instruction and reminders of the steps to take each morning and night. Visuals in the bedroom and bathroom can be helpful. *Taking Care of Myself* by Mary Wrobel is a great curriculum about healthy hygiene, puberty and personal care for young people with autism. It includes easy-to-understand directions, as well as visuals for many of the topics that need to be addressed. Teaching hygiene associated with private parts early can serve as a good bridge to sex education and help with the prevention of sexual abuse.

See the Developing Independent Living Skills section of this kit for information on the importance of teaching self-care skills and effective ways to make sure your child learns personal hygiene skills to the best of his or her ability, regardless of other challenges.

Puberty and Sexuality

The onset of puberty is a difficult time for all older children and adolescents, and the changes can be especially difficult for those with autism. Preparation is key so it is essential to teach your child in advance about these changes. Your child should understand what is happening to his or her body, as well as what will happen in the future.

The more information you share with your child in advance, the more ready he or she will be for events such as menstruation or erections and ejaculation. Other changes like the growth of pubic hair or under arm hair should be covered as well. While it may be uncomfortable, you can never be too thorough or explicit in getting this information across to your child. It is important to stress that these changes are a natural part of life for everyone and should not be viewed as odd or scary.

Many parents feel nervous and anxious when it comes to teaching their children about sexuality, especially children with autism. Many incorrectly feel that it is less important to teach young adults with autism about this subject because they think they are less likely to be exposed to issues related to this topic. But sexuality education is arguably more important for individuals with autism because they are less likely to learn about it from other sources such as peers, movies, etc. It is also crucial for them to understand the difference between appropriate and inappropriate behavior, and to distinguish between the various types of healthy relationships.

A developmental approach is most effective when teaching sexual education to young adults with autism. Each skill and behavior should be taught as a series of developmental sequences or hierarchy of events. For example, you can break the road to sexual intercourse into steps such two people meet, they become friends, go on a date and hold hands, etc.

It is important to teach these subjects as you would any other and to remember that you are the person responsible for teaching your child about sex and sexuality. Be sure to promote and emphasize appropriate behavior and stop and redirect any kind of inappropriate behavior. Encourage your young adult to ask you any questions and answer the questions in a simple and direct manner.

Dr. Shana Nichols, Ph.D., a specialist in autism and sexuality, suggests that a sexuality education curriculum include: the body, privacy, boundaries/touch, expressing affection, social skills and exploitation prevention. It is also important to stress the difference between public and private with regards to places, body parts, behaviors, etc.

Sexuality education is about more than just puberty and sex. Dr. Nichols also reports that relationship skills are often overlooked for young adults. The focus on teaching social and relationship skills often happens in the preschool years, but these skills are just as important later on, most especially during adolescence. At this time, there are new concepts to learn and understand like the different types of relationships and how they are similar and different. All relationships, including those with strangers, teachers, doctors, family members, etc. need to be addressed very directly to understand what makes each of them healthy and appropriate.

Though the idea may seem overwhelming, it is critical to start as EARLY as possible and to be as DIRECT as possible!

Conclusion

As many physical, mental and emotional changes happen as children enter adolescence and approach adulthood, it is important to monitor your child's health in each of these areas. Talk to your child's doctor about the changes you can expect and make sure you and your child are as prepared as possible for the changes in advance. Preparation and knowledge will make a world of difference when it comes to the health of a young adult with autism.

Technology

In today's day and age, it seems our whole world revolves around smart phones, tablets and the internet. "Google It!" or "I'll 'friend' you later!" or "Did you see that Tweet?" are just a few of the popular phrases associated with the internet and online social networking that can be heard almost everywhere we turn.

The goals and uses of technology are very different for adolescents and young adults. These tools can be very empowering for adolescents transitioning into young adulthood, especially for individuals with autism. Technology can help your child become more independent, work on his or her challenges and improve upon his or her strengths.

How Technology Can Help

Below is a list of just some of the ways technology can help your child:

Communication

Likely the most common use of technology to help children and adults with autism is to improve communication skills. There are hundreds of apps and many built-in features of these devices that can help support individuals with autism at all levels and abilities. One app for example could be geared toward a nonverbal child or adult, while another can help with social cues for an individual with strong verbal communication skills. You can find apps for communication in the Autism Speaks apps database at **autismspeaks.org/autism-apps**.

Visual schedules

Visual schedules on tablets can be a great tool to help your child complete tasks and work on skills like self-care and daily living. For example, a visual schedule for an evening routine can help him or her learn to manage time and gradually master a routine on his or her own – from an after school snack, to homework, to teeth brushing and everything in between. These visual schedules can be very helpful in helping your child learn independent living skills, among others.

Decision-making

Individuals with autism who have more difficulty communicating can use technology to make their "voices" heard regarding decisions, which helps foster the self-advocacy skills that are so important as they age into adulthood. You can start small, like instead of ordering for your child at a restaurant, he or she can use a smartphone or tablet to point to the item he or she wants.

Motivating tool

Technological devices like smartphone and tablets can also serve as motivation for your child. The use of an iPad or a favorite game app can serve as a reward for positive behavior like the completion of a chore or a homework assignment.

Video modeling

Video modeling is a method that involves teaching skills in a visual way. The video could be of the individual him or herself completing a task or assignment, or of a teacher, educator or parent teaching the skills and steps required. Your child can watch these videos as often as he or she likes/needs to help learn important skills. Because the videos involve using a tablet or smartphone, he or she is most likely more interested in learning the skills this way. Video modeling can help with a wide array of skills including hygiene, job tasks and more.

Jennifer is 15-years-old and has moderate autism. Her language is repetitive and she often has difficulty making her needs known. Her mother tries to encourage independence and suggests that Jen order her own drink at Starbucks. At first, Jen's mom carried pictures around with her and had Jen point at the coffee or the chocolate picture, and then the cold or the hot picture.

Jennifer's mother realized that this process was a challenge for Jennifer, and wasn't maximizing her potential for independence in making these decisions. Jennifer's mom decided to use an iPad to help with Jennifer's communication skills. She purchased an app that allows Jen to make menu choices right on the screen. Now, Jen can go into Starbucks with her iPad and place her order using the options she sees on the device. She can use this program to make menu decisions at other shops as well. Jennifer is thrilled that she is now able to get the drink she wants, all on her own.

In speaking with Jennifer's mother about this new process, she explained that there was a time when she would have answered for Jennifer, and may or may not have ordered what Jennifer wanted. In the past, this had been a cause for outbursts. But ever since she purchased her iPad, Jennifer can now use the device to communicate her wants, and outings such as trips to Starbucks are much more successful.

Social networking

It can sometimes be easier for an individual with autism to socialize via social networking than through the more traditional methods. Making friends or communicating with others online can help him or her work on the skills that might translate at school, work or out in the community.

Vocational assistance

Technology can be very helpful to some young adults and adults with autism in the workplace. For example, step-by-step checklists can help your child stay on top of tasks and complete them in an orderly and successful manner. Reminders and notes about each task in case he or she forget something, rather than continuously asking an employer or coworker, can also help your child become more independent in the workplace.

Social Media and Internet Safety

Individuals with autism are just as interested, if not more interested, in using the internet as a connection to mass amounts of information and people. To ensure the safety and success of internet usage, it is critical that these individuals learn how to protect themselves online, and that they understand what is and isn't appropriate on the internet.

Some organizations have specific classes to teach safe and fun ways to use the internet. You should closely monitor your child's internet use and constantly make sure that his or her activity is safe and appropriate.

Below are some social networking safety tips for tweens and teens from the Federal Trade Commission that you should share with your adolescent:

Think about how different sites work before deciding to join a site. Some sites will allow only a defined community of users to access posted content; others allow anyone and everyone to view postings.

Think about keeping some control over the information you post. Consider restricting access to your page or accounts to a select group of people for example, your friends from school, your club, your team or your family.

Keep your information to yourself! Don't post your full name, Social Security number, address, phone number or bank or credit card account numbers – and don't post other people's either. Be cautious about posting information that could be used to identify you or locate you offline. This could include the name of your school, sports team, club and where you work or hang out.

Make sure your screen name or account name doesn't say too much about you. Don't use your name, age or hometown. Even if you think your screen name makes you anonymous, it doesn't take a genius to combine clues to figure out who you are and where you can be found!

Post only information that you are comfortable with others seeing – and knowing about you. Many people can see your page, including your parents, your teachers, the police, the college you might want to apply to next year, or the job you might want to apply for in three years.

Remember that once you post information online, you can't take it back. Even if you delete the information from a site, older versions exist on other people's computers.

Flirting with strangers online could have serious consequences. Because some people lie about who they really are, you never really know who you're dealing with.

Be wary if a new online friend wants to meet you in person. Before you decide to meet someone, do your research. If you do decide to meet the person, be smart about it: Meet in a public place, during the day, with friends you trust. Tell an adult or a responsible sibling where you're going and when you expect to be back.

Trust your gut if you have suspicions! If you feel threatened by someone or uncomfortable because of something online, tell an adult you trust and report it to the police and the site. You could end up preventing someone else from becoming a victim.

The Importance of Digital Literacy

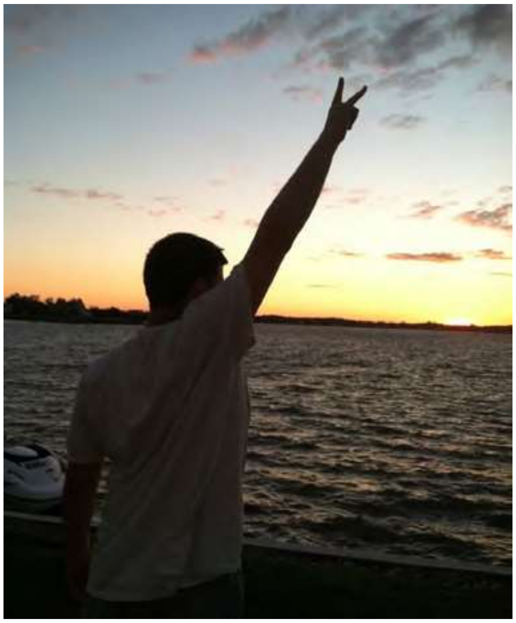
Digital literacy, or knowing how to operate digital devices like smartphones, tablets and computers, has become a very important skill over the last decade. Especially in a world where the large majority of employment opportunities involve the ability to use technology, teaching these skills to individuals with autism should begin at an early age. Your child may not have the ability to communicate in a traditional way or may become very uncomfortable in a workplace setting, but as long as he or she can contribute important work-related skills to his or her job, finding and maintaining one will be much less difficult.

Teaching your child things like email, word processing, internet browsing and more will be beneficial to him or her throughout the teen years and adulthood. These lessons also can include social media use and what is and isn't appropriate to share online. This knowledge can also help with fostering more independence for your child and can open the doors to more opportunities in high school, postsecondary education programs and eventually employment.

Autism Expressed is an online interacting learning system that teaches marketable, digital life skills to promote independence for students in a technology driven society and economy. Learn more and sign up at **autismexpressed.com**.

Assessments

Technology can also be used to conduct assessments that identify your child's strengths and help pinpoint areas where he or she may face challenges. Assessments that are conducted through interviews or by pen and paper can often be difficult for children and adults with autism, so those available through computers and tablets have been found to be very beneficial. These assessments can help you tailor your child's learning programs in a way that will continue to build upon his or her strengths and abilities and improve on skills he or she has trouble with.



For example, **Identifor** is the first digital tool that uses games to reveal how a person likes to spend his or her time and matches that with relevant career options, setting students on a personal path to a fulfilling future.

Ask your child's school about online or digital assessments that can allow you to identify factors that will help you develop a more personalized transition plan for your child.

Conclusion

Technology has the potential to play a major role in your child's transition plan, especially in today's world where it seems like technology rules all. There are definitely dangers out there on the internet that are important to make your child aware of, but for the most part, the internet and technological devices and advances have been and will continue to be vital resources for people with autism.

Do your research and learn how you can best maximize the effects of technology on your child. Find tools, apps and websites that will help prepare him or her for the future by teaching important skills, increasing independence and expanding upon abilities and strengths that will be critical on the road to adulthood. There is truly something for everyone!

Conclusion

As you can see after reading this kit, there are many factors that go into making the transition to adulthood as effective and successful as possible for a young adult with autism. We hope the information in this kit will help you during this critical time in your adolescent's life. Be sure to check the timeline we have provided for the transition process in your specific state, and use it as a guide to help you navigate this process.

We hope that this kit has served its purpose in helping you and your young adult with autism travel the road to a happy and fulfilling adult life! We welcome any feedback or input that you would like to provide in order to make this kit as helpful as possible – please email us at **transitiontoolkit@autismspeaks.org**.

The Autism Speaks Autism Response Team is here to help provide you with any additional resources and supports you may need during the transition process. Feel free to reach out any time by phone at 888-288-4762 (en Español 888-772-9050) or email at **familyservices@autismspeaks.org**.

We wish you and your family all the best on this exciting journey into adulthood!

There are several main conclusions we want you to take away from the Autism Speaks Transition Tool Kit:

Every individual with autism is different, so each will require different supports and services throughout the transition process.

It is so important to start early, evaluate your child's likes and dislikes, strengths and challenges, and make a plan to help create as independent and enjoyable of a life as possible for him or her.

Remember to involve your young adult in the journey to adulthood as best you can. In order to one day live an independent life, an individual with autism must have as much of a say as possible in decisions made regarding his or her future.

It is critical to teach young adults with autism how to advocate for themselves and ensure that they know how to get not just the services they might need, but the services they want as well.

Start teaching independent living skills at a young age and gradually build upon them. These skills may take time for your child to learn, but continue to motivate and support him or her until important life skills like hygiene are learned and understood. Don't be afraid to start small.

This process will take time, but if you start early and take the right steps, you will be able to successfully lay the foundation for the future of your young adult with autism.

The future may seem uncertain and scary right now, but taking the proper steps during the transition to adulthood will help ease these fears.

Resources

GENERAL TRANSITION RESOURCES

Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical and Transition Needs of Teenagers with Autism Spectrum Disorders
by Chantal Sicile-Kira

Autism & the Transition to Adulthood: Success beyond the Classroom
by Paul Wehman, Marcia Datlow Smith, Carol Schall

The Autism Transition Guide: Planning the Journey from School to Adult Life
by Carolyn Thorwarth Bruey, Psy.D., Mary Beth Urban, M.Ed.

Growing Up on the Spectrum: A Guide to Life, Love and Learning for Teens and Young Adults with Autism and Asperger's
by Lynn Kern Koegel, Ph.D., Claire LaZebnik

Guiding Your Teenager with Special Needs through the Transition from School to Adult Life: Tools for Parents
by Mary Korpi

Life's Journey Through Autism: A Guide for Transition to Adulthood
Organization for Autism Research, Southwest Autism Research and Resource Center, Danya International, Inc.
researchautism.org/resources/reading/documents/TransitionGuide.pdf

SELF-ADVOCACY

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum
edited by Stephen M. Shore, Ed.D.

The Everyday Advocate: Standing Up for Your Child with Autism
by Areva Martin, Esq.

The Integrated Self-Advocacy ISA® Curriculum: A Program for Emerging Self-Advocates with Autism Spectrum and Other Conditions
by Valerie Paradiz, Ph.D.

It's My Choice
by William T. Allen, Ph.D from the Minnesota Governor's Council on Developmental Disabilities
mn.gov/mnddc//extra/publications/choice/Its_My_Choice.pdf

Keeping It Real: How to Get the Supports You Need for the Life You Want
The Boggs Center on Developmental Disabilities
rwjms.umdnj.edu/boggscenter/projects/keep_real_more.html

Learning the Skills of Self-Advocacy and Disclosure
by Stephen M. Shore for Autism Spectrum Quarterly
autismtoday.com/library-back/Learning%20the%20Skills%20of%20Self%20Advocacy.pdf

Opening Doors to Self-Determination Skills: Planning for Life after High School - A Handbook for Students, School Counselors, Teachers and Parents
Wisconsin Department of Public Instruction
sped.dpi.wi.gov/sites/default/files/imce/sped/pdf/tranopndrs-self-determination.pdf

Person Centered Planning Education Site
Cornell University ILR School and Employment and Disability Institute
personcenteredplanning.org

Project STIR: Steps Toward Independence and Responsibility
Carolina Institute for Developmental Disabilities
self-advocate.org

DEVELOPING INDEPENDENT LIVING SKILLS

Keys to Successful Independent Living, Employment and a Good Social Life for Individuals with Autism and Asperger's
by Temple Grandin
autism.com/grandin_independence

Self-Help Skills for People with Autism: A Systematic Teaching Approach
by Stephen Anderson, Ph.D., BCBA, Amy L. Jablonski, Psy.D., Marcus L. Thomeer, Ph.D. & Vicki Madaus Knapp, Ph.D., BCBA

TRANSITION AND THE IEP

The IEP from A to Z: How to Create Meaningful and Measurable Goals and Objectives
by Diane Twachtman-Cullen, Jennifer Twachtman-Bassett

Individuals with Disabilities Education Act
idea.ed.gov

Individualized Education Program (IEP): Summary, Process and Practical Tips
developed by Goodwin Procter LLP for Autism Speaks
autismspeaks.org/family-services/tool-kits/iep-guide

Transition to Adulthood
Center for Parent Information and Resources
parentcenterhub.org/repository/transitionadult

LEGAL MATTERS TO CONSIDER

Academy of Special Needs Planners
specialneedsanswers.com

BEST: Benefit Eligibility Screening Tool
ssabest.benefits.gov

Centers for Medicare & Medicaid Services
cms.gov

Home & Community-Based Services Clearinghouse
hcbs.org

Legal Guidelines for the Autism Community
developed by Goodwin Procter LLP for Autism Speaks
autismspeaks.org/sites/default/files/documents/family-services/gp_legal_guidelines.pdf

Letter of Intent
child-autism-parent-cafe.com/letter-of-intent.html

The Medicaid Reference Desk: Your Source for State Medicaid Information
thedesk.info

National Association of Councils on Developmental Disabilities
nacdd.org

Understanding Medicaid Home and Community Services: A Primer
U.S. Department of Health and Human Services
aspe.hhs.gov/understanding-medicaid-home-and-community-services-primer-2010-edition

U.S. Social Security Administration
ssa.gov

COMMUNITY LIVING

Autism Speaks Autism Safety Project
autismspeaks.org/safety

Easter Seals Project ACTION: Training, an Online Community and Resources Dedicated to Travel Training
projectaction.org/Training/TravelTraining.aspx

Recognizing and Preventing Abuse
autismspeaks.org/family-services/autism-safety-project/abuse

EMPLOYMENT AND OTHER OPTIONS

Autism Speaks Employment Tool Kit
autismspeaks.org/family-services/tool-kits/employment

An Employer's Guide to Hiring and Retaining Employees with Autism Spectrum Disorders
autismspeaks.org/sites/default/files/docs/employer_guide_to_hiring_and_retaining.pdf

A Parent's Guide to Employment for Adults with Autism Spectrum Disorders
autismspeaks.org/sites/default/files/docs/employment_tool_kit_parent_booklet.pdf

The Spectrum Careers: Jobs Portal for Individuals with Autism, Employers and Service Providers
thespectrumcareers.com

Think Beyond the Label Jobs Portal
thinkbeyondthelabel.com

Work Support: Virginia Commonwealth University Rehabilitation Research and Training Center on Workplace Supports and Job Retention
worksupport.com

Job Accommodation Network
askjan.org

POSTSECONDARY EDUCATIONAL OPPORTUNITIES

Autism Speaks Postsecondary Educational Opportunities Guide
autismspeaks.org/family-services/tool-kits/postsecondary

AHEADD: Achieving in Higher Education
aheadd.org

Americans with Disabilities Act Q&A: Section 504 and Postsecondary Education
pacer.org/publications/adaqa/504.asp

College Internship Program (CIP)
cipworldwide.org

Postsecondary Education Resources, Autism Speaks Resource Library
autismspeaks.org/family-services/resource-library/post-secondary-education-resources

Section 504: A Guide for Parents and Educators
National Association of School Psychologists
nasponline.org/families/documents/35-1_S8-35_section_504.pdf

Students with Disabilities: Preparing for Postsecondary Education – Know Your Rights and Responsibilities
U.S. Department of Education Office of Civil Rights
2.ed.gov/about/offices/list/ocr/transition.html

ThinkCollege! College Options for People with Intellectual Disabilities
thinkcollege.net

HOUSING AND RESIDENTIAL SUPPORTS

Autism Speaks Housing and Residential Supports Tool Kit
autismspeaks.org/family-services/housing-and-community-living

Autism Speaks Housing and Community Living Initiative
autismspeaks.org/advocacy/advocacy-news/housing-and-community-living-initiative

The Disability Opportunity Fund
thedof.org

HUD's Section 811 Resource Center on Supportive Housing
811resourcecenter.tacinc.org

Medicaid Home & Community Based Services
medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html

National Association of Residential Providers for Adults with Autism (NARPAA)
www.narpaa.org

Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders
autismcenter.org/resources

U.S. Department of Housing and Urban Development (HUD)
hud.gov

HEALTH

Autism-Asperger's and Sexuality: Puberty and Beyond
by Jerry and Mary Newport

Autism & Mental Health Issues: A Guidebook on Mental Health Issues Affecting Individuals with Autism Spectrum Disorder
card-usf.fmhi.usf.edu/docs/resources/CARD_ASDMH_Brochure092109.pdf

Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-teen and Teenage Years
by Shana Nichols with Gina Marie Moravcik and Samara Pulver Tetenbaum

National Institute of Mental health
nimh.nih.gov

Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders: A Profesional's Guide to Understanding, Preventing Issues, Supporting Sexuality and Respond to Inappropriate Behaviors
by Davida Hartman

Taking Care of Myself: A Health Hygiene, Puberty and Personal Curriculum for Young People with Autism
by Mary J. Worbel

TECHNOLOGY

Autism Speaks Autism Apps Database
autismspeaks.org/autism-apps

Autism Expressed: Digital Skills for Adolescents with Autism
autismexpressed.com

Cyberbully411: Prevent CyberBullying & Internet Harassment
cyberbully411.org

Identifor: Use Games to Identify Strengths, Interests and Develop a Comprehensive Transition Plan
identifor.com

i-SAFE: The Leader in e-Safety Technology & Education
i-safe.org

Wrong Planet: Asperger & Autism Online Community
wrongplanet.net

Have more questions or need assistance? Please contact the Autism Response Team for information, resources and tools.

TOLL FREE: 888-AUTISM2 (288-4762)
EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG
WWW.AUTISMSPEAKS.ORG
Text ART to 30644

AUTISM SPEAKS®

Autism Speaks is the world's leading autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Mr. Wright is the former vice chairman of General Electric and chief executive officer of NBC and NBC Universal. Since its inception, Autism Speaks has committed $560 million to its mission, the majority in science and medical research. Each year, Walk Now for Autism Speaks events are held in nearly 100 cities across North America. On the global front, Autism Speaks has established partnerships in more than 70 countries on five continents to foster international research, services and awareness.

To learn more about Autism Speaks, please visit AutismSpeaks.org.