

Transition Planning

for Youth with Disabilities

from the
Child Welfare System to Adulthood:

A Guide for Youth



Juvenile Law Center

advancing the rights and
well-being of children in jeopardy

This Guide is the product of research and discussion with public policy experts, leaders of human service organizations, specialists in the field of behavioral health and physical health care, legal advocates, and transitioning youth. We give special thanks to our colleagues at Education Law Center-PA, Disability Rights Network of Pennsylvania, and Pennsylvania Health Law Project who have been generous in sharing their expertise and resources. In particular, Maura McInerney and Hallam Roth from Education Law Center and Rachel Mann, Gabe Labella, Robin Resnick, and Sallie Lynagh from the Disability Rights Network have contributed their thoughts, resources, and expertise to many sections of this Guide. Much appreciation and gratitude goes to Joann Viola, Megan Bruce, Lourdes Rosado, Lauren Fine, and Kacey Mordecai from Juvenile Law Center for their work on this publication.

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Finally, we acknowledge a publication that has motivated us to develop this Guide. The *Transition Health Care Checklist: Transition to Adult Living in Pennsylvania* was developed by the Pennsylvania Community on Transition State Leadership Team and supported by the Pennsylvania Department of Health. Last revised in 2010, this publication continues to be an excellent resource. It has created a framework for our thinking about transitioning youth with disabilities in the child welfare system.

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**TRANSITION PLANNING FOR YOUTH WITH DISABILITIES FROM THE CHILD
WELFARE SYSTEM TO ADULTHOOD: A GUIDE FOR YOUTH**

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Introduction

The transition to adulthood is an exciting process for all youth. Adulthood brings freedom, opportunity, and responsibility. The transition can also be complicated and confusing, especially when a youth has special health care or disability needs that make early transition planning essential. Youth in the child welfare system have the right to assistance and support as they make the transition to adulthood. They need this support to guide them through the complex systems they must navigate to access health care, housing, and other supports and benefits so that they end up with a good transition plan that is directed by them and reflects their needs, wishes, and strengths.

Youth also need guidance and support to help them acquire the knowledge and advocacy skills so that they can lead the transition planning process. This Guide was created to give youth some of the basic information they need to begin the transition planning process and understand the options before them. Successful transition planning will involve much more information than this Guide contains and will involve multiple people and agencies. We hope this Guide provides a roadmap for transition planning and some of the core information about services and supports that a young adult needs to know to be informed and knowledgeable about the planning process. Youth are the best advocates for themselves. We hope that this Guide will provide youth with knowledge about the planning processes, the services and supports available as well as advocacy strategies so that youth can play a central role in transition planning.

*We recommend that youth use this Youth Guide along with an advocate, caseworker, or mentor who is using the companion, *Transition Planning for Youth with Disabilities from the Child Welfare System to Adulthood: A Professional's Guide*. There is a lot of information in this Guide! Much of it may be new to a youth or adult reader who is less familiar with the adult system. We encourage youth to ask questions so that they understand the planning processes, the law, and the services and supports available to them as they make the transition to adulthood. Readers are encouraged to use these two resource Guides with the youth's planning team and should contact the Juvenile Law Center for any additional information and assistance that is needed.*

I. **Family, Permanency, and Age-Appropriate Placements for Teenagers in the Child Welfare System**

An important way to get ready for leaving the child welfare system and becoming an adult is making sure you are connected to family and a support system. Youth with disabilities, like all youth in the child welfare system, deserve to find stability and security with a family that will help and guide them as they enter adulthood. Youth with disabilities also have the right to experience activities, opportunities, and resources in the community so that they can learn independent living skills. This section talks about some the rights that youth in the child welfare system have to find a family and live in a community setting.

What obligations does the child welfare agency have to a youth with respect to working with their family or finding the youth another family?

The goal of the child welfare system is to keep families together and keep children safe. The children and youth agency (also called the child welfare agency) has an obligation to work with a youth's family so that it can safely care for the youth in the home. Specifically, the child welfare agency must make "reasonable efforts" to prevent a child from being removed from the home *and* to return the child to the home if the child is removed. What reasonable efforts are depends on the specific needs of the youth and family. That means that if the youth's special needs or meeting those needs are among the challenges the family is facing to keep the child safely in the home, services to help the family meet those needs should be part of the reasonable efforts made.

Some examples of services that could be provided to a youth and his or her family include:

- Help with getting medical coverage or treatment that a youth needs
- Instruction or classes in how to provide specialized care for a youth
- Counseling for the family so everyone can get along better

You and your family know best what you need to help keep the family together so it is important for you to speak up about what is needed.

If a youth cannot return home and be reunited with his or her parents, what should happen?

While youth are in the child welfare system, all efforts should be made to find them a family. The first choice is for that family to be your biological family. If that is not possible, the child welfare agency should still try to place you with your extended family. If you cannot be reunited with your family, the second preferred choice under the law is to be adopted. This is because adoption provides you with the legal and emotional permanence of family. The person or people who adopt you become your legal parents and are responsible for caring for you as their child. Under a new law that was enacted in 2012, called Act 101, there is an opportunity for youth who are adopted to have contact with their biological family after adoption if

everyone agrees.¹ Adoption does not mean that you have to end your relationship with your biological family.

If adoption is not possible, the following are some options available to provide you with family and permanency.

- **Legal guardianship with a caregiver, or Permanent Legal Custodianship (PLC)**

A legal guardian or permanent legal custodian is someone who agrees to care for you and assumes legal custody of you until you become an adult. This may be a foster parent, relative or someone else who cares about you. If placed with a permanent legal custodian, your case would be closed in the child welfare system and you would no longer have any court hearings, a lawyer, or a caseworker. Unlike with adoption, the rights of your biological parents do not need to be terminated for PLC to be granted. A visitation order can be issued when you enter into the PLC so that you can continue to visit with your family. This includes visits with parents and/or siblings. Usually a PLC caregiver will receive a subsidy (money each month) to care for you similar to what is paid to a foster parent. This is called Subsidized Permanent Legal Custodianship (SPLC). You also will remain eligible for Medical Assistance (health insurance). If the PLC subsidy begins when you are age 13 or older, the family may be eligible to receive the subsidy until you reach age 21.

- **Placement with a relative or kinship care**

If the relative you are living with meets all the same licensing requirements as a foster care provider, they can receive financial help to take care of you just as a foster parent would. That is usually called formal kinship care. If your relative is receiving kinship care payments, your case will stay open with the child welfare agency and you will continue to go to court for review hearings, and will have a lawyer and a caseworker. You can stay in this arrangement until age 21 if you meet certain requirements.

- **Another planned permanent living arrangement (APPLA)**

APPLA is the least preferred permanency plan because it does not really provide the permanency of a formal family. Youth who have the plan of APPLA still deserve permanency. For that reason, even an APPLA plan must include a stable place to live where your needs are met, and support in making and keeping connections with caring adults who are involved in your life and planning. Until you leave the child welfare system, the child welfare agency must make all efforts to find a family for you. Even if you are not placed with a family, the child welfare agency should work to connect you with mentors and other adult supporters who can

¹ The citation for the law that allows voluntary post adoption agreements to be made in certain situations is 23 Pa. C.S. A. §§ 2732-2742. Voluntary post adoption contact agreements allow a youth who is adopted to enter into an agreement for continued contact with birth relatives, including parents, grandparents, siblings, aunts or uncles if all parties, including the adoptive parents agree. This is a great option that supports adoption and permanency while continuing important ties with the biological family

provide advice, guidance, and be involved in your transition from the child welfare system. Tell the child welfare agency of any important people in your life now or from your past—such as teachers, pastors, neighbors—who you want involved in your life. They can help you make the connections.

Can youth be adopted at any age?

Yes. Some people think that only young children can be adopted, but you can be adopted at any age, even age 18, 19, 20, or 21 (or later!). It is never too late for a family. If you are interested in being adopted, tell your case worker, lawyer, and the judge in your case. You can participate in services, such as special recruitment, and other events and activities that can help you find an adoptive family.

Are there any supports for families who adopt or take legal guardianship of youth with special needs or disabilities?

Yes. Listed below are some supports that can help a family adopt or take guardianship of a youth from the child welfare system.

1. Adoption and Guardianship Subsidies

If a youth has a disability and is adopted or enters a guardianship arrangement from the child welfare system, the family is eligible for a subsidy. This subsidy provides financial assistance (money) to the family to care for the youth. The amount of money that the family receives is about the same as what was received to pay for foster care. The youth will also remain eligible for Medical Assistance (health insurance).

2. Extended Guardianship and Adoption Subsidies for Older Youth

Under a new law, called Act 80, if a youth and family begin to receive the adoption or guardianship subsidy when the youth is age 13 or older, the subsidy can continue until the youth is age 21.² If the subsidy begins when the youth is younger, it will only last until age 18.

3. Independent Living Services and Education and Training Grant for Older Youth Adoptions and Guardianships

If a youth is adopted or enters a guardianship arrangement from the child welfare agency at age 16 or older, he or she will be eligible for Independent Living services from the child welfare agency until age 21. The youth also will be eligible for the Education and Training Grant, which

² Act 80 amended our state law, the Public Welfare Code. The citation for this law is 67 P.S. § 772 for adoption subsidy and 67 P.S. § 1302 for guardianship. For more information about Act 80 see www.jlc.org/fosteringconnections.

provides up to \$3000 per year for post-secondary education or training. See below for more information about Independent Living services.

What is the child welfare agency's obligation to place siblings together or ensure that they have contact and visit?

While the importance of sibling bonds is acknowledged by all, the connection is especially important for youth who are removed from their homes and families. For many youth in foster care, permanency and family means being with their sister or brother. This connection is often very important for youth with disabilities who sometimes feel isolated from their peers. After much youth advocacy and recognition that many sibling groups were being separated in the foster care system, there is a new law in Pennsylvania—Act 115—to ensure that youth with disabilities have connections to family.³

The law requires that reasonable efforts be made to place siblings together when they are in foster care and that they visit frequently when they cannot be placed together. Under Act 115, the only reason that siblings would not be placed together is if it would threaten the safety or well-being of either of the siblings. The fact that one sibling requires special care should not prevent joint placement. For example, because medical foster care providers are also licensed foster care providers, such a placement could accommodate both siblings, or additional services could be provided to make a placement work for a youth with special needs.

When siblings need to be separated for safety, the situation should be reconsidered periodically with the goal of reunifying the siblings at a future time. The youth's team should continuously make efforts to figure out ways that separation can be avoided. Importantly, if siblings are not placed together, in-person visitation must be provided at least two times a month unless the court determines that visitation poses a risk to the safety or well-being of either child.⁴ Other contact like phone calls and letters should be encouraged, but does not replace the requirement for in-person visits. This legal provision must be enforced even if a youth is in a residential treatment center or nursing care facility.

Where should youth be placed when they are in the child welfare system?

If you are removed from your home and placed in the child welfare system, you have a right to a placement that is:

- the least restrictive,
- the most family like, and
- meets any of your special needs

³ Act 115 amended our state law, the Juvenile Act. The citation for this law is 42 Pa. C.S.A. § 6351 (b)(5) (reasonable efforts must be made to place together siblings removed from a home, unless joint placement is contrary to the safety or well-being of either child).

⁴ The portion of the law that talks about the right to visit with your siblings in care can be found at 42 Pa. C.S.A. § 6351 (b.1) (setting out visitation between child and his or her sibling).

This means that you should be placed with a family (your extended family, a foster family, or an adoptive family) or in a family-like home rather than a group home or institution. Medical and therapeutic foster care placements also are options that allow youth to be placed with a family that has special training in caring for a youth who has special health care needs.

Services from the physical health care and behavioral health care system also can be provided in a foster home or a home where a family members lives. If you are placed in a group home or institution, the county child welfare agency should look for a placement that is more family-like for the future. This process may include special recruitment of caregivers, a special contract with a service provider, or payment of a higher rate to a caregiver.

How can I get help in advocating for age appropriate placement rules and expectations?

As you get older, you should be given both more freedom and responsibility so that you can practice the skills you will need when you become an adult. Sometimes foster parents and caregivers have a hard time giving youth these opportunities. Youth advocates at Youth Fostering Change created a tool that can help youth have this discussion with their foster parents and caregivers. The Teen Success Agreement (TSA) is a document created by youth in foster care that can help youth discuss issues such as curfew, allowance, chores, friends, and dating. The TSA can be found at http://www.jlc.org/sites/default/files/topic_related_docs/Teen%20Success%20Agreement%20Packet%208%2029%2012.pdf. Having age appropriate freedom and responsibility is something that all youth need and deserve as they transition to adulthood. In some cases, you will need to advocate for yourself to get it!

Are there any special placement options for adolescents or young adults as they get older in the child welfare system?

As a youth gets older, there are some additional options for placement. Transitional Living Placements (TLP) and Supervised Independent Living (SIL) placements may be an option for youth as they get older and are preparing for the transition to adulthood. In these placements youth are given more responsibility and freedom to manage their daily routine and schedule, and are provided less supervision. Youth with disabilities should have access to these child welfare placements even if it means providing additional services or accommodations in the placement.

Do the federal laws that prohibit disability discrimination apply to youth in the child welfare system?

Yes. Not only are youth with disabilities entitled to the same services as all youth in the child welfare system, federal law also provides additional protections to ensure that they have full access to services and that the services match their needs. The Americans with Disabilities Act and Rehabilitation Act are two important federal laws that prohibit disability discrimination in the way services are provided. The laws require that individuals be served in the community and with their peers to the greatest extent possible. Individuals with disabilities should not be

excluded from activities and services or be required to attend separate programs or placements. Individuals with disabilities must be given an equal opportunity to benefit from all the services and benefits that are provided by the government, including all child welfare services. Accommodations and adjustments to these programs and placements must be made to ensure that equal access and opportunity is possible.

Reasonable Accommodations in Child Welfare Services and Placements:
Making SIL Work for Serena

At age 18, Serena, who was placed in a group home, requested to be placed in a Supervised Living Program (SIL). Serena had Cerebral Palsy, used a wheel chair, and needed minimal assistance during the day and the evenings when she returned from school. Despite the fact that she was a senior in high school, had completed her Independent Living skills classes, and demonstrated maturity, most SIL programs rejected Serena because of her need for assistance with some of her daily routine and a fear about having a youth with special needs alone in her own apartment,

Serena and her lawyer advocated for Serena's acceptance in SIL and proposed minor accommodations to the program to make it match Serena's needs. Serena was approved for personal care assistance under her Medical Assistance plan to help her with some of her daily living activities in the morning and evening. A wheelchair accessible apartment was located in an elevator building. A safety plan was developed to insure that Serena would have easy access to medical and other assistance if there was a need. Finally, Serena was matched up with a peer mentor from the local disability rights advocacy center who agreed to check in with Serena weekly and work with her on developing self- advocacy skills.

Serena's plan for making Supervised Independent Living work is not that different than a plan for SIL for any young person in the child welfare system. It is individualized, based on her strengths and needs, and is geared at helping her gain the skills she needs to transition successfully to adulthood.

What agencies can you contact if you think you are being discriminated against based on your disability?

All youth in the child welfare system have an attorney appointed to them in juvenile court to represent them. Tell your attorney if you think you are being discriminated against based on your disability so that he or she can raise this issue in juvenile court when your case is reviewed.

In addition, as a requirement of federal law, there are special agencies in each state called Protection and Advocacy Agencies (P & As) that help advocate for individuals with disabilities. In Pennsylvania, the Disability Rights Network is the P & A agency that helps individuals with disabilities. They have a helpline that provides assistance and can be reached by calling 1-800-

692-7443 or by emailing at intake@drnpa.org. You can call them or email them if you have a question about your rights or think you have been discriminated against based on your disability.

Organizations called Centers for Independent Living (CILs) are located in each county in Pennsylvania. CILs are run by individuals with disabilities and provide at least four main services: Information and Referral, Peer Mentoring, Individual and Grassroots Advocacy, and Independent Living Skills Training. CILs can be a good source of information and advice about what services and supports would work best to make sure you can stay in the community as well as in an environment that is the least restrictive and with your peers. Use this link to find the CIL for your county: http://www.pcil.net/pages/cils/locate_a_cil.aspx.

What are some examples of issues that a Protection and Advocacy Agency might look into for a youth who is in foster care and has a disability?

P & A agencies want to make sure individuals with disabilities, including children and youth, are treated fairly and not discriminated against because of their disabilities. Issues or complaints that they have looked into include:

- A youth who is deaf remains in a restrictive placement because there are no foster homes that can communicate with him using sign language.
- A school district or residential treatment center prevents a youth from attending the community school and requires that they attend the on-grounds school.
- A mental health facility will not accept a youth who has an intellectual disability.
- A youth is not provided with child welfare Independent Living Services while placed at a residential treatment center.
- A youth is not permitted to be placed in an SIL setting because of her complex health care needs.

The Top Five Advocacy Tips for Youth with Disabilities in the Child Welfare System

1. **Use your right to an attorney for your benefit.** Youth in the child welfare system are entitled under the law to be represented by a lawyer. Your lawyer should talk to you, and know your needs and wants so he or she can represent you well. YOU also should take steps to make sure your lawyer knows you and what you want.
2. **Go to your court review hearings and speak up!** You have a right to attend all your court hearings. The judge also must consult you on your permanency and transition plans. While your lawyer can speak up for you, you are in the best position to tell the judge what you need.
3. **Get involved in your local and state Youth Advisory Board (YAB).** The YAB is made up of current and former foster youth and advocates on behalf of youth in care. This is a great way to get your voice heard and make change. Check out the YAB's website at <http://www.independentlivingpa.org/about.htm>.
4. **Get involved with the Pennsylvania Youth Leadership Network (PYLN).** PYLN is a group of youth with disabilities who seek to develop the self-determination, empowerment, and leadership of youth and to promote successful post school outcomes in the areas of education, employment, independent living, and health and wellness among youth and young adults throughout Pennsylvania. To find out how to get involve see PYLN's website at <http://www.pylvn.org/>.
5. **Get informed about your rights, responsibilities, health and disability needs.** You have many rights to services, supports, and assistance to help you transition. One of the best ways to ensure that you can benefit from this assistance is knowing how the systems work and what the law requires. In addition, fully understanding your health and disability needs will put you in a great position to advocate for what you need and to make sure you get it.

II. Making Sure Your Health Care Needs are Met While in the Child Welfare System and When You Transition to Adulthood

As you transition to adulthood many things about your health care changes. Not only does health insurance coverage change, but when a youth turns age 18, he or she is the decision maker about health care and treatment. This section describes some basics about health care coverage when a youth is in care and some of the issues to plan for as you approach adulthood.

Who or what agency is responsible for making sure a youth's health care needs are met while in the child welfare system?

The county child welfare agency is responsible for a youth's care while in the child welfare system. Meeting a youth's health care needs is included in this responsibility. A youth's case plan, which is sometimes called a Permanency Plan or Family Service Plan, must include a description of all your health care needs and how they will be met. This information must be updated every time you change a placement and, at least every 6 months.

In addition, when your case is reviewed in juvenile court, the judge in your case must ask about any health care or disability needs that you have. Judges must follow Pennsylvania Juvenile Court Rules. Rule 1512 (D)(i) requires that the judge in your case make "any findings necessary to identify, monitor, and address the child's needs concerning health care and disability, if any, and if parental consent cannot be obtained, authorize evaluations and treatment needed."⁵

If you are not getting the care or treatment you need, the judge can order that actions be taken to make sure your health care needs are met. For example, if you are having trouble with your vision and no one is doing anything about it, tell the judge. The judge might order the child welfare agency to make an appointment with an eye doctor in a certain time period and report that date to the court and what happened at the visit. If you have questions about the amount or type of medication you are taking, the court may order the child welfare agency to find out more about your medications and to provide the court, and you, with a report on the reasons for your medication and any other alternative treatments.

What medical insurance do youth in the child welfare system have?

Almost all youth in the child welfare system are eligible for Medicaid. In Pennsylvania, Medicaid is usually called Medical Assistance (MA). This is comprehensive health insurance that covers all of the youth's physical health and behavioral health care needs. Any youth who is eligible for MA must be provided with all services that a doctor says are "medically necessary," including behavioral health services. This guarantee is called the Early Periodic Screening Diagnosis and Treatment (EPSDT) requirement. The EPSDT requirements also provide that youth receive health and dental screenings at specific frequencies to help keep them healthy. Depending on what part of the state a youth lives in, he or she will have a

⁵ Pennsylvania Juvenile Court Rule 1512 can be found at <http://www.pacode.com/secure/data/237/chapter15/s1512.html>.

managed care organization (MCO) that will provide a health plan for the youth. The youth and their agency caseworker will usually deal with the MCO when requesting authorization for a specific type of care or treatment.

When should you start getting involved in understanding your health care needs and the treatment you are receiving?

As early as possible! While the child welfare agency, your parents and caregivers should be making sure your health care needs are met, as you get older you should play a larger role in understanding your health care needs and any treatment or medication that you are receiving.

Here are some tips and goals to set as you get older, so you can be as knowledgeable as possible about your health care needs and treatment:

- Understand any diagnoses you have received
- Be able to ask any questions about your diagnoses
- Understand why you are receiving any treatment that has been prescribed
- Keep a notebook about your health care needs and treatment
- Know the medications that you have been prescribed, any side-effects, and why they are being prescribed
- Learn how to take medication on your own
- Have the contact information for your doctors
- Make and get yourself to health care appointments
- Know what health insurance you have, the name and contact information for your Managed Care Organization and how to reach them
- Do research at the library or on the internet to find out more about your health care conditions and treatment

For a detailed list of questions that will help you determine what skills you need to develop to take more control and involvement in your health care needs and treatment, check out the following sections of the *Transition Skills Inventory* in the helpful guide, *Transition to Adult Living in Pennsylvania*, which can be found at www.portal.state.pa.us/portal/server.pt?op:

- Hearing and Vision (pg. 7)
- Medication (pg. 8)
- Medical Management (pgs 15-16)

The Children's Hospital of Philadelphia also has a special project that helps youth navigate the transition to receiving health care in the adult system. They have several helpful tip sheets, which you can find using the following link: <http://www.chop.edu/service/transition-to-adulthood/resources-for-patients-and-families.html>:

- *It's Time: Are You Ready to Transition to Adult Healthcare? Ages 18-21*

- *Taking Charge of Your Health – A Guide for Teens and Young Adults Brochure*
- *Emergency Information Wallet Card*

Are there any tools or guides that can help me develop advocacy skills so that you can take greater control of your health care needs and treatment?

The Pennsylvania Youth Leadership Network (PYLN) is a group of youth leaders with disabilities from across the state that works to develop leadership and self-advocacy skills in youth with disabilities. They have created a *Secondary Health Care Transition Tool Kit*. It provides a comprehensive guide for young adults on how to navigate the health care system and how to advocate for your health care needs in the community, including at work and school. It is especially useful because it was created by youth, for youth! This guide is a must-have for all transitioning youth with disabilities and can be found at: <http://lifeafterieps.com/wp-content/uploads/2011/06/PYLNHealthcareToolkit1.pdf>

PYLN has also created several webinars for youth about topics such as self-advocacy. Here is an example of a webinar that focuses on speaking up and empowering yourself: <http://www.pyln.org/category/webinars-2/>.

What health insurance can a youth get once they are discharged from the child welfare system?

At age 21, an individual who discharged from the child welfare system can purchase or apply for health insurance in the same fashion as any adult. For example, they can apply for Medical Assistance, buy an insurance plan from a college, or pay for a plan that an employer provides. If an individual is eligible for Supplemental Security Income (SSI), which is discussed below, he or she will also be eligible for Medical Assistance.

A provision of the Affordable Care Act (“ACA”), which takes effect on January 1, 2014, provides youth who were in foster care at age 18 with access to MA coverage until age 26. This provision provides categorical eligibility regardless of income for youth who were in foster care at age 18 and enrolled in MA.⁶

There are some good opportunities for health care coverage for youth discharging from the child welfare system. The important thing to remember is that the Medical Assistance coverage that you have as a youth in the child welfare system will end when you discharge. So, you need to have a plan for application of re-application for health insurance to make sure you do not have any gaps in care.

⁶ **If you plan to move outside of Pennsylvania when you leave care, please read this caution about the MA to 26 Coverage:** When we published this Guide in September of 2013, the federal regulations for this provision of the ACA had not been issued. As of September 2013, it is not clear if youth who were in foster care and enrolled in MA at age 18 in Pennsylvania will be eligible for MA until 26 if they move to another state. Juvenile Law Center will update our website as more information becomes available.

Medical Assistance to 26: Tips for Youth Discharging from the Child Welfare System

At the time of the publication of this Guide, the state has not yet established policies for how the MA to 26 provision of the ACA will be implemented. To make sure you can be found eligible now, before the procedures are clear, you should ask the judge at the discharge hearing to issue an order or have a court stamp formalize the following statement:

For the purposes of establishing eligibility under the Affordable Care Act (42 U.S.C. §1396a(a)(10)(a)(i)(IX)), this Court finds that (Name of Youth) was in foster care at age 18 and was enrolled in the Medicaid Program at that time.

Then, you should keep this document in a safe place and present it at the County Assistance Office when applying for Medical Assistance.

Do the types of treatment and services that health insurance covers change for individuals who receive MA when they reach age 21?

Yes. When an individual turns 21, the EPSDT requirement no longer applies. MA provides adults a health plan that covers a group of services and treatment that insurance will pay for. This coverage is much more limited than what is covered for children. This means that some of the treatment you received as a child that was covered by insurance may not be covered by your insurance once you turn age 21. Good transition planning will help you figure out how to fill gaps in treatment and services.

What are examples of services and treatments that MA covers for children, but NOT for adults?

- MA covers hearing aids for children, but not adults.
- MA does not limit the number of wheelchairs a youth can get, but adults can only get one wheelchair every three years.
- MA covers therapeutic staff support services, or wraparound for children, but not adults.
- Home health services, including nurses aids, physical, occupational, and speech therapies are not limited for children, but are limited for adults.

What is a medical home and how can it help me make a good health care transition when I leave the child welfare system?

A medical home is not a place or building. It is a method or approach to health care that provides an individual with a plan for comprehensive and coordinated care. A part of this plan would be how to best to make sure your health care needs are met as you leave the child welfare system and become an adult. If you want to find a doctor or medical practice that uses the medical home model, or if you and your current doctor want to know more about medical homes, contact the Pennsylvania Medical Home Programs at www.pamedicalhome.orr or the Academy of Pediatrics at www.pafp.com/IPIP.

Can a young adult appeal or complain if MA does not meet their treatment needs when they reach adulthood?

Yes. If a request for a service or treatment is denied, you can appeal the denial. When you appeal something you are saying you do not agree with the decision. It is recommended that you take both of the actions below to appeal:

1. Request a Fair Hearing with the Department of Public Welfare within 30 days.

AND

2. File a grievance with the MCO within a time frame mentioned in the notice—usually 45 days.

For help with filing an appeal, a grievance or complaint, contact the Pennsylvania Health Law Project at 1-800-274-3258.

What else can a young adult do if she or he has treatment needs that are not covered by MA?

If you have many treatment and personal care needs due to a significant physical disability, you and your team should look into whether you may be eligible for MA Waiver (also called Medicaid Waivers) once you leave the child welfare system.

What is a MA Waiver?

Medicaid Waivers are technically called the Home and Community Based Services (HCBS) Waiver program (“the Waiver program”). The various Waivers provide long-term care and services for individuals who have significant disabilities and are at risk of institutionalization. The Waiver program funds medical and non-medical services to individuals living in the home of family or other community settings like group homes and supported living arrangements. MA Waivers may provide such services as home health care assistance, personal care assistance, skilled nursing, and rehabilitation services. These are services and treatment that may not be available—either at all or in the amount needed—through an adult’s typical MA coverage. You

may be eligible for various MA Waivers in Pennsylvania if you have very low income and meet a functional criteria based on your disability.

What types of MA Waivers are available in Pennsylvania?

Pennsylvania has a number of MA Waivers. The following are among those that may benefit young adults leaving the child welfare system:

- The Consolidated Waiver for Individuals with Intellectual Disabilities
- The Person/Family Directed Services Waiver for Individuals with Intellectual Disabilities
- The Autism Waiver for individuals testing in the autism spectrum
- The OBRA, Independence, and Attendant Care Waivers for individuals with physical disabilities
- The COMMCARE Waiver for individuals with traumatic brain injury
- The AIDS Waiver for individuals who are symptomatic for HIV or AIDS

How and when do you start an application for a MA Waiver?

How, when and where to apply depends on which MA waiver, but here are some general guidelines:

- The Consolidated and Person/Family Directed Services Waivers. A youth must be registered with the county office of Intellectual Disability (IDS) to apply for the Consolidated Waiver or Person/Family Directed Services Waiver. It is recommended that a youth be registered with IDS as soon as it is believed that he or she has an Intellectual Disability. Youth can be registered with IDS as early as age 3. At least two years before the youth's planned discharge, the young adult and his or her team should approach the youth's IDS Support Coordinator about Waiver applications. Youth must be registered with IDS to be able to apply for a Waiver.
- The Autism Waiver. It is recommended that an application be made when the youth is age 20. (This Waiver does not begin until age 21 and often has a waiting list). You can start the application process by calling the Bureau of Autism at 1-866-539-7689.
 - Please note that if a young adult who has been diagnosed with autism and lives in Chester, Dauphin, Cumberland, or Lancaster County, they may be eligible for a program called ACAP. To find out more about ACAP see this link: <http://www.dpw.state.pa.us/foradults/autismservices/adultcommunityautismprogramacap/acapgeneralinformationquestions/index.htm>. To apply for ACAP call the Bureau of Autism at 1-866-539-7689.
- OBRA, Independence, Attendant Care, COMMCARE, and AIDS Waivers. It is recommended that an application be made for these waivers at least one year before the youth's planned discharge. (An individual cannot access the AIDS and COMMCARE Waivers until age 21, while OBRA, Independence, and Attendant Care may be accessed, if available, as early as age 18). To begin the application processes for these Waivers, you should contact the Enrollment Broker at 1-877-550-4227. The Office of

Long-Term Living administers these Waivers and can be reached at 866-286-3636 for more information.

Completing a Plan for Post-Secondary Success: How Access To MA Waivers Made the College Experience a Reality for Cortez

Cortez has Muscular Dystrophy. He uses a scooter to get around, a computer to write, and a ventilator at night. Cortez needs personal care assistance for most of the day and night. Cortez did well in school and dreamed of going to college and becoming a biologist. He applied to and was accepted at several colleges. His dream college with the best biology program was several counties away so he would have to live in the dorms to attend. Cortez applied for and was found eligible for the Independence Waiver when he was age 19, and got off the waiting list in time for his transition from the child welfare system at age 21. The Independence Waiver covered the medical care and personal care Cortez needed, which he otherwise would have lost when he turned age 21. He received all his waiver services while living on campus in the dorms. Cortez was excited to get the full college experience in the dorms. By applying early for the Independence Waiver, he was able to use it to help fulfill his dreams for his education and career while also meeting his own health needs.

Why do you need to begin the application process so early for MA Waivers?

MA Waivers are not entitlements. Entitlements are benefits or services that you have a right to receive once you establish your eligibility. For Waivers, just because you establish eligibility does not mean that you will be able to receive the Waiver services. Many Waivers have limited capacities and waiting lists. You want to start early and get your place in line so that you will have a good chance of receiving services and supports by the time you transition from the child welfare system.

What are some important tips to keep in mind for all the Waivers?

- Ask for a list of the full array of services available with the Waiver you are applying for. You cannot know what to advocate for if you do not know what is available!
- Be part of the Individual Support Plan (ISP) Meeting and writing of the ISP. The ISP determines what services an individual will receive under each Waiver. If you do not get the service listed in the ISP, it will not be provided! Participating in the meeting and writing of the Plan will help ensure that all needed services are included. You should ask to invite any people who are involved in your care and who you would like to participate.

- You can appeal elements of the ISP if you do not think the youth will receive all the services needed to result in a successful transition.
- Because Waivers have a limited capacity, they may have waiting lists or even be closed. Check on the status of the Waiver you are applying for so that you can plan appropriately.

Who do you call if you have questions about MA waivers or are having problems with the application process?

You can call the agencies or offices that administer the Waiver you are applying for. You also can call the following advocacy agencies:

- Disability Rights Network of Pennsylvania: 1-800-692-7442
- Pennsylvania Health Law Project: 1-800-274-3258
- Juvenile Law Center: 1-800-875-8887

At what age can you start to make decisions about your own treatment?

A parent or legal guardian makes most of the treatment decisions for their children who are under age 18. There are some treatments and care that you can receive on your own when you are under age 18, without the consent of a parent, guardian or another adult. Examples include:

- Mental health treatment at age 14 or older
- Treatment for drug and alcohol addiction at any age
- Testing and treatment for sexually transmitted diseases at any age
- Testing and treatment for pregnancy (not including abortion) at any age
- Contraception and birth control at any age

It is important to remember that even though some treatments need the consent of a parent or guardian, you still play a role in decision-making and should have input. You should always ask any questions that you have about the health care treatment you are receiving and tell your doctor and those on your team how you feel about your treatment. The earlier you play a role in your health care, the better position you will be in to make those decisions when you reach age 18.

Does a young adult who is age 18 get to make his or her own health care decisions even if he or she is still in the child welfare system?

Yes. While the law allows youth to remain in the child welfare system past age 18, they still have all the legal rights that adults have. This includes being the decision-maker about your own health care and treatment. Similar to all young adults, you still can and should seek advice

and guidance from adults who you care about and trust. Under the law, at age 18 an individual makes his or her own health care decisions and this is true also for young adults who remain in the child welfare system.

What is a Health Care or Mental Health Care Power of Attorney?

A health care power of attorney, or “POA,” is a document in which an individual designates one or more persons, known as “health care agents,” to make health care decisions for the individual if he or she is determined to be incompetent to make those decisions in the future. A POA allows the individual, while he or she has the capacity to do so, to put in writing: (1) his or her wishes about the types of treatment he or she would want; and (2) the factors that should be considered in making treatment decisions in the event that he or she becomes unable to make those decision for himself or herself. A health care POA can apply to all health care decisions that come up after a person becomes incompetent, not simply to those decisions that come up at the end of life.

How do you create a POA?

There is no required form for a POA, and you can complete one without a lawyer or going to court. Pennsylvania law provides a sample form for a POA, which can be modified to fit an individual’s needs – you can find it here: *See Power of Attorney*, Pennsylvania Department of Aging, available at: <http://www.portal.state.pa.us/portal/server.pt?open=514&objID=616601&mode=2>. To be valid, a POA must be made in writing, and the person who makes it must sign and date it. It must also be signed by two witnesses who are over the age of 18. Additionally, each POA must identify the person who makes it, called the “principal,” and the health care agent, and must declare that the principal authorizes the health care agent to make decisions on his or her behalf. It is critical for the principal to tell his or her family, friends, and doctors that he or she has made a POA, and provide copies to those who may need it.

When and why would a transitioning youth with a disability need a Health Care POA?

A transitioning youth with a disability might need a POA when there is a possibility that, in the future, his or her disability could impact his or her ability to make certain health care decisions. A POA may be best for youth who have impairments or conditions that are expected to progress and impair their ability to make decisions.

Who should you talk to about creating a health or mental health care POA?

You should talk to your attorney about creating a POA as well as your caseworker.

What is a health care representative?

A health care representative is an individual who is designated to make health care decisions for another individual who is not competent to make those decisions. (The representative is not appointed as a guardian.) Designating a health care representative does not require court approval. Having a health care representative also does not require writing a POA or other document in advance.

Pennsylvania law provides a list of who may act as a health care representative, in descending order of priority:

- A spouse
- An adult child
- A parent
- A brother or sister
- An adult grandchild
- An adult who has knowledge of the individual's preferences and values

Your attending physician, health care provider, or any employee of your provider cannot serve as your health care representative, unless you are related by blood, marriage or adoption to the youth.

When and why would a transitioning youth with a disability need a health care representative?

The advantage of a health care representative is that court involvement is not required, and the process is generally less formal. Designating a health care representative enables a youth to choose someone to make health care decisions for him or her, according to his or her terms. If the individual is not competent at the time the decision needs to be made, the treating physician is able to designate someone based on the requirements of the law and without involving the court.

What is the process for appointing or designating a health care representative?

An individual identifies the person or persons he or she wishes to serve as his or her health care representative when he or she is able to make decisions. The youth must write and sign a document designating the person(s), or to tell his or her physician the name of the health care representative.

If an individual has not designated a health care representative and is or becomes unable to make health care decisions, one may be designated for him or her without court involvement. A health care representative can be designated to make medical decisions for an individual who is age 18 or older if:

- the individual’s attending physician has determined the individual to be incompetent to make a health care decision;
- the individual does not have a guardian who is authorized to make health care decisions; and
- the individual either does not have a health care POA or he or she does have a health care POA but the appointed health care agent is not willing to act and there is no alternative health care agent previously designated by the individual.

Who can you contact if you want to find out more about POAs, health care representatives, or talk about health care decision making?

Disability Rights Network of Pennsylvania has great expertise in the area of health care decision making and substitute decision making when an individual needs to plan for others to play a role in making important health care and other decisions. They can be reached at 1-800-692-7442.

III. Getting Child Welfare Independent Living Services

The law requires that by age 16, youth in the child welfare system receive an Independent Living Assessment and that a plan be created that describes the youth’s Independent Living goals and the services to meet those goals. As is discussed below, there are a wide range of IL services. You need many skills as you begin to assume the responsibilities of adulthood. Living on your own and maintaining an apartment, getting and keeping a job, getting around in the community, shopping, budgeting, and being an active citizen are just a sampling of IL skills. Youth with disabilities are entitled to IL services through the child welfare agency. Youth should work with the important people in their lives to make sure their IL Plan and services match their needs.

What are Independent Living services in the child welfare system and when must they be provided?

The child welfare agency must provide services that help prepare youth for adulthood by no later than age 16.⁷ These are referred to as Independent Living, or IL services. IL services include a large number of services, but examples include:

- educational planning and support
- vocational training
- job readiness training
- job placement

⁷ The federal law that requires that IL services begin at least at age 16 and that an IL plan is created is 42 USCA § 675(1)(D).

- budgeting
- apartment searching
- housing assistance
- financial management
- life skills instruction

For how long can a youth receive IL services?

Youth can continue to receive IL services until they are age 21, whether they are in care or out of care. If you leave care when you are age 16 or older and are still under age 21 and need some help, you are eligible for IL services. When you receive IL services after you leave care, they are called IL aftercare services. These services may include connecting you with health care or housing resources. Youth who left foster care at age 18 and are still under age 21 are eligible for room and board services as part of the aftercare IL services that the child welfare agency provides.

What is the Education and Training Grant (ETG) and who is eligible for it?

Under the Chafee Foster Care Independence Act,⁸ youth who were in foster care at age 16 and older are eligible for up to \$5000 per year to fund the cost of attendance at programs of post-secondary education and training. Due to the high demand currently, eligible youth in Pennsylvania can access \$3000 per year.⁹ Youth are eligible for these funds until age 21, or age 23 in some cases. These funds can be extremely helpful in covering the cost of attendance, including filling in gaps that other financial aid may not cover. To find out more about ETG and to access the short application, click on this link: <http://www.ilp.pitt.edu/edtraingrant.htm>.

Who provides IL services?

County child welfare agencies are obligated to provide IL services to youth who are in care beginning no later than age 16. The agencies can provide them directly, or hire another agency or program to provide the services. Each county has an IL coordinator who can give you more information about how IL services are provided in your county. Click on the following link to find the contact information for your county IL coordinator: <http://www.ilp.pitt.edu/ILprogramDirectory.htm>.

If a youth is still in care and placed in another county, the county children and youth agency that is legally responsible for the youth is responsible for providing IL services. They can provide the services directly to the youth, or contract with an agency to provide the IL services.

If the youth was in care at age 16 or older and left care and moved to another county in Pennsylvania, the county in Pennsylvania where the youth currently lives must provide the

⁸ The citation for the Chafee Foster Care Independence Act is 42 U.S.C.A. §677.

⁹ This amount is for the 2013-2014 Academic Year.

aftercare IL services if the youth is under age 21. Contact the IL coordinator in the county you currently live in to find out what IL services they provide:

<http://www.ilp.pitt.edu/ILprogramDirectory.htm>.

How should IL services be provided?

IL services can be provided in many ways. They can be provided through one-on-one instruction and in group settings. In addition to receiving IL services from a county IL program, youth also should have the opportunity to learn and practice IL skills where they are living. Skills such as cooking, doing the laundry, and budgeting are the types of skills that are learned best by doing. Youth must get these opportunities even if they are placed in a restrictive setting such as a residential treatment center. If this instruction and skills reinforcement in the home is not occurring, a plan should be created so IL instruction can take place in the placement setting and the community. If the caregiver does not know how to teach or reinforce these skills, contact your county IL coordinator or provider to find out if they can provide assistance to your caregiver.

Can youth receive IL services if they were adopted or entered a Permanent Legal Custodianship (PLC) arrangement?

Yes. A youth who was adopted or entered PLC when he or she was age 16 or older is eligible for IL services if he or she is still under age 21. These youth are also eligible for the Education and Training Grant.

What is an Independent Living (IL) Plan?

The Independent Living services a youth needs and receives should be listed in an Independent Living (IL) Plan. Some counties include this in the larger child welfare plan, which is called the Child Permanency Plan (CPP). The IL Plan should identify IL goals and needs and the services or experiences you will be provided with to achieve those goals. The plan should describe the person or agency that will provide the services and when they will be provided.

While the goals and the services will be different for each youth, here are some skill areas to cover in an IL Plan:

- Life Skills and Daily Living Skills
 - Cleaning, cooking, laundry, household management, getting around in the community, how to use public transportation, etc.
- Self Care
 - Hygiene, taking care of your health needs, including any family planning and contraception needs
- Budgeting and money management
 - Understanding how to make a budget, save money, apply for financial aid for postsecondary education and trainings, understanding credit

- Housing
 - How to find, pay for, and maintain a place to live after you leave care
- Employment and Career
 - Job searching and application skills, exploring careers, selecting and applying for vocational training, job coaching and support
- Education
 - Support to help you do well in high school, to look at colleges and vocational programs, tutoring to prepare for the SATs, ACTs, support applying to postsecondary programs
- Relationships and supportive connections
 - Mentoring programs, help in locating and maintaining connections with family or other supportive adults, participation in social activities and community groups

What can you do if you are told that you cannot receive IL services because of your disability or because you are in a specialized placement that cannot provide the services?

All youth in the child welfare system—regardless of placement type and disability—must be provided IL services beginning no later than age 16. There are no exceptions to this requirement, and the federal and state laws that prohibit disability discrimination do not allow youth with disabilities to be excluded from getting these services.

If the youth’s disability or placement location makes providing IL services challenging, an alternative service provider or placement should be considered. Many providers and organizations have experience and expertise in providing IL services to adolescents and adults with minor to severe disabilities in various settings. For assistance in connecting with these providers or experts, call the Center for Independent Living (CIL) in your county. Use this link to find the CIL in your county: http://www.pcil.net/pages/cils/locate_a_cil.aspx.

If you still are having troubling getting IL services, you should let your lawyer know and the judge in your case. You should also call the Disability Rights Network and see if they can help you. They can be reached by calling 1-800-692-7443.

What is the role of the judge in the youth’s IL planning?

By no later than your 16th birthday, the judge should begin talking about your IL goals and services at each court review hearing. Specifically, the judge should make findings about your IL needs and the services being provided to meet your IL goals. Pennsylvania Juvenile Court Rule 1608 (D)(1)(j)¹⁰ requires that the judge make findings in the order issued after each review hearing about the following:

1. the specific independent living services or instructions that are currently being provided by the county agency or private provider;

¹⁰ Pa. Juvenile Court Rule 1608 can be found at <http://www.pacode.com/secure/data/237/chapter16/s1608.html>.

2. the areas of need in independent living instruction that have been identified by the independent living assessment;
3. the independent living services that the youth will receive prior to the next permanency review hearing;
4. whether the child is in the least restrictive, most family-like setting that will enable him to develop independent living skills;
5. the efforts that have been made to develop and maintain connections with supportive adults regardless of placement type;
6. whether the child is making adequate educational progress to graduate from high school or whether the child is enrolled in another specified educational program that will assist the child in achieving self-sufficiency;
7. the job readiness services that have been provided to the child and the employment/career goals that have been established;
8. whether the child has physical or behavioral health needs that will require continued services into adulthood; and
9. the steps being taken to ensure that the youth will have stable housing or living arrangements when discharged from care.

Should you be present at the court hearings where IL services and goals are discussed?

Juvenile Court Rule 1128 requires that all youth must be present at their court review hearings.¹¹ In addition, youth have a right to speak to the judge about how they are doing, any concerns they have, or services they feel they need.¹² Older youth should think about telling the judge about any IL services they think would benefit them as well as their transition plan goals. The courtroom provides youth a great opportunity to advocate for themselves and be heard. At hearings, the judge sometimes will order that certain actions be taken or that services are provided. The services must be provided once they are ordered by the judge.

IV. The Child Welfare Transition Planning Requirement and Staying in Care Past Age 18

The child welfare transition planning requirement is one of the most important legal requirements for youth in the child welfare system who are leaving the system as adults. It is critical that youth and those working with them understand that they should not be discharged from the child welfare system as adults until an acceptable transition plan is created. An acceptable plan is one that will help the youth enter adulthood with safety, stability, health, and well-being. For youth with disabilities, this requirement is especially important because of the need to coordinate many systems, benefits, and services. Beginning early is essential, and understanding the benefits, laws, and services available as a youth transitions is necessary! This

¹¹ You can read Juvenile Court Rule 1128 at <http://www.pacode.com/secure/data/237/chapter11/s1128.html>.

¹² The citation for the federal law that requires that the judge consult with youth about their permanency and transition plans is 42 U.S.C.A. § 675(5)(C)(iii).

section highlights some of the key legal requirements to get youth started on their child welfare transition plan.

What is the child welfare transition planning requirement?

The child welfare transition plan must be developed when an older youth is about to discharge from the child welfare system. Since the enactment of the Fostering Connections to Success and Increasing Adoptions Act in 2008,¹³ when youth are age 18 or older, federal and state child welfare laws require that a transition plan be developed with the youth at least 90 days prior to discharge from the child welfare system. The goal of the planning requirement is to make sure that when youth leave the child welfare system and become adults, they have a safe place to go and that their needs are met. Transition planning is especially important for youth with special needs who may need to be connected with multiple agencies and be in line for needed services well before discharge.

Under federal law, the plan must specifically address several areas, including:

- health and health insurance,
- information and plans for health care decision making options,
- housing,
- education,
- employment, mentoring, and
- support services

How has the transition plan requirement been implemented in Pennsylvania?

Federal law requirements for the transition plan are fairly basic. Pennsylvania Juvenile Court Rule 1613 provide more detail about what must be included in a transition plan and requires that the plan be presented and accepted by the juvenile court before the youth can be discharged from care at age 18 or older. Specifically, an acceptable plan must include:

- the specific plans for housing;
- the child's source of income;
- the specific plans for pursuing educational or vocational training goals;
- the child's employment goals and whether the child is employed;
- the health insurance plan that the child is expected to obtain and any continued physical health or behavioral health needs of the child;
- any available programs that would provide mentors or assistance in establishing positive adult connections;
- verification that all vital identification documents and records have been provided to the child; and

¹³ The transition plan requirement can be found in the Fostering Connections law at 42 USCA § 675(1)(D). It is in our state law, the Juvenile Act at 42 Pa.C.S.A. § 6351 (f)(8,2).

- any other needed support services¹⁴

What happens if the transition plan presented to the court is not acceptable?

The transition plan must be presented to the court at a hearing at which the youth is present at least 90 days before the youth is discharged. The plan must be accepted by the court. If the plan is not acceptable, the court cannot close the youth's case. If, for example, there is no plan for housing or the plan is too vague, the case should not be closed. The court should order that action be taken in the form of holding meetings or providing certain assistance so that the problems with the plan can be resolved. The case should be brought back to court so that an acceptable plan can be presented to the court.

Does the child welfare agency have any obligation to provide a youth who leaves the system at age 18 or older their health and education records?

Yes. Under federal law, a youth's health and education records should be provided to them at no cost when they discharge from care at age 18 or older.¹⁵

Why would a youth want copies of his or her education and health records when they transition from care?

As discussed above, knowing about their health care conditions, needs, and treatment puts youth in the position to make good decisions about their care and empowers them to take charge of their health. Having and understanding their records is a first step to this process. Also, many benefits and services that the youth may want to apply for and receive require the submission of health or education records. The process will be much easier and faster for a youth who already has these documents. These include Supplemental Security Income (SSI), which is described below, and higher education and training programs. Your health and education records will help to establish your eligibility for a 504 Plan or accommodations plan at a college or educational program, as well as to develop the plan's elements.

Until what age can a youth stay in the child welfare system?

Under a new law called Act 91, youth can stay in the child welfare system until age 21 if they are doing at least one of the following activities:

- Completing high school or an equivalent program (such as a GED preparation program);
- Enrolled in college, community college or a vocational program or trade school;

¹⁴ If you want to learn more about this Court Rule, you can find the complete Juvenile Court Rule 1618 at <http://www.pacode.com/secure/data/237/chapter16/s1613.html>.

¹⁵ The citation for the federal law which requires that a youth be provided with their health and education records when they leave care at age 18 or older is 42 U.S.C.A. § 675(5)(D).

- Participating in a program or activity that is designed to remove barriers to getting a job;
- Working at least 80 hours per month; or
- The youth cannot do one of these activities because of a medical or mental health condition that is documented.¹⁶

To find out more about Act 91, check out the brochure, *Know Your Rights: Extended Foster Care and Re-Entry in Pennsylvania*. You can find this brochure at http://www.jlc.org/sites/default/files/topic_related_docs/Know%20Your%20Rights%20%20PA%20Act%2091%20brochure.pdf.

Can a youth ever re-enter the child welfare system after turning age 18?

Yes. Act 91 also allows youth to re-enter foster care in certain circumstances. To re-enter care, the youth must meet the following requirements:

- The youth discharged from care when he or she was 17 and nine months of age or older, and
- The youth is currently under age 21, and
- The youth is doing at least one of the following activities:
 - Completing high school or an equivalent program (such as a GED preparation program);
 - Enrolled in college, community college or a vocational program or trade school;
 - Participating in a program or activity that is designed to remove barriers to getting a job;
 - Working at least 80 hours per month; or
 - The youth cannot do one of these activities because of a medical or mental health condition that is documented.

Re-entering the child welfare system can be very helpful if a young adult is facing a hard time and does not have family or other support. If you re-enter, you can decide to stay in care for just a little while to get back on your feet, or until age 21. Also, remember that you are eligible for aftercare IL services until age 21. Talk to the IL coordinator in the county you are living in to find out more about what you can receive.

¹⁶ Act 91 amended a Pennsylvania law called the Juvenile Act. The part of the law that was changed and expands the options for remaining in care past age 18 can be found in the definition of “child” in the law at 42 Pa. § C.S.A. 6302. The text of the law and additional information can be found in the legal resources section of JLC’s Fostering Connections website at www.jlc.org/fosteringconnections.

Benefits to Staying in the Child Welfare System Until Age 21

- Placement and basic needs are met. (You do not always have to stay in the same placement. You should get the opportunity to live in an age-appropriate placement).
- Case management is provided to help with planning for the future, including education and health.
- Permanency services are provided, including help finding family, an adoptive resource, or even a mentor.
- Continued legal right to visit with siblings and parents.
- Court oversight of the case by a judge who can order individuals and agencies to do things to help you or get what you need.
- Legal entitlement to a lawyer (*Guardian ad Litem*) to represent and advocate for the youth.
- More time to make sure that services and benefits in the adult system that often have waiting lists are in place.
- More time to grow up. The average youth makes the transition to adulthood at age 25 and receives significant financial and moral support from parents after age 18.

V. Making Sure Your Educational Needs are Met as You Transition from High School

Getting a good education is one of the best strategies for preparing for a successful transition to adulthood. Several laws benefit youth in foster care to help them achieve school stability and ensure that they have individuals who can assist them in making important decisions about their education. Youth with disabilities also can take advantage of several laws that can significantly improve the quality of their education and their transition from the high school to the adult world of work, college, and training. This section highlights some of the key laws as well as advocacy strategies for effectively using those laws.

What school should youth who have disabilities or special needs and are in the child welfare system attend?

Being able to stay in the same school in middle and high school is important to school success. When you have to change placements and schools, you lose valuable school time and important relationships. A key law called the Fostering Connections to Success and Increasing Adoptions Act helps create school stability for youth in care by providing youth the following rights:

1. A youth in foster care has the right to attend the school he or she attended before he or she was placed in foster care or before he or she was moved to another placement in foster care, unless to do so would not be in the youth's best interests.
2. If it is determined that the youth will not attend the "home" school because it is not in his or her best interest, the youth has a right to be enrolled in the community school where the youth's placement is located.¹⁷

Can youth be required to attend an on-grounds school when they are placed in a group home or residential treatment center?

Youth should attend the school they were in when they entered or changed placement, or the school in the district in which their placement is located. In most situations, the community school is the preferred option. Restrictive settings are the least preferred. For a youth to be placed in an on-grounds school, the decision would have to be included in a valid IEP or ordered by the court.

If you are placed in an on grounds school and do not know why or think you have been treated unfairly, tell your lawyer as soon as possible and bring this up when you go to court. You should have input into the decisions made about your education, including your educational placement, even if you do not make the final decision.

¹⁷ The citation for the section of the Fostering Connections law that provides for school stability and immediate school enrollment is 42 U.S.C.A. § 675 (1)(G).

Can a youth with a disability be forced to attend a special or separate school just because of his or her disability?

No. The majority of students should attend their community school with their peers. In most cases, youth can only have a change in educational placement if the court orders it or it is in the Individualized Education Plan (IEP). The IEP team, which includes the youth and the youth's education decision maker, must agree to a youth's educational placement. The preferred placement under the special education laws is the least restrictive setting. The IEP should include the specific services and supports that are needed to make it possible for the youth to be in a setting with his or her non-disabled peers.

The Americans with Disabilities Act,¹⁸ which prohibits discrimination based on disability, also requires that youth receive all services, including education in the community with their peers to the greatest extent possible.

Who gets to make educational decisions for a youth in foster care?

In Pennsylvania, parents generally make all educational decisions for their children until they turn age 21. This also is true for youth in the child welfare system unless parental rights are terminated. Usually the child's parent or legal guardian maintains education decision-making authority—for both general and special education—for a youth in foster care. The parent or legal guardian of the child plays a key role in ensuring that the child's educational rights are enforced. It is important to remember that even if they have the legal right to make decisions about your education, you should have input in the decisions that are made. You should make sure your voice is heard so that you can influence the decisions that are made.

It is important to remember that while your parent, guardian, or other educational decision maker gets to make most educational decisions on your behalf, individuals such as your case worker and foster parent can help with enrolling you in school and in making some of the minor day-to-day decisions about your education.

What should happen if my parent is not around or involved in my education?

If your birth or adoptive parent is not around or able to make educational decisions for you, you will need to have an education decision-maker appointed. Without an education decision-maker, very little action can be taken to enforce your educational rights or to challenge a decision about educational placement or services. While all youth need general education decision-makers, only youth who receive special education services need a special education decision-maker. There are a few laws and considerations to keep in mind in this process, which will be discussed directly below.

¹⁸ The citations for the federal law, the Americans with Disabilities Act (ADA), is 42 U.S.C.A. § 12101 *et seq.* If you want to learn more about the ADA from a youth perspective see <http://www.ncwd-youth.info/blog/?p=201>

Who can act as a general education decision maker for a child in the child welfare system?

A parent should act a child’s general education decision maker even when the child is in the child welfare system. If the court removes educational rights from a parent, it should appoint a specific individual who has the expertise and time to serve in that role. Tell your caseworker and lawyer if you have an idea for a person who could play this role. If you receive special education services, the court should consider whether there is a special education decision-maker and whether that person can serve both roles.

Who can act as an educational decision-maker for special education purposes for a child in the child welfare system?

There are special rules about who can act as a special education decision-maker. The “parent” is the special education decision maker for a child, including a child in the child welfare system. Under the federal special education law—the Individuals with Disability Education Act (IDEA)—a “parent” includes the following people:

- A birth or adoptive parent,
- The foster parent,
- A legal guardian, or
- A family member with whom the youth lives who is caring for the youth (such as a grandparent or stepparent), or someone who is legally responsible for the youth’s welfare

If the youth’s biological parent is not available, the individuals listed above can be considered the special education decision-maker without being appointed by a court.¹⁹

What if there is no IDEA “parent” identified?

If none of the people listed above can be identified for youth, a Surrogate Parent should be appointed.

What is the process for getting a Surrogate Parent appointed?

The school district or by a juvenile court judge in your case can appoint a Surrogate Parent.

1. Appointment by the School District. The school district is responsible for appointing a Surrogate Parent for a child with a disability, or a child who is in need of an evaluation to determine if she has a disability, if:
 - a. The parent is unknown or cannot be located after making reasonable efforts,
 - b. No one is identified that can be considered an IDEA parent as described above,or

¹⁹ The IDEA regulation that lists who can act as a “parent” for special education decisions is 34 C.F.R. § 300.30.

- c. The student is an unaccompanied, homeless youth
2. Appointment by the Juvenile Court. A juvenile court judge has the authority to appoint a Surrogate Parent for a child in the custody of a child welfare agency unless the youth has a foster parent. The judge must follow the Juvenile Court Rules in making the appointment. Under Juvenile Court Rule 1147, the judge can only appoint a Surrogate Parent after giving the youth's parent notice and an opportunity to be heard, and only after determining that it would be in the youth's best interest to appoint a Surrogate Parent.²⁰

Who can request the appointment of a Surrogate Parent?

Anyone, including the youth, can request appointment of a surrogate parent. The school district should appoint a Surrogate Parent for a child within 30 days of the request. It is best to put the request in writing and keep a copy for your records in case a timely appointment is not made.

Who can serve as a Surrogate Parent?

If they are willing, possibilities include:

- Adult relatives,
- A Court Appointed Special Advocate (CASA),
- A child's attorney or guardian *ad litem*, or
- Another adult who knows the youth (such as a church member, a mentor, or a responsible family friend)

It is important to remember that a private or public caseworker for the child cannot serve as a Surrogate Parent for the youth.

What does a Surrogate Parent do?

The Surrogate Parent can make all special education decisions that a parent would make. Their authority, however, does not extend beyond special education decisions. The Surrogate Parent should regularly meet with and get input from the youth about the special education program, including the contents of the IEP and transition plan. The youth should ask the Surrogate Parent any questions the youth has so that the Surrogate Parent can make sure the youth's voice is heard. This is especially true for areas like the transition plan, graduation decisions, and decisions about the content of the IEP.

²⁰ If you want to read more about Juvenile Court Rule 1147, you can find it at <http://www.pacode.com/secure/data/237/chapter11/s1147.html>.

Until what age does a youth need a parent or Surrogate Parent to make special education decisions?

In Pennsylvania, a youth needs a special education decision maker until he or she turns age 21. However, as mentioned above, youth should be actively engaged in the decision making process, especially as they get older.

Why does a youth in care who is eligible for special education need a good IEP?

Youth who are eligible for special education have many rights to specialized instruction, services and accommodations as well as due process protections under the federal special education law, the Individuals with Disabilities Education Act (IDEA). The Individual Education Plan (IEP) spells out the kind of education a student needs, including specialized instruction and any needed support services based on the youth's disabilities and strengths. The youth must be provided with what is listed in the IEP, making it a powerful document and an important advocacy tool.

What is assistive technology and how is it paid for when youth are in school, and later when they transition from high school?

Assistive technology is an item or piece of equipment or services that are used to improve an individual's functioning. Examples include: wheelchairs, hearing aids, reachers, computers, and software that helps with communication. It also can include services such as evaluations to help figure out what assistive technology may work well for a youth, or training for caregivers or foster parents to use assistive technology with the youth. Assistive technology can be used in school, at work, in the home, and the community.

There are a variety of ways to pay for assistive technology. It can be funded by the school if it is in the IEP. It also may be covered by health insurance or through MA waiver funding. Regardless of who is responsible for paying, it is important to identify what assistive technology you might need when you transitions from school and the child welfare system; that way, the correct funding stream can be identified so that you can continue to use the device.

For more information on assistive technology and resources to help in getting what you need, contact Pennsylvania's Initiative on Assistive Technology (PIAT) at <http://disabilities.temple.edu/programs/assistive/piat/>.

What is the transition planning requirement in the IEP?

In addition to having child welfare transition planning requirements, youth in care who are eligible for special education services must also have a transition plan and receive transition services in their IEP beginning at age 14. While this plan will have goals that overlap with the child welfare IL and Transition Plan (the plan to help you transition from the child welfare system to adulthood), the transition plan in the IEP is very focused on the transition from

school to work or post-secondary education and training. The plan must have concrete and measurable goals in the areas that will be discussed below; must contain the services, instruction, or experiences that will help achieve the goal; and must designate the person or agency responsible for delivering each service.

Far too often the transition plans contain much less than they should and much less than the law actually requires. The information below gives you some basic information about transition planning so you can get what you need and deserve.

What areas must be included in the transition plan in the IEP?

The transition plan in the IEP includes an organized set of activities that help youth move from high school to college, post-secondary training, independent living, and work. It must include goals related to:

1. Post secondary education or training
This includes attending a 2-4 year university, community college, technical school, or anything that furthers the youth's education.
2. Employment
This includes goals related to getting a job and finding a career.
3. Independent Living
Independent living goals include getting around in the community, using community resources, and accomplishing daily tasks that an adult needs to live as independently as possible.
4. Community Participation
This includes participation in activities, clubs, and events in the community, such as church and cultural events, etc.
5. Adult Service Connections
Goals in this area involve connecting the youth with agencies and services that the youth will need as they become adults. Depending on the severity of the youth's disabilities, the youth should be connected to one or more of the following agencies: the Office of Vocational Rehabilitation (OVR), Careerlink, Centers for Independent Living, the Social Security Administration, the County Assistance Office, Adult Behavioral Health Services, Office of developmental Programs, the Bureau of Autism, and the Protection and Advocacy Agency.

How do you know if the transition plan is adequate?

In addition to making sure you have goals in the five areas listed above, the transition plan must:

- Have goals that are based on transition assessments,
- Include appropriate measurable goals that are updated each year,

- Include transition services designed to achieve the goals. The plan can and should include direct instruction, work experiences, practice and experiences in the community, and any supports that will reasonably enable the student to meet the goals, and
- Include the youth in its development!

What is a transition assessment?

Federal law requires that the goals set in the transition plan be based on transition assessments. These assessments help ensure that goals and services are informed by your interests, capacities, needs, and skills. The assessment process is ongoing and there are multiple types of assessments as well as versions of each type that can be used as you get older. Some assessments can help you explore how your current interests and strengths may translate into work and school goals when you graduate from high school.

Some types of assessments are:

- Life skills inventories
- Transition skills inventories
- Interest and aptitude inventories and questionnaires
- Situational assessments or observations
- Vocational assessments
- On the job or training evaluations
- Adaptive behavior and independent living assessments
- Personality or preference tests
- Career development measures

To find out more about transition assessments and how they help in developing the transition plan in your IEP, see *It's All About You! Tips to Getting the Most out of Assessments in the Pennsylvania Youth Leadership Network: Secondary Transition Toolkit* at 29-55, which is available at <http://pyln.org/Files/PYLN2ndTransitionToolkit.pdf>.

What are examples of acceptable transition planning goals?

The goals set should be concrete, specific, and measurable. To achieve the goals, you can be provided instruction, related services, community experiences, and support in acquiring daily living skills. The sky really is the limit in the goals that you chose. Do research and ask the questions to figure out the instruction and services will get you to that goal, taking into account your needs and your strengths. Involve your parent, Surrogate Parent or others who know you to help you come up with a plan and the services and instruction you need to get there.

For example, if getting into and attending cosmetology school is one of your postsecondary education goals, you will want to determine the steps that will get you there. Those steps may be broken down into smaller goals.

- Direct instruction and tutoring in science, math and reading.
Let's say you did your research and found out that you need a certain level of science, math, and reading skills to be admitted to cosmetology school that you do not have yet. In that case, you will want to make sure your transition plan in your IEP contains direct instruction and tutoring in math, science, and reading that matches the skills you need for cosmetology school.
- Direct instruction and community experience in using public transportation.
Maybe you have difficulty getting around in the community, using public transportation and following directions. Then you should include instruction and community experiences in learning and mastering public transportation in the plan so that you can get to and from school.
- Direct instruction and support in researching financial aid and completing school applications.
Finally, if you do not know how to pay for cosmetology school and complete the applications, you would also want to include instruction and support in researching financial aid and completing school applications as services and supports in your transition plan that will help you achieve the goal of attending cosmetology school.

Your transition plan should be detailed and really spell out what you need and the steps you have to take to be able to reach the goal you set by the time you complete school. It can be a great roadmap and guide, but you need to make sure you use it!

What resources exist in Pennsylvania to get help with developing and reviewing a youth's transition plan?

- The Pennsylvania Youth Leadership Network has developed a Secondary Transition Toolkit for youth and those working with youth. This Toolkit is a great resource and provides many concrete forms and tools for youth to use to help think about what should be included in the transition plan and to prepare the youth for participating in the IEP meeting. The Toolkit can be found at <http://lifeafterieps.com/wp-content/uploads/2011/06/PYLN2ndTransitionToolkit1.pdf>.
- The Pennsylvania Training and Technical Assistance Network of the Pennsylvania Bureau of Special Education has a Secondary Transition Guide, which is a website that provides multiple resource materials and opportunities for trainings. The Guide is available at http://www.pattan.net/category/Educational%20Initiatives/Secondary%20Transition/page/Pennsylvania_Secondary_Transition_Guide_website.html.
- Most counties or regions of the state have transition coordinators who have expertise in transition planning. To find the coordinator in your area see <http://www.pattan.net/category/Resources/Instructional%20Materials/Browse/Single/?id=5024e1108b03329426000005>

- The National Dissemination Center for Children with Disabilities also has some great resources, including examples of model transition plans (as well as a description of plans that are not acceptable). See <http://nichcy.org/schoolage/transitionadult/goals>.

What agencies can help out if a youth is not getting all he or she is entitled to under the federal and state special education laws in their IEP and transition plan?

For help, please call the following organizations:

- Disability Rights Network of Pennsylvania: 1-800-692-7442
- Education Law Center—Pennsylvania: 215-238-6970
- Juvenile Law Center: 1-800-875-8887

What is a 504 Accommodations Plan and why would youth need one when they are still in middle or high school?

If the youth has a disability that requires an accommodation so the youth can participate in school and extra-curricular activities, but the disability does not require specialized instructions, the youth may be eligible for a 504 Plan.²¹ To be eligible for a 504 Plan, a youth must have a disability that limits at least one of the following activities: walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, or performing manual tasks. The specific accommodations included in a 504 Plan depend on the youth’s disability and needs. Examples include: having a class assigned to the first floor for a youth who has mobility impairments and struggles with stairs, seating in the front of the class room for a student who has visual impairments, or availability of certain snacks for a youth with diabetes. If you have a disability, but are not eligible for special education services, you may be eligible for a 504 Plan that can improve your school experience in and out of the class room.

What is the Office of Vocational Rehabilitation (OVR)?

OVR provides services to help adults with disabilities prepare for, obtain, or maintain employment. OVR provides some services directly and contracts with other providers also. Services are provided on an individualized basis. There are 21 OVR offices in the state. Click on this link to find the OVR office nearest to you:

http://www.portal.state.pa.us/portal/server.pt/community/vocational_rehabilitation/10356/ovr_office_directory/606620.

²¹ The Accommodations Plan has become known as a 504 Plan because it is required under what is known as Section 504 of a law called the Rehabilitation Act, which prohibits discrimination based on disability. The citation for the law is 29 U.S.C.A. § 794. Like the Americans with Disabilities Act (ADA), the Rehabilitation Act is a federal law the prohibits discrimination against people with disabilities.

How and when can a youth access OVR services?

Adults—individuals age 18 and older—are eligible for OVR services. Youth with disabilities should be referred to OVR as they approach their 18th birthday. It is recommended that the referral be made even if the youth is attending high school past age 18. OVR can and should be made part of the youth's IEP meeting and IEP. You, a foster parent, your caseworker, your lawyer, or a member of your IEP team can refer you to OVR. Check the OVR office in your county for the application processes.

Do all eligible individuals receive OVR services automatically?

No. OVR services are not an entitlement so establishing eligibility does not result in immediate access to services. However, applying early is important and keeping on top of your application and calling to see if you can receive services is a good idea. Contact the [Client Assistance Program](#) at (888) 745-2357 if you need help getting services from OVR or think you are being asked to wait too long. Information about the Client Assistance Program is provided on the next page.

What are examples of OVR services that may work best for a young adult?

Below are examples of services, instruction, experience or training that OVR may provide directly or that it will pay for. If the service, instruction, experience or training is included in your service plan with OVR, it should pay for it if there are no other sources of funding, such as financial aid.

- Vocational exploration
- Career and interest assessments
- Trial-work experiences
- On-the-job training
- Job coaching
- Supported employment
- Career planning
- Counseling, guidance and referrals
- Technology (aids, devices, training)
- Assistance with transportation to services or programs
- Vocational training
- College
- Medical and psychological diagnosis and treatment
- Physical and mental restoration services
- Help with additional costs during rehabilitation
- Interpreters for the hearing impaired and readers for the visually impaired
- Personal assistance during rehabilitation
- Sheltered workshops, supported work programs, job coaches

- Assistive technology evaluations and services
- Job placement

What resources that can help an individual who is having trouble getting services, or the right services, from OVR?

Under federal law, advocacy services must be available for individuals who seek services from OVR and/or are not satisfied with the services they are receiving. In Pennsylvania, this assistance is provided by the Client Assistance Program (CAP). To find out more about the CAP program check out the website at: <http://www.equalemployment.org/about-pennsylvania-client-assistance-program/>. To ask a question or get assistance you can contact the CAP program by email at info@equalemployment.org or phone at (888) 745-2357.

Are youth with disabilities entitled to graduate with a regular high school diploma?

Yes! A youth with a disability in Pennsylvania who receives special education services is entitled to graduate with a regular high school diploma if: (1) he or she completes the same graduation requirements as a regular education child; or (2) the youth's IEP team determines that the youth has satisfied the IEP goals to the extent necessary for graduation. Make sure you know your graduation requirements and whether you will be graduating based on your IEP or credits.²²

Do youth with disabilities have to participate in state standardized assessment testing, such as the PSSA?

Youth with disabilities must participate in the state achievement test that most children take (called the Pennsylvania's System of School Assessment or PSSA), or must take the Pennsylvania's Alternate System of Assessment (PASA), which is designed for children with particularly severe disabilities who are taught according to alternate learning standards. The youth's IEP team, however, must determine what, if any, accommodations or modifications are necessary for the child to participate effectively.

To graduate, Pennsylvania youth are expected to score at the proficient level or better in reading, writing, and mathematics on the PSSA, the PASA, or on a district-wide assessment that is aligned with the state's academic standards. However, youth with disabilities who take the PSSA or the local test, but who cannot perform at the proficient level or better due to their disabilities, can still graduate and receive a regular high school diploma if they have met their IEP goals.

²² If you want to read more about graduation requirements for students with disabilities, please see the Pennsylvania Department of Education's Basic Education Circular on this topic, *Graduation Requirements for Students with Disabilities* (2013). It can be found at <http://bit.ly/18WzcS5>.

How long can a youth with disabilities remain in high school?

Youth with disabilities have the right to stay in school until they complete the school term in which they turn 21 or until they graduate—whichever comes first. A youth who is eligible for an extended school year also can attend school during the summer after he or she turns age 21. If a youth accepts a high school diploma prior to age 21, the youth cannot continue to receive free special education services.

Can a youth with a disability participate in a graduation ceremony with her class if she is not going to receive her diploma that year?

Yes. A youth with a disability who has completed four years of high school, but is not graduating and is continuing to receive special education and related services from the school district, must be permitted to participate in the graduation ceremony with her classmates. The youth is entitled to a certificate of completion as part of the graduation ceremony, but must receive a regular high school diploma when formal schooling ends. This means that a youth can “walk with” his or her own class at graduation and still have the benefit of a continued education.

Must the school district take steps to make sure that a youth with a disability can participate fully in her graduation ceremony?

Yes. A school district must make reasonable accommodations to enable youth with disabilities, including children with physical or cognitive impairments, to participate fully and on equal terms in graduation ceremonies. Such accommodations must be provided according to a child’s individual needs.

Can a youth with disabilities get special education services after they graduate high school?

No. The IDEA does not extend past high school. Youth with disabilities or impairments in post-secondary programs may be eligible for a 504 Accommodations Plan, but have no right to specialized instruction and related services and an IEP.

Can a youth get a 504 Accommodation Plan when they go to college or trade school?

Yes. 504 is a section of the Rehabilitation Act, a law that prohibits disability discrimination. Postsecondary institutions must make adjustments and accommodations to ensure that students are able to access all aspects of the program, including instruction, extracurricular activities, and all facilities. If a youth has a disability, the 504 Plan should outline the adjustments or accommodations the student needs based on his or her disability. While the precise accommodation will depend on the youth’s needs, below are some examples of parts of a 504 Plan for young adults who are headed to college or trade school:

- Qualified interpreters; assistive listening systems; captioning; TTYs; qualified readers; audio recordings; taped texts; Braille materials; large print materials; materials on computer disk; and adapted computer terminals.
- Rescheduling classes to an accessible location; early enrollment options for students with disabilities to allow time to arrange accommodations; substitution of specific courses required for completion of degree requirements; allowing service animals in the classroom; providing students with disabilities with a syllabus prior to the beginning of class; clearly communicating course requirements, assignments, due dates, and grading criteria both orally and in written form; providing written outlines or summaries of class lectures, or integrating this information into comments at the beginning and end of class; and allowing students to use note takers or tape record lectures.
- Extended time to complete a test or providing a distraction-free space, sign language interpreters, readers, or alternative test formats.

For more examples and more information about accommodations and how to request them see U.S. Department of Education Office of Civil Rights, *Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities* (2011), available at: <http://www2.ed.gov/about/offices/list/ocr/transition.html>.

How can you get ready to create a good 504 Accommodations Plan?

Your treatment providers should provide input into what accommodations would be helpful in a 504 Plan. Additionally, before a special education student graduates, the federal law requires that a Summary of Academic Achievement and Functional Performance²³ be completed. This form is an excellent tool to use in creating a 504 Plan for a postsecondary program. The IEP team is in a great position, and has expertise, to develop accommodations that will work for the postsecondary setting. A discussion of accommodations should occur at the last IEP meeting at which the Summary of Academic Achievement and Functional Performance is completed.

How can you get a 504 Plan?

You should contact the disability services office of the postsecondary educational or training program that you are planning to attend, as soon as possible. If there is no disability services office, inquire into what office handles 504 or Accommodations Plans. Unlike in the special education system in which the school district is obligated to identify youth with disabilities, postsecondary institutions have no such duty to find you and ask you if you want accommodations or a 504 Plan. For that reason, youth must be proactive in identifying themselves and requesting accommodations. The youth must provide some documentation of his or her disability. Educational or health records will be helpful in providing documentation.

²³ A copy of this form can be found at <http://www.pattan.net/category/Legal/Forms/Browse/Single/?id=4db2885acd69f9c443490100>.

If you are having problems getting a 504 Plan, call the Disability Rights Network of Pennsylvania at 1-800-692-7442.

What additional services and supports can help a youth succeed when they are attending post-secondary education and training?

Most post-secondary programs offer a wide array of student support programs that provide tutoring, counseling and other services that can help a student adjust to and succeed at the new program or college. Professionals and advocates should research the support services and extracurricular activities available as soon as possible so that the youth has an idea of the support he or she can utilize. Below are some examples of programs that may be available to youth in college or training programs:

- Act 101 Programs

These are student support programs authorized and funded under the state Higher Education Opportunity Act of 1971. Act 101 programs are overseen by the Pennsylvania Higher Education Assistance Agency (PHEAA) and are designed to serve economically and educationally disadvantaged students. PHEAA has recommended that Act 101 programs consider current and former foster youth for participation.²⁴

Act 101 Programs provide an array of student support programs targeted at improving rates of retention, graduation, and academic success. Examples include:

- Summer Bridge Programs that bring youth to college during the summer and provide continued support
- Tutoring
- Academic counseling
- Support groups
- Academic enrichment activities

Use the following link to find Act 101 Programs in Pennsylvania:

<http://www.pheaa.org/partner-access/schools/pdf/act-101/act-101-directory.pdf>.

- TRIO Programs--Student Support Services

The TRIO Programs refer to a series of programs funded by the federal Department of Education to help disadvantaged students get to college and succeed there. The Student Support Services portion of the TRIO Programs provides assistance and support for retention and success at postsecondary programs. Many programs provide services like those listed

²⁴ See *Act 101 Program Guidelines, 2013-14 Program Year* at 6, available at <http://www.pheaa.org/partner-access/schools/pdf/act-101/act-101-program-guidelines-2013-14.pdf>.

above for Act 101. To find a list of TRIO Student Support Programs in Pennsylvania see http://www.patrio.us/index.php?p=1_31_TRIO-Programs-in-PA-.

You owe it to yourself to get all the support you need. One of the big differences between college and training programs and high school is that you will need to seek out help. As you get older, the responsibility is yours more than ever before to find what you need and ask for help when you need it. Check out any programs that may help you succeed.

Are there any resource guides that can help me get the services and supports I need if I go to college?

Yes. Please see the following excellent resource:

Roody McNair & Arlene Solomon, *A Practical Guide for People with Disabilities Who Want to Go to College* (Temple University), available at: <http://bit.ly/16PIDnr>

VI. Accessing Supplemental Security Income (SSI) While in Care and When You Transition

SSI is an important benefit; in some cases, it can improve the supports and services to which youth in care have access. Without a doubt, access to SSI can improve the quality of a transition plan for a youth who is transitioning from the child welfare system to adulthood. As an important cash benefit that is also tied to health insurance, SSI can open up housing options by covering rent or other costs of living for a youth, and is a gateway to various other programs and benefits. This section provides some basics about SSI eligibility, how it can be used for youth in care, and how it can improve transition planning.

What is Supplemental Security Income?

Supplemental Security Income (SSI) is a federal program that provides cash assistance to aged, blind, and disabled people, including children and youth, who have limited income and resources. In addition to cash assistance, individuals who are eligible for SSI also are eligible for Medical Assistance (MA). The Social Security Administration (SSA) is the federal agency that administers the SSI program.

Usually states supplement the federal SSI benefits. In 2013, the SSI benefit rate for an individual in Pennsylvania, including the state supplement, was \$710.00 a month.²⁵

What are the eligibility criteria for SSI for children and adults?

To qualify for SSI, a child must meet the SSA definition of disability, and have little to no income or resources (e.g., a home, bank accounts). Income includes things such as money from a job,

²⁵ For more information, see *Supplemental Security Income in Pennsylvania* (Social Security Administration 2013), available at <http://www.ssa.gov/pubs/EN-05-11150.pdf>.

and may include some foster care payments. SSI recipients also must be United States citizens or have a qualifying immigration status.

Youth under age 18 are determined eligible based on the childhood standard of disability. SSI is available for children who have a physical or mental impairment that cause severe limitations in their daily functioning, and is expected to last for at least 12 months. For this determination, SSA compares the child's functioning to that of other children of the same age who do not have impairments.

For youth age 18 and older, eligibility is based on the adult standard. Once youth turn 18, they may be eligible for SSI if they have a disability that prevents them from working (or engaging in "substantial gainful activity") and is expected to last for at least 12 months.

What happens when a youth who is receiving SSI turns age 18?

A child is not automatically cut off from SSI benefits at age 18. Instead, as the child nears his or her 18th birthday, he or she will have a review to determine if he or she meets the adult standard for disability. At age 18, the standard is whether the disability interferes with the ability to work.

There is an exception to being evaluated under the adult standard. At age 18, if you are involved in an approved vocational rehabilitation program, still in high school and have an Individualized Education Plan (IEP), or are involved in another similar program approved by SSA, you may be able to continue your SSI eligibility at least until you complete the approved program. This is sometimes referred to as continued payment under Section 301. See <http://www.socialsecurity.gov/redbook/eng/ssdi-and-ssi-employments-supports.htm#6> for more information.

Can a youth who is in foster care receive SSI?

Yes, but it does not always make sense to do so. Youth in foster care who have disabilities can apply for SSI. As explained above, the SSI eligibility criteria are two-pronged. Youth with severe disabilities may meet the first criteria of proving they have a disability under the law. However, the second eligibility prong relates to income eligibility. How the youth's placement is being paid for and the cost of care is usually the determining factor for eligibility. This is because the law requires that certain funding for foster care be counted as the youth's income. In certain situations, this will make the youth ineligible for SSI based on income. You should ask your attorney and your caseworker if the child welfare agency is receiving SSI on your behalf, or if it would make sense for you to submit an application for SSI.

If a youth who is under age 18 receives SSI while in foster care, who is the payee?

Regardless of whether a child is in foster care or in his own home, a child under age 18 usually needs a representative payee to receive and manage the SSI benefit. In general, the

“representative payee” is the person who receives the check on behalf of a child receiving SSI and determines how it will be spent. This is usually the youth’s parent.

The SSA regulations provide a list of individuals or organizations who SSA prefers to serve as a payee for a youth if a parent cannot. The list includes:

- 1) A natural or adoptive parent who has custody, or a legal guardian
- 2) A natural or adoptive parent who does not have custody, but who is contributing to the support of the child and is demonstrating a strong concern for his or her well-being
- 3) A natural or adoptive parent who does not have custody, and who is not contributing to the support of the child but is demonstrating a strong concern for the well-being of the child
- 4) A relative or stepparent who has custody of the child
- 5) A relative or stepparent who does not have custody, but who is contributing to the support of the child and is demonstrating a strong concern for the well-being of the child
- 6) A relative or close friend of the child who does not have custody but is demonstrating concern for the well-being of the child
- 7) An authorized social services agency or custodial institution²⁶

If none of the individuals or agencies listed above is available, SSA may designate an organization or state or local government agency. Appointment of a governmental agency, such as the child welfare agency, is the least preferred option—however, this often happens for youth in care. A payee should be someone the child trusts to be concerned about his or her well-being and health, and helps the child understand his or her benefits and financial situation. If you know someone who could serve as a payee, let your lawyer and case worker know.

Can a minor ever receive payments directly as his/her own payee?

In certain cases, youth may be able to receive SSI payments directly. A youth should talk with his or her attorney about being his or her own payee. It is important to remember, however, that even if the youth or another individual is the payee, the child welfare agency can ask that all or a portion of the youth’s SSI be used to pay for the youth’s cost of care while the youth is in the child welfare system.

Does a youth who is in care, over age 18 and eligible for SSI get to be *his own payee*?

It is assumed that an 18 year-old is competent and able to manage his or her own money. Therefore, an 18 year-old would generally be his or her own payee. However, depending on the youth’s disability, SSA may ask that the youth have a payee appointed for him or her. To overcome this, a youth may be able to get documentation from a doctor that he or she can

²⁶ The federal regulation where this list is found is at See 20 C.F.R. §404.621(c) (order of preference in selecting a representative payee).

manage his or her own money. If it is determined that a payee is needed, as described above, preference should be given to an individual who has a close relationship with the youth and is familiar with his or her needs. The child welfare agency would still be the least preferred payee.

Does a youth who is under age 18 and in foster care *receive* any of the SSI benefit while he or she is in care?

It depends. If a youth is in the care of the child welfare agency, the agency may require that the SSI funds be used to reimburse the child welfare agency for the cost of care (placement, room, and board costs). This means that if the cost of care exceeds the SSI benefit, the youth will likely not have access to any of the SSI funds for his or her personal use.

It is recommended that the youth and his or her attorney discuss the following issues with the child welfare agency to determine if the SSI funds could be used in a way that assists the youth's transition from the child welfare system:

- Can some portion of the SSI payment be allocated to the youth to make decisions about areas such as purchase of food and clothing so that the youth gains supported budgeting experience? Setting aside even a small amount, such as \$30 a month, for which the youth can be held responsible for budgeting while receiving instruction and support, can provide a great practical learning experience for the youth.
- Are there any unmet treatment or enrichment needs that are not covered by other funds and could be covered by a portion of the SSI funds? If so, a request can be made to the child welfare agency or juvenile court to, for example, use SSI funds for a special program or activity that would assist the youth in achieving his or her goals.
- Can some portions of the SSI funds (not to exceed \$2000) be set aside as an emancipation fund for transition from care expenses?²⁷

What is the SSI money used for while the youth is still in care, and is the youth involved in those decisions?

While a youth is in care, SSI payments are to be used to benefit the child based on his or her "best interests." This includes the cost of food, shelter, clothing, and the cost of care. In virtually all cases in which the child welfare agency is designated as the representative payee, it will use the benefits to pay for the cost of the child's foster care or cost of placement and services. The representative payee is responsible for accounting for the use of SSI funds. The youth and his or her attorney should request an accounting if they are concerned about misuse

²⁷ A discharge fund is a great idea to pay for items such as a security deposit for an apartment or furniture and other start-up costs. Be aware that the individual cannot have more than \$2,000 in savings or his or her income eligibility for SSI may be impacted.

to determine if sanctions should be sought or another payee should be appointed. In addition, the youth should consider requesting being part of the decision-making as to how money is spent so that he or she can get some hands-on budgeting experience.

If a youth does not receive SSI while in care, when should an application be made to ensure that he or she receives SSI upon leaving care?

Youth should be ready to file an application for SSI 90 days before the planned discharge date.²⁸ This means that all medical records, documents, and forms should be completed and ready to go so that they can be submitted with the application on the 90th day before discharge, which is the earliest date that an application can be submitted.

It is important for youth to apply 90 days before leaving, rather than waiting until exiting care, because the SSA takes several months to process SSI applications. Even an application made at the 90-day mark may not result in you receiving the benefit immediately when you leave care.

Whose responsibility is it to file the SSI application for a youth who is still in the care of the child welfare agency?

It is the child welfare agency's responsibility to ensure that transition planning is occurring, including making an application for SSI. It is recommended that the transition planning team determine who will be responsible for what tasks in preparing the SSI application at least six months before the youth's planned discharge date.

What is the process if the application is made when the youth is age 18 or older?

The applicant (or young adult) will need to fill out an application that asks for basic information about the applicant and the disability as well as provide a birth certificate, social security card, and proof of valid immigration status if the youth is not a citizen. The applicant will have to complete the Adult Disability Report in addition to going in to the SSA office for a scheduled interview. The Adult Disability Report can be found at <http://www.socialsecurity.gov/hlp/radr/10/global-report-works.htm>.

The application process will include submitting medical or behavioral health records based on the disability claimed, records of treatment, and educational records. Records or observation from caregivers that speak to the youth's ability to care for himself or herself and manage his or her daily activities should be submitted as well. As explained above, it is the child welfare agency's responsibility to file the application or make sure that it is filed. The youth or young adult should participate in the process as well as the transition plan team members to ensure that the most complete information is provided.

²⁸ This Social Security Administration Policy can be found at <https://secure.ssa.gov/apps10/poms.nsf/lnx/0500601011!opendocument>. It is listed as POMS SI 00601.011.

To find out more information about how to begin the application process and prepare for the interview, see the *Adult Disability Starter Kit* at http://www.ssa.gov/disability/disability_starter_kits_adult_eng.htm.

**SSI Application Tips for Youth Discharging Out of
the Child Welfare System**

- Submit relevant medical, treatment, and educational records with the application. Do not wait for SSA to request the records!
- Submit any observations of teachers, caregivers, or treatment providers that give a full picture of your functioning, including your ability to care for yourself and manage daily activities.
- Submit information about ability or inability to work that may be contained in IEPs, transition plans, and vocational assessments. If there are records of unsuccessful work attempts or sheltered workshops, submit these as well.
- Prepare answers for the application and Disability Report at least four months prior to planned discharge so that it is completed and ready to submit with supporting records at the earliest date possible (90 days before discharge).
- Seek assistance from others in completing the Adult Disability Report! It is a long form and can be complicated to complete.

Can a youth work while receiving SSI?

Yes. Even though an individual's income is part of the SSI eligibility determination, in certain circumstances money earned from work may not count against an individual's eligibility. In most cases, this has to do with providing incentives to get individuals back to work and off of SSI.

For example, an individual who is under age 22 and is in school or a post-secondary education or training program, is able to earn some income from work and not have it negatively impact his or her eligibility for SSI or the amount received.

In addition, several programs allow individuals to set aside more money than is usually allowed to maintain SSI eligibility as long as an approved plan is in place to help an individual achieve self-support. For example, your plan may include setting aside some money for a training program or tools or equipment for a training program or job. One of these programs is called a Plan for Achieving Self Support (PASS). To find out more about the work incentives for which an individual receiving SSI may be eligible, contact Disability Rights Network of Pennsylvania at 1-800-692-7442 and ask for the Community Work Incentives Coordinator.

How can SSI be a helpful part of a transition plan? What other benefits and services can be accessed while receiving SSI?

Receiving SSI can be a major benefit to youth making the transition into young adulthood. Because many youth exiting care have a difficult time securing housing and sufficient income to cover the cost of basic needs, SSI can be critical during the transition period. In Pennsylvania, the average monthly SSI benefit is about \$710.²⁹ This can help pay for the cost of housing or provide a young adult some income to contribute to housing and other costs if he or she decides to get a roommate or share housing with family.

Young adults who receive SSI also can access other benefits and programs. For example, the disability determinations made for SSI eligibility may automatically qualify a youth for certain types of housing assistance that require the demonstration of a disability. Eligibility for MA is also linked to SSI eligibility. Finally, a housing arrangement called domiciliary care (dom care) is only available to individuals with disabilities who receive SSI.

VII. Developing a Housing Plan for the Transition to Adulthood

As everyone gets older, they want more independence and freedom, but sometimes they still need support. Below are some resources to consider if you are looking for housing or living settings in the community. Where you will live and how you will pay for it is a key component of your transition plan, so start planning early and develop multiple plans! This section discusses some of the resources and options that can help you create a plan.

Can youth return to their family when they transition from the child welfare system?

Yes. Reunification with parents or living with a family member is always an option and can be a good way to make sure you have a housing plan *and* some support if you do not think you are ready to live on your own. Tell your lawyer and the child welfare agency of any family members you can live with when you leave care. Ideally, you should be working with these family members and doing some visits several months before you discharge so you can have confidence that the arrangement will work and meet everyone's needs. The agency may be able to provide services to you and the family member to make the living situation work for everyone in the home.

Here are some things to consider if your housing plan includes moving in with family:

- What are the house rules and will I be treated as an adult?
- Will I have my own room and enough privacy?
- If there are conflicts, how will we resolve them?
- What responsibilities will I have in the home in terms of paying bills, doing chores, etc.?

²⁹ This is the reported amount for 2013. The exact amount of SSI that an individual receives on a monthly basis is affected by several things. Those can include: income from work and other sources and where an individual lives.

- Will the home need any physical modifications to meet my needs and how will we get them?
- Will my family members need any training in how to assist me with any of my health care or special needs?

One tool to help you with this conversation is California’s Shared Living Agreement.³⁰ Complete this form with the people in the home well before you move into the home so rules and expectations are clear for everyone.

Can I still live with my foster family once I leave care?

Yes, if you want to remain in your foster home and your foster parents allow you stay. Tell your foster parents and talk with them if you are interested in staying. Nothing prohibits you from staying in the home if your foster parents allow it. If your foster parents will continue to provide care to other foster children, you should discuss any restrictions in how many individuals can be in their home and other requirements.

Just like living with your biological family, if you stay in your foster home, you should consider all the issues discussed above in the bulleted list. As an adult and an individual no longer in the child welfare system, your relationship with your foster parents is likely to change. You may want more freedom (later curfews, less restrictions) and your foster parents may want you to take more responsibility (pay rent, help with more household tasks). It is important to discuss these issues so you all agree on expectations.

Sometimes a foster family may be willing to become certified as a dom care provider. See directly below for more information on dom care. If the foster family becomes a dom care provider, they may be able to receive some financial support for providing care to you and some case management support from the dom care program. Families interested in this option should contact the local Office on Aging that runs the dom care program for the county you live in. This is a great way to continue providing support and continuity for the young adult while also receiving some level of financial support. This is an option for you to consider if you are receiving or will receive SSI.

What are some other resources for housing and living arrangements if I am a youth with a disability who is leaving the child welfare system?

- Domiciliary Care (“dom care”) is for individuals who are age 18 and older who have a disability and need some help with activities of daily living, but do not need 24 hour care. There is a dom care program in every county run by the Office on Aging. In dom care you live in someone’s home. The homeowner provides you some support and care as well as meals. You create house rules with the dom care provider to make sure there

³⁰ You can find the Shared Living Agreement at <http://bit.ly/14PHYDP>.

is agreement about things such as going in and out of the house, having visitors, etc. You have rights in the dom care program that have to be respected and you are able to file grievances if you feel you are not treated well. The cost of dom care is usually covered by your SSI benefit and a state supplement. Find the contact information for your local area agency on aging to find out more about dom care in your community, using this link: <http://www.portal.state.pa.us/portal/server.pt/community/aaas/17958>.

- Supportive Housing through the Office of Behavioral Health and/or Your Health Insurance. If you have a behavioral health impairment that prevents you from living completely on your own, you may be eligible for a supportive housing arrangement either through the county office of behavioral health or through your Managed Care Organization (MCO) as part of your health insurance. The options may be different in each county so do a little investigation as you approach your 18th or 21st birthday.
- Local Housing Option Teams (L-HOTS). If you have a behavioral health impairment, your local L-HOT will be a great source of information regarding supportive housing options. The role of L-HOTS is to expand housing opportunities and to seek long term solutions to the housing needs of people with mental illness and co-occurring disorders. Please see the following link for contact information for L-HOTS throughout the state. <http://www.pahousingchoices.org/housing-resources/local-housing-options-teams/>
- Mental Health Housing Specialists. Please see the following link for a list of the mental health housing specialist for your county: <http://www.pahousingchoices.org/housing-resources/mh-housing-specialists/>
- Affordable Housing Locator Websites. You can consult at least two websites to help you find affordable housing in Pennsylvania. They list options for individuals with and without disabilities, and allow you to search for units that are subsidized as well as units that have special accessibility accommodations. Unfortunately, affordable housing is far too rare in Pennsylvania so start your search early.
 1. Pennsylvania Affordable Apartment Locator
<http://pal.phfa.org>
 2. Columbia Property Management Home Finder
<http://www.cpmhomefinder.com>
- Centers for Independent Living (CILs). CILs provide a variety of services for individuals with disabilities so that they can live fully and successfully in the community. Information and referral is among the services provided. CILs can be great resources for finding housing in the community. Use this link to find the CIL in your county: http://www.pcil.net/pages/cils/locate_a_cil.aspx.

- Housing Vouchers/Subsidies. Housing vouchers provide rental assistance to individuals or families who meet certain income criteria. Sometimes these vouchers are targeted at particular groups that may face barriers to finding and maintaining stable, accessible, and affordable housing. Below are some of the programs targeted at individuals with disabilities. Each county differs in how it uses its vouchers and other resources. Ask your county House Authority or agency that administers supportive housing programs how it is using the vouchers or programs listed below and if a young adult with disabilities discharging from the child welfare system would be eligible for any existing programs.

 1. Section 811 Supportive Housing for People with Disabilities
In this program, funds are provided to housing developers or service providers to develop housing for disabled individuals and to cover rental subsidies.
 2. Permanent Supportive Housing for Homeless Individuals with Disabilities and Shelter Plus Care
While these funds are targeted at individuals with disabilities, eligible persons must also be homeless. Some county child welfare agencies have partnered with their housing authority to provide housing vouchers or subsidies to families and youth aging out who are at risk of becoming homeless and have a disability. Check with the child welfare agency in your county to see if it has vouchers or subsidies that youth who are aging out who have disabilities could use.
 3. Family Unification Program Vouchers (FUP)
These are housing vouchers that can be used for youth aging out of the child welfare system who are under age 21. Check to see if your county child welfare agency has access to these vouchers.
- Personal Care Homes. Personal care homes are group facilities that provide shelter, meals, and supervision for individuals with physical, behavioral health, or cognitive disabilities who cannot care for themselves. Individuals who are eligible for personal care homes need help with daily living tasks such as eating, drinking, bathing, meeting hygiene needs, and taking medications. Personal care homes do not provide medical and nursing care. Personal care homes can be small scale or very large. Some personal care homes accept SSI as payment for providing care. These facilities are licensed and inspected by the Department of Public Welfare. Personal care homes are likely not a preferred living setting for a young adult and other alternatives should be exhausted before opting for such a plan. If personal care homes are being explored, it is recommended that the planning team work with the youth to research and visit personal care homes to make sure the facility chosen is the right fit. Given the wide range of facilities, it is important to spend some time doing the research. The Department of Public Welfare has a Personal Care Homes Directory that can help you

start the search: <http://www.dpw.state.pa.us/searchforprovider/pchdirectory/index.htm>. Finally, see DPW's Personal Care Home Frequently Asked Questions for more information on personal care homes and what to ask and look for when you are doing research, which can be found at: <http://www.dpw.state.pa.us/fordisabilityservices/personalcarehomeinformation/personalcarehomefrequentlyaskedquestions/index.htm>.

For questions about this guide or for more information, contact Juvenile Law Center at (215) 625-0551 or visit our website at www.jlc.org.

