

Transition to Adult Living in Pennsylvania

OPPORTUNITY

INDEPENDENCE

EMPLOYMENT

EDUCATION

HEALTH

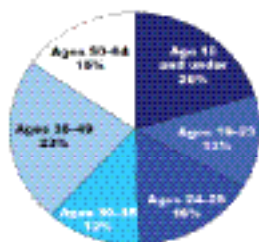
Transition Health Care Checklist

Revised 2018

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Concern:

Youth are leaving school and discovering they have no health insurance or doctor and are having difficulty obtaining medications and treatments.

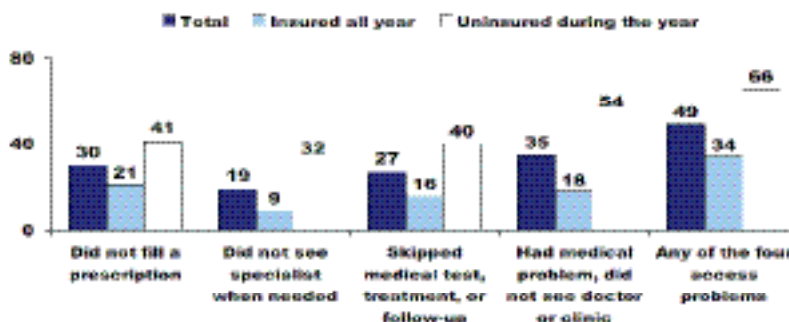


There were 13.7 million uninsured young adults, ages 19-29, in the US, in 2006.

Source: Analysis of the March 2007 Current Population Survey by S. Glied and B. Mahato for The Commonwealth Fund

Lacking health insurance threatens young adults' access to care in the US.

Percent of adults ages 19-29 reporting the following problems in the past year because of cost:



Source: The Commonwealth Fund Biennial Health Insurance Survey (2007) [unpublished]

Goal:

To provide a checklist, resources and steps to assist youth and families in making a successful transition to adult living that includes health and health care.

Disparity:

People with disabilities are truly a minority population with disparities in obtaining health care due to issues of access, provider availability, income, discrimination and communication.

The number of unemployed persons in Pa. with a disability in 2005 was 54,000:

Source: <http://www.disabled-world.com/news/america/pennsylvania/>



Within Pennsylvania, there were 317,835 persons with disabilities receiving Supplemental Security Income. Among these persons, [only] 16,945 (5.3 percent) reported earned income from employment during the prior year. (SSA, December 2008)

We welcome this document to be a springboard to future endeavors or documents. If you would like to partner, please contact the Pa. Community on Transition State Leadership Team.

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Transition Health Care Checklist:

Transition to Adult Living in Pennsylvania

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Transition Planning in the Educational System

Where do I begin?

Secondary Transition is the process of preparing youth for life after high school. Transition planning in Pennsylvania is legally required in the Individualized Education Program (IEP) by age 14; however, thoughtful transition planning can begin at any age. In a youth's high school program, there are three main post-secondary goals that must be addressed: post-secondary education or training, employment and independent living. These three areas are the driving force behind the IEP written for students in high school. Transition planning continues through high school as instruction and community experiences support these postsecondary goals. By beginning to discuss transition as early as possible, the IEP team can work with each youth and their family to plan for the future. This includes selecting classes, activities, and services that will be meaningful and motivating to the youth and lead to his/her postsecondary goals. To assist youth and families in this process the Pennsylvania Department of Education (PDE), Bureau of Special Education (BSE) and the Pennsylvania Training and Technical Assistance Network (PaTTAN) provide to all 14 year-old students with an IEP a copy of Pennsylvania's Secondary Resource Folder and CD. This information can be obtained through your school district, by visiting the PaTTAN website at www.pattan.net (found in the section for secondary transition under publications) or by calling **1-800-360-7282**. Throughout the planning process, it is important to remember that, once a student graduates from high school or reaches age 21, she/he is no longer entitled to services through the educational system. A youth must apply and meet eligibility requirements for services provided by adult agencies.

What happens next?

Transition planning involves a partnership between the youth, their family, educational staff, school-age services, post-school services, program providers and local community members that results in higher education, employment and independent living. Transition should be viewed as a bridge between school programs and the opportunities of adult life. The Secondary Transition Process entails ongoing assessment that results in the youth's understanding of current strengths, interests, preferences, needs and planning for services and supports needed to achieve future success. This Transition Skills Inventory (pages 2-18) should be used as part of the transition planning process to ensure that a youth's healthcare needs are recognized and incorporated into the plan.

What type of services are available?

The PDE, through the BSE and local school districts, offers a variety of supports to students, parents and family members to ensure a successful transition to post-secondary life. These supports include special education teachers, transition coordinators, rehabilitation counselors, guidance counselors and school health programs. Regionally throughout Pennsylvania, there are 29 Intermediate Units (IU), each with at least one designated transition coordinator. Information regarding Pennsylvania's Intermediate Units can be found on the PDE website at www.pde.state.pa.us. The PaTTAN works collaboratively with local school districts and Intermediate Units to provide professional development, technical assistance and information regarding transition projects, products and activities that promote successful outcomes for transitioning youth. More detailed information on supports and services provided by PaTTAN can be found at www.pattan.net.



Transition Skills Inventory

"How does the individual's health impact the transition activity?"

The hope is that skills can be taught and learned. If a particular skill cannot be achieved for independence, a plan is then developed.

Do you know? Youth at age 18:

- Are legally adults and can sign healthcare documents;
- Need to have their own legal signature;
- Need to give permission for family members to talk with hospitals, schools, police departments and other community agencies; and
- Need to understand that services change from entitlement to eligibility.



Introduction to the Transition Skills Inventory

- Know when transition begins. Ideally speaking, transition begins at the time of identification. It represents a process as opposed to an event.
- Learn cultural differences and practices. Culture is a shared way of life passed on from generation to generation. It includes what people think and what people do, value and believe. In working across multi-cultural communities, practitioners and providers need to be aware of cultural differences and practices.
- Review transition goals for post-secondary, employment and independent living.
- Identify current and expected future healthcare and medical needs.
- Work through the Transition Skills Inventory to determine what the individual can do now, what needs to be learned and what supports may be needed.
- Make a comprehensive transition plan:
 - Have current assessment information from youth, family, doctors and therapists.
 - Know current functioning level at home, school, and in real life situations.
 - Set goals and write these into all your plans with schools, agencies and doctors.
 - Are you receiving the help you need? See Resources throughout document.
 - Identify individuals who family and youth can invite to assist with transition planning, to include:
 - General education teacher, school nurse, doctor, therapists, mental health/mental retardation, Office of Vocational Rehabilitation, Social Security Administration, County Assistance Office, Children, Youth & Families, case managers and/or local advocates.
 - Continue to use this inventory at key transition times and adjust the plan according to the changing needs of the individual in transition.

Pennsylvania Youth Leadership Network (PYLN) has been the source of inspiration for the changes to this document. We thank the PYLN for their permission to use their words and ideas from the Pennsylvania Youth Leadership Secondary Transition Toolkit.

ACCEPT YOURSELF: WHO AM I?

SELF-AWARENESS

	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
Can describe likes & dislikes					
Know name, birthdate, address, telephone number, etc.					
Know height & weight					
Know when & how to ask for help					
Can describe needed accommodations					
Know present medical conditions/allergies					
Can describe disability					

Planning for the future:

ACCEPT YOURSELF: WHO AM I?

SAFETY

PERSONAL SAFETY	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
Carry appropriate personal ID when leaving home					
Understand who can help					
Know how to avoid dangerous situation(s)					
Understand who is allowed to have personal information					
Know when and how to dial 911					
Have emergency plan for fire, medical or disaster					
Understand proper use of matches/lighters/chemicals					
Has and maintains fire extinguisher & a smoke detector					
Can respond appropriately to fire alarm (exits, meeting places)					
Understand abuse: physical, emotional, sexual, financial, legal					
Understand 'stranger danger' (including internet safety)					
Know where Social Security card & a birth certificate are; when to use					
Able to problem solve for unexpected situations					

Planning for the future:

ACCEPT YOURSELF: WHO AM I?

SAFETY_{continued}

HEALTH SAFETY	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
Know signs and symptoms of personal health emergencies					
Know contact information for healthcare providers					
Can treat minor cuts, scrapes, burns					
Avoid tobacco, alcohol & drugs					
ENVIRONMENTAL SAFETY					
Understand dangers of hot & cold					
Know how to use household chemicals properly (do not mix)					
Know how to protect themselves by wearing gloves, safety glasses					
Can read & understand labels or know who to ask for help					

Planning for the future:

ACCEPT YOURSELF: WHO AM I?

COMMUNICATION

KNOW COMMUNICATION METHODS	Can X Already	Needs Practice	Accommodations	Who & k here	Included in plan
Verbal: how well understood by others					
Signs/lip reading: know how to arrange for interpreters					
Devices: know how to care for, get routine maintenance, use independently					
Written: has basic writing skills necessary to provide name, whereabouts, etc.					
Non-verbal: has support person available who is familiar with individual's methods of communication					
Know when, why & how to sign name					
Know how to communicate by phone/TTY/TTD					

Planning for the future:

ACCEPT YOURSELF: WHO AM I?

HEARING & VISION

	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
Know who provides service & how/when to get equipment repaired					
Use hearing devices independently					
Get hearing checked, get options					
Get eye exam, get glasses/contacts					
Know who provides service & how/when to get a new prescription					
Ask for accommodations for vision/hearing (as needed)					
Has had comprehensive visual and auditory processing evaluation(s)					

Planning for the future:

ACCEPT YOURSELF: WHO AM I?

MEDICATION

	Can You	Needs	Accommodations	Who & k here	Included in plan
Know why, when & how often to take medication					
Recognize medication appearance (size, color, consistency) and question differences					
Know how medications are to be taken (oral, sub-lingual, rectal, vaginal, topical, eye/ear drops, ointments, inhalants, injections)					
Know never to share medication					
Know who to call with questions or to get help					
Can open "child resistant" caps or can ask for bottles that can be opened					
Can fill daily/weekly pillbox					
Know when and who to call for prescription refills					
Know how to purchase and properly use over-the-counter medication (OTC)					
Know medication(s): name, purpose, side effects and restrictions					
Understand OTC, herbal or alternative remedies and how they interact with prescription					
Talk to MD or pharmacist when having difficulty getting medications paid for (may have information on prescription assistance programs or exception forms)					

Planning for the future:

DECLARE YOURSELF: WHO I AM

SELF-ADVOCACY

	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
Know how to ask for accommodations					
Know about disability card (www.arcindiana.org/IAMD.pdf)					
Understand disability rights laws					
Know when to speak up					
Know how to make contact with community advocacy organizations					
Know when to disclose information (GOOGLE: "411 Disclosure")					

Planning for the future:

DECLARE YOURSELF: WHO I AM

MONEY MANAGEMENT

	Can X Uready	Needs dractice	Accommodations	Who & k here	Included in dlan
Understand use and need for money					
Understand values of U.S. coins & paper money					
Know source(s) of money					
Understand difference between wants & needs					
Understand appropriate use of cash, check, debit card					
Understand responsible use of credit cards & loans					
Can develop a household budget (food, utilities)					
Understand how to pay bills					
Understand contracts (door-to-door sales)					

Planning for the future:

DECLARE YOURSELF: WHO I AM

POST-SECONDARY CONSIDERATIONS

	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
Know career/employment goals & related education options					
Know who can help with transition planning (transition coordinators at IU; PaTTAN)					
Know funding sources for educational & training options					
Have considered pros & cons of full-time & part-time enrollment; effect on benefits					
Have developed a plan to explore & evaluate career goals; possible education options					
Able to discuss conditions that require individualized accommodations					
Know rights and responsibilities under ADA & 504 Rehabilitation Act laws					
Have toured schools & visited with the office for students with disabilities					
Know how to work with the Office of Vocational Rehabilitation (OVR)					
Have worked with health services to plan for medical emergencies					

Planning for the future:

DECLARE YOURSELF: WHO I AM

EMPLOYMENT CONSIDERATIONS

	Can X Uready	Needs dractice	Accommodations	Who & k here	Included in dlan
Understand value æ å benefits of being employed					
Explore æ å discuss what type of employment is desired					
Know funding sources for employment options					
Understand how health concerns impact various career options					
Describe employability skills					
Is able to discuss with employer the conditions that require individualized accommodations					
Consider pros æ å cons of full-time æ å part-time work					
Understand how to get to/from work; have good transportation plan					
Understand employee benefits					
Know how to work with Office of Vocational Rehabilitation (OVR)					
Know if work place has people trained for medical emergencies until 911 arrives					
Has emergency form completed; form given to appropriate people					

Planning for the future:

EMPOWER YOURSELF: I AM!

COMMUNITY LIVING

	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
LIVING ARRANGEMENTS					
Aware of options of where to live					
Able to evaluate living arrangements for accessibility to healthcare providers					
Aware of living expenses & how to pay for them					
Aware of need(s) for supports					
Aware of how to pay & maintain supports					
TRANSPORTATION					
Able to safely get around in the community					
Aware of equipment & adaptations needed					
Aware of how to apply for para-transit services					
Able to use appropriate transportation to get to work, medical appointments & community activities					
Aware of who can provide transportation & able to make arrangements					
Aware of how to apply for PennDOT's accessible parking placard					
Aware of how to obtain driver's license & related support services					
Aware of funding or saving money for vehicle; needed adaptations; maintenance & related expenses					

Planning for the future:

EMPOWER YOURSELF: I AM!

COMMUNITY LIVING continued

SOCIAL RELATIONSHIPS	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
Aware of opportunities to make friends and meet new people					
Aware of people to trust & ask for advice					
Respectful of other's personal space & property					
Aware of the guidelines for dating & healthy relationships					
Aware of safe sexual practices & options for individual choices					
EMERGENCY PLANNING					
Aware of potential emergencies					
Have a portable crisis kit packed and available					
Have back-up plans and people for all events					
Think about what is needed to travel locally & vacation					
Practice a drill					
Become involved in local planning					

Planning for the future:

EMPOWER YOURSELF: I AM!

MEDICAL MANAGEMENT

INSURANCE & BENEFITS	Can Xo Uready	Needs dractice	Accommodations	Who & k here	Included in dlan
Aware of need to take all insurance cards to all appointments					
Able to use insurance cards appropriately					
Able to understand what services are covered by insurance					
Able to pay co-pay æ å out-of-pocket expenses as necessary					
Able to identify approved providers under insurance plan					
Aware of insurance plan's special needs unit or case manager					
Aware of pre-approval and pre-certification rules					
MANAGE MEDICAL INFORMATION & RECORD-KEEPING					
Able to follow instructions from healthcare providers					
Able to fill out medical forms or ask for assistance					
Able to maintain a system for keeping medical records (binder or file, electronic folder)					
Able to compile medical tests æ å results/summaries/functional assessment					
PERSONAL CARE ATTENDANTS, EQUIPMENT & TREATMENTS					
Able to evaluate need for personal care attendants, equipment æ å treatments					
Aware of need for physician orders æ å insurance approval					
Able to manage personal care attendant services					
Able to understand æ å use remedial/prosthetic devices æ å equipment as prescribed					
Able to arrange for equipment maintenance (routine æ å emergency)					
Aware of who provides treatments æ å therapies					
Able to follow instructions for treatments æ å therapies					
Able to schedule æ å attend all treatments æ å therapies					

Medical Management continued on next page.

EMPOWER YOURSELF: I AM!

MEDICAL MANAGEMENT continued

TRANSITION TO ADULT HEALTHCARE PROVIDERS	Can You Already	Needs Practice	Accommodations	Who & Where	Included in Plan
Able to respond to questions from healthcare providers					
Able to prepare questions for healthcare providers					
Aware of confidentiality & a need to sign HIPAA forms					
Aware of differences between primary care providers & specialists					
Aware of benefits of interviewing prospective healthcare providers					
Able to evaluate accessibility of office & exam rooms					
Able to make appointments for specialists, family planning, genetic counseling, hospital & laboratory tests					
Able to call for referrals (as needed)					
Aware of Medical Home model					

Planning for the future:

EMPOWER YOURSELF: I AM!

ACTIVITIES OF DAILY LIVING

	Can You	Needs	Accommodations	Who & Where	Included
UNDERSTANDING HOW TO ESTABLISH DAILY ROUTINE	Already	Practice			in Plan
Get enough sleep					
Eat a healthy diet					
Exercise & get enough fresh air					
Manage stress					
MAINTAIN GOOD HYGIENE ROUTINE					
Bathe, wash hands and keep clean					
Wear clean clothes					
Brush teeth					
Wear deodorant					
TIME MANAGEMENT					
Understand passage of time					
Has basic ability to keep track of time					
Keep calendar of appointments & important events					
Include time for hobbies & social activities					
WELLNESS					
Participate in physical activity (with modifications as needed)					
Understand and deal safely with food allergies					
Understand specialized diet needs, foods, medical follow-up					
Follow routine health care: doctor visits, breast & testicular self-exams, pap test, prostate health					
Keep immunizations current & records easily accessible					
Understand sexual awareness to prevent pregnancy, STD's & HIV/AIDS					

Planning for the future:

TRANSITION QUICK-REFERENCE RESOURCE GUIDE

Are you receiving the help that you need?
Here are some additional resources to look into.

SELF-DETERMINATION			
Self-Determination http://education.ou.edu/zarrow http://pyn.org www.arcindiana.org/IAMD.pdf	POST-SECONDARY EDUCATION & TRAINING	EMPLOYMENT	INDEPENDENT LIVING (Community Participation)
Assistive Technology www.fctd.info www.ataporg.org/index/html www.assistivetech.net www.disabilities.temple.edu www.jan.wvu.edu www.patf.us	Preparing for College www.pepnet.org/itransition.asp www.going-to-college.org www.educationplanner.com www.thinkcollege.net	Employment www.ncwd-youth.info www.monster.com www.sharedwork.org www.pacareerzone.org www.pennsylvaniajobs.com www.dli.state.pa.us (Office of Vocational Rehabilitation) www.worksforme-pa.org	Independent Living www.publictransportation.org www.helpinpa.state.pa.us www.sdhpa.org www.projectaction.org @j Kp & q ^ d æ ^• Bq [&æ' æ & qæ] cÅ
General Transition Sites www.sharedwork.org www.pacer.org/tatra www.gottransition.org www.autismhandbook.org www.nichcy.org @j Kp & q ^ d æ ^• Bq [&æ' æ & qæ] cÅ www.thearca.org www.nsttac.org	Preparing for Career and Technical Education www.collegebound.net/vocational-school-guide www.pacareerstandards.com www.khake.com/page36.html	SSI and SSDI Work Incentives www.socialsecurity.gov/work/WIPA.html www.yourtickettowork.com www.cwds.state.pa.us	Health and Wellness www.ncpad.org www.covd.org www.asha.org www.health.state.pa.us www.paelkshomeservice.org
Emergency Planning www.fema.gov www.ready.gov www.serv.pa.gov www.prepare.pitt.edu www.temple.edu/instituteondisabilities POISON CONTROL: 800-222-1222	Additional Resources www.pealcenter.org www.parentednet.org www.mentorparent.org www.huneinc.org www.paddc.org http://gucchd.georgetown.edu/64331.html www.gotoskn.state.pa.us	Career Interest and Occupational Information http://online.onetcenter.org www.pacareerzone.org www.acinet.org www.careeronestop.org/ www.bls.gov/k12	Benefits and Financial Planning www.specialneedsalliance.org Recreation and Leisure www.helpinpa.state.pa.us www.specialolympics.org www.kidsource.com
	PA Youth Leadership Network Toolkits www.pyn.org/health/toolkits	Casey Life Skills Assessments (Caregiver & Youth): www.casey.org/resources/tools/clis/	



PA Youth Leadership Network **Resources**

What is the Pennsylvania Youth Leadership Network (PYLN)?

The PYLN is a team of youth leaders with disabilities from across Pennsylvania with a purpose to develop the self-determination, empowerment, and leadership of youth that promotes successful post school outcomes in the areas of education, employment, independent living, and health and wellness among youth and young adults throughout Pennsylvania.

Goals of the PYLN

- Provide a youth voice at the table on important boards and committees that impact the lives of youth with disabilities.
- Recruit and match mentors who are young adults with high school youth to help them prepare for their future success.
- Develop and share transition, self-determination, self-advocacy, and empowerment resources geared toward youth in high school.
- Ensure unbiased policies, practices and attitudes that affect individuals with disabilities

The PYLN Wants to Connect with YOU!

- Connect to the PYLN by visiting our website: <http://www.pylvn.org>
- This URL address will connect you to informational videos, materials and updates regarding the PYLN.

Developed BY Youth FOR Youth!

- **Pennsylvania Youth Leadership Network Secondary Transition Toolkit**

- Youth driven, youth written tool for youth
- 110 page guide and workbook for the transition process
- Accessible
- Divided into three phases
 - Phase One: ACCEPT YOURSELF!
 - Phase Two : DECLARE YOURSELF!
 - Phase Three : EMPOWER YOURSELF!

- **PYLN Health Care Toolkit**

As a follow up to the 2008 Pennsylvania Youth Leadership Network's (PYLN) Secondary Transition Toolkit the PYLN, with funding support from a Heinz Endowment Youth Philanthropy grant, has created the PYLN Health Care Toolkit. With a focus on living a fulfilled healthy life, The PYLN Health Care Toolkit is designed to further assist youth in their transition into the adult world. The best thing about the toolkit is that it was written and designed by youth with disabilities who are members of the Pennsylvania Youth Leadership Network (PYLN) for youth. It can also be used with families and professionals as a youth-friendly resource for transition.

Appendix A: Health Insurance Options

If you are 18 years old and have:

Then:

- No Medical Assistance (MA)
- No Medical Assistance for Children with Special Needs
- No private insurance

- Apply for MA programs including MA for Workers with Disabilities (MAWD)
- Apply for CHIP
- Obtain private health insurance
- College-apply for student plan

- MA with SSI
- MA for Children with Special Needs

- Apply for SSI (Adult Criteria)
- MA may continue*
- Apply for MA programs including MA for Workers with Disabilities (MAWD)

Children's Health Insurance Program (CHIP) will end the month of your 19th birthday

- Explore private insurance options
- Visit www.pahealthoptions.com

Private insurance

- Student status or coverage as adult disabled dependent child
- Check HIPAA Portability and conversion policies (group to self plan)
- Group plan through employer (may include HIPP**)
- Opt for COBRA

Patient Protection and Affordable Care Act (ACA)

- Parent's group plan up to 26th birthday
- No denial or premium penalty for pre-existing conditions
- No lifetime limits for coverage
- Call "high-risk pool" PA Fair Care (888-767-7015)
- Check out www.pafaircare.com or www.healthcare.gov for more information

* You may lose Medical Assistance if you do not meet SSI adult disability criteria.

** Health Insurance Premium Payment (HIPP)-A Medical Assistance Program that will pay your premium for insurance plan at work if you qualify.

Appendix A: Tips to Maintain Health Insurance

Youth may be able to continue on their family's private insurance plan as long as they are considered an "adult disabled dependent child", are in school/college or qualify under the provisions of the ACA.

- Ask Human Resources or insurance company for information/application. This information should include the process and form for the doctor to complete.
- Include all medical conditions.
- This may be available as the youth leaves high school.

Adult Disabled Dependent Child - Depending on company and policy

- May continue on family plan if dependent for life
- Be on family plan prior to turning 18
- Annual re-certification - disability and dependent

Student status - Depending on company and policy

- Proof of college class load each semester (often requires full-time status)
- Ages 18 - 22, sometimes older
- Annual re-certification

Coverage up to 26th birthday - Depending on company and policy

The Health Insurance Portability and Accountability Act (HIPAA) - stands also for portability

- When changing group health insurance, get a certificate of coverage for portability.
- This will waive the waiting time and any increased costs for pre-existing conditions.
- You can contact your health insurance plan for more information about how the certificate of coverage will apply to your specific situation.

Social Security as an adult is one pathway to public insurance (Medical Assistance).

Youth receiving Social Security Disability Benefits (SSDI) as a child will need to reapply as an adult with disabilities.

Youth may want to apply for Medical Assistance for Workers with Disabilities (MAWD).

It is critical to have current evaluations and assessments, including educational, medical and psychological. These are needed to apply and qualify for many services and programs.

Remember to return to the doctor for prescriptions and referrals for testing and services paid by public and private insurance.


Depending on whether private or public insurance is used as primary, explore the type and level of services available. Check if covered services meet the needs of the youth.

Be sure to show all service providers all insurance cards.

Keep updated on National Healthcare Reform Law (www.whitehouse.gov/healthreform).

REMEMBER: at certain ages, services and benefits change from entitlement to eligibility.

Appendix B: Transition Timeline

Before Age 14	Age 14	Age 18	Age 21
If determined appropriate by the IEP team, transition services may be included in the IEP.	Transition Services must be included as part of the IEP. 	A youth has the right to make decisions about health care and finances OR evaluate and consider other decision-making options that need to be investigated (Power of Attorney and/or Guardianship).	This is the last year the youth is entitled to special education services through Pa. Department of Education (PDE). 
Begin to consider interests and preferences that can be connected with the education and medical plans.	Youth have the right to be part of the IEP transition team.	A youth may choose not to continue in school. A parent may override this decision until age 21.	
Review attached appendices to determine eligibility for services and when to apply.	Start thinking and talking about transition from pediatric to adult health-care providers.	Transition to adult health-care providers should be in progress.	Transition to adult health care providers should be complete unless special provisions are made.
Prepare Standby Guardianship (appropriate for all children less than 18 years).	Begin to update evaluations and assessments, including medical and psychological, at age 16.	Apply for SSI and reapply for MA programs. 	When a youth reaches age 21 and continues to be MA eligible, limits are applied to certain MA benefits.
	Mental Health: At age 14 and older, either the parent or the minor has the power to admit the minor to inpatient or outpatient care. 	Contact private insurance company about continued coverage.  Males need to register for selective service. A youth can register to vote.	

Continue the development of social skills and interests in community and recreational activities throughout these years.

Appendix C: Financial and Legal Concerns

Be able to provide a signature:

- At age 18, a youth has the right to make health care decisions.
- Demonstrate adequate decision-making capabilities or have options in place for assistance.

Consider the following in their financial and estate planning:

- Income or funding (SSI/SSDI/employment/waiver)
- Estate planning - for youth, parents and grandparents who plan to gift to a child with special needs
- Special Needs Trusts - three types of trust funds: third party, first party and pooled trusts. Trust funds should be established early to maintain eligibility for public funds and programs
- Power of attorney (physical and mental health care and financial) or guardianship

Power of Attorney to help with legal, financial and healthcare matters:

- Know about HIPAA and sign release to share medical information.
- Representative payee has been appointed to help with social security income and expenses.
- Client advocate has been identified to help get services.
- Co-signer can help with banking and obtaining credit.

Guardianship (full, limited, emergency) for individuals over age 18 who have been declared “incapacitated” (This term is used in Pa.):

- Definition: a person is legally incapacitated in Pennsylvania if they are an adult whose “ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that he is partially or totally unable to manage his financial resources or meet essential requirements for his physical health and safety.”
- Petition is filed by attorney; decision is made by judge. (This may be a lengthy process: start early.)
- Individual needing guardianship must be included in proceedings unless they would be harmed by being present.
- Guardianship proceedings should only be initiated if there are no other solutions to address an identified problem.
- An attorney may file for emergency guardianship only for a very good cause. Emergency guardianship can be in effect for as little as 72 hours or extended for up to 20 days.

Consider the advantages and disadvantages of what it means to be emancipated:

- Definition varies with different agencies - ask your agency to explain
- Generally emancipated minor means:
 - Person under 21, employable, no longer under the care and control of parents or legal guardians
 - Not claimed as a dependent on another individual's federal income tax form
 - Pregnant, married, divorced or widowed
 - Acceptable written proof of verification of emancipation which may include marriage license, income tax forms or court order

Other considerations

- Be able to fill out income tax forms or know who can help
- Know about unemployment and how to apply or know who can help
- Understand money - how to create and follow a budget
- Know who to ask (Trustee) and how to ask for disbursement from Special Needs Trust

Appendix C: Financial and Legal Concerns Special Needs Trust

Does your child, youth, adult, sibling with special needs have assets over \$2000 in their own name? *

No

Yes

Will your child inherit anything of value from you or someone else? *

No

Is it a substantial amount?

Yes/Maybe

Yes/Maybe

No

Does your child earn more than the SSI limit? *

Yes

Refer to:

- Academy of Special Needs Planners
www.specialneedsanswers.com
- Special Needs Alliance
www.specialneedsalliance.com

PA Health Law Project - 1-800-274-3258
www.phlp.org

No

What families need to consider:

- Prepare/review your (and spouse's) long-term care plan, will, powers of attorney, and medical directives.
- Prepare a letter of intent - this details directions for daily routines and needs. (Examples may be found online or contact your attorney.)
- Consider a Special Needs Trust:
 - Gifts could be paid to Special Needs Trust, not individual with disabilities.
 - Review/update all beneficiary designations for the Special Needs Trust, not individual with disabilities.
 - Notify family and other interested parties of Special Needs Trust.
- Prepare a Life Care Plan - this calculates the cost of a disability over a lifetime.



*You or your child must meet income, resource & other eligibility requirements in order to qualify for Medicaid, SSI, and related programs.

Appendix D: HIPAA/COBRA

Health Insurance Portability & Accountability Act (HIPAA)
US Department of Labor
www.dol.gov/dol/topic/health-plans/portability.htm

Consumer Hot Line 1-877-881-6388
or www.insurance.state.pa.us

HIPAA-The Health Insurance Portability and Accountability Act

- Provides rights and protections for participants and beneficiaries in group health plans, including protection for coverage that limits exclusions for pre-existing conditions
- Allows for opportunities to enroll in or purchase a group health plan

HIPAA has implications for youth with disabilities.

- States are required to provide individual insurance to people losing group coverage access regardless of their health status. This can help youth who qualify through their parent's group coverage.
- Youth with disabilities can apply for individual coverage as a "HIPAA eligible individual."
- Eligible individuals include those who have had insurance for at least 18 months where the most recent coverage was under a group health plan or Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1986 coverage.
- Applications must be made within 63 days of losing the group coverage.
- It is critical that the person who has paid the premiums for the insurance request a **certificate of coverage for portability** from their human resources or insurance company. This proves the person with a disability had insurance.
- The youth then needs to present this document to their new employer. This will eliminate or reduce the waiting period for pre-existing conditions.

COBRA - Consolidated Omnibus Budget Reconciliation Act of 1986

- COBRA allows individuals and their dependent children the right to temporarily continue health coverage at group rates when the employee is laid off, resigns or gets fired.
- Continued coverage will cost more than the normal group rate (COBRA plans include the employer's share and the employee's share of the health plan), but it is less expensive than many individual health plans and provides time to find other health insurance.
- An individual must apply within 60 days of loss of employment and will need to pay premiums.



Appendix E: Social Security Administration (SSA)

To Apply for Social Security
Benefits: Call toll-free
1-800-772-1213

Get More Information or
Apply Online at:
www.socialsecurity.gov

Where do I begin?

Remember it may be possible to work and receive Social Security benefits.

- Consider filing for benefits.
- Know how to contact the Social Security office.
- Be aware of the appropriate use of SSI or Social Security payments.
- Comply with reporting requirements to prevent penalties/loss of benefits. Report the following:
 - Change in income, resources, or living arrangements
 - Change of address, dropping out of school, getting or changing a job, getting married
 - Going on to post-secondary schooling
- Consider contacting: OVR, MH/MR, Ticket to Work Program for assistance in getting a job.
- Review/determine if continued eligibility may be scheduled.
- Be aware that appeals can be filed; follow them through.

Supplemental Security Income (SSI)

- Under age 18:
 - Eligibility is based on income and resources of the parents and of the child.
 - Eligibility is also based on applicant's approved disability (as a child).
- One month before the 18th birthday:
 - To ensure timely benefits for adult eligibility, begin the application process at www.socialsecurity.gov or by calling the **1-800-772-1213**.
 - Eligibility will be based only on applicant's income and resources at age 18.
- Over age 18:
 - Consider filing for SSI and agreeing with the Medicaid re-evaluation.
 - Eligibility is based on the income and resources of the applicant.
 - Eligibility is based upon applicant's disability determination (as an adult).
- Consider taking advantage of Ticket to Work.



Social Security Benefits as a Disabled Adult Child (SSDAC)

- Definition: An adult child who is disabled (before age 22) may be eligible based on the parent's work history if the parent retires, becomes disabled and collects benefits, or if the parent is deceased.
- Benefits may begin at age 18.
- Medicare will take effect 24 months after this benefit begins (not before age 20).
- Payment of benefits can be sent directly to a child, under the age of 18, if the child:
 - Is on active duty in the armed forces, is living alone, or is self-supporting;
 - Is a parent and filed for their own or their child's benefits;
 - Is within seven months of attaining age 18; or
 - Demonstrates the ability to handle finances and no qualified payee is available.

Appendix E: Social Security Administration (SSA) *continued*

Social Security Disability Benefits (SSDI)

- Definition: Benefits may be payable if the child has enough Social Security work credits to be “insured” for disability and meets the medical criteria. The amount of work required depends on the age of the child. A minimum of six work credits (a year and a half of work), is needed.
- Medicare will take effect after 24 months of SSDI checks.
- Payment amount is based on the actual earnings of the child.

Ticket to Work

- The Ticket To Work is a part of the Social Security Administration. It is for people who receive SSDI benefits and/or SSI benefits because of a disability. The program offers greater choices in getting the services needed to go to work and earn more money.
- Under the Ticket To Work, employment, vocational and other services can be received to assist going to work and earning more money. These services are provided by Employment Networks, which are private organizations or government agencies that have agreed to work with the Social Security Administration in providing employment services to beneficiaries with disabilities. (See Work Incentive Planning and Assistance.)
- www.yourtickettowork.com
- Candidates must be over 18 and under full retirement age and have a determined disability to qualify.

Work Incentive Planning and Assistance (WIPA)

- WIPA provides work incentive planning and assistance to beneficiaries with disabilities.
- WIPA can meet with the families to think through options of working and SSA benefits, also can assist with Individual Education Program (IEP).
- This service is available after the person is getting SSA benefits.
- For individual assessment, contact your local work incentive counselor.

This service is available statewide by calling the following numbers:

Southwestern PA - 866-802-4333

Northwestern PA - 866-627-8610

Southeastern PA - 877-375-7139

Northeastern PA - 866-541-7005

Central PA - 866-541-7005

Section 301 – Provision to Continue Receiving SSA Benefits

- Individuals can continue to receive SSA cash benefits and also medical benefits if participating in an approved vocational rehabilitation program prior to age 18, or with an active IEP.
- This section of the Social Security law can be used when a youth, at age 18 years, no longer meets the SSA medical qualifications.

Be aware that appeals can be filed. And then follow through.

<http://www.socialsecurity.gov/redbook/eng/ssdi-and-ssi-employments-supports.htm#6>

Appendix E: Social Security Administration (SSA) *continued*

Medicare

1-800-MEDICARE (1-800-633-4227)

- Can continue to receive SSA cash benefits and also medical benefits if participating in an approved vocation
- Medicare is for people age 65 and older and those individuals who have been on SSDI or SSDAC benefits for 2 years. Coverage may also be available for those who have End Stage Renal Disease and those with Lou Gehrig's Disease (ALS).
- Understand who is eligible and how to contact SSA
- Carry a Medicare card with them and contact SSA if it is lost
- Be aware of Medicare premiums and coinsurance
- Know how to look for a physician/supplier
- Be familiar with Medicare prescription drug act/Medicare savings programs
- Know Medicare rights and appeals process
- Be aware of the Medicare web site www.medicare.gov
- Understand they may be eligible for both Medicare and Medical Assistance (Medicaid)
 - If an individual is eligible for both, he/she must enroll in Part D or a comprehensive plan for prescription coverage.
 - Part B (monthly premium) should be paid by Pa. Department of Welfare.
 - Part D premium will be paid by the Federal government through the Social Security Office.
- Medicare Prescription Drug Program
 - Enroll in a Medicare Prescription Drug Plan www.medicare.gov
 - Apply for extra help with Social Security Administration (those who are on Medical Assistance do not need to apply for extra help) www.socialsecurity.gov
 - Consider all needs and be aware of Medigap insurance and Medicare Advantage Plans and know where to go for help in deciding whether to purchase one and how to choose www.medicare.gov/Choices/Overview.asp

Additional Information from www.youthlaw.org

The article, "Establishing Disability For Young Adults" was written for www.youthlaw.org Nov. 3, 2003. The article alerts families to look more deeply into this benefit. This helps them to strategize, therefore limiting interruption or loss of benefits at a time when it is most crucial.

- If age 18 or older, a youth must show disability using the adult SSI standard. SSA defines "disability" as the inability to engage in any substantial, gainful activity by reason of medically determinable physical or mental impairment, which can be expected to last for at least 12 months or result in death.
- If a youth is working, there is the possibility that SSA may determine that the youth is gainfully employed and, therefore, no longer disabled. It is important to have as much documentation as possible to support the claim that the youth is still disabled even though able to work.
- The childhood disability regulations provide a guide to assessing the functional limitations of a youth. Find common ground between this childhood standard and the adult disability standard that the youth must meet. Use this information to communicate to SSA the true impact of the functional limitations.

Appendix F: Center for Independent Living (CIL)

PA Statewide Independent Living Council (PA SILC)

is a nonprofit, cross-disability, consumer-controlled organization dedicated to securing public policies that ensure civil rights for people with disabilities by supporting the independent living philosophy.

www.pasilc.org/about.html / 717-364-1732

PA Council on Independent Living (PA CIL)

The mission of the Pennsylvania Council on Independent Living is to support the network of Centers for Independent Living (CILs) and to advance the Independent Living movement.

www.pcil.net/pages/cils/locate_a_cil.aspx / 717-920-0530

What is Center for Independent Living?

A Center for Independent Living (CIL) is a consumer-controlled, community-based, cross-disability, nonresidential, private, nonprofit agency. All centers implement the Independent Living philosophy by providing services to people with disabilities, as well as families of individuals with disabilities, community service providers, government agencies, private businesses and the community at large.

CILs empower people with disabilities to live at their highest achievable level of independence through:

- Following the Independent Living Philosophy
- Engaging in collective systems change
- Promoting the availability of Independent Living options regardless of disabilities
- Conducting outreach to un-served and underserved persons

Core Services

1. Advocacy

Centers work to remove barriers to independent living through the following:

- Self-advocacy - working a person with a disability to ensure necessary services are obtained from government agencies and eliminating discrimination
- Community Advocacy - pursuing changes in each community to ensure independent living is attainable for all consumers
- Systems advocacy - achieving legislative and regulatory reforms that benefit thousands or millions of people with disabilities at the state and national level

2. Peer support

- Provides a comfortable and trusting outlet for consumers to talk about their concerns and experiences and received support or advice from another person with a disability who is living independently.
- Problems solving in areas such as learning to use community services more effectively, adjusting to a new disability, changes in living situations and sharing tips for independent living are a few of the common topics.
- Individual and group support through role models encourage consumers to develop ways to enhance their quality of life and to contribute to their community.

Appendix F: Center for Independent Living (CIL) *continued*

3. Information and referral

Centers provide people with disabilities access to information and resources from many sources that they need to make informed decisions and get what they need to live independently.

Independent living skills training

One-on-one or group education that enables individuals to acquire the skills necessary to live independent lifestyles. This often includes classes on how to hire and manage personal assistants, manage a personal household and budget, how to access public transportation and respond to discriminatory action.

What does it mean for youth?

A Center for Independent Living (CIL) is a disability resource center (no one lives there!). A CIL can help you as you are getting ready to leave school and enter adulthood.

What can a CIL do for you?

A CIL can help you look at your choices on where to live, where to go to college, what benefits you are entitled to, and to know where to get help, among other things. You can learn from people who have been where you are and have done the things you want to do with your future. All services are YOUR CHOICE, you decide what you want to do with YOUR life.

Appendix G: Medical Assistance (Medicaid)/MAWD or CHIP

To apply for Medical Assistance (Medicaid)/MAWD or CHIP on the same application:

GO ONLINE

www.compass.state.pa.us

To contact toll-free number
of contractor go to:

www.chipcoverspakids.com

Statewide Customer Service Center (SCSC): **1-877-395-8930** or
in Philadelphia> Customer Service Center **1-215-560-7726**

or **www.dpw.state.pa.us** choose: Apply for Benefits

DPW Helpline **1-800-692-7462** TTY/TTD **1-800-451-5886**

Healthy Kids Helpline 1-800-986-5437

Medical Assistance (Medicaid)

In this document, the word Medicaid is interchangeable with the term Medical Assistance.

Medicaid is a federal/state program designed to provide comprehensive and quality medical care for low-income families with special emphasis on children, pregnant women, the elderly, the disabled and parents with dependent children. In Pennsylvania, this process is known as Medical Assistance (MA) because it includes Medicaid as well as benefits that are not part of Medicaid.

At age 18:

- Apply for SSI benefits. This can be done either on your own or with the help of the County Assistance Office (CAO).
- After applying, a Disability Advocate Program (DAP) worker, located in your CAO, will contact you to assist you with your application for SSI.
- Provide disability documentation to both your CAO and SSA offices.
- If SSI is denied, complete SSI appeals process working with DAP worker.

County Assistance Office (CAO)

- Report all changes to your CAO or SCSC. Call **1-877-395-8930** or in Philadelphia **1-215-560-7726**.
- Follow through with the renewal process once a year.
- Indicate on all applications or renewals that there is a child with a disability in the household. Remind the CAO when applying or reapplying that you have a child with special needs.
- Know how and when to use the ACCESS/Managed Care card:
 - Do not destroy your ACCESS and/or Managed Care cards. If a replacement ACCESS card is needed, contact the local CAO. If a replacement Managed Care card is needed, contact the Managed Care plan.
 - If a letter has been received that your Medicaid benefits will end, appeal within 30 days of the notice date. If you were receiving benefits as a family when Medicaid was closed, be sure to alert the CAO that you have a child with special needs. If additional help is needed, contact Legal Services listed in your letter.

Appendix G: Medical Assistance (Medicaid)/MAWD or CHIP

continued

Managed Care Special Needs Unit

- If unfamiliar with Managed Care, ask your caseworker or case manager in the Special Needs Unit. To contact a Special Needs Unit in your area:

Access Plus	1-800-543-7633	TTY 1-800-654-5984	http://www.accessplus.org
AmeriHealth Mercy Health Plan	1-888-991-7200	TTY 1-888-987-5704	http://www.amerihealthmercyhp.com
Gateway Health Plan	1-800-392-1147	TTY 1-800-654-5988	http://www.gatewayhealthplan.com
United HealthCare Community Plan	1-877-844-8844	TTY 711	http://www.uhc.com
UPMC for You	SW 1-800-286-4242	TTY 1-800-361-2629	http://www.upmchealthplan.com
	Lehigh/Cap 1-866-353-4345	TTY 1-800-361-2629	
Keystone Mercy Health Plan	1-800-521-6860	TTY 1-800-684-5505	http://www.keystonemercy.com
Aetna Better Health	1-866-638-1232	TTY 711	http://aetnabetterhealth.com
Coventry Cares by Health America	1-866-903-0748	TTY 1-800-613-3087	http://healthamerica.coventryhealthcare.com
Health Partners	1-800-553-0784	TTY 1-877-454-8477	http://www.healthpart.com

To locate regional consumer meetings, please visit www.enrollnow.net/PASelfService/home.html.

Medical Assistance for Workers with Disabilities - MAWD

- Full Medicaid coverage is available for those:
 - Age 16 years to 64 years
 - Who live in Pa. and are US citizens or qualified non-citizens
 - Who are considered disabled by meeting Social Security criteria and are employed or self employed
 - Who meet income and resource criteria
 - MAWD has higher income/resource limits than some Medicaid programs.
 - There are deductions that may apply.
- Participants pay a monthly premium based on their income.
- For more information, visit www.dpw.state.pa.us or call 1-800-692-7462.

Children's Health Insurance Plan (CHIP) - General Information and Tips:

- CHIP provides free and low-cost coverage for uninsured children who are not eligible for Medicaid.
- Candidates must be a PA resident and under age 19.
- Child must be a US citizen or be in lawful status.
- Eligibility determination considers age of child and household income.
- Determination considers child for either CHIP or Medicaid.
- Pre-existing conditions and assets are not a consideration for CHIP.
- Enrollment is for 12 consecutive months; must renew benefits yearly.
- Benefits are a comprehensive package with no deductibles.
- No co-pays or monthly premiums with free CHIP. There are co-pays and premiums with low-cost and full-cost programs based on income.
- Identification cards are from insurance plans and are not unique to CHIP.
- Letters are sent from insurance plans to advise of changes.
- An Eligibility Review Process (ERP) exists to allow for a review of an eligibility decision.
- A single application can be used to apply for CHIP or Medicaid.

Appendix G: Medical Assistance (Medicaid)/MAWD or CHIP

continued

Other Insurance to Consider

- Life and Car Insurance, Liability Insurance, Property and Casualty Insurance
- Group Private Health Insurance Options: Examples are Special Care from the Blues (Blue Cross/Blue Shield plans), Advantage from Aetna
- For other healthcare options that may be available, go to www.insurance.pa.gov and click on the gold “Health Insurance” tab or visit http://www.portal.state.pa.us/portal/server.pt/community/health_insurance/9189/adultbasic_phase-out_health_options/822230.



Appendix H: Medicaid Funded Waivers (also called Medicaid Home and Community Based Services - HCBS)

For information about or to apply for HCBS: **1-800-757-5042**

DPW Helpline **1-800-692-7462** or

www.dpw.state.pa.us

Online Application

www.compass.state.pa.us

Where do I begin?

- Most services have functional and financial requirements for eligibility.
- To apply for services you will need to complete an HCBS Waiver and/or Medicaid application that can be obtained at any of the following:
 - **www.compass.state.pa.us**;
 - Local county assistance office;
 - Area agencies on aging;
 - Centers for independent living;
 - Hospitals; and
 - County human service agencies.
- You will need to provide the following:
 - Proof of Income;
 - Proof of Assets; and
 - Information on any transfer of assets during the past three years.
- You should receive a letter within 30 days after you apply.

What happens next?

- Some services may have a waiting list, particularly the waivers for people with developmental disabilities.
- If services are available, you may have a choice of service providers.
- If you want to use a service provider who is not enrolled in that program, ask to become an approved service provider.

What types of services are available?

- The type and amount will depend on the program(s) in which you are enrolled.



Appendix H: Medicaid Funded Waivers *continued* **(also called Medicaid Home and Community Based Services - HCBS)**

Support Services Waivers

Go to: www.dpw.state.pa.us

Adult Community Autism Program (ACAP)

The ACAP is not a traditional HCBS waiver but a service delivery option. It is a managed care program that provides physical, behavioral and community-based services to adults (21 and older) with autism in Dauphin, Cumberland, Lancaster and Chester county only.

Adult Autism Waiver

- For Pa. residents or those who live in Pa. by time of enrollment
- For those who have a diagnosis of Autism Spectrum Disorder
- For those 21 years or older by time of enrollment
- Meet Medical Assistance financial eligibility
- IQ NOT considered for eligibility

AIDS Waiver

The AIDS Waiver provides home-and-community based services to eligible persons age 21 or older who have symptomatic HIV Disease or AIDS.

Attendant Care/Act 150

- This is available to Pa. residents ages 18 through 59 who are mentally alert, have physical disabilities, are capable of managing their own legal and financial affairs and of selecting, supervising and terminating an attendant.
- Attendant Care Medicaid Waiver Program has income and resource requirements.
- Attendant Care Act 150 Program has NO income and resource requirements, but includes sliding scale co-pays.

COMMCARE Waiver

- This is available to Pa. residents age 21 and older who experience a medically determinable diagnosis of Traumatic Brain Injury (TBI), have substantial functional limitations and require a Special Rehabilitative Facility (SRF) level of care.
- TBI is defined as a sudden blow or jolt to the brain or its coverings, not of a degenerative, congenital or post-operative nature, which is expected to last indefinitely.

Consolidated Waiver for Individuals with Mental Retardation

The Consolidated Waiver for Individuals with Mental Retardation provides services to eligible persons with mental retardation so that they can remain in the community.

Independence Waiver (including former Michael Dallas Waiver)

This is available to Pa. residents age 18 and older with a severe physical disability requiring a nursing facility level of care. The disability must result in substantial functional limitations in three or more of the major life activities (mobility, communication, self-care, self-direction, capacity for independent living and learning) services to eligible persons of any age who are technology-dependent. Technology dependence is defined as requiring technology to sustain life or replace vital bodily function and avert immediate threat to life.

OBRA Home and Community-Based Waiver

Provides services to people with developmental physical disabilities to allow them to live in the community and remain as independent as possible

- This is available to Pa. residents age 18 and older with substantial functional limitations in three or more of the following major life activities: mobility, communication, self-care, self-direction, capacity for independent living, and learning.
- Other related conditions (ORCs) include physical, sensory, or neurological disabilities which manifested before age 22.
- A limited number of individuals with an Autism Spectrum Disorder diagnosis can be served under the OBRA Waiver.

Person/Family Directed Support Waiver

The Person/Family Directed Support Waiver provides services to eligible persons with mental retardation so that they can remain in the community.

Appendix I: Special HealthCare Programs

Pennsylvania Department of Health - Bureau of Family Health
Health & Welfare Building, 7th Floor East Wing, Harrisburg, PA 17120

1-800-986-4550

www.health.state.pa.us

The Pennsylvania Department of Health, Bureau of Family Health supports many specialty clinics and programs.

Call the Special Kids Network System of Care at 1-800-986-4550 to locate a clinic or program closest to you for the following:

- Child Rehabilitation
- Cooley's Anemia
- Cystic Fibrosis
- Galactosemia
- Hemophilia
- Maple Syrup Urine Disease (MSUD)
- Phenylketonuria (PKU)
- Sickle Cell Disease
- Spina Bifida
- Ventilator Dependency

Appendix J: Services through the Office of Developmental Programs (ODP)

Bureau of Supports for People with Intellectual Disabilities (ID)
Customer Service Number - **1-888-565-9435**

Where do I begin?

- Call to register with the County Office of Mental Health and Retardation (MH/MR). Number for your county MH/MR office is in the phone book.
- The county offices serve individuals of all ages.
- You will need documents such as medical, psychological and school records. The County Office of Mental Retardation will then determine if you are eligible for services. Onset of MR, an intellectual disability, must occur and be diagnosed prior to age 22.
- If eligible, you may choose a Supports Coordinator.
- If eligible, consider applying for Medical Assistance programs.
- Ask for the brochure about waivers, and talk with a Supports Coordinator about eligibility.

What happens next?

- Depending on services available and your needs, the Supports Coordinator may:
 - Attend your IEP meeting to help you with planning for your future;
 - Talk with you about your needs and goals;
 - Help you develop your individual plan;
 - Offer you an opportunity to complete an application for the Consolidated or Person/Family Directed Support Waiver;
 - Help you arrange to work with individuals or agencies in the community;
 - Offer you the opportunity to complete a Prioritization of Urgency of Need for Services (PUNS) form and place you on the waiting list; and
 - Help to identify other types of community supports and services that would help you while you are waiting.
- Youth or families should report changes in needs to Supports Coordinators.

What types of services are available?

- Home and community services
- Employment services
- Habilitation services
- Respite services
- Supports coordination services
- Transportation services

Appendix J: Services through the Office of Developmental Programs (ODP) *continued*

Bureau of Autism Services (BAS)

For assistance call BAS toll-free in Pa.: **1-866-539-7689**

Web address: www.autisminpa.org

Email: DPW-AutismOffice@pa.gov

Bureau of Autism Services Adult Programs

The Bureau of Autism Services has **two** adult programs: **The Adult Autism Waiver (AAW)** and the **Adult Community Autism Program (ACAP)**. Both programs are designed to help adults with an autism spectrum disorder (ASD) participate in their communities in the way that they desire through services based on their identified needs. The goals of both programs are to:

- Increase the person's ability to care for themselves;
- Decrease family/caregiver stress;
- Increase quality of life for both the person and the family;
- Provide specialized supports to adults with an ASD based on need;
- Help adults with an ASD reach their employment goals;
- Support more involvement in community activities; and
- Decrease crisis episodes and psychiatric hospitalizations.

Eligibility Criteria

Please visit our website for additional eligibility criteria specific to each program. The basic criteria for both programs include:

- Being a Pennsylvania resident;
- Having a diagnosis of ASD;
- Meeting MA qualifications;
- Meeting functional eligibility; and
- Being 21 or older.

Where do I begin?

- Visit www.autisminpa.org to review the information about both programs, including **Program Overviews, Eligibility, Application Processes, Services, Provider Networks** and **Comparison Charts**. You can also call us toll-free at 1-866-539-7689 to request an information packet.
- Call **1-866-539-7689** to request an application. Applications are processed on a first-come-first-served basis. All application requests must be made through the toll-free number. Applications may not be requested by email and are not available online.
- Contact BAS at any time with questions through the toll-free number, website or email address provided above.

Appendix K: Mental Health (MH)

Phone Book Blue Pages under County - Look for local county MH/MR office

Web address: www.dpw.state.pa.us

Regional Office: **Central 717-705-8396**

Southeast 610-313-5844

Northeast 570-963-4335

Western 412-565-5226

Where do I begin?

- Call the local county office of Mental Health and Mental Retardation (MH/MR):
 - The county MH/MR offices serve as a referral source. Most mental health services are delivered by contracted local provider agencies.
 - If experiencing mental health crisis, contact your county's crisis intervention or go to your nearest emergency room.
- The county MH/MR office determines a person's eligibility and discusses funding options, assesses the need for treatment or other services, and makes referrals to appropriate programs to fit the needs. If determined eligible, a case/care manager will be assigned, and frequency and type of contact between consumer and case/care manager will depend on need.
 - A case/care manager in your insurance plan may assist you to locate services.
 - The cost of these services will vary and may be covered by: private insurance, Medical Assistance programs through behavioral health managed care or fee-for-service; Children's Health Insurance Program (CHIP) pays for some of these services. For eligible individuals, see page 20 of this checklist.
 - People who use services but are not on Medical Assistance and are without access to other insurance, will be assessed for their ability to pay for services by the county MH/MR office.
 - Physicians (primary doctor or psychiatrist) or psychologist may need to complete an evaluation or assessment to document medical necessity for a specific level of care or treatment.

What happens next?

- Depending on services available and your needs, the case/care manager may:
 - Help you get needed insurances or benefits (e.g., Social Security, Medical Assistance;
 - Talk with you about your needs and goals;
 - At age 18, help you develop a plan to transition from the children's service system to the adult service system (children's services are more intensive than adult services);
 - Help you arrange for and work with individuals or agencies in the community; and
 - Attend and participate in the IEP with the permission and invitation of consumer and parent.
- Youth or families should report changes in needs to case/care manager.

What types of services are available?

- | | | |
|----------------------------------|---------------------------------------|----------------------------|
| • Short-term Inpatient Treatment | • Emergency Services | • Residential Arrangements |
| • Partial Hospitalization | • Specialized Rehabilitation Training | • Housing |
| • Outpatient Care | • Vocational Rehabilitation | • Peer Support |

Eligibility for Behavioral Health Rehabilitation Services continues until the youth reaches his or her 21st birthday. An adolescent may continue in treatment in a Joint Commission on Accreditation of Health Care Organizations (JCAHO) accredited Mental Health Residential Treatment Facility program until the age of 22, as long as he/she is in treatment at the program prior to his/her 21st birthday. If a consumer is lost to their County System, he/she may re-enter by calling the county MH/MR office, his/her behavioral health managed care plan case/care manager, or primary care physician.

Appendix L: Children, Youth & Families (CYF)

If you have any questions please contact your local County Children and Youth Agency (CCYA) or Juvenile Probation Office (JPO):

Children Receiving Services while Living in their own Home

- Children who are living in their own home and receiving services from the CCYA or JPO will carry their health insurance coverage and receive health care services in the same manner as they did prior to receiving CCYA or JPO services.

Children Receiving Services while Living in Out-of-Home Placement

- Children or youth living in out-of-home placement are in the legal custody of the county children and youth agency or under the jurisdiction of the juvenile court.
- Out-of-home placement settings include: shelter homes; foster homes; group homes; supervised independent living; residential treatment facilities; child residential facilities; juvenile detention centers; and youth development centers.
- When it is determined that a child needs out-of-home placement services, a family service plan and child permanency plan is completed. The ultimate goal is for the youth to have adults in their life who have made a commitment to care for and support them to the age of maturity and beyond.
- While a child or youth is in out-of-home placement, a caseworker or probation officer should work with other appropriate agencies to assist the child or family in planning for transition out of the CCYA/JPO system prior to the youth's discharge.

At the Youth's 18th Birthday

- The youth may return to his/her own home.
- The youth, the youth's attorney or the attorney who is appointed as the Guardian Ad Litem may petition the court to continue out-of-home placement services in order to complete a course of treatment or educational instruction up to age 21.
- The youth who is adjudicated either dependent or dependent and delinquent with shared case management may participate in an Independent Living (IL) program anytime from age 16 up to 21, including after discharge from placement services. IL services available to youth include:

- Life Skills
- Employment
- Stipend

- Support Services
- Education and Training
- Housing

- Prevention Services

While in out-of-home placement, many youth are covered under the Pennsylvania Medical Assistance (MA) Program

- The youth needs to ask their health insurance plan or MA/ACCESS Plus Plan for a "portability statement" of the insurance coverage they have, including the length of time they have been covered under the plan.
- Youth remaining in the custody of the CCYA will remain covered under MA while in out-of-home placement.
- Prior to the 18th birthday, the youth can follow the suggestions on page 10 and ask for assistance, as needed, to apply for appropriate programs.
- If a youth is no longer in out-of-home placement at age 18, the youth must apply or re-apply for the MA program.

Appendix M: Office of Vocational Rehabilitation (OVR)

Disability Services **1-800-442-6351 • TTY 866-830-7327**
Labor & Industry Website: www.dli.state.pa.us Click: **Disability Services**

Where do I begin?

- Youth with a disability who meet eligibility criteria for employment and are interested in working, should be referred to the local OVR office.
- Referral can be made up to two years prior to graduation and can be made by anyone.
- Initial Interview – Take with you the following:
 - A medical history related to the youth's disability (names and addresses of doctors and specialists, hospital admissions, names of medications);
 - An expectation to discuss how the youth's disability may affect their ability to work;
 - Education History/Individual Education Program (IEP) and Job History; and
 - Vocational tests and reports that are available.

What are the eligibility criteria?

- Unlike the entitlement services provided by special education, OVR is an eligibility program, which means a referred youth must meet the following criteria to qualify for services:
 - Have a disability that is a physical, mental or emotional impairment resulting in a substantial impediment to employment;
 - Be expected to benefit in terms of an employment outcome from services provided; and
 - Be involved in vocational rehabilitation services to prepare for, enter, engage in, or retain competitive minimum wage, integrated community setting employment.
- Eligibility for services is determined within 60 days by a qualified VR counselor.

What happens next?

- If eligible, services will be provided based on severity of disability (federal law).
- An Individualized Plan for Employment (IPE) will be jointly developed by the individual and OVR counselor. The goals of the IPE and IEP should support the youth's employment outcome.
- A financial needs test will determine what costs will be covered by OVR and what the youth or family may be required to contribute.
- Diagnostic services, vocational evaluations, vocational counseling and guidance, and job placement services are always provided by OVR at no cost to the youth and/or family.

What types of services may be included in the IPE?

- Diagnostic & Vocational Evaluations; Counseling, Guidance & Placement Services; Training Services & Supports; Physical Restoration Services; Assistive Technology Services.

Employment and Completion of the Program

- OVR services will end when the youth achieves the IPE goals and is successfully employed for at least 90 days. The case will then be closed.
- If necessary, OVR post-employment services are available after the case is closed.

Additional Programs Offered by OVR

- Bureau of Blindness and Visual Services (specialized children services, orientation and mobility, rehabilitation teaching)
- Office for the Deaf and Hard of Hearing (information and referral, advocacy, interpreter database)
- Hiram G. Andrews Center (comprehensive vocational training program)

Appendix N: Assistive Technology

Companion Guide to the Transition Health Care Checklist: Transition to
Adult Living in Pennsylvania

Visit Pennsylvania's Initiative on Assistive Technology (PIAT)

www.disabilities.temple.edu

Click: Programs: Assistive Technology: Companion Guide
to the Transition Health Care Checklist: Transition to Adult Living in PA

1-800-204-7428 or TTY 1-866-268-0579

What is Assistive Technology (AT)?

- Assistive Technology (AT) means any item, piece of equipment or product system whether acquired commercially, modified or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities.
 - AT includes DEVICES such as wheelchairs, hearing aids and reachers.
 - AT also includes the SERVICES you need to find and use the devices, including evaluation, customization, maintenance and repair, and training for you and the people who support you.
- Assistive Technology devices can help you with activities related to work, school and community living. Examples of AT devices include:
 - For work or school: devices or software that enlarge and/or read print
 - For work or school: keyboards with large keys and hands-free mouse
 - For community living: changes to your home or vehicle so you can get around
 - For community living (recreation): special gloves and handles that allow you to participate in hunting, fishing, gardening and other activities

What are the resources for learning about and getting Assistive Technology?

- AT may have been provided to you from your school:
 - As you prepare for transition, you will need to know who owns the AT devices and whether or not you can take it/them with you.
 - As you plan for transition, think about other AT devices you don't have now. Some insurances may pay for AT while you are still in school.
- In school, your Individualized Education Program (IEP) team can help you identify the devices you will need and help you use them:
 - Your school district may have staff who is knowledgeable about AT.
 - Your intermediate unit has at least one Assistive Technology consultant who can help.
 - If you need AT for employment, contact your OVR counselor and consider including AT in your Individualized Plan for Employment (IPE).
- **At any age, Pennsylvania's Initiative on Assistive Technology (PIAT) can help you learn about, borrow and try AT devices that might be helpful to you in education (including post-secondary education), employment and/or community participation and independent living.**

Appendix O: Medical Homes

Pennsylvania Medical Home Programs
www.pamedicalhome.org

Pa. Chapter, American Academy of Pediatrics (PAAAP)
800-414-7391 • 484-446-3005

Pa. Academy of Family Physicians (PAFP)
PAFP Foundation Patient-Centered Medical Home Project

www.pafp.com/IPIP
800-648-5623 • 717-564-5365

What is a Medical Home?

A medical home is not a building, house or hospital, but rather an approach to providing health services in a high-quality and cost-effective manner. A medical home is defined as health care that includes:

- Practice based quality improvement
 - Provision of preventative care
 - Assurance of ambulatory and inpatient care for acute illness 24 hours daily
 - Provision of care over an extended period of time
 - Identification of the need for subspecialty consultation and referrals
 - Interaction with school and community agencies
 - Maintenance of a central record and database with all pertinent medical information
 - Coordination of care

What does it mean for youth?

With health care services for adolescents who have special needs, the focus is on the following:

- Offering a comprehensive approach to providing adolescent healthcare services;
- Increasing access to healthcare services for adolescents, including the documentation of health needs;
- Promoting health and mental well being as part of a successful transition from youth to adulthood;
- Reducing health disparities among adolescents;
- Finding connections to other medical and non-medical community resources;
- Providing an environment of trust and mutual responsibility; and
- Identifying and facilitating transition in the myriad of areas where change is required.

What can families and youth do?

- Contact the PAAAP or the PAFP to see if there is a patient-centered medical home practice near you.
- Talk with your doctors to see if they are connected to the PAAAP or PAFP and if are they interested in participating in the Medical Home Projects.
- You or your doctors may contact the above programs.

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Pa. Department of Health: Bureau of Family Health/
Division of School Health Bureau of Community Health
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www.health.state.pa.us

Pa. Department of Education,
Bureau of Special Education
www.education.state.pa.us

Pa. Training and Technical Assistance
Network (PaTTAN)
www.pattan.net

Pa. Youth Leadership Network (PYLN)
www.pyln.org

Special Kids Network System of Care
<http://www.gotoskn.state.pa.us>

Pa. Department of Public Welfare
www.dpw.state.pa.us

Pa. Department of Labor and Industry
www.dli.state.pa.us

Children's Hospital of Pittsburgh
www.chp.edu

Penn State Children's Hospital Hershey
www.pennstatehershey.org/web/childrens/

Children's Hospital of Philadelphia
www.chop.edu

