

Transition Planning

for Youth with Disabilities

from the
Child Welfare System to Adulthood:

A Guide for Professionals



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. The author, Juvenile Law Center Supervising Attorney Jennifer Pokempner, gives special thanks to 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**

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Introduction

While many youth with disabilities face challenges as they make the transition to adulthood from the child serving system, youth in the child welfare system are particularly vulnerable to poor outcomes. Youth in the child welfare system have many and multiple health and other special needs. For example, research shows that:

- 35–50 percent of children entering foster care have significant emotional and behavioral health problems;
- 20–60 percent of young children entering foster care have a developmental disability or delay;
- 25 percent of children entering foster care have three or more chronic health conditions.¹

Particular attention to this population is needed because youth with disabilities are over-represented in the child welfare population and more likely to be maltreated than their non-disabled peers. Once in the child welfare system, youth with disabilities face outcomes that are even poorer than those of their peers in foster care. Compared to nondisabled peers, youth with disabilities are:

- More likely to be maltreated while in the system
- More likely to have placement instability
- More likely to be institutionalized
- Less likely to achieve permanency including reunification, guardianship, and adoption
- More likely to stay in foster care longer
- More likely to have poorer educational outcomes²

Youth with disabilities in foster care also face additional challenges because many do not have a parent or caregiver to help them navigate this transition and advocate for them to make sure they get the services they need. Many of these youth rely on systems, caseworkers, and changing caregivers to meet their needs. Their status as youth in out of home care—rather than in the care of their parents—puts them at greater risk for being lost between the cracks of the child welfare system and between the child and adult serving systems. For this reason, planning for these youth requires increased attention and scrutiny if the transition to adulthood is to be successful.

This Guide is intended to give professionals working with youth with disabilities in the child welfare system tools to guide their transition planning and information about the resources, benefits, and systems with which these youth need to connect to successfully transition. To meet requirements under state and federal law, child welfare professionals must know how to obtain needed services for youth with disabilities while they are in the child welfare system. This will ensure that they are prepared for adulthood *and* know how to access services and supports in the adult system, making the transition from the child welfare system as smooth as possible.

¹ Laurel K. Leslie *et al.*, *Comprehensive Assessments for Children Entering Foster Care: A National Perspective*, 112 *Pediatrics* 134 (2003).

² *Forgotten Children: A Case for Action for Children and Youth with Disabilities in Foster Care* 5 (Children's Rights & United Cerebral Palsy 2006) (summarizing the research) available at: <http://www.childrensrights.org/policy-projects/foster-care/children-with-disabilities-in-foster-care/>.

This Guide is divided into two sections. The first section outlines the types of treatment and services that a youth with disabilities should receive while they are in the child welfare system; the aim is that they develop the skills and competencies as well as the relationships and connections that they need to be in a good position to transition to adulthood. Many youth are unnecessarily placed in institutions and overly restrictive programs that neither comply with the child welfare and disability laws for least restriction and community integration, nor meet their well-being and transition needs. This section will highlight what the law requires as well as strategies for accessing services and supports.

Section Two focuses on the transition from the child welfare system to the adult world and systems of care. Specifically, this section describes some of the key benefits, programs, and services that youth with disabilities can access as they make the transition to adult systems that function very differently from the child serving systems. Unlike many benefits in the child serving world, many programs for adults with disabilities are not entitlements, and thus establishing eligibility may not mean immediate access. For this reason, and many others, the planning for the transition to adulthood for youth with disabilities must begin early and must be concrete. We must work together and with youth to specifically identify the service or support needed, how it will be paid for, and then navigate and allocate responsibility preparing the application and subsequent actions. Section Two covers benefits and services for once a youth *leaves* the child welfare system, with one exception: Supplemental Security Income (SSI) is a benefit that youth can receive while they are still in the child welfare system. SSI is a cash assistance benefit for individuals who have low or no income and have a disability. Accessing this benefit for transitioning youth is often crucial to filling in the gaps of an acceptable transition plan. For several reasons related to income eligibility that will be discussed below in Section Two, few youth actually receive SSI while they are still in care. There are situations, however, in which applications can and should be made.

We conclude this Introduction with a disclaimer. This Guide is written by lawyers, not experts in physical or behavioral health. The information contained in this Guide is based on our research and experience working and planning with youth with disabilities who are transitioning from the child welfare system. In all questions of treatment and medical necessity, we defer to the health professionals. To the extent that we discuss specific types of services or treatments, it is not to speak to their clinical appropriateness in specific cases. Instead, our goal is to equip professionals and advocates with tools so that they can play an active role in ensuring that youth receive treatment and services that match their needs. Similarly, many organizations have expertise in understanding and accessing health care services and services for individuals with disabilities. This Guide utilizes this expertise and refers readers to many helpful publications and resources. Our goal is to highlight and address planning and service access issues that have a particular impact on transitioning youth due to their special status as youth in the child welfare system. We also have tailored this Guide to introduce the nuts of bolts of the adult serving system to professionals and advocates who are most familiar with the child serving system.

SECTION ONE: IMPROVIDING TRANSITIONS BY ENSURING APPROPRIATE SERVICES, PLANNING AND TREATMENT WHILE IN THE CHILD WELFARE SYSTEM

One of the best ways we prepare youth with disabilities in the child welfare system for a successful transition is by meeting their needs while they are in that system. Ideally, we improve their transition by returning them to their family, or finding them a family that will support and guide them as they grow into adulthood. If we cannot find family for the youth, we must do a better job of developing their skills and competencies while they are in the system and helping them form supportive relationships. This section outlines the child welfare agency’s obligations to youth in the system, highlighting those services, supports, and legal guarantees which should be leveraged on their behalf. These include quality treatment services that help them develop their capacities; placements in the community that allow them to develop and practice their independent living skills and form supportive relationships; and case planning.

A. Placements and Permanency

Connecting youth with family, caring adults and community supports is sometimes overlooked for youth who have complex health and other special needs. Youth in care are entitled to have their treatment and well-being needs met and to have permanency and family. All youth need and deserve family and connections with the community and a support system. Youth with disabilities especially benefit from these connections because they can provide support, consistency, and knowledge as a young person navigates and accesses benefits and services.

What obligations does the child welfare agency have to a youth to prevent removal from their family’s home?

The child welfare system’s goal is to keep families together and children safe. The children and youth agency has an obligation to work with a youth’s family so that they can safely care for their children. As the federal regulations make clear, the “safety and well-being of children and of all family members is paramount. When safety can be assured, strengthening and preserving families is seen as the best way to promote the healthy development of children.”³ Specifically, the child welfare agency must make reasonable efforts to prevent a child from being removed from the home *and* to return the child home if they are removed.⁴

What constitutes reasonable efforts depends on the specific needs of the family. That means that if meeting the youth’s needs is part of 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.

³ 45 C.F.R. § 1355.25 (a) (principles of child and family services).

⁴ 42 U.S.C.A. § 671(a)(15) (requirements for state plan for foster care and adoption assistance); 42 Pa. C.S.A. § 6351(b) (required pre-placement findings); 55 Pa. Code § 3130.12(c) (responsibilities of the county children and youth agency).

What are examples of services that the child welfare agency may provide to a family to help care for a youth with a disability?

Examples of services that may be provided to help a family safely care for a youth with disabilities could include:

- Assisting the family access health insurance for the child
- Assisting the family in identifying and accessing the appropriate treatment providers
- Assisting the family in appealing denials of treatment under the health insurance plan
- Referring the parents to parent support groups and other groups to obtain support and learn advocacy skills so that they can navigate systems of care on behalf of their child
- Assisting the parents in accessing training and support in how to meet their child's health and other needs
- Assisting the family with finding resources or providing funding to make a home wheelchair accessible
- Assisting the family in accessing cash assistance benefits programs such as Temporary Assistance to Needy Families (TANF), Supplemental Security Income (SSI), or food stamps (SNAP)
- Assisting the family with accessing educational advocacy to ensure that the youth is receiving appropriate educational services
- Assisting the youth in accessing after school programs and recreational activities

The most effective services are customized to meet the family's exact needs and are informed by input from the parent and child involved. Agencies that can help identify services and supports for families caring for youth with disabilities in Pennsylvania include:

- Disabilities Rights Network: 1-800-692-7443
- The Special Kids Network: 1-877-986-4550

The managed care organizations for the provision of physical⁵ and behavioral health services for individuals covered by Medical Assistance have Special Needs Units that can provide information and assistance.⁶ Contact these units to understand the array of services that can be provided to the youth and the family.⁷ In addition, the Mental Health Association in Pennsylvania and Pennsylvania Mental Health Consumers' Association (PMHCA) provide information and assistance regarding behavioral health services through Behavioral Health Navigators. They can be reached by calling 717-346-0549 or 1-866-578-3659, extension 2 or by emailing navigator@mhapa.org. Finally, many state and local organizations provide information and assistance to individuals and families with certain disabilities.

⁵ Health Choices is the managed care organization for physical health for the majority of individuals in Pennsylvania who have Medical Assistance. To find out more about managed care organizations for the various counties and enrollment in health plans, see <http://www.enrollnow.net/PASelfService/home.html>.

⁶ For a list of the Special Needs Units by MCO see this link: http://www.dpw.state.pa.us/ucmprd/groups/webcontent/documents/communication/s_002108.pdf

⁷ A list of some of the most common behavioral health services for youth is discussed below.

Child Welfare System Basics: Tips for Advocacy

- If a child is removed from the home and the court becomes involved in the case, under Pennsylvania law, both the parents and the youth are entitled to representation by a lawyer.
- Parents and youth should work with their lawyers to provide effective advocacy in and out of the courtroom to ensure that the family and child's needs are met and that their voices are heard.
- Planning meetings (permanency, family service and individual service planning meetings) and court review hearings are good times to present issues and requests for services and actions to be taken.
- The juvenile court judge has the authority to order treatment and services that are in a child's best interest and meet their special needs. This includes a broad array of services and supports.

If the child cannot safely remain in the home of his or her parents or be returned to that home, what obligation does the child welfare agency have to help the youth find a family?

If a child who has been removed from his or her family cannot safely return home, the child welfare agency must make efforts to find the child an alternative permanent family.⁸ All planning for youth in the child welfare system includes the development of a permanency plan. While the concept of permanency can be complicated, simply put, a permanency plan is a plan for providing a family environment for the child with caring adults who will nurture and support the youth as he or she grows up *and* makes the transition to adulthood.

The law requires that youth be placed in the least restrictive, most family like placement.⁹ The preference is for a setting that provides "family" and has legal permanency as well. Under federal law,¹⁰ the hierarchy for child welfare permanency planning is the following, in descending order:

- Reunification with parents
- Adoption
- Legal guardianship¹¹

⁸ 45 C.F.R. § 1356.21 (b)(2) (judicial determination of reasonable efforts must be made to finalize the permanency plan); 42 Pa. C.S.A. § 6301(b)(1) (the purpose of the child welfare agency is to "preserve the unity of the family whenever possible or to provide an alternative permanent family when the unity of the family cannot be maintained.").

⁹ 42 U.S.C.A. § 675 (5)(A) (the case plan for the youth must provide the least restrictive, most family like setting where the youth's needs can be met).

¹⁰ 45 C.F.R. § 1356.21(h)(3) (to adopt an alternate plan or APPLA, instead of reunification, adoption, legal guardianship, or permanent placement with a fit and willing relative, the title IV-E agency must document to the court the compelling reason for the alternate plan).

¹¹ In Pennsylvania, this permanency arrangement is often referred to as Permanent Legal Custodianship (PLC). In this arrangement, an individual takes legal guardianship of the youth and is empowered to make many of the legal decisions that a parent would. For PLC to occur, however, a parent's rights do not need to be terminated, and visitation and contact with the biological family can continue. When a PLC arrangement occurs, the child welfare case is closed; the court no longer reviews the case and there is no children and youth caseworker assigned to the

- Placement with a fit a willing relative¹²
- Another Planned Permanent Living Arrangement

Because placement with family in a legally assured arrangement is the preference, the law does require that if the permanency plan for the youth is going to be Another Planned Permanent Living Arrangement (APPLA), the judge that reviews the case must find that compelling reasons exist to rule out the other preferred plans.¹³

Far too often older youth and youth with disabilities are assigned the permanency plan of APPLA. This should not be case. APPLA as a plan should be rare. Being an older youth or having a disability should not be considered a compelling reason to rule out the other plans. If a youth does have the permanency plan of APPLA, at the very least that plan should contain a stable living setting where the youth’s health and well-being needs are met, as well the identification of at least one supportive adult who is connected with the youth. At each court review, an APPLA plan should be scrutinized to determine if a more preferred plan can be adopted.

What services and supports are available to help find families for older youth with disabilities in the child welfare system?

The child’s permanency plan should include the goal and all the services and supports that will be provided to achieve the goal. All special or additional services that must be provided to the birth family or a new family to meet the child’s needs should be identified in the permanency plan. Please see the text box above for examples of services that may assist families caring for a child with a disability. Such services also can assist a foster family, prospective legal guardian, or adoptive resource care for a youth with a disability. Youth with disabilities have a right to family and permanency like all children in the child welfare system. Identifying what is needed to make that possible is essential to creating a permanency plan that will provide the youth with a family and meet their needs.

Other services that should be used to find individuals who are willing and able to provide permanency for a youth with a disability and can help prepare a youth for permanency include:

- Family Finding
Child welfare agencies now have the technology to do sophisticated and comprehensive searches for a youth’s family members. Once family members are identified, there is still much work to be done in assessing their appropriateness and willingness and ability to care for the youth. Family finding has been very successful in opening up permanency options for youth and should be considered for all youth in the child welfare system who

case. The family may be eligible for a subsidy from the children and youth agency as well as Medical Assistance for the youth.

¹² This often takes the form of kinship foster care. However, relatives can also adopt a youth or become a permanency legal custodian.

¹³ 45 C.F.R. § 1356.21(h)(3) (to adopt an alternate plan or APPLA, instead of reunification, adoption, legal guardianship, or permanent placement with a fit and willing relative, the title IV–E agency must document to the court the compelling reason for the alternate plan).

are seeking connections with family and have not found permanency. It is important to note that law was recently amended to require that the child welfare agency conduct family finding for all youth in the child welfare system at least annually until the youth leaves the child welfare system.¹⁴

- Child Profile
This is a comprehensive review of the youth's history, including placement and treatment history. It can be helpful in clarifying the youth's needs and also can assist in identifying permanency resources that have not yet been considered, such as a former teacher, coach, or caregiver.
- Child Specific Recruitment
This is a service that works to locate and identify adoptive and permanency resources that meet a specific youth's needs. Child Specific Recruitment can be very effective for finding permanency resources for youth with disabilities.
- Permanency Preparation
This service can be used to provide a transition to permanency for the youth and permanency resource (adoptive parent or guardian). It can ensure that all plans for services and supports are clearly in place prior to finalizing the permanency plan.
- Post Permanency Services
These are services that can be provided to a youth and family after permanency is achieved. They can be very helpful in ensuring a stable and smooth adjustment from the child welfare system to permanency. The services can include counseling, referring for community services, and other supports.

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, advocates can utilize a new law in Pennsylvania—Act 115—to ensure that youth with disabilities have connections to family.¹⁵

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

¹⁴ 62 P.S. § 1302.1 (family finding required). This law, Act 55, amended the Public Welfare Code and took effect on September 9, 2013.

¹⁵ 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).

prevent joint placement. For example, because medical foster care providers are also licensed foster care providers, such a placement could accommodate both siblings.

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.¹⁶ 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.

How can you make sure the services described above are provided to youth with disabilities in the child welfare system?

Requests for services should be made directly to the county child welfare agency that is responsible for the youth. All counties should provide the services listed above. (Note that some may be referred to by different names than those used in this Guide.). You also can call the Statewide Adoption and Permanency Network (SWAN) at 1-800-585-SWAN (7926) to find out more about services and how to access them.

If you face barriers to accessing these services, make a request to the juvenile court judge in the case. As discussed above, the child welfare agency has a legal obligation to make reasonable efforts to provide permanency to all youth in its care. The services listed above—in addition to others—are examples of what it takes to meet the reasonable efforts requirement to achieve permanency. A judge has the authority under the Juvenile Act to order such services to ensure that permanency is achieved and the youth's well-being needs are met.¹⁷

How long does the obligation to achieve permanency for a child in the child welfare system last?

This important obligation lasts as long as the youth is in the child welfare system or until permanency is achieved. This can be until the youth is age 21. Under federal law and regulation, the children and youth agency has a continuing obligation to make reasonable efforts to finalize the permanency plan of the youth.¹⁸ A youth is never too old to be a member of a family, and adoption can occur at any age. Some youth misunderstand what adoption would mean for continuing their connection to their biological family. Time should be spent on

¹⁶ 42 Pa. C.S.A. § 6351 (b.1) (setting out visitation between child and his or her sibling).

¹⁷ Under the Juvenile Act, the court has the authority and obligation to order a disposition (placement, services, and supports) that is "best suited to the safety, protection and physical, mental, and moral welfare of the child." 42 Pa. C.S.A. § 6351(a). *See also In the Interest of Tameka M.*, 580 A.2d 750, 755 (Pa. 1990) (reiterating that the juvenile court judge has plenary jurisdiction to order a disposition that meets the youth's needs, including his or her treatment needs).

¹⁸ 45 CFR § 1356.21(b) (establishing that the title IV-E agency must make "reasonable efforts" to keep a family together as long as the child's safety in the home is assured, and setting the standard for determining reasonable efforts).

explaining to the youth permanency and how it can be achieved.¹⁹ Youth should be made aware of all options—such as post-adoption voluntary contact agreements²⁰ that make connection with biological family an option—before saying no to permanency.

What financial benefits or other supports are available for families that want to provide permanency to older youth with disabilities?

The following may help support a youth and family interested in adoption or permanent legal custodianship:

1. Adoption and Permanent Legal Custodianship Subsidies
Subsidies are provided to families that adopt or enter into permanent legal custodianship arrangements for youth in the foster system. The subsidy is in the form of financial assistance provided to the family to help with the cost of care. The family negotiates the amount with the child welfare agency, but it cannot exceed the amount the family received as a payment for providing foster care. The youth also receives Medical Assistance (MA). Under a new state law—Act 80—if the adoption subsidy or permanent legal custodianship subsidy begins when the youth is age 13 or older, it can now continue until age 21 (rather than age 18).²¹
2. Independent Living Services and Education and Training Grants
If the youth was in foster care at age 16 or older and then left to adoption or permanent legal custodianship, the youth is eligible for Independent Living Services and the Education and Training Grant. Independent Living Services (which are discussed in detail below) include instruction in life skills, financial management, preparation for college and work, among other things. The Education and Training Grant provides youth up to \$3000 a year in financial assistance for postsecondary education and training.
3. Independent Student Status for the Purposes of Financial Aid for Postsecondary Education and Training
If a youth was in foster care at age 13, he or she is considered independent for the purposes of assessing eligibility for financial aid under the Free Application for Federal

¹⁹ In the summer of 2013, the Statewide Adoption Network released a video that profiles several older youth interested in being adopted. This video, which includes a 20 year old young woman with physical disabilities, provides a great tool to open up the discussion of older youth adoption and permanency. This video can be found at https://www.facebook.com/adoptpa?v=app_601735633191973&app_data=gaReferrerOverride%3Dhttp%253A%252F%252Fwww.facebook.com%252Ffl.php%253Fu%253Dhttp%25253A%25252F%25252Fa.pgtb.me%25252FqK17sg%2526h%253DiAQFahfX4%2526s%253DI.

²⁰ 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.

²¹ 62 P.S. § 1302 (setting out definition of eligible child). For more information about the adoption and permanent legal custodianship subsidies under Act 80 see Juvenile Law Center's Fostering Connections PA website at: <http://www.jlc.org/fosteringconnections/legalresources>.

Student Aid (FAFSA).²² To be eligible for federal student aid, such as a Pell grant, the FAFSA must be completed. In addition, state aid program and post-secondary programs require that the FAFSA be completed to determine eligibility for state and institution based financial assistance. The amount of aid an independent student is eligible for is based solely on his or her own income, not that of a parent or caregiver. As long as the youth was in foster care at age 13, he or she is considered independent even if the youth then exited the system to adoption, permanent legal custodianship or some other permanency arrangement.

What obligations does the child welfare agency have with respect to placement?

Federal law requires that states have a case review system in place to ensure that each youth has a case plan designed to achieve placement in a setting that is:

- the least restrictive,
- most family like,
- consistent with the youth's best interests, and
- meets the youth's special needs.²³

Consistent with the permanency obligation, youth are entitled to be placed in the least restrictive, most family-like setting available. For a child to be removed from the home, the court must find that he or she is in the least restrictive placement that meets his or her needs and that there is not a less restrictive alternative.²⁴ This means that youth should be placed with a family (extended family, a foster family, or an adoptive family) or in a family-like home rather than a group home or institution. The law requires that the youth's family be notified within 30 days of him or her being removed from the home, and gives preference to placement with family and kin.

Family Foster Care or Kinship Foster Care²⁵ is the least restrictive placement type for a youth who is placed in the child welfare system.²⁶ Family foster care is regulated under 55 Pa. Code § 3700. It is important to remember that youth can receive an array of treatments and services deemed medically necessary through their health insurance while they are living in a foster home, including treatment, nursing service, and equipment. Receiving these services often can help stabilize and make a placement possible. If a youth is denied a treatment or services through his or her health insurance, it should be appealed.

In addition to ensuring that youth receive all medical and other services guaranteed to them based on the federal Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)

²² 20 U.S.C.A. 1087vv(d)(1)(B) (an independent student includes an individual who "is an orphan, in foster care, or a ward of the court, or was an orphan, in foster care, or a ward of the court at any time when the individual was 13 years of age or older").

²³ 42 U.S.C.A. §675(5)(A) (Federal Payments for Foster Care and Adoption Assistance).

²⁴ Juvenile Court Rule 1514 (Dispositional Finding Before Removal from Home), available at: <http://www.pacode.com/secure/data/237/chapter15/s1514.html>.

²⁵ A formal kinship care placement is a licensed foster home provided by family or kin.

²⁶ A youth can be adjudicated dependent and under court supervision and remain in the home of his or her parents. This is clearly least restrictive and an ideal setting. The discussion above begins with the least restrictive setting once a youth is removed from the home and placed by the child welfare system.

requirement,²⁷ family foster care can be enhanced or specialized to meet the special needs of certain youth. Here are a few examples:

Medical Foster Care. Medical Foster Care is provided for youth with medical needs to allow them to stay in the community rather than in institutional care. It can be provided by a county or private child welfare agency that is licensed to provide family foster care.²⁸ These agencies must also become enrolled with the Office of Medical Assistance Programs (OMAP) as providers of medical foster care service so that they can bill Medical Assistance for the services.

Medical foster care services do not replace the medical services that a youth is eligible for through his or her Medical Assistance coverage—such as nursing care and other prescribed treatment. Instead, medical foster care services provide support, training, and care in the home to help maintain the living setting. Examples include: teaching foster parents how to operate and maintain medical equipment; teaching foster parents about feeding techniques and the use of feeding tubes; and assisting youth with personal care needs and hygiene.

To be eligible for medical foster care services, the youth must have a chronic medical condition or physical disability that a doctor determines requires medical foster care services so that the child may remain in a foster care placement that is less restrictive than an institution or hospital. Currently, four levels of medical foster care services are available depending on the child's level of need. This ranges from youth with fairly limited needs to youth who require intensive interventions, monitoring, and care. The four levels are:

Therapeutic Foster Care (TFC)

TFC is usually provided to youth who have mental health or behavioral health needs. In these settings, foster parents have special training to work with special needs youth, and targeted services are provided to the youth and family. TFC can be funded through the youth's Medical Assistance coverage when it is determined to be medically necessary. When TFC is funded by the youth's MA coverage through the behavioral health system, it is referred to as a Community Residential Rehabilitation (CRR) Host Home.²⁹ Most county child welfare agencies also fund TFC programs to serve youth who need and would benefit from the service, but do not meet medical necessity. If this is the least restrictive and most family like setting that meets the youth's needs, it should be

²⁷ 42 U.S.C. § 1396d.

²⁸ Currently, the details of how medical foster care services are provided, what can be provided, and requirements to be a medical foster care services provider are contained in a Special Transmittal issued by the Department of Public Welfare in 1994. See Special Transmittal, *Medical Foster Care Services for Children Served by County Children and Youth Agencies* (July 1, 1994), available at: http://www.pccyfs.org/Calendar_Details/special_medical_foster_care_special_transmittal.pdf. The information contained in this section is taken from this Special Transmittal. At the time this Guide was released, several state working groups were working with the state to revise and update this Transmittal.

²⁹ State regulations for CRRs can be found at 55 Pa. Code § 5310 *et seq.* The provisions related to children are 5310.91 *et seq.* If a youth who is in the care of the child welfare agency is placed in a CRR Host Home, the provider must also follow the 3800 regulations. 55 Pa. Code § 5310. 92.

provided, and must be provided if ordered by the court, regardless of how it is funded.

Transitional Living Placement (TLP)³⁰ or a Supervised Independent Living (SIL) Placement. As a youth gets older, he or she may be placed in a Transitional Living Placement (TLP)³¹ or a Supervised Independent Living (SIL) Placement.³² TLPs often take the form of small group settings (no more than four youth). Youth in these settings are provided more freedom and responsibility and the requirements for staffing and supervision correspondingly are reduced.³³ Some have described TLP to be akin to the structure of a college dormitory setting. SIL placements offer youth in the child welfare system the maximum freedom and responsibility as they transition to adulthood. SILs tend to take the form of scatter site or clustered apartments where the youth have a good deal of independence and responsibility for their daily routines and meeting their needs. In the majority of these settings, staff does not live on site 24/7. Supervision is calibrated to the youth's needs, but the goal is to provide youth with opportunities for independent living while they still have the support and guidance of the child welfare system. These programs, however, can be designed to provide greater supervision and structure if needed. In addition, as discussed above, youth in the TLP and SIL settings can receive an array of services through their health insurance to aid in stabilizing and making it possible for them to live in these more independent settings.

Residential Treatment Center or Congregate Care. A youth may also be placed in a residential treatment center or congregate care (group homes or institutions). These placements are regulated under 55 Pa. Code § 3800 *et seq.* and are the most restrictive settings in the child welfare system. Some youth are placed in residential treatment centers by the child welfare agency and paid for with agency funds, while the majority of youth in residential treatment centers are placed there based on medical necessity and the cost is covered by the youth's MA. The majority of group home facilities are child welfare funded placements and youth are not placed there as a result of a prescription or determination of medical necessity.

³⁰ 55 Pa. Code §3800.5 (Definitions). A *Transitional living residence* is defined as a "home or living unit for fewer than five children, who are 16 years of age or older, with or without their own children, who are all able to live in a semi-independent living setting. A child's own children are counted to determine the maximum number of four children per transitional living residence." Under the regulations, the county child welfare agency is reimbursed for 80% of the cost of TLP by the state, which is the same reimbursement rate for foster family and group care. See 55 Pa. Code § 3140.22(c)-(e)(1) (Reimbursable services and reimbursement rates).

³¹ 55 Pa. Code §3800.5 (Definitions). A *Transitional living residence* is defined as a "home or living unit for fewer than five children, who are 16 years of age or older, with or without their own children, who are all able to live in a semi-independent living setting. A child's own children are counted to determine the maximum number of four children per transitional living residence." Under the regulations, the county child welfare agency is reimbursed for 80% of the cost of TLP by the state, which is the same reimbursement rate for foster family and group care. See 55 Pa. Code § 3140.22(c)-(e)(1) (Reimbursable services and reimbursement rates).

³² 55 Pa. Code § 3140.22(e)(3). *Supervised independent living service* is defined as "the provision or arrangement of living quarters and social services designed to support and supervise children who are living on their own. The child may be in the custody of the child's parents, the county agency, or another agency or individual." Under the regulations, the county child welfare agency is reimbursed for 80% of the cost of SIL by the state, which is the same reimbursement rate for foster family and group care. *Id.*

³³ The requirements for TLPs can be found at 55 Pa. Code §§ 3800.291-293.

What flexibility is available in placements for youth who remain in foster care between ages 18 and 21?

The federal Fostering Connections to Success and Increasing Adoptions Act allows states such as Pennsylvania that extend youth in care past 18 years of age to receive federal reimbursement for the cost of SIL settings.³⁴ As discussed above, these settings are age-appropriate and provide youth an opportunity to practice their independent living skills while still receiving support and guidance.

Federal guidance makes clear that states have great discretion in providing SIL placements that are eligible for federal reimbursement. The Administration for Children and Families (ACF) states that

a Title IV-E agency has the discretion to develop a range of supervised independent living settings which can be reasonably interpreted as consistent with the law, including whether or not such settings need to be licensed and any safety protocols that may be needed. For example, a Title IV-E agency may determine that when paired with a supervising agency or supervising worker, host homes, college dormitories, shared housing, semi-supervised apartments, supervised apartments or another housing arrangement meet the supervised setting requirement. We encourage the Title IV-E agency to be innovative in determining the best living arrangements that could meet an older child's needs for supervision and support as he/she moves toward independence.³⁵

The law currently allows much more room for creativity and flexibility to design placement and living settings for older youth, including those with disabilities, which are age-appropriate and meet their needs. It is likely that taking advantage of these opportunities can reduce costs of care, move youth to less restrictive placements, and allow them access to more opportunities to practice and master their independent and adult living skills.

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, but federal law also provides additional protections to ensure that they have full access to services and that those services match their needs. The Americans with Disabilities Act³⁶ and Rehabilitation Act³⁷ prohibit disability discrimination in the provision of services and require that individuals be served in the most integrative setting appropriate to their needs.

³⁴ The federal law included as a Title IV-E reimbursable setting “a supervised setting in which the individual is living independently” for youth ages 18 to 21. 42 U.S.C.A. §672(c).

³⁵ U.S. Department of Health and Human Services Administration on Children, Youth and Families, *Guidance on Fostering Connections to Success and Increasing Adoptions Act of 2008, Program Instruction*, ACYF-CB-PI-10-11 (July 9, 2010), available at: http://www.acf.hhs.gov/programs/cb/laws_policies/policy/pi/2010/pi1011.htm#sectb.

³⁶ 42 U.S.C.A. § 12101 *et seq.* (Equal Opportunity for Individuals with Disabilities).

These federal laws also require that individuals with disabilities be provided an equal opportunity to benefit from the programs, services, and activities provided by federal, state, and local government. This includes all child welfare services. Thus, similar to the guarantee in child welfare law that youth should be in the least restrictive, most family-like setting, federal anti-discrimination law also supports this principle in terms of placement and the type of services provided.

What agencies can provide information and assistance about how to address and remedy disability discrimination?

As a requirement of federal law, Protection and Advocacy Systems (P & As) are in place in each state for the following individuals:

- PADD: Protection and Advocacy for Individuals with Developmental Disabilities
- PAIMI: Protection and Advocacy for Individuals with Mental Illness
- PAIR: Protection and Advocacy for Individual Rights. PAIR provides advocacy for individuals with disabilities who do not fall in the above categories
- CAP: Client Assistance Program for individuals with disabilities receiving services related to employment and vocation under the Rehabilitation Act, such as the Office of Vocational Rehabilitation (OVR)

In Pennsylvania, the Disability Rights Network of Pennsylvania (DRN) is the P & A agency serving the first three categories of individuals listed above, including children. They have a help line that provides assistance and can be reached by calling 1-800-692-7443 (Voice); 1-877-375-7139 (TDD), or by emailing at intake@drnpa. If you are working with a youth who is placed in a state other than Pennsylvania, you can find the state P & A agency at <http://www.ndrn.org/en/ndrn-member-agencies.html>. To contact the Client Assistance Program (CAP), email info@equalemployment.org or call (888) 745-2357.

What kind of assistance can the P & A agencies provide?

In addition to providing advice, advocacy, and assistance in accessing services and benefits for individuals who are disabled, P & As have extraordinary authority to investigate concerns regarding treatment and access to services for individuals with disabilities. For example, these agencies have authority to meet with individuals with disabilities in the placements or facilities they are in when a complaint is made. They also have access to all records related to an investigation. This includes access to any placements of youth in foster care if the complaint includes a foster youth with a disability.

³⁷ 29 U.S.C.A. § 701 *et seq.* (Vocational Rehabilitation and Other Rehabilitation Services). The Rehabilitation Act prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, including Title IV-E child welfare funds. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in Title I of the Americans with Disabilities Act.

Examples of Complaints a P & A May Address Involving Youth in Foster Care

- A youth remains in a restrictive placement because there are no foster homes that can accommodate a youth who is deaf.
- A school district or residential treatment center prevents a youth from attending the community school.
- A mental health facility will not accept a youth who also has a developmental disability.
- A youth is not provided 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.

What is the relationship between providing the least restrictive setting and preparing youth for the transition to adulthood?

Older youth in the child welfare system, especially youth with disabilities, tend to be over-represented in institutional and congregate care. Sometimes this results from a lack of appropriate placements. More often, it is due to a lack of understanding of what services can be provided in less restrictive settings and the legal requirements in child welfare and disability law to create a placement and service array that meet the needs of disabled youth.

When teenagers and young adults remain in overly restrictive settings, they tend to have less access to the community and their non-disabled peers. In addition, institutional settings may not provide youth the opportunity to develop independent living skills through practice and real world experience. In general, outcomes tend to be poorer in congregate care and other restrictive settings, and best practices support utilizing community and integrative settings that “normalize” a youth’s experience. In addition, access to people and resources in the community helps youth build skills and a support network that can help them as they transition to adulthood. Finally, the successful development of independent living skills relies upon exposure to the community.

What are Centers for Independent Living (CIL) and how can they be helpful in creating appropriate placements and services for youth with disabilities?

CILs are led by individuals with disabilities and provide four core services: information and referral, advocacy, peer mentoring and independent living skills training. CILs can provide advocacy and expertise in ensuring that individuals with disabilities have full access to opportunities in the community. They are a great resource of information for concrete strategies to provide youth with disabilities opportunities for less restriction and community living. To locate the CIL in your county see this link: http://www.pcil.net/pages/cils/locate_a_cil.aspx.

Tips for Providing Age-Appropriate Opportunities in All Child Welfare Placement Settings

- Ensure that all youth 16 and older are receiving Independent Living Services.
- Use Youth Fostering Change’s Teen Success Agreement (TSA) as a guide to adjusting placement rules and responsibilities. The TSA can be found at http://www.jlc.org/sites/default/files/topic_related_docs/Teen%20Success%20Agreement%20Packet%208%2029%2012.pdf.
- Make sure youth have access to the community school and have a quality Individualized Education Plan, including a Transition Plan.
- Placements should review their program rules and policies to determine if they are age-appropriate and consider developing young adult programs.
- Advocates should request that the court order specific program adjustments and opportunities based on the youth’s age and independent and transition needs if the program will not accommodate the youth’s needs.
- Consult with the P & A and CIL agency to determine if it can provide suggestions for program adjustments or actions that can be taken to move the youth to a more appropriate placement.

B. Child Welfare Independent Living and Transition Planning Requirements

In addition to the obligations to provide permanency and the least restrictive placement setting for youth in the child welfare system, the child welfare agency also has an obligation to prepare youth for independent living and the transition to adulthood beginning at age 16 so that they are have a good discharge plan when they do leave the system. Youth with disabilities should have full access to these services—which will be described in greater detail below—even if accommodations or program enhancements need to be made to adequately serve all youth. Youth with disabilities often are excluded from these services or do not receive full access to them despite the fact that learning and practicing these skills are crucial to preparing them for adulthood. This section provides information on the legal requirements as well as strategies for accessing Independent Living and Transition Planning Services that meet the specific needs of youth with disabilities.

What are Child Welfare Independent Living (IL) Services and when must they be provided?

Beginning at age 16, the child welfare agency must provide youth with services that help prepare them for adulthood.³⁸ These are referred to as Independent Living or IL services. The law does not mandate the exact services that are provided, but examples include educational planning and support, vocational training, job readiness, job placement, budgeting, apartment searching and financial management.³⁹ Youth can continue to receive these services until they are age 21, even

³⁸ 42 USCA § 675(1)(D) (the case plan must include a written description of the programs and services that will help each child prepare for the transition from foster care to independent living).

³⁹ In 1999, the John Chafee Foster Care Independence Act (“Chafee Act”) amended the Social Security Act to increase the funding available to states to provide IL Services to older youth in foster care and those who have aged out and are under age 21. 42 U.S.C.A. § 677. The Chafee Act provides examples of the IL services states can provide as well as other requirements that states must follow in delivering services.

if they are no longer in care. Youth with disabilities in the child welfare system are entitled to these services as well. In addition, under both the Americans with Disabilities Act and Rehabilitation Act, the child welfare agency must ensure that accommodations are made so that youth with disabilities do have an opportunity to benefit from IL services.

What is an IL Plan?

An Independent Living Plan (IL Plan or Plan) is a document that sets out the IL goals and the services that will be provided to achieve the goals. It should also indicate who or what agency is responsible for providing the specific services. Some counties include this in the Child Permanency Plan (CPP). The youth must be a key participant in the creation of the IL Plan. The Plan should be created when the youth reaches age 16. However, it is recommended that IL planning begin earlier, especially for youth who may need more instruction and support.

While the goals and the services needed to meet them will be different for each youth, here are some skill areas to consider 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 health needs, including medication management, and 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 leaving care

Employment and Career

Job searching and application skills, exploring careers, selecting and applying for vocational training, job coaching and support

Education

Tutoring to assist with high school success, looking at colleges and vocational programs, SATs and ACT preparation, 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 is the Education and Training Grant (ETG) and who is eligible for it?

Under the Chafee Foster Care Independence Act, youth who were in foster care when they were age 16 or older are eligible for up to \$5000 per year to fund the cost of attendance for programs of post- secondary education and training.⁴⁰ Due to the high demand, currently eligible youth in Pennsylvania can access \$3000 per year.⁴¹ 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?

In Pennsylvania, the county child welfare agency is obligated to provide IL services to youth who are in care beginning when they are at least age 16. The agencies can provide services directly, or hire another agency or program to deliver 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 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 aftercare IL services if the youth is under age 21. Contact the IL coordinator in the county the youth currently lives 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/classroom settings. In addition to receiving IL services from a county IL program, youth should also get 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. Advocates and professionals working with youth in care should ask the youth's caseworker and caregivers how the youth is being provided with IL instruction in the home or placement. If this instruction and skills reinforcement 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, assistance should be sought from the county IL coordinator or an appropriate provider.

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

⁴⁰ 42 U.S.C.A. 677(i) (educational and training vouchers).

⁴¹ This amount is for the 2013-2014 Academic Year.

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 role does the juvenile court judge have in a youth's IL planning?

The juvenile court judge in dependency cases plays a crucial oversight role. The traditional role of the judge is to ensure that the law is being followed and that a dependent youth's needs are being met, including needs related to permanency, safety, and well-being. Beginning at least at age 16, the law requires that the judge make findings in court regarding the youth's IL needs and the services being provided to meet the youth's IL goals.⁴² At each court review hearing the judge must make specific findings and orders on the following:

- the specific independent living services or instructions that are currently being provided by the county agency or private provider;
- the areas of need in independent living instruction that have been identified by the independent living assessment;
- the independent living services that the youth will receive prior to the next permanency review hearing;
- whether the child is in the least restrictive, most family-like setting that will enable him or her to develop independent living skills;
- the efforts that have been made to develop and maintain connections with supportive adults regardless of placement type;
- 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;
- the job readiness services that have been provided to the child and the employment/career goals that have been established;
- whether the child has physical health or behavioral health needs that will require continued services into adulthood; and
- the steps being taken to ensure that the youth will have stable housing or living arrangements when discharged from care.⁴³

What is the federal child welfare transition planning requirement?

Since the enactment of the Fostering Connections to Success and Increasing Adoptions Act in 2008, federal law requires that a transition plan be developed with a youth age 18 or older at least 90 days prior to discharge from the child welfare system.⁴⁴ The law also requires that the transition plan be presented in court when the case is reviewed and that the court consult with the

⁴² 42 Pa. C.S.A. § 6351(f)(8) (“At each permanency hearing, a court shall determine ...[t]he services needed to assist a child who is 16 years of age or older to make the transition to independent living.”)

⁴³ Pennsylvania Juvenile Court Rule 1608 (D)(1)(j), available at: <http://www.pacode.com/secure/data/237/chapter16/s1608.html>.

⁴⁴ 42 U.S.C.A. § 675(5)(H) (Definition of Case Review System).

youth about the plan to ensure that the youth has fully participated in its creation and is in agreement with it.⁴⁵

The contents of the transition plan should demonstrate that the youth has a good plan for life outside the child welfare system as an adult. The plan must at least include specifics in several areas, including health, health insurance, housing, education, employment, mentoring, and support services.⁴⁶ The Affordable Care Act amended the transition plan requirement to include in the plan: “information about the importance of designating another individual to make health care treatment decisions on behalf of the child if the child becomes unable to participate in such decisions and the child does not have, or does not want, a relative who would otherwise be authorized under State law to make such decisions, and provides the child with the option to execute a health care power of attorney, health care proxy, or other similar document recognized under State law.”⁴⁷

How has the transition plan requirement been implemented in Pennsylvania?

The federal transition plan requirement has been embedded in state law at 42 Pa. C.S.A. § 6352 (f)(8.2). In addition, Juvenile Court Rules provide more detail for what must be included in a transition plan for a youth to be discharged from the child welfare system. Court Rules also require that the plan be presented and accepted by the juvenile court judge in the case before the youth can be discharged from care at age 18 or older. The purpose of Rule 1613 is to ensure that youth are not discharged without appropriate plans. This is of the utmost importance for youth with disabilities who may need to be connected with multiple agencies and be in line for needed services well before discharge.

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 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
- any other needed support services.⁴⁸

The plan must be presented to the court at a hearing at which the youth is present and at least 90 days before the youth is discharged.⁴⁹ The plan must be accepted by the court. If the plan is not

⁴⁵ 42 U.S.C.A. § 675(5)(C)(iii) (Definition of Case Review System).

⁴⁶ 42 U.S.C.A. § 675(5)(H).

⁴⁷ *Id.* Please see below for more information about health care decision making options.

⁴⁸ Pennsylvania Juvenile Court Rule 1613 (E), available at: <http://www.pacode.com/secure/data/237/chapter16/s1613.html>.

acceptable, the court *shall* not close the case.⁵⁰ Action must be taken in the form of ordering meetings, other actions or services to rectify the plan’s shortcomings.

The Transition/Discharge Hearing Tips

- Prepare the youth for participating in the hearing. Use Youth Fostering Change’s Youth Developed Discharge Hearing Form to prepare a youth. It can be found at <http://www.jlc.org/yfc>.
- If the plan is not adequate, be prepared to suggest actions that the court can order to remedy the problem with it.
- Ensure that Juvenile Court Rule 1613 is followed and that the case is not closed unless the plan is appropriate.

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

Yes. Under federal law, a youth’s health and education records should be provided to him or her at no cost when he or she discharges from care at age 18 or older.⁵¹ Youth will need these records to access various services and benefits in their adult lives. Thus, it is important to make sure that this legal requirement is enforced and that youth understand why they need their records and how to safeguard them.

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

If youth do not achieve permanency, a new law⁵²—Act 91—allows them to remain in the child welfare system until age 21 if they are engaged in 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; or
- Working at least 80 hours per month.

If a youth has a medical or behavioral health condition that prevents him or her from meeting any of the activity requirements listed above, he or she is also eligible to remain in care past age 18 as long as updated records are maintained to document the condition.

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

⁴⁹ Pennsylvania Juvenile Court Rule 1613 (E)(1), available at: <http://www.pacode.com/secure/data/237/chapter16/s1613.html>.

⁵⁰ Pennsylvania Juvenile Court Rule 1613 (E)(3), available at: <http://www.pacode.com/secure/data/237/chapter16/s1613.html>.

⁵¹ 42 U.S.C.A. § 675(5)(D) (Definitions).

⁵² Act 91 became effective in July 2012. It amended several portions of the Juvenile Act. The extension of foster care provisions are now located at 42 Pa.C.S.A. § 6302 by expanding the definition of a “child.”

Yes. Under the same new law—Act 91—a youth can re-enter foster care if certain requirements are met. A youth is eligible to re-enter if he or she:

- was discharged from care at age 17 and nine months or older;⁵³
- is still under age 21; and
- is engaged in at least one of the activities listed directly above, or cannot meet one of the requirements because of a medical or behavioral health condition.⁵⁴

Under the law, a youth re-enters foster care when the judge resumes jurisdiction of the case. That is, the judge re-opens the youth’s old dependency case; it is not a new dependency case. This new law provides youth an important safety-net that many youth raised in their own homes take for granted. If a youth ages out and then needs assistance and support, they should contact their former attorney or Guardian *ad Litem* and county child welfare agency to let them know they would like to re-enter care.

Benefits to Staying in the Child Welfare System Until Age 21

- Placement and basic needs (room, board, clothing, etc.) are met
- Case management to ensure needs are met and assistance with planning for the future, including education
- Permanency services, including child specific recruitment
- Continued legal right to visit with siblings and parents
- Court oversight of case and authority to issue orders that serve the youth’s best interest
- Legal entitlement to a lawyer (Guardian *ad Litem*) to represent and advocate for the youth
- More time to ensure 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 24 and receives significant financial and moral support from parents after age 18.

C. Meeting Physical Health and Behavioral Health Care Needs in the Child Welfare System

What obligation does the child welfare agency have to monitor and meet the health and other needs of youth in the child welfare system?

The following laws and Rules of Court impose obligations on the child welfare system to monitor the health needs of youth in its care:

- Federal child welfare law (Fostering Connections) requires that states have a plan for the ongoing oversight and coordination of health care services for any child in foster care

⁵³ This provision of Act 91 was written to target youth who “age out.” Youth who discharged from the system at a younger age are not eligible to re-enter the child welfare system under Act 91, but may be eligible for other services.

⁵⁴ 42 Pa.C.S.A. § 6351(j) (resumption of jurisdiction).

placement, including how needs will be met and for continuity of care following the transition from foster care to the adult world.⁵⁵

- Federal and state child welfare law requires that the child welfare agency monitor the health and well-being of youth in its care in the youth’s case plan and at court reviews.⁵⁶
- Federal child welfare law requires updating health and educational records in the case file and providing youth who age out a copy of their records at no charge.⁵⁷
- The federal Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) requires that certain health screenings occur at various intervals.⁵⁸ State regulation provides additional detail on the scope and timing of screening and services.⁵⁹
- State regulations require health screenings and examinations when youth enter residential placements and family foster care, and that care be provided are required intervals.⁶⁰
- Pennsylvania Court Rules require that the court make findings and orders related to any health and disability issues at every court hearing.⁶¹
- Pennsylvania Court Rules empower judges to enter orders for evaluations and treatment in certain circumstances.⁶²

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

Almost all youth in the child welfare system are eligible for Medicaid—or Medical Assistance (MA). This is comprehensive health insurance that covers all of the youth’s physical and mental health care needs. Once a youth comes into the care of the child welfare agency, the agency is responsible for making contact with the county assistance office (CAO) to apply for MA on behalf of the child.

The EPSDT program provides special protections to children enrolled in Medicaid, from birth until their 21st birthdays.⁶³ Under EPSDT, children enrolled in MA are entitled to two types of health care services:

1. A number of initial and periodic screening examinations from birth until the child’s 21st birthday; AND

⁵⁵ 42 U.S.C.A. §622(b)(15)(A) (state will develop health care plan).

⁵⁶ 42 U.S.C.A. § 675 (1)(C), § (5)(D) (health and education records); 42 Pa. C.S.A. § 6351(f) (matters to be determined at permanency hearing).

⁵⁷ 42 U.S.C.A. § 675 (5)(D).

⁵⁸ 42 U.S.C. § 1396d(r) (intervals must “meet reasonable standards of medical and dental practice, as determined by the State after consultation with recognized medical and dental organizations involved in child health care and, with respect to immunizations”).

⁵⁹ 55 Pa. Code § 1241.1 *et seq.* (Early and Periodic Screening Diagnosis and Treatment Program; Policy).

⁶⁰ *See* 55 Pa. Code §§ 3700.51 (medical appraisal must be given within 60 days of the child’s admission to foster family); 3800.141, 143, 144 (child in residential or day treatment facility must have a written health and safety assessment within 24 hours of admission; all children should receive dental care as needed, in addition to an examination and cleaning at least semiannually after age 3).

⁶¹ Juvenile Court Rule 1512 (D)(i) (the court must 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”), available at: <http://www.pacode.com/secure/data/237/chapter15/s1512.html>.

⁶² *Id.*

⁶³ 42 U.S.C. § 1396d(r) (all children are to receive early and periodic screening, diagnostic, and treatment services).

2. All medically necessary follow-up care that the child needs to:

- correct a condition discovered during the screens; OR
- lessen the condition's effects; OR
- achieve and maintain maximum functional capacity to perform daily functions.

The EPSDT mandatory screens and services that children must receive on a regular basis include but are not limited to: physical exams; developmental assessments; mental health assessments; immunizations; sickle cell screening (for African American children); vision exams; hearing exams; and dental exams and care (including preventive, restorative, and emergency care). Federal law requires each state to develop a timetable—called a periodicity schedule—of when each of these screens or services must be made available to children on MA. EPDST also requires that MA-covered children receive screens between regularly scheduled screens if there is reason to suspect that they may have a health problem.

Importantly EPSDT requires that MA-covered children receive all medically necessary services, treatment, and equipment to address any physical or mental conditions discovered during the screens. This can include a wide variety of services and equipment including:

- mental health treatment,
- substance abuse treatment,
- family planning services and supplies,
- case management services,
- transportation,
- physical or occupational therapy,
- in-home nursing services,
- personal care,
- home health services,
- prescription medication,
- augmentative communication devices,
- specialized equipment, and
- various equipment and medical supplies including diapers, eyeglasses, hearing aids and assistive communication devices.

How can you find out exactly what services are available to a youth?

Depending on what part of Pennsylvania the youth lives in, youth eligible for MA will be covered by a Managed Care Organization (MCO), which provides a health plan. It is the MCO that youth and their advocates will often deal with when trying to access services. Asking for a description of the health plan offered to the youth through the MCO and the array of services provided is a great first step to understanding the services to which youth may access. While the array of services and treatment listed do not include all that could potentially be covered by MA, it is a good starting point. In most cases, individuals have to get treatment from providers in the HMO health plan's network. However, there are exceptions to this general rule.

Assistive Technology

Assistive Technology (AT) is an item or piece of equipment or services that is used to improve a person's functioning. Examples include: wheelchairs, hearing aids, reachers, computers or software that help communication. As technology has improved, the array of devices and aids has vastly improved—especially in the areas of communication—so it is important to learn what is available. Evaluations can be done to help determine what assistive technology will work best for a youth, and training should be provided to the youth and any caregivers in how to use assistive technology.

Assistive technology can and should be used in school, at work, in the home, and the community. Professionals and advocates should make sure plans are made so that youth have access to the AT they need across various settings. For example, do not assume that the youth can take a device that is used in school to his or her home. Arrangements may need to be made for this to occur, or it may be necessary to have a second device that is paid for by the youth's health insurance for use in non-school settings. Similarly, training for caregivers must be provided for the youth to fully get the benefit of the AT. To make their services accessible to individuals with disabilities, placement and foster care providers must ensure the youth and his or her caregivers can use the AT effectively.

Assistive technology can be paid for a variety of ways. It can be funded by the school if it is in the IEP. It also may be covered by health insurance when the youth is under age 21 and through MA Waiver funding after age 18 or 21. Because AT can make a huge difference in a youth's quality of life and ability to interact with peers and in the community, making provisions for it in the IL and Transition Plans is extremely important. For more information on assistive technology and resources to help make sure youth get what they need before and after age 21, contact Pennsylvania's Initiative on Assistive Technology (PIAT) at <http://disabilities.temple.edu/programs/assistive/piat/>.

What types of services should youth with behavioral health needs receive while in the child welfare system?

A youth's behavioral health care will be delivered through an MCO that is different from the physical health MCO.⁶⁴

Because of the EPSDT requirement, youth should receive whatever services are deemed medically necessary. While there are services that all MCOs must provide because they are in the state's MA plan, optional and additional services may be provided. So it is important to find out the array of behavioral health services provided by the youth's health plan.

Below are some of the typical treatment services for youth with behavioral health needs that are likely to be available through the MCO:

⁶⁴ Use this link to find the contact information for the youth's behavioral health managed care organization: <http://www.mhapa.org/children-youth/pa-roadmap-to-help/roadmap-to-care-county-specific-resources/>.

- Case management services, including intensive case management and resource coordination
- Outpatient therapy
- Intensive outpatient drug and alcohol treatment
- School-based behavioral health services
- Behavioral health rehabilitation services (BHRS)⁶⁵
- Summer therapeutic staff support
- Evidence-based treatment such as multi-systemic therapy, functional family therapy, and multidimensional treatment foster care⁶⁶
- Partial hospitalization services
- Family-Based Mental Health Services
- Community residential rehabilitation services (CRR)⁶⁷
- Residential treatment facilities
- Inpatient hospitalization
- Crisis intervention and emergency services

For an excellent description of many of the services listed above as well as the clinical indications for each, see Gordon R. Hodas, *Making the Best Choice: Service Selection in Children's Mental Health* (Office of Mental Health and Substance Abuse Services 2004).⁶⁸ Services should always be provided in the least restrictive setting and can be provided in the youth's home to aid with reunification as well as in foster care and more independent settings such as TLP or SIL. Residential treatment should only be used in rare circumstances as a last resort and only for brief periods of time.

What is the process for requesting any treatment services?

Treatment services must be prescribed as medically necessary and authorized by the MCO. It is important to find out the MCO's specific requirements for authorization. Many behavioral health services require a psychiatric or psychological evaluation, while others also will require an Interagency Service Planning Team (ISPT) meeting. Authorization for physical health services may require Letters of Medical Necessity that explain the need for the services. It is important to understand the authorization process so that those involved with the youth's care can be included and have input, and bring appeals of denials of services as quickly as possible.

What do you do if a request for a service is denied?

⁶⁵ BHRS is often referred to as "TSS" or "wrap around." Services are provided to the youth and the youth's caregiver(s) through a team that is comprised of a behavioral specialist consultant, a mobile therapist, and therapeutic staff support. Treatment is intended to be provided in the youth's every day environment so that the youth can learn coping and other skills in the settings that he or she will confront on a daily basis. It should also include work with the youth's caregivers so that they can reinforce skills and learn constructive ways to interact with the youth. Youth are eligible for these services until age 21.

⁶⁶ The EPIS Center, run by the Prevention Research Center at Penn State University, provides research and information about various evidence-based programs and treatment that youth in care may benefit from. See <http://episcenter.psu.edu/ebp/ART>.

⁶⁷ There are two levels of CRRs: small group homes and host homes, which resemble therapeutic foster care.

⁶⁸ This document can be found at: http://www.parecovery.org/documents/Hodas_Best_Choice.pdf.

If a request for a service is denied, the denial should be made in a formal written notice, which provides instructions for how to appeal the decision. For appeals of a denial of services or a decision to terminate or reduce services, it is recommended that both of the following actions be taken:

- Request a Fair Hearing with the Department of Public Welfare within 30 days.⁶⁹
AND
- File a grievance with the MCO within a time frame mentioned in the notice—usually 45 days.

While the appeal is being decided, it also is recommended that additional information, evaluations, and Letters of Necessity be submitted to the MCO and that the prescribing physician consult with the Office of Medical Assistance Programs. For more detail about the appeal, complaint and grievance process, see David Gates, *Appealing Medical Assistance or Waiver Denials (or Don't Take No for an Answer)* (Pennsylvania Health Law Project), available at http://www.pahomecare.org/files/live/Appeals_PPT.pdf.

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

Who can file an appeal or grievance?

The youth,⁷⁰ the parent or guardian of the youth if they are under age 18, someone who has power of attorney, or the service provider with the youth's authorization. It is recommended that the youth's lawyer or advocate assist him or her in filing an appeal or grievance if there is not someone else authorized to do so.

Why is trauma informed treatment and care important?

Trauma informed treatment and care is important because many youth who are in the child welfare system have witnessed traumatic events.⁷¹ While removal from the home and placement in care is traumatic in itself, many youth in foster care have been exposed to multiple traumatic events before entering the child welfare system. In many cases, the symptoms of this exposure are addressed in treatment without confronting the root cause. Making sure a youth's treatment is trauma informed is important, especially in cases in which he or she is not making progress in treatment. Some individuals who have been exposed to trauma exhibit behaviors that can limit their chances of successful social and other interactions. Examples include: hyper-vigilance that can result in overreacting or aggressive behavior, and reluctance to trust individuals, which can

⁶⁹ If an appeal is of a reduction or termination of services is made with 10 days, the services will continue pending the appeal.

⁷⁰ Youth can appeal or file a grievance even if they are under age 18. This is because the individual in whose name the benefit is sought is always among the category of individuals who can appeal, complain or grieve.

⁷¹ There is much research and data on the high numbers of youth who have been exposed to trauma who end up in the child welfare system. For example, it is reported that more than 21% of foster youth alumni suffer from PTSD, which indicates that their trauma issues were not adequately addressed while in the system. See Paul J. Pecora *et al.*, *Improving Family Foster Care: Findings from the Northwest Foster Care Alumni Study* (2005), available at http://www.casey.org/resources/publications/pdf/improvingfamilyfostercare_es.pdf.

lead to a difficulty in forming and keeping healthy relationships. Addressing these issues is important to meeting the youth's behavioral health needs, but also to ensuring that the youth is successfully able to develop independent and adult living skills.

What questions can I ask to tell if a treatment or service is trauma informed?

- Ask if the placement and/or the treatment provider is certified in the Sanctuary Model. The Sanctuary Model⁷² is a trauma informed model of organization, treatment, and care pioneered by Dr. Sandra Bloom. To identify facilities that are certified, click on this link: http://www.parecovery.org/services_trauma_informed_care.shtml#sanc.
- Ask about the type of therapeutic intervention that is being provided to the youth. Some of the common types of treatment for trauma for adolescents and youth include:
 - Trauma-focused cognitive behavioral therapy (TF-CBT)
 - Attachment self-regulation, and competency therapy (ARC)
 - Structured Psychotherapy for Adolescents Responding to Chronic Stress (SPARCS)⁷³
- Ask if the youth's caregiver has implemented any strategies to constructively address behaviors that may be resulting from unaddressed trauma.

⁷² To find out more about the Sanctuary Model in Pennsylvania see [Pennsylvania Children and Adolescent System Services Program Newsletter \(2009\) 18\(1\): 1-8](#), available at: http://www.sanctuaryweb.com/PDFs_new/CASSP%20Newsletter%20Creating%20a%20Sanctuary%20for%20Trauma-informed%20Care%20CASSP.pdf.

⁷³ For more information about the treatments listed see: *Trauma Focused Cognitive Behavioral Therapy (TF-CBT)* (National Child Traumatic Stress Network 2007), http://www.nctsn.org/nctsn_assets/pdfs/promising_practice_sheet_3-20-07.pdf; *ARC: Attachment, Self-Regulation, and Competency: A Comprehensive Framework for Intervention with Complexly Traumatized Youth* (National Child Traumatic Stress Network. 2008), http://www.nctsn.org/sites/default/files/assets/pdfs/arc_general.pdf; *Structured Psychotherapy for Adolescents Responding to Chronic Stress (SPARCS)* (National Child Traumatic Stress Network 2007), http://www.nctsn.org/nctsn_assets/pdfs/promising_practices/SPARCS_fact_sheet_3-21-07.pdf.

Addressing Trauma and the Development of Adult Living Skills

Exposure to trauma affects not just a youth's mental health and how he or she feels, but also his or her ability to successfully function in the adult world. Siena was diagnosed with depression and oppositional defiant disorder. She was in outpatient therapy and was not making much progress. At age 18, she still easily got in fights at school and at her group home. She continued to lose jobs because she overreacted to any criticism of her employer and had great difficulty interacting with customers in most of her retail jobs. In response to the problems at school, Siena's education decision maker (EDM) did a full review of her child welfare and mental health records and realized that Siena had a significant trauma history that had never really been addressed.

The EDM worker asked that the youth's IEP be revised to include job coaching to help Siena learn coping and conflict resolution skills on the job, as well as role playing job and community situations that may be stressful for Siena. Siena's case worker also requested that Siena receive trauma-focused cognitive behavioral therapy. She asked the group home staff to work with the new therapist and Siena to create a plan so that the coping skills that Siena was learning could be reinforced in the group home, and so that staff interactions with Siena could take into account her trauma history and triggers. With these services and supports, Siena was able to maintain a job and establish a good relationship with her employer. She has made progress in therapy and has also begun trauma art narrative therapy. Taking into account a youth's trauma history and addressing it in treatment, programming, and interactions can sometimes result in a breakthrough for a youth that allows him or her to succeed in many areas.

What can I do if the youth is not receiving services that seem appropriate or effective?

How a youth progresses in treatment and what progress looks like will depend on the individual youth and his or her condition or impairments. Some youth will need treatment or services in certain areas for the rest of their lives, while others need to address specific issues or stabilize their conditions with a certain type of treatment. Because of these differences, to be able to gauge progress, it is important to understand from the treatment provider the goals of treatment. Below are some actions to take if the youth is not making progress with the treatment after a reasonable period of time, or if you believe additional or different treatment or services should be considered:

- Ask for specific information about the type of treatment the youth is receiving and the barriers to progress to help determine if another service or treatment should be tried. Certain treatments may not work well given a youth's special needs. For example, a youth who has verbal and communication delays may not do well with psychotherapy that focuses on only verbal communication. Some youth may benefit from non-traditional treatment modalities, such as trauma art narrative therapy and equine therapy.

- Do some research about evidence based and best practices. It is helpful to know as much as you can about the treatment and service the youth is receiving and the array of available services. The information provided in footnote 66 provides a starting point for information on evidence-based and best practices.
- Get feedback from the youth and people who are important to the youth about the challenging behavior or issues and their views about treatment. Do not be afraid to ask youth about what they think of the treatment they are receiving and what they think would be most helpful. This feedback can be very useful in identifying treatment and service options and potentially improving the way an existing service is being delivered. Individuals who do have a positive relationship with the youth—teachers, mentors, family—are also great resources of information about what works.
- Contact the Special Needs Unit and Consumer and Family Satisfaction Team at the MCO.⁷⁴ The Special Needs Unit at each MCO has a great deal of expertise to help access services within and outside of the MCO. Staff at the Special Needs Unit have specialized training and often have access to higher level decision makers at the MCO. The Consumer Satisfaction Teams can help navigate the system and assist with complaints and other concerns.
- Contact the Regional Offices of OMHSAS.⁷⁵ The Regional Offices receive complaints about the provision of services and concerns about access to the most appropriate services.
- Get help from experts in the field. Talk to behavioral health professionals about the issues you are facing to get recommendations. In addition to contacting the CASSP coordinator for assistance (see directly below for more on this), there are multiple organizations that can be helpful. Here are just a few:
 - Disability Rights Network of Pennsylvania: 800- 692-7443
 - Mental Health Association of Pennsylvania: 717-564-4930, ext. 112
 - Pennsylvania Health Law Project: 800-274-3258

What is a Child and Adolescent Service System Program (CASSP) Coordinator and how can they help ensure that youth in the child welfare system receive the right treatment services?

Each county has a CASSP coordinator whose role is to understand how the children’s behavioral health system works in their respective counties and to serve as a resource to family members,

⁷⁴ You can find the contact information for the MCOs at:
http://www.dpw.state.pa.us/ucmprd/groups/webcontent/documents/communication/s_002108.pdf.

⁷⁵ Use the following link to find the contact information for OMHSAS Regional Office:
<http://www.dpw.state.pa.us/helpfultelephonenumber/regionalmentalhealthsubstanceabusefieldoffices/index.htm>.

providers, and advocates. CASSP coordinators are great resources for information and treatment planning. A list of CASSP coordinators can be found at the following link: http://www.parecovery.org/documents/CASSP_Coordinators_Current.pdf. They can help with figuring out what treatment services are most appropriate for a youth, how to access services, and how to coordinate with the various systems involved in the youth's life.

What is the Complex Case Planning Process and when should it be used?

This two-step process was set up by the Department of Public Welfare⁷⁶ to address complicated cases in which at least one of the following criteria is met:

- The clinically appropriate solution requires support from multiple program offices/agencies or stakeholders at the county level who together cannot agree on a solution.
- The funding solution comes from multiple sources, which may include external entities.
- The case involves complexities that render it unresolvable through the established county or Regional Office process.

To use this process, you first must contact the Regional Department of Public Welfare Office and ask for assistance with planning. The Regional Office—in collaboration with the State Coordinating Teams—should assist in coordinating individuals and agencies at the county level to ensure that all efforts at the county level have been exhausted. If the Regional Office and the State Coordinating Teams cannot resolve the issue, they can refer the case to the Department Complex Case Team. The Complex Case Team is able to call on representatives from the various systems to coordinate and seek authorization for services. It also has access to Deputy Secretary Review for issues related to funding and allocation of resources.

If the youth's case meets one of the criteria listed above, you should use this two-step process. It is recommended that requests be put in writing and that the written request include the following language:

Step 1—Request to Regional Office: “I am requesting that the following case be referred for the Complex Case Planning Process at the Regional level pursuant to Department of Welfare Bulletin 00-10-02 (December 12, 2010).

Step 2—Request to Regional Office to Refer to State Complex Case Planning Team: “Because the complex case planning process was not successful to resolve the youth's issues at the regional level, I am requesting that the Regional Office refer the following case to the Complex Case Planning Process at the State level pursuant to Department of Welfare Bulletin 00-10-02 (December 12, 2010).”

⁷⁶ This Bulletin, *Complex Case Planning*, Department of Welfare Bulletin 00-10-02 (December 12, 2010), can be found at: http://www.pccyfs.org/dpw_ocyfs/DPWBulletin00-10-02_ComplexCasePlanning.pdf.

D. Special Issues Related to Treatment and Services for Intellectual Disabilities

What services should youth with intellectual disabilities⁷⁷ who are in the foster care system receive?

Youth with intellectual disabilities, including autism, in the child welfare system should receive all of the same child welfare services as their peers without intellectual disabilities. These include services to help the youth achieve permanency and independent living skills instruction as well as general case planning and monitoring of health, safety, and well-being needs. Most services and supports will be delivered through their MA coverage and, if eligible for special education services, their Individualized Education Plan (IEP).⁷⁸ Based on their needs, youth with intellectual disabilities may benefit from a TFC or Medical Foster Care Placement. However, many of these youth can thrive in general foster care homes or SIL or TLP when they are older with the appropriate treatment and life skills support.

What services can a family receive so that their child with an Intellectual Disability (ID) can return to them from placement in the child welfare system?

The child welfare agency is legally obligated to make reasonable efforts to help the family reunite. Reasonable efforts should be individualized and match the needs of the family. Thus, services should be provided that respond to what brought the youth into the system and what the family needs to have the youth return and remain at home. These could include, but are not limited to:

- Parenting skills training
- Family communication building
- Accessing behavioral health services such as BHRS (“wraparound”)
- Teaching behavior management
- Access to respite care
- Life skills training
- Safety planning
- Assistance in accessing community services and public benefits, including health insurance and Supplemental Security Income (SSI)
- Parent support groups and other coaching and guidance

⁷⁷ Generally speaking, an intellectual disability refers to below average cognitive ability that is marked by three characteristics: a specific intelligent quotient (IQ), significant limitations in adaptive behavior, and an onset in childhood. The most common syndromes associated with intellectual disabilities are autism, Down Syndrome, Fragile X syndrome and Fetal Alcohol Spectrum Disorder (FASD). The term “mentally retarded” is no longer widely used to refer to an individual with an intellectual disability. In this publication, the term Intellectual Disability will be used. If the information provided is related to a specific condition or syndrome, such as Autism Spectrum Disorder, it will be referenced. Many counties refer to the agency formerly responsible for services for individuals with mental retardation as Intellectual Disabilities Services (IDS). We will use that reference and acronym here even though some counties do continue to use the agency name, Office of Mental Health and Mental Retardation.

⁷⁸ An IEP is a contract that formalizes a child’s specialized instruction and related services as part of his or her special education services.

What additional specialized services or treatment should a child with an intellectual disability who is placed in the child welfare system receive to meet those needs?

A youth and his or her caregiver can receive all the services listed above while the youth is in a placement. The exact services that the youth should receive will depend on his or her intellectual capacity and capacity with respect to adaptive functioning. Services may include BHRS services, mobile therapy, or life skills instruction, among others. Services that are deemed medically necessary will be covered by the youth's MA.

There are multiple agencies and advocacy groups that specialize in programs and have expertise in working with individuals with intellectual disabilities that should be consulted for information regarding state of the art treatment for youth. A good place to start is the Arc, which is a national organization that has state and local chapters that provide services and advocacy for individuals with intellectual and developmental disabilities. To locate the Arc chapter in your county, click on this link: <http://www.thearc.org/Page.aspx?&pid=327> or http://www.thearcpa.org/who_we_are/local-chapters.html. The Disability Rights Network of Pennsylvania also provides assistance in finding resources for treatment for youth with intellectual disabilities.

In addition, a youth with an intellectual disability may be eligible for special education services. If that is the case, they will have an Individual Education Plan (IEP). The youth's IEP should also meet his or her special needs and be consistent with treatment and services received outside of school. Often the IEP can provide caregivers and treatment providers with tips on how best to communicate and work with the youth. Similarly, educators working with the youth may have good ideas on treatment and activities that would be beneficial for the youth outside of the school setting.

What services should a youth who is testing in the autism spectrum be receiving while he or she is still in the child welfare system?

The Department of Public Welfare has created the Bureau of Autism Services to develop and manage services related to the care and treatment of individuals with autism. The Bureau of Autism Services, rather than the county Intellectual Disabilities Services (IDS) agency, is one of the central points of contact when looking for or applying for services for individuals with autism in Pennsylvania.

What services and treatment a youth may need depend on the individual youth and where he or she falls in the autism spectrum. For most youth in care, these services will be provided through their behavioral health MCO and through their IEP. Services such as BHRS (described above) and outpatient therapy may be appropriate for youth with autism. Listed below are some of the many helpful resources available to find out more information on effective treatment:

- The Autism Services, Education, Resources, and Training Collaborative (the Collaborative) is an initiative of the Bureau of Autism and the Department of Public Welfare. It is a collaborative of medical centers, centers of autism research and services, universities and other providers of services involved in the treatment and care of individuals with autism and their families. To find the Collaborative for your region check out <http://www.paautism.org/>.

- The National Autism Resource and Information Center: Autism Now is a collaboration between the Arc, The Administration on Developmental Disabilities (ADD), and other key stakeholders and organizations. It is a good source of information on treatment and resources and can be found at <http://autismnow.org/>.
- The Autism Speaks website contains a broad array of information and resources. Among the toolkits provided is one that helps caregivers and others working with youth with autism on how to appropriately address challenging behaviors. This toolkit can be found at <http://www.autismspeaks.org/family-services/tool-kits/challenging-behaviors-tool-kit/>.

What questions can a professional or advocate ask to make sure the youth is receiving appropriate and effective services if he or she is testing on the autism spectrum?

You can find out about specific types of treatment by using the resources listed above. Based on what we know about autism, it is important to ask what types of treatment are being provided in and outside of school in the following areas:

- Language and communication
- Social skills
- Challenging behaviors
- Cognitive Skills
- Sensory and motor skills
- Adaptive behaviors

For example, youth with autism may require speech and language therapy to address language and communication delays. Others may benefit from assistive technology to improve and facilitate their communication skills in and out of the classroom. Schools routinely complete Functional Behavioral Assessments and Plans⁷⁹ when a youth's behavior interferes with his or her learning; these assessments and plans can be completed and used outside of the school setting and can be extremely effective in addressing behaviors that interfere with the youth's success, and in teaching and reinforcing other more appropriate behaviors.

It is critical to make sure that any effective strategies also are implemented and reinforced in the youth's placement setting and the community in addition to school. Professionals and advocates working with the youth must monitor that strategies and systems such as behavioral plans are consistent and carried across the school, home, and community setting. Lack of consistency in treatment and expectations sometimes accounts for a lack of progress and the recurrence of challenging behaviors. This is especially true for some youth with autism for whom routine and consistency may be critically important.

Finally, it is crucial that youth who are testing in the autism spectrum and are very high functioning also receive adequate attention. These youth may be eligible for gifted programs and

⁷⁹ For more information on Behavioral Assessments, Plans, and Positive Supports, see <http://nichcy.org/schoolage/behavior/behavassess/>.

a Gifted Individualized Education Plan (GIEP)⁸⁰ while they are in secondary school or a 504 Accommodation⁸¹ plan to ensure that any social or other delays are addressed and that their academic skills are supported.

Why does a youth who has an intellectual disability need to register with the county Office of Intellectual Disabilities Services (IDS) when he or she may not access many supports and services from IDS until he or she exits the child welfare system?

While many of the treatment services that a youth with ID who is in the child welfare system will receive will be delivered through his or her MA coverage and school, state and federal laws do make a range of services and benefits available to children with intellectual disabilities that require registration to access. In addition, once a youth turns age 21 or when he or she exits the child welfare system as an adult, the MA Waiver program will be the primary source of treatment and support services. (MA Waivers will be discussed in detail below).

Registration establishes that the youth has an intellectual disability and is eligible for services through IDS. Without registration, the youth will not be able to access services and supports through the IDS system.⁸²

What information must be provided for the youth to register?

- Social Security Card
- Birth Certificate
- Proof of address
 - It is recommended that the address used be that of the child welfare agency. It is recommended that the point person for the registration be a supervisor or administrator to avoid any gaps or missed correspondences.
- Medical Assistance Card
- Psychological Testing, including IQ testing and functional assessments
- A signed release of information and records by the youth's parent or guardian if he or she is under age 18. If the youth is age 18 or older, he or she can sign the release.

⁸⁰ For more information on the rights of gifted students in Pennsylvania and how to access services see Education Law Center's Fact Sheet, *The Rights of Gifted Students*, <http://www.elc-pa.org/Gifted.2009.pdf>

⁸¹ See below for more information on 504 Accommodations Plans.

⁸² This section attempts to provide child welfare professionals with some basic information about accessing services for youth with intellectual disabilities from the county IDS office. Much of the information provided is summarized from two excellent publications that are highly recommended for more detail: Disability Rights Network of Pennsylvania, *Intellectual Disabilities Waiver Services in Pennsylvania*, available at <http://drmpa.org/wp-content/uploads/2012/08/Intellectual-Disabilities-Waiver-Services-in-Pennsylvania.pdf>; Vision for Equality, *Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services* (2010), available at <http://www.temple.edu/thetrainingpartnership/resources/umrspa/goldbook201007.pdf>. (Hereinafter "*Understanding the Office of Developmental Programs*").

What are the eligibility criteria to register for IDS services?

Listed below are eligibility criteria for registration with IDS:

1. There must be a diagnosis of mental retardation, reflected by intellectual functioning (IQ) and adaptive functioning.

To be eligible an individual must have sub-average intellectual functioning *and* significant limitations in adaptive functioning based on standardized assessments. These delays and limitations must begin before the youth turns age 22.

IQ testing usually provides information about the individual's intellectual functioning. In most cases, a youth's IQ must be below 70 to be eligible. If the IQ is in the borderline range (70-75), it may be appropriate to request an independent evaluation. In all cases, but especially in close cases, it is important to submit information about the youth's adaptive functioning. This information can come from testing, but it also can come from notes or observations of those working with the youth on a daily basis. Adaptive functioning is very similar to what child welfare professionals know as Independent Living skills.

It includes the age-appropriate behaviors necessary for people to live independently and safely in daily life, e.g., grooming, dressing, safety, food handling, following rules and directions, keeping a schedule, ability to work, money management, cleaning, making friends, and social skills.

The youth's Independent Living Services provider and caregiver (foster parent, group home parent or staff) should have a formal assessment of some of these skills and submit information about the youth's progress in acquiring these skills.

Educational records also can be helpful in assessing intellectual and adaptive functioning. If a youth 14 years or older receives special education services and has an IEP, an assessment of adaptive functioning should have been completed and in the youth's records. Submit these records or teacher's observations to IDS during the registration process.

2. The individual must require active treatment.

Medical professionals and others must submit information that shows that the individual will benefit from treatment and services and requires them to function at his or her greatest potential. This can be demonstrated by current records of treatment including school records.

3. The individual must be recommended by a medical evaluation for Intermediate Care Facilities for Persons with Intellectual Disabilities (ICF/MR) level of care.

An Intermediate Care Facility is a residential program that provides treatment and other support services for individuals with intellectual disabilities and individuals who may have other health impairments.⁸³ ICFs are institutional placements that provide a high level of care. To

⁸³ Intermediate Care Facilities (ICFs) are institutional placements, and many individuals remain in them for their entire lives. While an adult can choose to be placed in an ICF, all efforts should be made to find alternatives to these

demonstrate that an individual needs this level of care, a medical professional must fill out a Department of Public Welfare form called the MA-51. Demonstrating that an individual requires an ICF level of care does not mean that he or she will go to an ICF. It just demonstrates a level of need for services and supports. An ICF is paid for by MA.

Alternatively, an individual who is registered with IDS and wants to live in the community may be eligible for MA Waiver services so that placement in the community can occur. For youth in the child welfare system, this type of placement would occur after they leave the child welfare system. When medical professionals document on the MA-51 that the youth needs ICF/MR level of care, they are indicating that that level of services would be needed *but for* the treatment and services that would allow placement in the community.⁸⁴ Individuals need to be registered with IDS so that services can be arranged and an ICF placement can be avoided.

What happens if you disagree with the decision of IDS about eligibility?

Eligibility decisions can be appealed. For example, if it appears that the IQ test was not accurate, an independent evaluation by a psychologist can be requested. In addition, a request can be made through the youth's MCO for an evaluation. Alternatively, a court order for an evaluation can be requested at the youth's next court review hearing, or an emergency order can be sought at any time.

If it appears that IQ testing was relied upon without consideration of adaptive functioning, more information and assessments about adaptive functioning should be requested from the behavioral health treatment providers and the school. In situations in which those working with the youth on a daily basis do not believe the IQ adequately reflects the youth's level of functioning, it is critical to document those observations and concerns and submit them to IDS.

Because registration is the key for access to almost all the crucial services that a youth with intellectual disabilities will need as an adult, appeals should be pursued.

At what age should a youth be registered with IDS?

It is recommended that a youth be registered with IDS as soon as he or she is identified as having an intellectual disability. Identification should be done as early as possible so that the youth receives the treatment and services to match his or her needs. In all circumstances, registration should occur well before the youth reaches age 18. If this does not occur, all efforts should be made to complete registration as soon as the need comes to the attention of the professionals

placements, including seeking services through the MA Waivers that provide sufficient support to the individual so that he or she feels comfortable in a less structured setting. In addition, while youth can be placed in ICF, such a placement should be discouraged as there are multiple other placement options for youth in the child welfare system. If you are working with a youth who is placed in an ICF, contact the Disability Rights Network for assistance. To find out more about ICFs and facilities in Pennsylvania see the information provided by the Department of Public Welfare at <http://www.dpw.state.pa.us/foradults/intellectualdisabilitiesservices/intermediatecarefacilities/>.

⁸⁴ ICFs are covered by MA. See Medicaid, *Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MR)*, available at: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Intermediate-Care-Facilities-for-Individuals-with-Mental-Retardation-ICFMR.html>. If an individual is placed in an ICF he or she is not eligible for the MA Waiver. Unlike the MA Waiver, however, there is an entitlement to placement in an ICF if the eligibility criteria are met.

working with the youth. If facing a lack of cooperation to start or complete the process or procure the information for registration, the following is recommended:

- Schedule a Family Service Plan or Permanency Plan meeting to discuss registration;
- Notify all members of the youth's team of the need to complete registration and the dire consequences that could result if the process does not occur; and
- Contact the youth's lawyer and request that this issue be addressed in the next court review hearing for the youth.

Who is responsible for registering a youth who is in the child welfare system?

As the agency legally responsible for the care and case planning for children in the child welfare system, the county children and youth agency has final responsibility for ensuring that a youth in its care is registered. Because of the complexity and importance of the process, it is highly recommended that the county child welfare agency establish a protocol for registration and identify a point person or department responsible for identifying and completing the registration process for youth in the agency's care. The registration process will require the collaboration and cooperation of the service providers working with the youth as well as any family members or caretakers, as these agencies and individuals will likely be sources of testing and input on adaptive functioning.

While the child welfare agency is legally responsible for planning for the youth, including registration, it is still highly recommended that professionals and advocates working with the youth take any actions—including initiating the process, gathering the necessary documents, and signatures for forms—to expedite the process and ensure that it occurs. If all efforts to get the process going have been unsuccessful, the issue should be raised at the youth's next court review hearing so that appropriate action can be ordered.

What does a Supports Coordinator do?

As soon as the youth is found eligible for IDS services and registered, the youth should be assigned a Supports Coordinator (SC). The SC helps the youth plan and apply for all services and funding that the youth needs through IDS. The SC will work with the youth and the youth's team to create a plan for services, which will be contained in an Individual Support Plan (ISP). Some SCs may not have much experience with the child welfare agency. For that reason, it is recommended that the professionals working with the youth take some time to introduce themselves to the SC and explain their respective roles. Inviting the SC to the various planning meetings while the youth is still in the child welfare system will ensure service coordination and that the SC has full and accurate information about a youth.

Effective System Collaboration: The SC and Child Welfare Worker

Cortez spent 10 years in the foster home of the Jones family. His caseworker successfully registered him with IDS when he was age 16; she consistently provided updates to his SC about his progress and included her in family service planning and transition planning meetings. The team ascertained that Cortez’s foster parents were interested in continuing to care for him after age 21 if they could receive support and assistance. The SC worked with the caseworker and the Jones family to get them certified as life share providers that could be funded through the IDS Consolidated MA Waiver. (See below for more on this). The close collaboration and communication between the caseworker and the SC facilitated a smooth transition for Cortez that allowed him to maintain his family and be set up to receive adult services through IDS upon discharge from the child welfare system. Without this, the Jones family may not have understood the option to become a life share provider in the IDS system and the caseworker may not have had the knowledge to support them in this process.

What is the PUNS and why is it important?

One of the first things that the SC will do with the youth and his or her team is fill out the PUNS, which stands for Prioritization of Urgency of Need for Services. This form is VERY IMPORTANT for accessing services when a youth discharges from the child welfare system. It is considered the “gateway to the IDS system.”⁸⁵ Because MA Waiver services are not an entitlement, eligibility does not guarantee access to services. The PUNS is what each county uses to determine who gets services first from the waiting list. Currently, there are thousands of individuals in Pennsylvania who are categorized as emergency status on the waiting list.

Those working with the youth should make sure they have input into completing the PUNS. For example, it should be made clear to the SC when the youth will “age out” or discharge from the child welfare system and whether or not there are any placement or family resources available. If the youth will be without a place to live and services when she discharges, that should be reflected in the PUNS. An individual is categorized as critical when he or she will need services in more than six months, but less than two years, and as an emergency when he or she will need services within the next six months. It is a priority to ensure the youth’s status is recorded with county office of Intellectual Disabilities to get him or her in line for these high demand services.

At what age should a youth start receiving services from IDS?

A child may be eligible for services from IDS as early as age three. However, in many cases, children can access the services they need through their MA coverage, their IEPs, and the provision of other child welfare services. Often, IDS does not play a significant role in providing services until a youth makes the transition to adulthood and exits the child welfare system at age 21. However, establishing eligibility with IDS early is important in case there is a service IDS can provide that youth cannot access through other means. Ensuring registration and

⁸⁵ *Understanding the Office of Developmental Programs*, at 4.

establishing eligibility maximizes service access for the youth, but frequently the youth may not need to access an MA Waiver and other IDS services until after age 21.⁸⁶

E. Meeting Educational Needs in Preparation for a Successful Transition

What school should youth with disabilities in the child welfare system attend?

Regardless of whether or not they have a disability, youth in the child welfare system have a right to a free public education, like any other youth. Some special laws help ensure that foster youth get the educational services they need. These laws have been enacted because research and experience has shown that many foster youth have poor educational outcomes compared to their peers who are not placed in the child welfare system. This is largely due to the fact that foster youth often experience placement and school instability and because their educational rights are not always enforced in regular and special education matters.

Under the Fostering Connections to Success and Increasing Adoptions Act, youth in foster care has the right to attend the school they were attending (their “home” school) before they were placed in foster care or before they were moved to another placement in foster care, unless to do so would not be in their best interests.⁸⁷ Alternatively, 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 “immediate and appropriate enrollment” in a school where the youth’s placement is located “with all of the educational records of the child provided to the school.”⁸⁸

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

No. The presumption is that 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 all these situations, the community school—not a restrictive or segregated setting—is the default setting. In most cases, for a youth to be placed in an on-grounds school requires a change in their educational placement.⁸⁹ This can only occur if it is included in a valid IEP or ordered by the court. In addition, it violates the Department of Public Welfare’s licensing regulations for placement providers to require youth placed in its facility to attend its school as a condition of placement.⁹⁰

⁸⁶ Many youth who are in child welfare system who are registered with IDS will be receiving supports coordination only until they discharge from the child welfare system. The SC should be involved in transition planning with the child welfare agency and the IDS ISP should be consistent with the child welfare transition plan.

⁸⁷ 42 U.S.C.A. § 675 (1)(G)(ii)(I) (A plan for ensuring the educational stability of the child while in foster care).

⁸⁸ 42 U.S.C.A. § 675 (1)(G)(ii)(II) (A plan for ensuring the educational stability of the child while in foster care).

⁸⁹ 34 CFR § 300.503(a).

⁹⁰ *Educational Portions of “Non-Educational” Residential Placements*, OMHSAS Bulletin 10-01 at 4 (January 4, 2010) (clarifying that placement/treatment providers cannot condition placement on attendance at the on-grounds school), available at: http://www.pccyfs.org/dpw_ocyfs/Education/EducationalPortions_Non-Educational-Residential-Placements.pdf.

How Attendance at the Community School Can Improve Treatment Outcomes for Youth at Residential Treatment Facilities

Sean was placed in a residential treatment facility (RTF) due to mental health needs. He was a strong student who played on the basketball team before he was placed in an RTF. A Court Appointed Special Advocate (CASA) was appointed to be Sean's Education Decision Maker for special and regular education matters because he did not have a parent or other individual who was available. The CASA worked to ensure that Sean was enrolled in the community school where the RTF is located and that he was able to play on the basketball team. His IEP included counseling services to address emotional issues and a behavior plan to respond to Sean's actions when he felt anxious or upset. Sean's CASA noticed that Sean's behavior and progress at the RTF improved soon after he enrolled and got accustomed to the community school. Because school and sports had been an area of strength for Sean, having a community school experience helped Sean continue to experience success. In addition, Sean's CASA made sure that the credits that Sean would receive could be transferred to his home school district and county towards his graduation requirements. Sean told his CASA that attending the community school made him feel like he was just like any other kid and that this helped him feel like he could focus on improving his life.

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

A parent generally makes all educational decisions for his or her child. This is also generally true for youth in the child welfare system unless their parental rights are terminated. For both general and special education decisions, it is usually the child's parent or legal guardian who maintains education decision-making authority. The parent or legal guardian of the child plays a key role in ensuring that the child's educational rights are enforced.

However, for children in the custody of a child welfare agency in out-of-home care, the birth or adoptive parent may not be available or able to make these decisions. If that is the case, attempts should be made to engage the parent or ensure that a decision-maker is appointed. Without a decision-maker appointed, no one may act to enforce a child's rights or challenge decisions about educational placement or services for a child. All students need Educational Decision Makers (EDM) to make decision about where a youth will attend school when there is choice, discipline, and other issues. Youth who receive special education services need a "parent" or a "Surrogate Parent" who meet certain qualifications under the federal special education law. In many cases, the EDM and the Surrogate Parent can be the same person. A school district can appoint a Surrogate Parent, while the juvenile court can appoint a Surrogate Parent as well as a general education decision maker.

Does the education decision maker need to enroll the youth in school?

No. Ideally, the EDM would go with the youth and enroll him or her in school. However, a caseworker for the youth or caregiver can actually enroll the youth in school once the EDM, the youth, and the youth's team have determined the youth's school placement. Enrollment should

occur as soon as possible, and can be facilitated by any number of individuals working with the youth.

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

A parent should act as a child's general education decision-maker even when the youth is in the child welfare system. If the court removes educational rights from a parent, the court should appoint a specific individual who has the expertise and time to serve in that role. If the child receives 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 a child for special education purposes when they are in the child welfare system?

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
- A foster parent
- A "guardian" who has the authority to act as the child's parent or who has the authority to make education decisions for the child
- A family member with whom the child lives, and who is caring for the child (such as a grandparent or stepparent), or someone who is legally responsible for the child's welfare
- A "Surrogate Parent"⁹¹

If the birth parent or adoptive parent is "attempting to act" as the decision-maker, the school must accept that person as the decision-maker. If no such biological or adoptive parent is involved, the other individuals listed can be considered the "parent" and do not need to be appointed.

A private or public caseworker for the child cannot serve as a surrogate parent for the child. If a caseworker is signing a youth's IEP, the IEP is not valid.

What if there is no IDEA parent identified?

If there is no IDEA parent, a Surrogate Parent should be appointed to make special education decisions for the youth.

What is the process for getting an EDM or Surrogate Parent appointed?

A general EDM and/or Surrogate Parent can be appointed by the juvenile court. The school district can appoint a Surrogate Parent.

⁹¹ 34 C.F.R. § 300.30.

1. Appointment by the School District

School districts are 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 he or she has a disability, in the situation in which the youth has no IDEA “parent.” The request should be made in writing. An appointment should occur within 30 days of the request.

2. Appointment by the Juvenile Court Judge

Pursuant to Juvenile Court Rule 1147, a juvenile court judge has the authority to appoint an EDM and/or Surrogate Parent if the youth receive special education services, unless the child has a foster parent or another person who falls within the definition of an IDEA parent. Any party involved in the case—the children and youth agency, the youth’s attorney, or the parent’s attorney—can request that the order be issued. The judge can appoint an EDM or Surrogate Parent after a hearing at which the court determines that either the child has no guardian, or “the court, after notice to the guardian and an opportunity for the guardian to be heard, has made a determination that it is in the child’s best interest to limit the guardian’s right to make decisions regarding the child’s education.”⁹²

The judge’s order should include a statement that the birth or adoptive parent’s right to make decisions for the child is suspended, list a specific person to act as the child’s “Surrogate Parent,” and specifically state that the individual is appointed “to make all special education decisions for the child.” If a judge appoints a Surrogate Parent, that person preempts all other potential “parents”—even a Surrogate Parent who has been appointed by the school.

Although the court has this broad power to appoint a Surrogate Parent even if there is a birth or adoptive parent available, it should use this power sparingly and with consideration of the importance of keeping birth parents involved with the child’s education.

Who can serve as an EDM or Surrogate Parent?

If they are willing, possibilities include:

- Adult relatives (even if the relative is not in a position to have the child live in his or her home, the relative may be involved in the child’s life)
- A Court Appointed Special Advocate (CASA)
- A child’s attorney or guardian *ad litem* (some attorneys may not be comfortable with this role or feel it is appropriate, so be sure to ask the attorney before you recommend him or her)

⁹² Juvenile Court Rule 1147(A) is available at: <http://www.pacode.com/secure/data/237/chapter11/s1147.html>.

- Another adult who knows the child (perhaps a church member or a responsible family friend)

What if the youth needs an evaluation to see if he or she is eligible for special education and a “parent” or Surrogate Parent has not yet been identified?

An initial evaluation can be done if the child is in the custody of the child welfare agency, and is not living with the birth or adoptive parent or with a foster parent, and:

- The school documents that it has made repeated attempts but cannot locate the parents, or
- The birth parents’ rights have been terminated under State law, or
- The birth parents’ rights to make education decisions have been suspended by a judge, and an individual who has been appointed by the judge consents to the initial evaluation.⁹³

Do all youth in group homes or institutional care need a surrogate parent?

It depends on the factors described above. If a birth or adoptive parent is available, that person is the parent both for general and special education decision-making. A child in congregate care would need an EDM if his or her parents’ rights have been terminated or the parents cannot be found. A Surrogate Parent must be appointed if there is no one in the child’s life who counts as a “parent” under the law and who can make special education decisions for the child. While all youth in congregate care will not need an EDM or Surrogate Parent appointed, this group of youth are more likely than others to not have a decision maker active in their life. Identifying the EDM—and parent or Surrogate Parent if special education issues are involved—at the start of the case is important so you can determine what actions must be taken to protect the youth’s educational rights.

What does a Surrogate Parent do?

The Surrogate Parent can make all special education decisions that a parent would make. That includes making sure that the youth has a good IEP, including an excellent transition plan. Their authority, however, does not extend beyond that sphere. If the surrogate parent was not also the regular education decision maker, he or she would not be empowered to make general education decisions, such as those related to discipline, etc.

If the Surrogate Parent has also been appointed the general EDM, what activities should he/she perform in addition to meeting the youth’s special education needs?

Under the Juvenile Court Rules, a general education decision-maker should “make appropriate inquiries and take appropriate actions” to ensure that a wide array of issues are addressed. Among the issues the EDM must address are:

⁹³ 34 C.F.R. §300.300 (a)(2).

- Maintenance of educational stability
- School discipline
- Progress being made towards graduation
- Child welfare IL and transition planning requirements; they must be met and coordinated with educational planning

The general education decision maker should address these issues by meeting with the youth, participating in any meetings where educational issues are discussed, and making recommendations to the court.⁹⁴

Until what age does a youth need a parent or surrogate parent to make regular and special education decisions?

In Pennsylvania, a youth needs a special education decision maker and a regular education decision-maker until he or she turns age 21.

Are all youth with disabilities in foster care eligible for special education services?

Youth in foster care are overrepresented in their receipt of special education services. It is estimated that approximately 30-40 percent of youth who are in foster care receive special education services.⁹⁵ At the same time, foster youth often are not identified or evaluated for eligibility for special education services due to their mobility and frequent school moves.

It is important to make sure youth are screened for special education services if it is thought that they may have a disability that interferes with their ability to learn. If they are eligible for special education, they have many rights to services and due process protections under the federal special education law, the Individuals with Disabilities Education Act (IDEA). This law, passed by Congress in 1975, is an entitlement program. Children eligible for special education services are entitled to a “free and appropriate public education” (FAPE). This means that they are entitled to specially designed instruction and related services so that they can learn. The nature of the specialized instruction and related services will depend on the youth’s individual needs and good advocacy can make a tremendous difference. The specialized instruction and related services are formalized in an Individualized Education Plan (IEP), which is a contract. These services and instruction must be provided in the least restrictive setting with non-disabled peers to the maximum extent possible. For more information on getting a youth screened for special education services and how to advocate for an effective IEP, see *The Right to Special Education In Pennsylvania: A Guide for Parents and Advocates (2009)*, available at: <http://www.elc-pa.org/pubs/downloads2010/2009ATheRighttoSpecialEducationinPennsylvaniaGuideforParents.pdf>.

⁹⁴ Juvenile Court Rule 1147(C).

⁹⁵ *Negotiating the Curves Toward Employment: A Guide About Youth Involved in the Foster Care System*, at 3 (National Collaborative on Workforce and Disability for Youth 2007).

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 related activities, but the disability does not require specialized instruction, the youth may be eligible for a 504 Plan. To be eligible for a 504 Plan, a youth needs to 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 a youth is not eligible for special education services, but has a disability that requires accommodations to ensure the youth's full participation in school, including extracurricular activities, a 504 Accommodations Plan should be requested. For more information on requesting and developing a 504 Accommodations Plan see the following Education Law Center Fact Sheet, *Can a Child with Chronic Health Impairment or Serious Illness Get Special Help from Her School*, which is available at: <http://www.elc-pa.org/pubs/downloads%202011/CanChildwithChronicHealthImpairmentGetHelp4-09A.pdf/>.

What are the transition planning requirements in the IEP?

In Pennsylvania, transition planning must begin, and be incorporated into the IEP, when the youth turns age 14.⁹⁶ The transition plan in the IEP includes an organized set of activities that helps youth move from high school to college, postsecondary training, independent living and work. It must focus on improving academic and functional achievement to achieve the goals set out in the document. To achieve the goals, the plan should include: instruction, related services, and community experiences. While the most familiar goals will be related to pursuing post-secondary education and training and getting a job, it is important to include independent and community living goals and services to achieve those goals. The school can be an excellent source of instruction and support in community living skills, especially for youth who are in placements that are not providing them much opportunity to practice independent living skills in the community. The school often can provide the staff, expertise, and environment for youth to have meaningful and supported opportunities to learn and practice these skills.

While the IEP will have goals that overlap with the child welfare IL and Transition Plan (the plan to assist the youth with transitioning out of the foster care system), the transition plan in the IEP is very focused on the transition from school to work or postsecondary education and training.

Youth who receive special education services are entitled to a quality transition plan. These plans are invaluable tools for making sure a youth is ready to leave high school and make it in the adult world. Far too often the transition plan requirement is not enforced, and this is especially true for youth in the foster care system. The transition plan in the IEP can be a vehicle

⁹⁶ 22 Pa. Code § 14.131(a)(5).

for accessing an array of services and instruction so they can gain the skills they need to be successful as adults.

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

It must include goals related to:

1. Postsecondary Education or Training
This includes going to a two- to four-year university, community college, technical school, or anything that furthers the youth's education.
2. Employment
This includes goals related to securing a job and finding a career.
3. Independent/Community Living
Independent living goals include getting around in the community, use of community resources, and accomplishing daily tasks that an adult will need 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.
5. Adult Service Connections
Goals in this area involve connecting the youth with agencies and services that the youth will need as he or she becomes an adult. Depending on the severity of the youth's disabilities, agencies to connect the youth with could include: the Office of Vocational Rehabilitation (OVR), Careerlink, Centers for Independent Living (CILs), the Social Security Administration, the County Assistance Office, Adult Behavioral Health Services, Office of Developmental Programs (ODP), the Bureau of Autism, and the Protection and Advocacy Agency (Pennsylvania's Protection and Advocacy Agency is the Disability Rights Network of Pennsylvania).

How do you know if the transition plan is adequate?

In addition to making sure the youth's IEP has goals in the five areas listed above, the transition plan must include all of the following:⁹⁷

- Appropriate measurable postsecondary goals that are annually updated
 - Is it a goal related to the youth's postsecondary life?
 - Can the goal be counted?
 - Have the goals been updated annually?

⁹⁷Some of the information provided below is an adaption of a checklist created by the National Secondary Transition Technical Assistance Center to determine if transition goals are appropriate (NSTTAC Indicator 13 Checklist Form A). It is available at <http://nstattac.org/sites/default/files/assets/pdf/ChecklistFormA.pdf>.

- The goals must be based upon age appropriate transition assessments related to training, education, employment, and independent living skills.
 - What assessments were used to inform the goals in each area?
- Transition services designed to achieve the goals, including courses of study, that will reasonably enable the student to meet those postsecondary goals, and annual IEP goals related to the student’s needed transition services
 - Are there transition services that focus on improving academic and functional achievement to facilitate achieving the goals?
 - In addition to instruction, are related services, community experience, and development of employment and other post-school adult living objectives included?
- The youth must be invited to and participate in the development of the IEP⁹⁸
 - What efforts were made to invite the youth?
 - What strategies or activities were employed or undertaken to prepare the youth for participation in the meeting and to engage the youth at the meeting?

The youth has the right to be invited and actively participate in the development of his or her IEP. The Surrogate Parent or other advocate for the child should ensure that the child is afforded this right and prepared to exercise it.

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 the youth’s interests, capacities, needs, and skills. In addition, identifying what excites and interests the youth and how that can be translated into transition goals is central to keeping the youth engaged. The assessment process is ongoing and there are multiple types of assessments that can be used as the youth gets older. Assessments can be informal and formal. Such assessments may be even more important for youth in care who may not have a consistent caregiver to help inform the IEP team about the youth’s skills in relation to their placement, education, vocation or community participation.

Examples of assessments include:

- 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 measure

⁹⁸ 34 C.F.R. § 300.320(b).

For a more detailed discussion of transition assessments, including examples of assessments, see *Age Appropriate Transition Assessment Toolkit* (National Secondary Transition Technical Assistance Center 3rd Ed. 2013), available at: <http://nsttac.org/content/age-appropriate-transition-assessment-toolkit-3rd-edition>.

What is an example of acceptable transition planning goals in the education and training domain?⁹⁹

Postsecondary Education Goal 1: Jasmine will enroll in the cosmetology program at School X upon graduation.

What are examples of discrete IEP goals to include in the transition plan to meet the overall education goal, and the services to achieve those goals?

IEP Transition Goals	Courses of Instruction, services, community experiences to meet the goal
Jasmine will meet the academic requirements for the cosmetology program at School X by achieving the required levels for math, reading, and science.	<p>Direct instruction and supplemental tutoring in math, science and reading sufficient to meet pre-requisites for the cosmetology program at School X.</p> <p>Direct instruction and counseling in study skills.</p> <p>Counseling to ensure that all credit and curricular requirements will be met by graduation.</p>
Jasmine will successfully apply and receive funding to finance her postsecondary program.	<p>Counseling and assistance in completing the application for School X.</p> <p>Counseling and assistance in completing the following to finance her cosmetology program at School X:</p> <ul style="list-style-type: none"> o FAFSA o ETG application o Other identified scholarships
Jasmine will have an appropriate 504 Plan for her cosmetology program at School X.	<p>Assistance by her IEP team in creating a draft 504 Accommodations Plan for School X and contacting the disabilities services office upon acceptance.</p> <p>Direct instruction and community experience in self-advocacy skills.</p>

⁹⁹ The two examples below of postsecondary education and independent living/community living goals are meant to provide simple examples of the comprehensive array of supports and services that can be provided through the transition plan. In the text several resources are referenced so that you can find other helpful examples for the many goals that can and should be included in a transition plan and the services and instruction that should be provided to youth to achieve those goals.

What is an example of an acceptable transition planning goal in the independent/community living domain?

Independent Living/Community Living Goal 1: Upon completion of postsecondary education, Marcus will be able to use public transportation independently, including the bus and the subway system.

What are examples of discrete IEP goals to include in the transition plan to meet that independent/community living goal and the services to achieve those goals?

IEP Transition Goals	Courses of Instruction, services, community experiences to meet the goal
In travel situations, Marcus will demonstrate sitting quietly and refraining from conversation with strangers while using public transportation at least 80% of the time.	Travel and orientation and mobility training. Direct instruction in how to understand safety risks and address unsafe situations.
Marcus will demonstrate how to count money and make change to successfully purchase tokens and transfers while using public transportation at least 80% of the time.	Direct instruction in functional math, including counting money and making change. Travel, orientation, and mobility training.
Marcus will successfully travel independently to and from various locations in the city at least 80% of the time.	Direct instruction in reading and literacy related to sight word identification. Direct instruction in math related to telling time. Travel, orientation, and mobility training.

What resources exist in Pennsylvania and nationwide for developing and reviewing a youth’s transition plan?

Transition plans in the IEP are often poorly done and do not include the minimum of what youth are entitled to under the law. This is an opportunity that advocates should not miss! The resources below can be useful in developing transition goals and services to achieve them, such as providing examples to propose in an IEP. The options are only limited by creativity and research.

- The Pennsylvania Training and Technical Assistance Network (PaTTAN) of the Pennsylvania Bureau of Special Education has a Secondary Transition Guide (website) that provides multiple resource materials and opportunities for trainings. It is available at: http://www.pattan.net/category/Educational%20Initiatives/Secondary%20Transition/page/Pennsylvania_Secondary_Transition_Guide_website.html.

- Transition Coordinators are county representatives that provide assistance in creating a transition plan. A Resource Directory of local transition coordinators and other advocacy groups can be found at: <http://www.pattan.net/category/Resources/Instructional%20Materials/Browse/Single/?id=5024e1108b03329426000005>.
- The National Dissemination Center for Children with Disabilities also has some great tools, including examples of model transition plans (as well as a description of plans that are not acceptable), at the following website: <http://nichcy.org/schoolage/transitionadult/goals>. The tools do an excellent job of analyzing appropriate and inappropriate goals and explaining how to develop a goal in a manner that meets the requirements of the IDEA.

Finally, if you are having trouble advocating for a quality transition plan, contact the Disability Rights Network of Pennsylvania for advocacy assistance.

What action can be taken if the transition plan is not acceptable under the IDEA?

If the transition plan is not adequate and the school refuses to improve the IEP, there are several actions that the youth's education decision maker or surrogate parent can take. Taking action is important to ensure youth gets the services they need before they leave high school. Sometimes pursuing appeals and other resolution mechanisms can result in an allocation of compensatory education services for a youth to make up for the inadequacies in the IEP. The advocate and youth can design the services.

To find out more about ways to resolve these disputes see Chapter 12: How to Resolve Special Education Disputes, *The Right to Special Education In Pennsylvania: A Guide for Parents and Advocates* (Education Law Center 2009).¹⁰⁰

What agencies can provide assistance if the youth is not getting all he or she is entitled to under the federal and state special education laws?

For help, please contact:

- Disability Rights Network of Pennsylvania at 1-800-692-7443, or
- Education Law Center-Pennsylvania at 215-238-6970

Education Law Center also has accumulated a list of agencies that may be able to assist advocates and family members who need help in accessing special education services for youth. It can be accessed at: <http://www.elcpa.org/pubs/downloads%202009/Advocacy%20and%20Support%20Groups%204-09A.pdf>.

¹⁰⁰ This publication can be found at <http://www.elc pa.org/pubs/downloads2010/2009ATheRighttoSpecialEducationinPennsylvaniaGuideforParents.pdf>.

What is the Office of Vocational Rehabilitation (OVR)?

OVR provides vocational rehabilitation 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.

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 prior to turning age 18 so that they can access them as soon as they turn age 18. It is recommended that the referral be made even if the youth is attending high school past age 18. An OVR representative can and should be participate in the youth's IEP meeting and development of the IEP.

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, access should be timely, and the assistance of the Client Assistance Program (see below) should be sought if the youth feels that he or she is not being treated fairly or there is a great need for services that are not being met.

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

Under federal law, advocacy assistance 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 by calling 888-745-2357.

What are examples of services that OVR can provide for a young adult?

Based on the individual's needs, OVR can directly provide or fund other agencies to provide an array of services. For OVR to provide or pay for the services, it must be included in the vocational or service plan created. Examples of training and services include:

- 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

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

Yes. A child with a disability in Pennsylvania who is receiving special education services is entitled to graduate with a regular high school diploma if: (1) she completes the same graduation requirements as a regular education child; or (2) the child’s IEP team determines that the child has satisfied the IEP goals to the extent necessary for graduation. Pennsylvania does not award children with disabilities a “certificates of attendance” as is done in some other states.¹⁰¹

Do youth with disabilities have to participate in state standardized assessment tests, such as the Pennsylvania’s System of School Assessment (PSSA)?

Children with disabilities must participate in the state achievement tests that most children take (e.g., the Pennsylvania’s System of School Assessment or PSSA), or must take Pennsylvania’s Alternate System of Assessment (PASA), which is designed for children with particularly severe disabilities who are taught according to alternate learning standards. In order to have the youth take the PASA, his or her IEP team must determine what, if any, accommodations or modifications in administering the test are necessary for the child to participate effectively.

To graduate, Pennsylvania children are expected to score at the proficient level or better in reading, writing, and mathematics in the PSSA, the PASA, or in a district-wide assessment that is aligned with the state’s academic standards. However, children 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.

¹⁰¹ Graduation requirements for youth with disabilities can be found at 22 Pa. Code 4.24(e). The Pennsylvania Department of Education issued a Basic Education Circular (BEC), titled *Graduation Requirements for Students with Disabilities*, in June 2013. This BEC can be found at <http://bit.ly/18WzcS5>.

How long can a youth with disabilities remain in 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. Youth who are eligible for an extended school year may attend the summer session following the school term in which he or she turned age 21. If a youth accepts a high school diploma prior to age 21, the youth cannot continue to receive free special education services.

What are the benefits to a youth of remaining in school until age 21?

The IDEA's protections and guarantees are comprehensive and provide students with significant services and supports to develop their academic, work-related, and independent living skills. The program outlined in the IEP includes specialized instruction, related services, and other supports and experiences. With good advocacy and support, a youth can receive excellent services that will position him or her well to take advantage of an array of opportunities in education, work, and the community upon leaving school.

To a large extent, a youth's educational experience is limited by the creativity of the IEP team. The educational program in an IEP created for a youth who is age 18-21 can look very different from a traditional high school experience. In short, the IEP can create a truly transitional experience for the youth. For example, a youth may have in his IEP that he or she will attend several classes at the local community college or participate in an internship for a portion of the school day.

Finally, many youth in foster care who have disabilities, especially those who have had a lot of educational instability, may approach graduation without having the basic and functional skills in reading and math that they will need for any path they take in the adult world. Having extra time in high school to receive direct instruction in those basic skills can be very valuable. This instruction can be paired with work experiences and independent living skills instruction to make the program engaging for the youth.

Must a youth with a disability be permitted to participate in a graduation ceremony with his or her class if he or she is not going to receive his or 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 his or 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, consistent with his or her IEP.

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

Yes. A school district must make reasonable accommodations to enable children with disabilities, including youth with physical or cognitive impairments, to participate fully and on

equal terms in graduation ceremonies. Such accommodations must be provided according to a youth's individual needs.

What services can help youth in foster care prepare for postsecondary education and training?

Many county IL programs provide academic support, college counseling and tutoring as part of their array of IL services. Check with the county IL program to see what educational and academic support it provides.

In addition, many programs work with high school students to increase the odds that they will graduate and pursue postsecondary education. Many of these programs are targeted at disadvantaged students. Youth with disabilities in foster care should have access to these programs and can request accommodations if needed for their participation. Check out the following website to find programs that youth you work with may benefit from as they prepare for postsecondary education and training: <http://www.collegeaccess.org/accessprogramdirectory/search.aspx?s=PA>.

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

No. The IDEA does not extend past high school. Youth with disabilities or impairments in postsecondary programs may be eligible for an Accommodations Plan (504, see below), but have no right to specialized instruction and related services. In addition, youth who received their assistive technology (AT) through their IEP will need to figure out another source to fund that equipment when they leave school.

Can youth request 504 Accommodation Plans when they go to college or attend a postsecondary training program?

Yes. 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 accommodations in postsecondary settings:

- 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, 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.

The youth's treatment providers should contribute 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 Performance¹⁰² be completed. This form provides an excellent basis for the creation of a 504 Plan for a postsecondary program. The IEP team is in a great position, and has expertise, in developing accommodations that will work for the postsecondary setting. A discussion of accommodations should occur at the last IEP meeting where the Summary of Academic Achievement and Functional Performance is completed.

How can you get a 504 Plan for a student in college or a training program?

The youth should contact the disability services office of the postsecondary educational or training program that he or she is scheduled to attend as soon as possible. If there is not a 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 obligation. For that reason, youth must be proactive in identifying themselves and requesting accommodations. The youth will have to provide some documentation of his or her disability.

What additional services and supports can a youth access when they are attending postsecondary education and training?

Most postsecondary programs offer a wide array of student support programs. 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.¹⁰³ In addition to reaching out to all disadvantaged students, PHEAA recommends that Chafee Educational Training Grant recipients be considered for Act 101 participation.

¹⁰² A copy of this form can be found at <http://www.pattan.net/category/Legal/Forms/Browse/Single/?id=4db2885acd69f9c443490100>.

¹⁰³ 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>.

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 acclimate 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 your county:

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

- TRIO Programs—Student Support

The TRIO Programs refer to a series of programs funded by the federal Department of Education to help disadvantaged students go to college and succeed when they get 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 akin to those listed 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-.

SECTION TWO: PLANNING FOR A SUCCESSFUL TRANSITION FROM THE CHILD WELFARE SYSTEM

Youth lose many supports and benefits when they leave the child welfare and child-serving systems. These include the EPSDT requirement, an IEP under the IDEA, court oversight of the child welfare case and access to a lawyer and a system of support. Many youth transitioning from the child welfare system lose a place to live and a system that meets their basic needs. Often we have not done enough to prepare them for the reality they face. This section is meant to give child welfare professionals and advocates a basic understanding of the key benefits and services youth with disabilities will need to access to transition successfully as well as the organizations and agencies that can help you navigate the complicated transition process.

A. Health Insurance Coverage Upon the Transition from the Child Welfare System

What health insurance can young people get once they are discharged from the child welfare system?

At age 21, a youth can purchase or apply for health insurance, including MA, in the same fashion as any adult. Even if the young adult is eligible for MA as an adult, his or her coverage under the foster care/child welfare category will end when the case is discharged. A new application for insurance will need to be made in most cases.

A provision of the Affordable Care Act (ACA), which takes effect on January 1, 2014, provides MA coverage for youth who aged out of the child welfare system as adults. Specifically, this provision provides categorical eligibility regardless of income for youth who were in foster care at age 18 and enrolled in MA.¹⁰⁴ This ACA provision mirrors the provision that allows youth to stay on their parent's health insurance until age 26.

At the time of this writing, Pennsylvania had not yet issued guidance on how this provision of the ACA will be implemented. To aid in establishing eligibility until procedures are clear, it is recommended that the attorney for the youth and/or the solicitor for the child welfare agency request that the following language be put in the last court order before a youth who is age 18 or older is discharged from the child welfare system:

For the purposes of establishing eligibility under 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.

The youth should be provided a copy of the order or document issued so that it can be submitted to the County Assistance Office when the youth applies for MA.

¹⁰⁴ 42 U.S.C. §1396a(a)(10)(a)(i)(IX)(2014).

Does health insurance coverage 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 funds a group of services and treatment. This coverage is much more limited than what is covered for children.

What are some examples of MA covered services and treatments for which children are eligible but adults are not?

- Hearing aids are not covered for adults
- Adults can only get one wheelchair every three years
- Stays at psychiatric hospitals are limited to a number of days a year for adults
- Adult therapeutic staff support services are not covered
- For adults, home health services, including nurse's aides, physical, occupation, and speech therapists are limited to a specific number of visits per month

B. Health Care and Behavioral Health Decision-making for Adults

At what ages can youth start to make decisions about their own treatment?

A parent or legal guardian makes most of the treatment decisions for their children who are under age 18.¹⁰⁵ There are some treatments and care youth can receive on their own when they 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, the youth still plays a role in decision making and should have input. Youth should be encouraged to ask any questions that they have about the health care treatment they are receiving. The earlier they play a role in their health care, the better position they will be in to make those decisions when they reach age 18.

¹⁰⁵ For more information regarding federal and state laws on consent to treatment and confidentiality of records for minors in the child welfare system see Lourdes Rosado *et al*, *Consent to Treatment and Confidentiality Provisions Affecting Minors in Pennsylvania* (2nd Ed. 2006), available at: <http://www.jlc.org/resources/publications/consent-treatment-and-confidentiality-provisions-affecting-minors-pennsylvania>.

What resources exist to help prepare youth for understanding and playing an active role in their health care and treatment?

Listed below are three great sources of information that can be used with youth to develop skills around taking control of their own health care and treatment:

- The Pennsylvania Youth Leadership Network has developed the *Secondary Health Care Transition Tool Kit*. It provides a comprehensive guide for young adults on how to navigate the health care system and their own health care needs in the community, including 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/wpcontent/uploads/2011/06/PYLNHealthcareToolkit1.pdf>.
- *The Guide, Transition to Adult Living in Pennsylvania*, created by the Pennsylvania Department of Health, contains several *Transition Skills Inventories* that address health care issues, and is available at www.portal.state.pa.us/portal/server.pt?op.
- The Children's Hospital of Philadelphia (CHOP) has a special project that helps youth navigate the transition to receiving health care in the adult system. CHOP has several helpful tip sheets that prompt youth to develop skills about taking control of their own health care, which can be accessed at: <http://www.chop.edu/service/transition-to-adulthood/resources-for-patients-and-families.html>.

Does a youth who is age 18 or older who decides to remain in the child welfare system have the legal authority to make personal health care decisions?

Yes. Pennsylvania law allows youth to remain in the foster care system past age 18. Youth who exercise this option still have all the rights of adults who are living on their own or in the home of their parents. Remaining in foster care past age 18 in no way interferes with their right to consent to their own treatment. Instead, it simply means that at age 18, the youth makes all of his or her own physical and behavioral health care decisions and is the one who consents to release of his or her own records. The only exception to this rule would be if a court found that the individual was incompetent (under Pennsylvania law, this is referred to as incapacitated).

What options exist if there are concerns that youth are not able to make their own treatment decisions when they turn age 18?

It should be assumed that young people are capable of making their own health care decisions at age 18; those working with young adults should equip them with the skills they need to take on that responsibility. Like all adults, having the legal authority to make decisions does not mean you cannot consult with others and get assistance in making those decisions. Creating strong and trusting relationships with youth will put professionals in the position to assist and participate with them in the decision-making processes without disrespecting the youth's autonomy and legal status as an adult. In addition, just because a young adult makes a decision that others—

including more experienced individuals—disagree with, does not mean the young adult is not capable of making decisions.

An adult’s legal right to control his or her own treatment is a sacred and important right that must be respected. Our laws reflect the great respect we have for individual autonomy in decision-making and set the bar extremely high to interfere with that individual right. Discussed below are some of the options to consider about health care decision-making. Legal guardianship is one of the most extreme and intrusive forms of substitute decision-making. It is important to understand the options under the law because in most cases such an extreme measure is not necessary to ensure that a youth’s needs are met as a young adult.¹⁰⁶ In the majority of cases, guardianship is not necessary—rather, good planning and preparation of the youth for the types of decisions he or she might need to make, as well as ensuring that the youth has a support system to turn to for advice is the ideal. If it is determined that a guardianship petition should be filed, planning must be done so that all the steps, including filing in Orphans Court and having a hearing, are completed before a youth discharges from the child welfare system.

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

Specifically in the health care context, a power of attorney, or “POA,” is a document in which an individual, known as the “principal,” 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. A POA allows the principal—while he or she has the capacity to do so—to put in writing his or her wishes about the types of treatment he or she would want, and the factors that should be considered in making treatment decisions in the event that the principal becomes unable to make those decision for him or herself. Unlike a living will, a health care POA can apply to all health care decisions that arise after a person becomes incompetent, not simply to those decisions that arise at the end of life.

How do you create a POA?

There is no required form for a POA, and completing one does not require 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.¹⁰⁷ 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 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 let his or her family, friends, and doctors know that he or she has made a POA, and provide copies to those who may need it.

¹⁰⁶ Much of the information presented below is summarized from various chapters of publication *Consent, Capacity and Substitute Decision-Making* (Disability Rights Network and Pennsylvania Developmental Disabilities Council 2013), available at <https://www.drnpa.org/wp-content/uploads/2013/06/Chapter-2-Consent-and-Capacity-to-Make-Decisions.pdf>, and is reproduced here in summary form with the permission of the Disability Rights Network and Pennsylvania Developmental Disabilities Council. We highly recommend that this publication be consulted for more details and precise information regarding substitute decision making.

¹⁰⁷ 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>.

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 most appropriate for youth who have impairments or conditions that are expected to progress and impair their ability to make decisions.

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, without needing to be 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 law¹⁰⁸ 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

A youth's attending physician, health care provider, or any employee of his or her provider cannot serve as his or her health care representative, unless they 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 without judicial involvement.

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

An individual can identify 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. This requires the youth to write and sign a document designating the person(s), or to tell his or her physician who he or she would like to serve as a health care representative.

¹⁰⁸ 20 Pa. C.S.A. §5461(d).

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.¹⁰⁹

What is guardianship?

Guardianship of the person is one of the most, if not the most, intrusive forms of substitute decision-making; it imposes the greatest limits on the personal autonomy of the individual with a disability. It also is usually unnecessary since lesser forms of substitute decision-making can be used in most situations without imposing the same restrictions on the individual's choices and right to control his or her own life and services.

A court can appoint a guardian over an adult to make some or all decisions after it has been determined that the adult lacks capacity to do so. A "guardian of the person" can only be appointed by the court and after the court has determined that the adult is "incapacitated" with respect to making certain decisions (see below for a more detailed definition). A person will be deemed incapacitated if his or her ability to receive and evaluate information effectively and to communicate decisions is so impaired that he or she cannot meet the essential requirements for his or her physical health or safety.

What types of guardianship are there?

There are various types of guardianship that a court can order:

- A "plenary" guardian has authority to make medical decisions for the person who has been deemed to lack capacity.
- A "limited" guardian acts only in the capacity outlined by the court.
- A "guardian of the estate" deals exclusively with financial matters and has no authority to make medical decisions.

¹⁰⁹ 20 Pa. C.S.A. §5461(a).

What types of decisions can the guardian make?

A guardian's legal decision-making authority is defined by the court that appoints him or her. The scope of the order should reflect the young adult's needs and should allow the young adult to have maximum decision-making authority to the fullest extent possible. The guardian should respect the wishes of the individual and encourage him or her to participate in decision-making.

The guardian of the person must submit annual reports to the court concerning the services the individual is receiving, the number of times the guardian visited the person during the year and the length of those visits, and any major medical or mental health problems the individual experienced during the year.

What is the process for getting a guardian appointed for a young adult who is in foster care past age 18 or who is about to age out of foster care?

Guardianship petitions must be filed in the county Court of Common Pleas, Orphans Court Division. The petition must allege that the individual is incapacitated. Under the law, an incapacitated person is defined as:

An adult whose ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that he is partially or totally unable to manage his financial resource or to meet essential requirements for his physical health and safety.¹¹⁰

The law makes clear that being institutionalized does not create a presumption of incapacity.¹¹¹ Specific facts must be alleged and presented in the petition to demonstrate the individual's incapacity and its impact on decision-making. The petition must also spell out the scope of the order requested and the identity of the proposed guardian.¹¹² Specific evidence and testimony must also be presented to support the allegations.¹¹³ The individual for whom the petition is being filed has the right to hire counsel in the proceeding, and the court "in appropriate cases" may appoint counsel to the individual if he or she is not able to hire counsel.¹¹⁴

What are some factors to consider in determining if a guardianship petition should be filed?

You should consider whether guardianship proceedings are necessary, or whether less intrusive means exist to assist the individual with decision-making. If you determine that a petition should be filed, here are some important factors to consider:

- Who will file the petition in Orphans Court?

¹¹⁰ 20 C.S.A. § 5501.

¹¹¹ 20 C.S.A. § 5512.1(f).

¹¹² 20 C.S.A. § 5511(e).

¹¹³ 20 C.S.A. § 5518.

¹¹⁴ 20 C.S.A. § 5511(a).

- Note that it may be a conflict for the youth’s Guardian *Ad Litem* to file a petition alleging incapacity of his or her client.
 - Is *pro bono* counsel available to file a petition?
 - Can a request be made at the youth’s permanency review hearing for the juvenile court to appoint an attorney to file the petition as part of the court’s plenary jurisdiction and the transition planning obligation?
- Who will serve as the guardian?
 - Is there a relative, mentor, or involved individual who is willing to be appointed?
 - Is there an agency that provides individuals who could serve as a guardian?

For more detailed information about the guardianship process, please see *Guardianship In Pennsylvania, in Consent, Capacity and Substitute Decision-Making* (Disability Rights Network and Pennsylvania Developmental Disabilities Counsel 2013), available at:

<https://www.drnpa.org/wp-content/uploads/2013/06/Chapter-2-Consent-and-Capacity-to-Make-Decisions.pdf>.

What can be done if a youth is not able to manage his or her disability benefits when he or she reaches adulthood?

An adult can be appointed as a representative payee to help manage a youth’s SSI or other cash assistance benefits. It is not necessary to appoint a guardian for this purpose. See directly below for more information about SSI.

C. Accessing Supplemental Security Income (SSI) in the Child Welfare System and upon Transition

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, who have limited income and resources. In addition to cash assistance, individuals who are eligible for SSI are also 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 benefit. In 2013, the SSI benefit rate for an individual in Pennsylvania, including the state supplement, was \$710.00 a month.¹¹⁵ Based on an individual’s living arrangement and funds that may be counted as income, the full benefit may not be received by the recipient.

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

In large part, eligibility for SSI depends on two main factors: (1) a determination of disability; and (2) very low or no income and resources. There is a children’s standard for disability and an adult standard. While the income and resource limits for minors usually depend on their parents’

¹¹⁵ *Supplemental Security Income in Pennsylvania* (Social Security Administration 2013), available at <http://www.ssa.gov/pubs/EN-05-11150.pdf>.

income, the issue is more complicated for youth who are placed in the child welfare system. It is this complexity that often makes receipt of SSI while a youth is in the child welfare system less common than it might otherwise be. If a youth's placement is paid for with Title IV-E funds, that cost is counted as the child's income for the purpose of determining SSI income eligibility.

What is the disability standard for individuals under age 18?

Eligibility for youth under age 18 is determined based on the childhood standard of disability. SSI is available for children who have a "medically determinable physical or mental impairment, or combination of impairments, which causes marked and severe functional limitations, and which can be expected to cause death or which has lasted, or is expected to last, for a continuous period of not less than 12 months."¹¹⁶ For this determination, the SSA compares the child's functioning to that of other children of the same age who do not have impairments.

What is the disability standard for an individual who is age 18 or older?

The adult standard for disability is demonstrated when an individual shows

the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. To meet this definition, you must have a severe impairment(s) that makes you unable to do your past relevant work or any other substantial gainful work that exists in the national economy.¹¹⁷

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

If child is already receiving SSI when he or she reaches age 18, he or she is not automatically cut off from SSI benefits at age 18 and the adult standard is not immediately used. Instead, as the child is nearing his or her 18th birthday, he or she will undergo a review to determine if he or she meets the adult standard for disability. This is referred to as the Age 18 Redetermination.

There is one exception to this rule. If youth are involved in an approved vocational rehabilitation program, still in high school and with an Individualized Education Plan (IEP), or involved in another similar program approved by the SSA, they may be able to continue SSI eligibility at least until they complete the approved program. This is sometimes referred to as continued payment under Section 301.¹¹⁸

What is included in an SSI application for a youth under age 18?

An SSI application includes several forms that request information about the youth's disability and income.

¹¹⁶ 20 C.F.R. § 416.906 (Basic definition of disability for children).

¹¹⁷ 20 C.F.R. § 404.905 (Basic definition of disability for adults).

¹¹⁸ See *CDR or Age-18 Medical Redetermination Waiver*, Social Security Administration Program Operations Manual DI 60060.030, available at: <https://secure.ssa.gov/poms.NSF/lrx/0460060030>.

First, SSA will have to see the youth's birth certificate and social security card. If the youth is not a citizen, proof of valid immigration status will need to be presented.

Second, the following forms will need to be submitted to the SSA:

1. The Disability Report – Child, which can be found at <http://www.ssa.gov/online/ssa-3820.pdf>.
2. The Questionnaire for Children Claiming SSI Benefits, which can be found at <http://www.ssa.gov/online/ssa-3881.pdf>.

The two forms listed above should be filled out with the youth along with someone who has comprehensive information about the youth's disability, the treatment received, and how the disability impacts the youth's functioning. A caseworker or Guardian *ad Litem* who is familiar with the youth's history and case file is in an ideal position to provide the information requested.

3. The Teacher Questionnaire, which can be found at <http://www.ssa.gov/online/ssa-5665.pdf>.

This form should be completed by the youth's teachers for submission to the SSA. While the SSA will ask for contact information for the youth's teachers and send them this form, it is recommended that those working with the youth confirm that the teachers have completed the form and provide a copy to submit if they have not received it. The information provided by the teachers can be extremely helpful so it is important to stay on top of this.

While the SSA will request records and other information from the treatment providers that are identified on the forms listed above, it is recommended that you work with the youth to submit the records that you have related to the youth's disability and treatment. Submitting records with the application can expedite the disability determination process by providing the SSA with the most comprehensive information and eliminating the need for additional evaluations and requests for records. Many of the needed records are in the child welfare agency's case files; submit them to the SSA once the proper releases are signed.

Third, a Disability Interview will need to occur.

To find out more information about the SSI application process for a youth under age 18, see the SSI Child Disability Starter Kit at http://www.ssa.gov/disability/disability_starter_kits_child_eng.htm.

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

The application process looks similar to the application process for youth under age 18, but different forms are used and the standards for determining eligibility change for adult applicants, as discussed above. The applicant will need to fill out an application that asks for basic information about him or her 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>.

Just like the application for youth under age 18, 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.

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.

What happens once the application is filed and all the documents and forms have been submitted?

Once an application is filed, the SSA sends all of the information provided about the child to the Disability Determination Services office. Doctors and other trained staff in that state agency will review the information. If they have not received enough information, they will request the youth's medical and school records, and any other information needed to decide if the individual is disabled. If the state agency cannot make a disability decision using only the medical information, school records and other facts they have, they may ask you to take the child for a medical examination or test, which is conducted at the expense of the SSA.¹¹⁹ Because the process can take some time, it is recommended that you submit the youth's records and any other information you think is relevant along with the application. This may expedite the determination process by providing the SSA with the most comprehensive information possible. If the youth is in care, chances are that many of these records are easily accessible and can be submitted to the SSA with the proper release.

Who can apply for SSI benefits on behalf of a youth in foster care who is under age 18?

An application may be signed and submitted by a court appointed representative or person who is responsible for the care of the youth (such as a relative), or a social service agency, such as the county child welfare agency.¹²⁰

Who can apply for SSI benefits for a youth in foster when the youth is age 18 or older?

Because an 18 year old is a legal adult, he or she should be the applicant unless he or she has been found incapacitated. The child welfare agency and the youth's lawyer can and should help the youth with the application, however, the young adult should be involved in the process and sign the application.

¹¹⁹ Social Security Administration, *Benefits for Children with Disabilities*, at 7, available at: <http://www.ssa.gov/pubs/10026.pdf>.

¹²⁰ 20 C.F.R. § 416.315.

What if the application for SSI is denied?

If the application is denied, the denial should be appealed as soon as possible. An appeal must be filed within 60 days. If the youth is under age 18, the individual applying for the youth should file the appeal. If the youth is age 18 or older, he or she should file the appeal with the assistance of a lawyer or caseworker. After the appeal is filed, contact the local legal services agency to see if they provide representation in appeals of SSI denials. To find a legal services agency in your area check www.palawhelp.org.

Can a youth who is in foster care receive SSI?

Yes. Youth in foster care (under or over age 18) who have disabilities can apply for and receive SSI. As explained above, the SSI eligibility criteria is two-pronged. Youth with severe disabilities may meet the criteria for 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 deemed the youth's income. In certain situations, this will make the youth ineligible for SSI based on income.¹²¹

If a youth is Title IV-E eligible, the foster care maintenance payment (both the federal and state portions) is counted as the youth's income. The SSI benefit is offset dollar-for-dollar by the foster care maintenance payment. In the event that the Title IV-E payment is greater than the SSI payment, the SSI amount will be reduced to zero, and the SSI benefits will be placed in suspense. After 12 consecutive months of benefit suspension for any reason, SSI benefits are terminated. If the Title IV-E payment is less than the SSI benefit, the dollar-for-dollar offset will result in the child receiving the entire IV-E payment and an SSI benefit equal to the difference between the two benefits, but the total benefit the child receives will not exceed the SSI rate.

If the youth is not IV-E eligible and the foster care placement is funded by state and local dollars, depending on the eligibility criteria for payment, it is possible that the cost of care may not be deemed as the youth's income and would not offset any amount of the SSI benefit.¹²²

In practice, this means that for youth who are in the child welfare system and meet the required disability standard:

- Most Title IV-E eligible youth will not be income eligible for SSI unless the cost of the care is less than the SSI payment,
AND

¹²¹ What is counted as income for the purposes of SSI eligibility is defined in the federal law and regulations. The policy that breaks down how different types of foster care funding is counted can be found at Programs Operations Manual Systems (POMS) SI 00830.410, available at: <https://secure.ssa.gov/apps10/poms.nsf/lnx/0500830410#a1>. It is important to note that while Title IV-E foster care placement maintenance funds are counted as income for the youth, funds or benefits provided to youth under the Chafee Foster Care Independence Act, 42 U.S.C.A. § 677 are not counted as income.

¹²² See POMS SI 00830.410 ("Foster care payments funded wholly by a State or local government and under a program that uses income as a factor of eligibility are assistance based on need" and are "excluded from income.")

- Many youth who are not IV-E eligible and have their care funded by state and local dollars are likely to be income eligible for SSI.

If a youth is both income eligible and meets the disability standard, what would be the benefit of receiving SSI while in care?

While it will depend on the specific needs of the youth and his or her placement needs, the benefits to receiving SSI while in care may include:

- The SSI monthly payment may provide more funds than the foster care rate to assist with meeting needs and exposing the youth to more opportunities and enrichment activities.
- Receipt of SSI and an understanding of the responsibilities of the representative payee may lead the youth’s team to focus more carefully on meeting the youth’s disability needs, especially as the youth transitions.
- While the bulk of the SSI funds will be used for the care and maintenance of the youth (room, board, etc.), a portion can and should be used for any unmet disability needs.
- Receipt of SSI while in care will allow for a smooth transition and will open up housing and other service options for youth when they transition from care.

If a youth gets SSI while in foster care, who is the payee?

Regardless of whether a child is in foster care or in his or her own home, the majority of youth under age 18 need a representative payee to receive and manage the SSI benefit.¹²³ In general, the “representative payee” is the person who receives the check on behalf of a child receiving SSI. In most cases, it is the youth’s parent. The federal regulations provide a descending hierarchy of individuals and organizations who can serve as the representative payee for an individual under age 18:

- 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 wellbeing 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 institution.¹²⁴

The representative payee should have a continuing relationship with the youth and know about his or her disability and treatment needs. Appointing the child welfare agency as the youth’s representative payee is the least preferred option. All efforts should be made to identify an

¹²³ 20 C.F.R. §416.610 (b) (When payment will be made to a representative payee).

¹²⁴ See 20 C.F.R. §404.621(c) (order of preference in selecting a representative payee).

individual who cares for and has a relationship with the youth and is familiar with the youth's disabilities and needs. In determining the appropriate representative payee, the SSA should select the individual who will "best serve the beneficiary's interests."¹²⁵ To make this determination, the SSA will consider: "(a) The relationship of the person to the beneficiary; (b) The amount of interest that the person shows in the beneficiary; (c) Any legal authority the person, agency, organization or institution has to act on behalf of the beneficiary; (d) Whether the potential payee has custody of the beneficiary; and (e) Whether the potential payee is in a position to know of and look after the needs of the beneficiary."¹²⁶

Can minors ever receive payments directly as their own payees?

Yes, in certain cases. Upon an application, a youth may receive the payments directly if the SSA determines that he or she "shows the ability to manage the benefits."¹²⁷ SSA provides three examples of when this may be the case:

- (1) A parent and files for himself or herself and/or his or her child and he or she has experience in handling his or her own finances; or
- (2) The young person is capable of using the benefits to provide for his or her current needs and no qualified payee is available; or
- (3) The young person is within 7 months of attaining age 18 and is initially filing an application for benefits.¹²⁸

Does a youth who is still in the care of the child welfare agency and is over age 18 get to be his or her own payee for SSI?

Generally, yes. As a legal adult, at age 18, an individual is assumed to be able to manage his or her own funds and 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. This would be done in the following situations, when the individual is:

- legally incompetent or mentally incapable of managing benefit payments; or
- physically incapable of managing or directing the management of his or her benefit payments; or
- eligible for benefits solely on the basis of disability, and drug addiction or alcoholism is a contributing factor material to the determination of disability.¹²⁹

To overcome this, a youth may be able to get documentation from a doctor or treatment professional that he or she can manage his or her own money. If the SSA determines that the 18 year-old cannot manage his or her own funds, a payee should be appointed. The regulations provide a hierarchy of who can be appointed as a representative payee for an adult.¹³⁰ Just like

¹²⁵ 20 C.F.R. §416.621.

¹²⁶ 20 C.F.R. §416.620 (Information considered in selecting a representative payee).

¹²⁷ 20 C.F.R. §416.610(b).

¹²⁸ 20 C.F.R. §416.610(b).

¹²⁹ 20 C.F.R. §416.610(a).

¹³⁰ See 20 C.F.R. § 416.621. The hierarchy is the following: (1) A legal guardian, spouse (or other relative) who has custody of the beneficiary or who demonstrates strong concern for the personal welfare of the beneficiary; (2) A

the considerations for appointing a payee for a minor, the appropriate individual should have a relationship with the young person and have knowledge of his or her special needs, treatment, and services. The child welfare agency remains the least preferred payee.

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

Generally, no, but it depends. If a youth is in the care of the child welfare agency, the United States Supreme Court has ruled that the child welfare agency may require that the SSI funds be used to reimburse the agency for the cost of care.¹³¹ While the child welfare agency does not need to do this, it does not violate any laws when it requires that the SSI funds be used for this purpose. This means that if the cost of care meets or exceeds the SSI benefit, the youth will likely not have access to any of the SSI funds for his or her personal use.

To determine how the SSI is being used and if it can be used in a manner that is helpful to the youth's preparation for adulthood, it is recommended that the youth and his or her Guardian *ad Litem* investigate the following:

- Are there any excess SSI funds once the cost of care has been covered, which could be used either for future planning or additional services?
- 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 addressed through 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?¹³²

friend who has custody of the beneficiary or demonstrates strong concern for the personal welfare of the beneficiary; (3) A public or nonprofit agency or institution having custody of the beneficiary; (4) A private institution operated for profit and licensed under State law, which has custody of the beneficiary; and (5) Persons other than above who are qualified to carry out the responsibilities of a payee and who are able and willing to serve as a payee for the beneficiary; e.g., members of community groups or organizations who volunteer to serve as payee for a beneficiary.

¹³¹ *Wash. State Dep't of Soc. & Health Serv. v. Guardianship Estate of Keffeler*, 537 U.S. 371 (2003).

¹³² An emancipation 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.

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 him or her based on his or her “best interests.”¹³³ This includes using funds for “for the beneficiary’s current maintenance,” or “costs incurred in obtaining food, shelter, clothing, medical care, and personal comfort items,”¹³⁴ including the cost of foster 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.¹³⁵ As discussed above, if there are excess SSI funds left after the cost of care is covered, those funds should be conserved and used for the youth’s benefit.¹³⁶ In addition, as the youth gets older, he or she should request to be part of the decision making process in how funds are used as a means to learn budgeting and money management skills.

The representative payee is responsible for accounting for the use of SSI funds. The youth and his or her Guardian *ad Litem* should request an accounting if they are concerned about misuse to determine if sanctions should be sought or another payee should be appointed. A governmental entity is the least preferred payee. Thus, if the youth has an idea for a more appropriate payee, the Guardian *ad Litem* can raise this in court and then communicate it to the SSA.

If a youth does not receive SSI while in care, when should an application be made to ensure that he receives the benefit upon leaving care? Whose responsibility is it to file?

If a youth’s cost of care is being paid for by Title IV-E funds, the youth can and should apply for SSI 90 days before his or her federal foster care benefits end.¹³⁷ This is pursuant to a new Social Security Administration Programs Operation Manual System (POMS) rule that will allow eligibility to be determined even if the youth would otherwise be ineligible because of the Title IV-E deemed income. This policy was put in place so that youth do not have to wait until discharge to apply and take the risk of being without SSI income for a period of time.

As explained above, if the cost of care is state funded, the youth does not face a similar bar to eligibility determination that IV-E eligible youth face. Thus youth whose foster care placement is state and locally funded, rather than funded by Title IV-E, should apply well before 90 days of

¹³³ 20 C.F.R. § 416.635 (What are the responsibilities of your representative payee?).

¹³⁴ 20 C.F.R. § 416.640 (Use of benefit payments).

¹³⁵ Umar Moulta-Ali, Adrienne L. Fernandes-Alcantara and Emilie Stoltzfus, *Child Welfare: Social Security and Supplemental Security Income (SSI) Benefits for Children in Foster Care* (CRS 2012), available at: http://greenbook.waysandmeans.house.gov/sites/greenbook.waysandmeans.house.gov/files/2012/documents/RL33855_%20v3_gb.pdf.

¹³⁶ 20 C.F.R. § 416.645(a) (“If payments are not needed for the beneficiary’s current maintenance or reasonably foreseeable needs, they shall be conserved or invested on behalf of the beneficiary.”).

¹³⁷ See POMS SI 00601.011 (Providing as background to this rule change: “Disabled youth receiving Title IV-E federal foster care benefits usually cannot become eligible for SSI until foster care payments have stopped. Eligibility for foster care payments in most States ends at age 18 attainment. These youth need the income support and health services that result from SSI eligibility to ease the transition to independent living. To help with this transition, SSA may accept an SSI application from a youth up to 90 days before his or her foster care eligibility will end due to age. This is an exception to the general rule of accepting an SSI application in the month before the month of eligibility...”).

discharge; we recommend at least 6-9 months in advance of discharge to ensure a smooth transition.

While the new 90 days rule is an improvement, in many cases the disability determination process takes far longer than three months. Recognizing that this could often lead to a gap in services for a child aging out, the U.S. Department of Health and Human Services allows youth in foster care to apply for SSI during any month in which they are only receiving state-funded care.¹³⁸ This means that a request could be made to the child welfare agency to temporarily stop receiving IV-E payments for the youth and switch to state-only funding during the application process. While it is likely that the county child welfare agencies will be resistant to this request, nothing prevents them from doing this, and the youth can be switched back to Title IV-E funding the month following the application. If the youth's application is approved, the benefits can be placed in suspense for up to 12 months and reinstated upon emancipation, allowing a smooth transition.¹³⁹

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 the youth's functioning, including his or her ability to care for himself or herself 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 4 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).
- Assist youth in completing the Adult Disability Report! It is a long form and can be complicated to complete.

¹³⁸ Laura King and Aneer Rukh-Kamaa, Social Security Administration, Office of Retirement and Disability Policy, *Note: Youth Transitioning Out of Foster Care: An Evaluation of a Supplemental Security Income Policy Change*, available at: <http://www.ssa.gov/policy/docs/ssb/v73n3/v73n3p53.html#mn4>. This model—switching a youth to state funds during the month of application—has been embedded in California law to create a policy where SSI eligibility is established well before discharge from care. Cal. Welf. & Inst. Code §13757 (a) requires that youth in care be screened for SSI eligibility at age 16.5 and that the application is timed to allow for a determination of eligibility by the Social Security Administration “prior to the youth’s emancipation from care including, if appropriate, the suspension of Supplemental Security Income benefits for no more than 12 months.” In addition, the law requires that “for a youth receiving federally funded [Title IV-E] benefits, the county shall, if necessary, forego federally funded [Title IV-E] and instead use state ... resources to fund the placement in the month of application or in the month after making an application, and to subsequently reclaim federally funded [Title IV-E], in order to ensure that the youth meets all of the SSI eligibility requirements in a single month while the application is pending, as provided by federal law and regulation ... this section shall apply to a foster youth regardless of his or her federal [Title IV-E] eligibility.” Cal. Welf. & Inst. Code §13757 (b).

¹³⁹ Hannah Haley, Chris Lee, Angie Schwartz and Amy Lemley, John Burton Foundation, *Two Years Later: Has California’s Approach to Securing SSI Benefits for Disabled Youth Who “Age Out” of Foster Care Made a Difference?*, at 3, available at: http://www.ssitransitions.org/pdfs/Two%20Years%20Later_Final.pdf.

How can SSI be a helpful part of a transition plan? What other benefits and services can it help access?

Because many youth exiting care have a difficult time securing housing and sufficient income to cover the cost of basic needs, SSI is critical to youth during the transition period. This is especially true for youth with mental health impairments who have access to fewer targeted programs for housing than do youth with other disabilities.

In addition to being a crucial source of income for meeting basic needs, establishing SSI eligibility can often lead to eligibility for other important services that can complete the transition plan. For example, the disability determinations made for SSI eligibility may automatically qualify a youth for certain types of housing assistance that depend on the demonstration of a disability. As will be discussed below, an individual must be receiving SSI to be eligible for the living arrangement of domiciliary care. Further, SSI is categorically linked to Medical Assistance, ensuring that youth have access to the medical services (including mental health care) they require.

SSI payments can encourage caregivers to continue providing care to a youth who is exiting formal foster care, but may still want to live with the same individual or family. The cash payments can help offset the loss of economic support from the court system, and provide the financial stability necessary to continue providing care.

Can a youth work while receiving SSI?

Yes. Even though part of the SSI eligibility determination has to do with the amount of income an individual makes, there are certain circumstances where money made from work may not count against an individual's eligibility for SSI. 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 postsecondary education or training program is able to have a certain amount of his or her income from work excluded from the income that is counted for the purposes of eligibility.¹⁴⁰

In addition, there are several programs that allow individuals to set aside money to use to implement a plan to enter or re-enter the work force or achieve self-sufficiency. This could include money set aside to attend a vocational program or money for special tools or equipment to be used in a program or on the job. One of these programs is called a Plan for Achieving Self Support (PASS).¹⁴¹ The money set aside to spend on a training program, equipment, or other supports that is set out in the PASS would not be counted as income. To find out more about the work incentives that an individual receiving SSI may be eligible to receive, contact Disability

¹⁴⁰ "In 2013, disabled students younger than age 22 [were able to] exclude \$1,730 of their monthly earnings, with an annual limit of \$6,960, when counting their income for SSI purposes. These limits may increase each year. Social Security Administration, *Benefits for Children with Disabilities*, available at: <http://www.socialsecurity.gov/pubs/EN-05-10026.pdf> at 14.

¹⁴¹ 20 C.F.R. § 416.1180.

Rights Network of Pennsylvania at 1-800-692-7442 and ask for the Community Work Incentives Coordinator.

D. Accessing Medicaid Waivers and Similar Programs

Because of the limitations in Medical Assistance coverage for adults, individuals may need significant supports and services that exceed the limits of their insurance coverage both in terms of level and type of services. These individuals will need to figure out benefits and supports that will help them meet their health and support needs to fill the gaps. One of the sources of treatment services and supports includes Medicaid Waivers. Medicaid Waivers provide medical and non-medical services for individuals with significant cognitive, developmental, and physical disabilities so that they can remain in the community. Services can be paid for through Waivers that may be limited under Medical Assistance coverage. For transitioning youth, these Waivers are crucial for maintaining their level of care, ensuring that they continue to progress in treatment, and have an opportunity to flourish in the community.

What are Medicaid Waivers?

Medicaid Waivers are technically called the Home and Community Based Services (HCBS) Waiver program (“the Waiver program” or “the Waivers”). The various Waivers provide long-term care and services for individuals who have significant disabilities and who are at risk of institutionalization. The Waiver program funds medical and non-medical services to individuals living in the home of family members or in other community based settings. The Waivers fund services and supports in addition to what can be provided under the individual’s MA coverage.

Under federal law, the Medical Assistance (MA) program has various requirements and restrictions on the provision of care. These include prohibitions on covering non-medical services and limitations on the amount of service hours provided. Section 1915(c) of the Social Security Act¹⁴² was enacted in 1981 and allows states to apply to the federal Medicaid agency to waive some of these requirements for the purpose of providing care and services to individuals with disabilities to avoid institutionalization. All states, including Pennsylvania, created Waiver programs to provide a comprehensive package of medical and non-medical services to eligible individuals. Below is information about some of the Medicaid Waivers that are offered in Pennsylvania. Each Waiver is targeted at individuals with certain disabilities or impairments. They each have functional eligibility criteria as well as income criteria. Because the majority of youth transitioning from the child welfare system will meet income criteria, we do not focus on that portion of the requirements.

Waiver funded services provide alternatives to institutionalization. This, of course, means that there are institutions throughout the state in which individuals with disabilities can reside if they meet certain criteria. But there are other options available for them as well. Therefore, institutionalization should be a last resort and should not be accepted as an alternative to making

¹⁴² Sometimes Medicaid Waivers are referred to as 1915(c) Waivers. One program, called Act 150, provides services similar to the Medicaid Attendant Care Waiver. The Act 150 program is state-funded and is for individuals who have more income than is required for eligibility for the Medicaid Waivers. To apply for Act 150 Services use the same process described below for the application for the Attendant Care Waiver.

efforts to support an individual in the community. The information below provides tools for seeking community based services and settings for young adults rather than institutionalization.

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 the young adult is seeking. 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. Involve in the ISP meeting all professionals and other individuals who work with and provide treatment to the youth. ISP meetings must occur to write 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 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 the youth is applying for so that you can plan appropriately.

Why are Medicaid Waivers important for transitioning youth with disabilities?

Youth with significant disabilities in the child welfare system have the majority of their medical needs met through their MA coverage under the EPSDT requirement, which guarantees that medically necessary services be provided with few restrictions. When a youth loses the EPSDT guarantee at age 21, many needed services are no longer covered by MA and no other system—equivalent to the child welfare system—exists to cover the gaps. Youth entering adulthood who want to live in the community and not in an institution will need a source of funding for medical and non-medical services. Medicaid Waivers often provide that source of funding, and make up one piece of the planning puzzle, which often also includes SSI and MA.

What Waivers are available for individuals with Intellectual Disabilities (ID)?

For youth to be eligible for ID Medicaid Waivers they must be registered with the county office of Intellectual Disabilities (IDS) well before they age out of the child welfare system. Please refer to the information presented in Section One (D) for more information on the registration process. These services are not entitlements and there are long waiting lists for them. In general, services for adults registered with IDS will be delivered through one of two Medicaid Waivers: the Person/Family Directed Supports Waiver and the Consolidated Waiver. Medicaid Waivers, a combination of federal and state monies, fund the bulk of services and supports for an individual with ID as they transition to adulthood. But there also are some state funds—called Base funds—that are allocated to provide some services to individuals with ID. Professionals and advocates should ask their county IDS offices what Base funds are used for and if the youth they are working with may access them. Base funds may be especially useful if there is a gap in services or supports while the youth is waiting to get off a Medicaid Waiver waiting list.

1. Person/Family Directed Support Waiver (PFDS)

If the young adult has a family or caregiver that he or she can live with upon discharge from the child welfare system, and the cost of the services needed does not exceed \$26,000 a year,¹⁴³ the PFDS Waiver may meet the individual's transition needs. In this situation, the PFDS Waiver combined with the SSI benefit and MA coverage may provide sufficient support for a successful transition. Examples of services that can be provided through this Waiver include:¹⁴⁴

- Behavior support
- Companion services
- Home accessibility adaptations
- Home and community habilitation services
- Homemaker/chore services
- Licensed day habilitation
- Nursing
- Prevocational services
- Respite
- Specialized Supplies
- Supports broker
- Supports coordination
- Therapy (physical, occupational, visual/mobility, behavioral and speech and language)
- Educational support
- Transitional work
- Supported employment
- Assistive technology
- Transportation
- Vehicle accessibility adaptations¹⁴⁵

Where would an individual receiving the PFDS Waiver live?

The majority of individuals receiving this Waiver would live in the home of family who are able to care for them with the support of the services listed above. In these situations, the individual would also receive SSI to help defray the cost of room and board.

2. **Consolidated Waiver**

If the individual with ID does not have a family setting to go to and has fairly high needs for supervision and support, he or she likely will need the Consolidated Waiver. The majority of

¹⁴³ This is the amount set for 2013.

¹⁴⁴ For a detailed description of the services listed below for the PFDS and Consolidated Waiver, please see *Individual Support Plan (ISP) Manual for Individuals with an Intellectual Disability 28-99* (Commonwealth of Pennsylvania Department of Public Welfare Office of Developmental Programs 2013), available at: http://www.temple.edu/thetrainingpartnership/resources/mrBulletins/ss/00-12-05_ISP_Manual.pdf

¹⁴⁵ To learn more about what each of the listed services include see *Understanding the Office of Developmental Programs*, at pp.26-50.

youth in the child welfare system with ID will need this type of Waiver because of a lack of family resources. The types of services provided under this Waiver include all of the services listed above for the PFDS Waiver except for respite care. It also includes licensed residential habilitation, which involves support in the areas of self-care, communication, motor skills, mobility, therapeutic activities, relationship development, socialization, and community resources. These services are provided to the individual in family living/life share and licensed residential settings. Finally, one of the key differences between the PFDS and Consolidated Waiver is that there is no financial cap on the Consolidated Waiver. As with all Medicaid Waivers, for a service to be provided, it must be listed in the ISP so it is important to be involved in the ISP development meeting.

What living settings are funded through the Consolidated Waiver or may be paired with the Consolidated Waiver?

Small group settings or community group homes are options. Another option is family living or life share. In family living/life share, individuals live in a family home, but are treated as adults and are given the freedom and independence of adults while still receiving supports. Some child welfare foster care providers may opt to become licensed or certified as a life share home so that they can continue caring for a youth when he or she discharges from the child welfare system. *See Text Box on page 40 for an example of where this has occurred.* Finally, supported living settings in apartments are an option for individuals who require less than 30 hours of staff support per week. For more information on these settings *see “Choosing Where You Want to Live,” in Understanding the Office of Developmental Programs, at pp. 60-61.*

How do you start the application process for an ID Waiver?

Once the youth is registered with IDS, the Supports Coordinator (SC) will consider which of the two ID Waivers will be appropriate. Advocates and professionals working with the youth should provide input into this decision because they are in the best position to know the youth’s resources and capacities. As explained in Section One (D), IDS registration is done through the county office of Intellectual Disabilities. Once the youth is registered, the SC will coordinate and be responsible for the Waiver applications. However, it is important for those working with the youth to ask about which Waiver will be sought and the timelines for referring to living arrangements.

Are there any Waivers available for individuals with autism?

The Adult Autism Waiver is available for eligible individuals who are age 21 or older.

What are the eligibility criteria for the Adult Autism Waiver?

In addition to meeting income eligibility requirements, the individual must meet the following two criteria:

- have a diagnoses of autism spectrum disorder, which includes:
 - Autistic disorder
 - Pervasive developmental order, not otherwise specified
 - Asperger Syndrome
 - Childhood Disintegrative Disorder
 - Retts Disorder

AND

- have functional limitations in at least three of the areas listed below, and those imitations must have been evident prior to the individual reaching age 22:
 - self-care
 - understanding and using receptive and expressive language
 - learning
 - mobility
 - self-direction
 - capacity for independent living

What services are provided under the Adult Autism Waiver?

Examples of services provided under the Adult Autism Waiver include:¹⁴⁶

- Assistive technology
- Behavioral Specialist Services
- Community inclusion
- Community transition services
- Day habilitation
- Environmental modifications
- Family counseling
- Family training
- Job assessment and finding
- Nutritional consultation
- Residential habilitation
- Respite
- Supported employment
- Supports coordination
- Temporary crisis services
- Transitional work services

¹⁴⁶ For detailed descriptions of these services, see *Understanding the Office of Developmental Programs*, at pp. 94-101.

- Therapy, including:
 - Counseling
 - Occupational therapy
 - Speech and language therapy

As noted below, in the past some individuals with autism have been served in the OBRA Waiver so it should also be considered for young adults with autism who meet the eligibility criteria for the OBRA Waiver.

Where does an adult live if he or she receives the Adult Autism Waiver?

If the individual has a family able and willing to care for him or her, services can be provided in that setting as well as in the community. An adult who does not have family resources could live in a community home or family living/life share home. In most cases the Waiver covers the staffing of the living setting and the individual’s SSI would cover the cost of room and board.

How do you begin an application for the Autism Waiver?

Call the Bureau of Autism at 1-866-539-7689 to begin the application process. Leave a message with the name of the applicant and your (the caller’s) contact information if you are facilitating the application. Be prepared with documentation of the youth’s autism diagnosis.

What is the Adult Community Autism Program (ACAP) and what counties have it?

The ACAP program offers a wide array of treatment and support services for individuals with autism. Currently ACAP is only available in the following counties: Chester, Cumberland, Dauphin, and Lancaster.

To be eligible, the individual must meet the following criteria:

- Be age 21 or older
- Be eligible for MA
- Have a diagnosis of Autism Spectrum Disorder
- Be certified as meeting MA requirements for eligibility for an Intermediate Care Facility
- Not be currently enrolled in an MA Waiver
- Not be enrolled with a Managed Care Plan at the time of enrollment
- Be able to live in the community safely without 16 or more paid or unpaid staff and supervision hours per day
- Not exhibit behaviors that would post a danger to self or others

For more information about this program see: <http://www.dpw.state.pa.us/foradults/autismservices/adultcommunityautismprogramacap/acapgeneralinformationquestions/index.htm>.

If you are working with a transitioning youth who is diagnosed with autism in Chester, Cumberland, Dauphin, and Lancaster County, the ACAP program may provide the necessary supports to complete a solid transition plan. Individuals in these counties are still able to apply

for the Autism Waiver. However, an individual cannot be in the Autism Waiver and served by the ACAP program at the same time.

How do you begin the application for the ACAP Program?

Call the Bureau of Autism at 1-866-539-7689 to begin the application process.

Who is eligible for the Attendant Care Waiver?

To be eligible, the individual must meet the following criteria:

- Be age 18-59
- Have a physical impairment that will last at least 12 months
- Be mentally alert and able to direct his or her own care
- Be certified to be Nursing Facility Clinically Eligible¹⁴⁷

What services can an individual receive through the Attendant Care Waiver?

- Personal assistance services
- Personal Emergency Response System
- Community transition services if the individual is leaving an institution

How do you begin the application for the Attendant Care Waiver?

Call Maximus, the company contracted to be the enrollment broker for this Waiver, at 1-877-550-4227. You should receive a call to do an Initial Assessment within seven days. The Office of Long-Term Living administers this Waiver and can be reached at 866-286-3636 if you need information.

Who is eligible for the Independence Waiver?

To be eligible, the individual must meet the following criteria:

- Be age 18 or older
- Have a severe physical disability
- Not have mental retardation/another major mental disorder as a primary diagnosis
- Be certified to be Nursing Facility Clinically Eligible
- Have substantial functional limitations in at least three of the following areas:
 - Mobility
 - Communication
 - Self-care
 - Learning

¹⁴⁷ This level of care generally means that the individual needs help with non-medical activities such as bathing, dressing, and moving from a bed, chair, etc., to a wheelchair, and skilled care needs such as nursing, and physical and occupational therapy.

- Self-direction
- Capacity for independent living

What services are available through the Independence Waiver?

- Adult Daily Living Services
- Accessibility Adaptations, Equipment, Technology and Medical Supplies
- Community Integration
- Community Transition Services
- Financial Management Services
- Home Health Care, including nursing and other therapies
- Non-Medical Transportation
- Personal Assistance Services
- Personal Emergency Response System (PERS)
- Respite
- Service Coordination
- Supported Employment
- Therapeutic and Counseling Services

How do you begin the application for the Independence Waiver?

Call Maximus, which is a company contracted to be the enrolment broker for this Waiver, at 1-877-550-4227. You should receive a call to do an Initial Assessment within seven days. The Office of Long-Term Living administers this Waiver and can be called at 866-286-3636 if you need more information.

Who is eligible for the OBRA Waiver?

To be eligible, the individual must meet the following criteria:

- Be age 18 or older
- Have a developmental disability that manifests itself before the individual reaches age 22
- Not have mental retardation/another major mental disorder as a primary diagnosis
- Meet the Intermediate Care Facility/Other Related Condition Level of Care (See Section One (D) for the discussion on ICF level of care)

It is important to note that in the past some individuals with autism have been served through the OBRA Waiver.

What services are available through the OBRA Waiver?

- Adult Day Health Services
- Accessibility Adaptations, Equipment, Technology and Medical Supplies
- Community Integration

- Community Transition Services (if the individual is leaving an institution)
- Day Habilitation Services
- Home Health Care, including nursing and other therapies
- Non-Medical Transportation
- Personal Assistance Services
- Personal Emergency Response System
- Respite
- Prevocational Services
- Supported Employment
- Therapeutic and Counseling Services

How do you begin the application for the OBRA Waiver?

Call Maximus, which is a company contracted to be the enrolment broker for this Waiver at 1-877-550-4227. You should receive a call to do an Initial Assessment within seven days. The Office of Long-Term Living administers this waiver and can be called at 866-286-3636 if you need more information.

Who is eligible for the COMMCARE Waiver?

To be eligible, the individual must meet all of the following criteria:

- Be age 21 or older
- Have a medically determinable diagnosis of traumatic brain injury
- Require a Special Rehabilitative Facility (SRF) level of care¹⁴⁸
- Have limitations in at least three of the following areas:
 - Mobility
 - Communication (understanding and use of language)
 - Self-Care
 - Learning
 - Self-direction
 - Capacity for independent living

What services are available through the COMMCARE Waiver?

- Accessibility Adaptations, Equipment, Technology and Medical Supplies
- Adult Daily Living Services
- Community Integration
- Community Transition Services (if the individual is leaving an institution)

¹⁴⁸ A Special Rehabilitative Facility is defined as a “nursing facility with residents more than 70 percent of whom have a neurological/neuromuscular diagnosis and severe functional limitations.” 55 Pa. Code § 1187.2.

- Day Habilitation Services
- Home Health Care, including nursing and other therapies
- Non-Medical Transportation
- Personal Assistance Services
- Personal Emergency Response System (PERS)
- Residential Habilitation
- Respite
- Structured Day Program
- Supported Employment
- Therapeutic and Counseling Services

How do you begin the application for the COMMCARE Waiver?

Call Maximus, which is a company contracted to be the enrolment broker for this Waiver, at 1-877-550-4227. You should receive a call to do an Initial Assessment within seven days. The Office of Long-Term Living administers this Waiver and can be called at 866-286-3636 if you need more information.

Who is eligible for the AIDS Waiver?

To be eligible, the individual must:

- Be age 21 or older
- Have a diagnosis of Symptomatic HIV or AIDS
- Require hospital, skilled nursing, or Intermediate Care Facility level of care
- Be determined to benefit from medically necessary Waiver services

What services are available through the AIDS Waiver?

- Skilled Nursing services
- Home health aide services
- Homemaker Services
- Specialized Medical Equipment /Supplies
- Nutritional Consultations
- Transitional Services (if leaving an institution)

How do you begin the application for the AIDS Waiver?

Call Maximus, which is a company contracted to be the enrolment broker for this Waiver, at 1-877-550-4227. You should receive a call to do an Initial Assessment within seven days. The Office of Long-Term Living administers this Waiver and can be called at 866-286-3636 if you need more information.

For more detail on Medicaid Waivers, please see:

- *Home and Community Based Services Waiver Programs: A Manual For Consumers and Advocates in Southwestern PA* (Pennsylvania Health Law Project 2012), available at: <http://www.phlp.org/wp-content/uploads/2011/03/HCBS-MANUAL-Final-May-2009.pdf>.
- *Intellectual Disabilities Waiver Services in Pennsylvania* (Disability Rights Network 2012), available at: <http://drnpa.org/wp-content/uploads/2012/08/Intellectual-Disabilities-Waiver-Services-in-Pennsylvania.pdf>
- *Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services* (Vision for Equality 2010), available at: <http://www.temple.edu/thetrainingpartnership/resources/umrspa/goldbook201007.pdf>.

E. Special Issues Related to Behavioral Health and Housing Resources

There often is a lack of housing resources for transitioning youth who have mental health needs, but do not need an institutional level of care and should be able to live in the community with treatment. In this short concluding section, we provide a description of some resources that may exist in the counties in which you work to find housing resources for young adults. Some of these resources also may be helpful for individuals who have a disability that may qualify them for SSI, but not Medicaid Waiver services.

What is Domiciliary Care (“dom care”)?

Dom care is defined as “a supervised living arrangement in a homelike setting for a period exceeding 24 consecutive hours.”¹⁴⁹ The young adult lives in the dom care provider’s home. The homeowner provides some support and care as well as meals. The young adult creates House Rules with the dom care provider to make sure there is agreement about things such as going in and out of the house, having visitors, etc.

Who is eligible for dom care?

An individual is eligible for dom care if he or she meets the criteria below:¹⁵⁰

- Is 18 years of age or older
- Is independently mobile or semi-mobile
- Does not require skilled or intermediate nursing care, or general or special hospital care on a 24-hour residential basis
- Has no relative or resource willing or able to provide the necessary support for independent living
- Is incapable of living alone regardless of available services, or requires services to live alone and the services are not available

¹⁴⁹ 6 Pa. Code § 21.1. As discussed above, the dom care program is administered by the Area Aging Agency, but dom care is for individuals who are age 18 and older.

¹⁵⁰ The full eligibility criteria can be found at 6 Pa. Code § 21.21 (a)-(b).

- Meets one or more of the following criteria:
 - Has demonstrated difficulties in accomplishing activities of daily living
 - Has demonstrated difficulties in social or personal adjustment
 - Has demonstrated difficulties resulting from disabilities, such as blindness, deafness, amputation, paralysis or birth defects, if the individual is independently mobile or semi-mobile.

How is an application for dom care made?

Call the county agency for the aging in your area and tell them that you would like to begin an application for dom care for a young adult. Contact information for your local area agency on aging is found at this link: <http://www.portal.state.pa.us/portal/server.pt/community/aaas/17958>.

What does SSI have to do with dom care?

The main source of funding for dom care is the individual's SSI benefit and a state supplement that can only be accessed if the individual receives SSI. For all intents and purposes, an individual needs to have SSI to be eligible for dom care.

Are there any tips for accessing dom care for youth aging out of the child welfare system and making sure the setting is appropriate?

- Develop a relationship with your county dom care agency and a process for pre-screening transitioning youth prior to discharge from the child welfare agency. Generally, the application for dom care cannot be processed until the youth can demonstrate that he or she is eligible for SSI. Because SSA approval may not be available until close to the youth's discharge, consider building a formal or informal relationship with the dom care provider agency to develop a process for receiving applications and screening youth who are likely to be determined eligible for SSI.
- Prepare all materials and forms for the dom care application as soon as possible so that upon proof of SSI eligibility, the intake process can begin. There are several portions of the application that can be completed in advance of submission.
- Work with the youth to identify resources who may be willing to become a dom care provider. An individual who is not interested in becoming or remaining a foster parent may be interested in becoming a dom care provider due to the different obligations and certification process. Child welfare agencies and IL Programs should consider recruiting resources who could become certified as dom care providers who have some expertise and experience working with transitioning youth.
- Providers and agencies that have expertise in working with transition age youth should provide training and general support to dom care providers. Dom care is a great resource for young adults who need some degree of supportive living/housing. While dom care is for individuals age 18 and older, some dom care providers may have less experience

working with young adults. Building in some aftercare/transitional case management even after age 21 can go a long way to stabilizing the living setting.

Can young adults with behavioral health or physical health impairments be eligible for dom care?

Yes. As long as they meet the functional criteria, an individual with behavioral or physical health impairments could be eligible for dom care as long as he or she is receiving SSI.

What are personal care homes?

Personal care homes are residences that provide shelter, meals, supervision and assistance with personal care tasks for the elderly or individuals with a variety of disabilities, including cognitive, behavioral health, and physical disabilities.¹⁵¹ Sometimes personal care homes are also referred to as “assisted living facilities” or “boarding homes.” Eligible individuals need help with personal care, but do not need nursing homes or medical care. Personal care services include things such as:

- Eating and drinking
- Toileting, bathing, and hygiene
- Arranging for and managing health care
- Taking medications
- Doing laundry
- Shopping and managing finances
- Walking
- Getting in and out of a bed and chair

Personal care homes are inspected and licensed by the Department of Public Welfare and can be run by private agencies, not-for profits, and governmental agencies. Personal care homes are regulated pursuant to 55 Pa. Code § 2600 *et seq.* Some personal care homes are small (4 is the minimum capacity) while others house several hundred individuals. Some personal care homes will accept an individual’s SSI benefit to cover the cost of room and board and care.

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.¹⁵²

¹⁵¹ “Personal care homes are designed to provide safe, humane, comfortable and supportive residential settings for adults who do not require the services of a licensed long-term care facility, but who do require assistance or supervision with activities of daily living, instrumental activities of daily living, or both.” 55 Pa. Code 2600.1(b).

¹⁵² This FAQ can be found at <http://www.dpw.state.pa.us/fordisabilityservices/personalcarehomeinformation/personalcarehomefrequentlyaskedquestions/index.htm>.

What other programs or resources may be available to provide housing and support to a young adult with behavioral health impairments or other disabilities?

- Supportive Housing through the County Office of Behavioral Health and/or the young adult's MCO
Many counties have developed supportive housing programs to reduce the use of institutional care and hospitalization for individuals with behavioral health impairments. These programs come with varying level of support and different types of living arrangements. They are in high demand so check with your county Behavioral Health Agency, Homeless Services Office, as well as the young adult's MCO.
- Affordable Housing Locator Websites
There are at least two affordable housing search engines in Pennsylvania. These websites allow individuals to search for units that are subsidized as well as units that have special accessibility accommodations or are targeted at special populations. A subsidized or low cost unit, paired with other behavioral health services, may provide the youth sufficient support.
 1. Pennsylvania Affordable Apartment Locator
<http://pal.phfa.org>.
 2. Columbia Property Management Home Finder
<http://www.cpmhomefinder.com>.
- Local Housing Option Teams (L-HOTS)
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. Not all counties have L-HOTs, but it is helpful to consult them if they exist in your county. You can find a list of L-HOTS here: <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 specialists for each county: <http://www.pahousingchoices.org/housing-resources/mh-housing-specialists/>.
- 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 a 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.

Juvenile
Law Center
advancing the rights and
well-being of children in jeopardy

