



Pennsylvania Partnership
for the Deafblind

Hopscotching Your Way Through Transition:

**Questions Parents Need to Ask as Their Child with
Deafblindness Moves from School to the Adult World**

January 2010

Preface

This publication has been developed by the Board of Directors of the **Pennsylvania Partnership for the Deafblind (PPDB)**. The 2009-2010 Board is listed below:

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Susan Green – Vice President
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PPDB is a private, non-profit (501(c)(3)) corporation. The Partnership is a statewide organization. Our **mission** is to provide support to those who are deafblind and their families. PPDB includes all age groups in its membership.

Our goals are to:

1. Assist families in similar situations to connect with each other.
2. Inform members on key issues.
3. Collaborate with other organizations to ensure that our members' concerns on issues affecting people who are deafblind are heard and addressed.
4. Educate policymakers on deafblind issues.

PPDB has four committees – Finance, Membership, Outreach and Social/Events

To learn more about the organization, its activities, and how you can join, please go to the PPDB website: www.papdb.org

You can also contact Molly Black at 724-863-1283 or mblack@pattan.net

This document uses “he,” “she,” “his,” “hers,” “son,” “daughter” interchangeably. Services are the same for males and females.

A final note: This document is written **by** parents **for** parents. We are not “experts” on anything but our own children. Some of what we say will not apply to everyone in every situation, and we have many more questions than answers. Our purpose, however, is to help you develop a structured, logical, and effective approach to your child’s transition to the adult world.

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HOPSCOTCH & TRANSITION

Hopscotch was invented by the ancient Romans, as a way to improve the footwork of their soldiers. The hopscotch course was over 100 feet long and run in full armor and field backpacks.

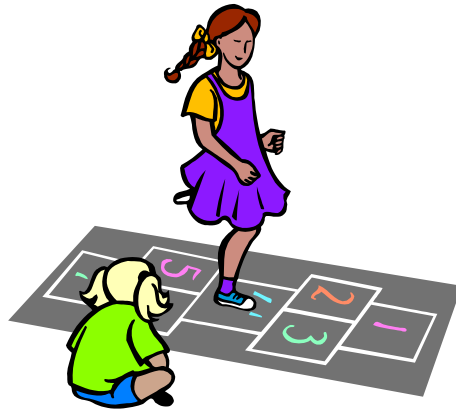


To successfully complete the hopscotch course, the Roman soldier needed:

- Good strategy
- Agility
- Balance
- Adaptability
- Strength
- Stamina

Today, the game is played much differently than in ancient times. Now it's played mostly by young children.

However, the players still develop many of the same skills of the Roman soldier – strategy, speed, balance, agility, etc. Once a player loses her balance, steps on a line, or misses her assigned square, her turn ends and she can lose the entire game.



But what does hopscotch have to do with the transition of a child who is deafblind from school to the adult world?

In thinking of the transition process for our children who are deafblind, the hopscotch analogy just seems to fit. Parents and their children must develop a strategy to hop from one service system to another, avoid problem squares, maintain our equilibrium, develop the strength and stamina to complete the process and win the game.

It's a bit more serious than just "winning the game," though, isn't it? In real life, the consequences of stepping on a crack, losing our balance, or missing a square are more serious than just losing a turn.

A single misstep can mean falling off a cliff – agonizing delays of some services, loss of eligibility for other services, missed opportunities for placements, and little or no funding for essential needs.



Thus, the transition game has real consequences. A real person’s quality of life is in the balance. Our kids will have to live with our successes and mistakes, because they often have limited ability to take corrective action for themselves.

Our kids are unique, because deafblindness is not simply the loss of two senses – it is much, much more complicated than that. To paraphrase Helen Keller: Blindness cuts you off from **things**, deafness cuts you off from **people**.

People who are deafblind have what is called “limited access to incidental learning.” That means that much of what they learn about the world is from touch. To a person with deafblindness, if something or someone can’t be seen or heard, it doesn’t exist! It could be just out of reach, but it doesn’t exist.

Consequently, transition is a high priority for our group, partly because of the unique needs of those who are deafblind

In addition, a large proportion of children with deafblindness in Pennsylvania are currently of transition age (about 33%). Since deafblindness is one of the lowest of the “low incidence” disabilities, however, this percentage, translated into real numbers, means that only about 140 transition-age children under 21 in the Commonwealth are deafblind!

The focus of this guide is to assist parents and families of children with deafblindness to develop an organized approach to transitioning their children from school to the adult world. Answers can’t be provided for each circumstance, but there are some questions that all parents should ask in order to keep their child who is deafblind from falling off the transition cliff.

WHAT IS TRANSITION?

“Transition” has been defined a number of ways, but PPDB has chosen to define transition as

The **PROCESS**

Of **PREPARING**

YOUNG PEOPLE with **DEAFBLINDNESS**

To **MOVE**

SUCCESSFULLY

From a **WORLD THEY KNOW**

To a **WORLD THEY DON'T**

Thinking about it, this definition can apply to all maturing young adults. We all leave school and enter a world we don't know. But most of us have a much easier time preparing to enter that world than do kids with deafblindness.

To cite one difference, it is more difficult for those who are deafblind to assimilate changes in routine, places, and people. Another complication is that communication is usually a much bigger issue than for other people. Finally, the youth who is deafblind often has much less direct, day-to-day input into the decisions that are being made on his behalf.

For these and other reasons, the transition process for those who are deafblind needs to be:

- Led by parents/caregivers (with as much input from the youth as possible)
- Comprehensive in scope
- Initiated as early as possible
- Sustained over a long period of time

The Goal of Transition

The goal of transition is to maximize the potential of the young adult who is deafblind to:

- Live as independently as possible
- Obtain appropriate post-secondary education
- Have a job
- Lead an active social life
- Participate in the community

But in the Real World...

...young adults who are deafblind often find this goal extremely difficult to attain. According to a 2007 survey¹ conducted by the National Family Association for Deaf-Blind (NFADB's website is www.nfadb.org):

- Only 30% of adults with deafblindness hold paying jobs
- Only 11% live independently --
 - 57% still live at home
 - 19% live in group homes
 - 3% are in residential school programs

In addition, only 17% participate in any type of post-high school education program (e.g., vocational rehabilitation, community college, four-year college).²

Finally, most adults with deafblindness have few friends outside of their families, and most are isolated from their communities.

According to the NFADB survey, the greatest challenges and barriers for adults who are deafblind include:

- The availability of qualified personnel to provide services (80%)
- Funding for appropriate services (76%)
- Access to appropriate services (70%)

¹ "Transition and Post-School Life Survey – 2007 Position Paper," published in **News From Advocates for Deaf-Blind**, Winter 2009/2010, National Family Association for Deaf-Blind, pp.6-7.

² "Transition," **Practice Perspectives**, National Consortium on Deaf-Blindness, January 2009, p. 1. NCDB's website is <http://nationaldb.org>

Basic Rules of the Transition Hopscotch Game

Rule # 1 - Youth “age out” of ENTITLEMENT and “age into” ELIGIBILITY

Probably the most fundamental change you and your child will experience during this period is that the game itself changes from the Hopscotch of your childhood to the more brutal exercise invented by the Romans.

Up to now, your child has been **ENTITLED** to such services as:

- * Free, appropriate public education
- * Therapies (physical, O&M, speech, etc.)
- * Assistive technology
- * Support services
- * Perhaps medical care

Once your child reaches a certain age (which varies among programs), she loses her rights to these services and only becomes **ELIGIBLE** for them – if they are available at all.

For example, once a student **graduates** from high school **OR** reaches **21 years old**, she is no longer entitled to services through the **educational** system.

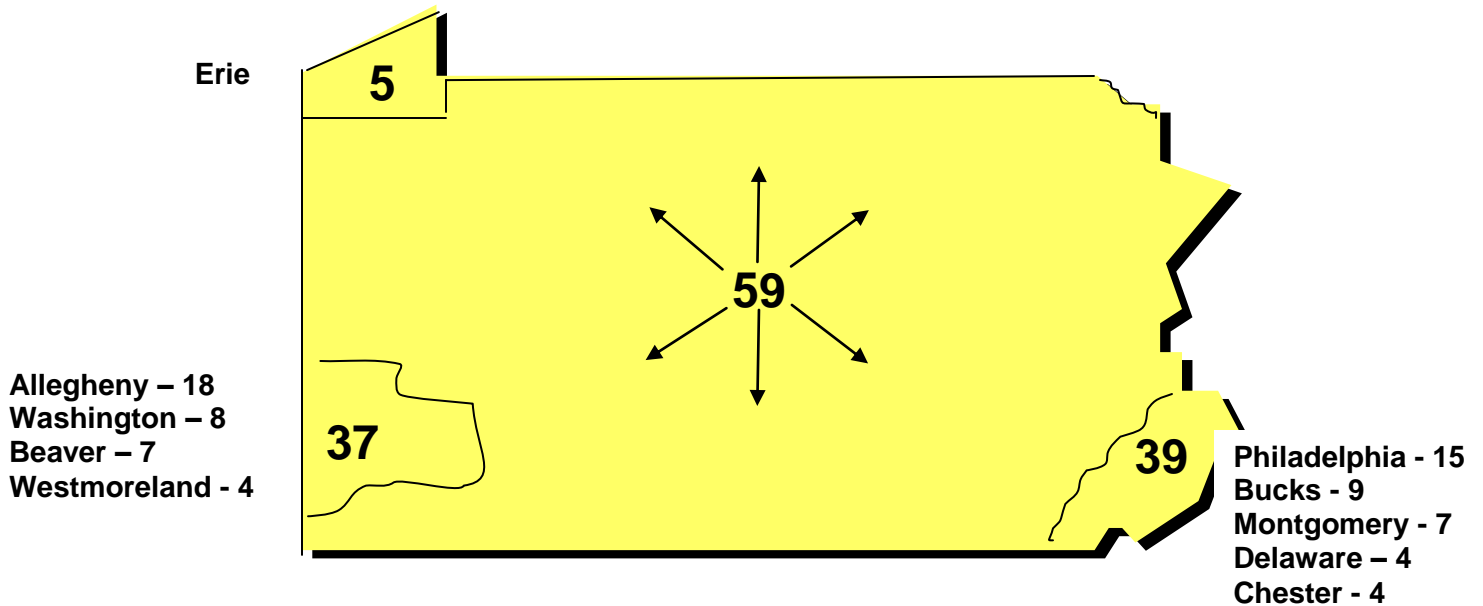
To take another example: If your child receives MA (Medical Assistance) with SSI, he needs to apply for SSI and reapply for MA programs at **age 18**. At 18, SSI eligibility is based on the income and resources of the applicant, as well as the applicant’s disability determination from the Social Security Administration.

As an adult, your child with deafblindness will be viewed much differently by all components of the services “system” than she was as a child. Nothing is guaranteed any longer – everything is based on **eligibility** for services and whether those services are **available**.

Rule # 2 - The population of transition-age youth with deafblindness is extremely small

According to the 2008 census of children who are deafblind in Pennsylvania, the total population was approximately 405. Of that number, only 140 children and youth were of transition age (14 to 21).

As the map on the next page shows, the 140 transition-age youth are scattered throughout the Commonwealth.



In examining the implications of such a low population, NFADB concludes, “Families consistently report that they experience feelings of isolation and frustration as they attempt to obtain appropriate services for their children who are deaf-blind.”³

Rule # 3 - Youth who are deafblind have complex needs

Deafblindness is a “distance” disability. A person who is deafblind finds that her ability to determine where she is (**orientation**), her ability to get where she wants to go (**mobility**), her consciousness of what is going on in the world (**awareness**), and her ability to converse with others (**communication**) decrease geometrically with each foot of distance. For example, if the child who is deafblind is in the living room, mom can’t just call her into the kitchen for dinner, nor can mom give her a visual signal that dinner is ready. Mom or dad must actually travel to the child to let her know that she can join the rest of the family for dinner.

In addition, over 90% of those with deafblindness have other disabilities:

- 66% have cognitive difficulties
- 57% have physical disabilities
- 38% have complex health care needs
- 9% have behavioral challenges

³ “Transition and Post-School Life Survey – 2007 Position Paper,” op. cit., p.7

Rule # 4 - Parents often will remain their child's case manager after transition

In transitioning youth without disabilities, parents themselves generally transition from a role of decision-maker to one of advisor. Young adults begin to make their own life decisions – where to go to college, which branch of the military to join, what career they want to pursue, whom to marry, etc. In addition to their parents, maturing students may reach out to their friends, teachers, employers and others for advice and counseling.

For those with deafblindness, however, many of these options are not available. Furthermore, governmental, educational and private service providers are often ill-prepared to meet the complex needs of those who are deafblind. Solutions and services that work for people with other disabilities often aren't viable for those who are deafblind.

It shouldn't be surprising that such a small population, spread across a large geographic area in Pennsylvania, with complicated and diverse needs, served by a number of different agencies without much experience in dealing with those who are deafblind, would need to continue to rely on their parents to help manage their lives. This need increases even more if the young adult with deafblindness is medically involved, has cognitive challenges, or has poor communication skills.

Rule # 5 - Parents must be the initiators

If parents sit back and don't push the process, the "system" will sit back, as well. If parents aren't proactive, the "system" will likely provide what it's required to by law, and not much else. If parents aren't vigilant, who will check to make certain a service is in place and functioning correctly?

How Do We Prepare to Play This Transition Hopscotch?

First, **start planning for transition early!** In Pennsylvania, transition planning begins with the educational system. At age 14, the Individualized Education Plan (IEP) for each student who is deafblind must include goals for successful transition to post-secondary education or training, employment and independent living. Therefore, by the time your child reaches age 14, you should be involved with the team at her school in developing an IEP that begins to reflect her goals for life after school. By the way, nothing precludes you from beginning the process prior to age 14, so you can begin much earlier if you desire.

Second, **involve your son as much as possible.** Work with him to identify his interests, aptitudes and talents. If he has difficulty communicating or has difficulties in addition to deafblindness, you may have to work with the team at

school to develop methods to overcome these issues. The important thing, however, is not to underestimate your son's capacity to have interests, aptitudes and talents. Of course, the more difficulties he faces, the more leadership you will need to take.

Third, **develop your network of parents, friends, and providers.** Due to the small population spread over a large state, it may seem that you are the only family who is experiencing issues that are specific to those who are deafblind. It may feel like you have to "reinvent the wheel" for every step of the transition process. That is not the case! A number of organizations and groups exist to provide support, advice and training. Reach out to them and use them as much as possible. You can start with PPDB (www.papdb.org); the Pennsylvania Deafblind Initiative (www.pattan.net then click on Deafblind from the list on the left); and NFADB (www.nfadb.org). These organizations won't provide all the answers, but you can branch out from them to identify other resources and people.

Once you have developed your network, **Person Centered Planning** is a great way to plan when you have a student who has difficulty communicating. This pulls together family, friends, teachers and other interested people who know the student well enough to share his or her likes and dislikes. The Deafblind Initiative can provide advice and training on using this technique.

Fourth, **get training.** The Pennsylvania Deafblind Initiative holds training on such key issues as transition, leadership, developing effective IEPs, resolving conflicts and many more issues affecting our families. In addition, the Initiative works with educational teams to maximize their effectiveness.

Fifth, **research the new world of transition.** Use the contacts you make to develop shortcuts to get to the information you need. You don't have to spend all of your time exploring the Internet for information that someone else already has. Get that information from them and apply it to your situation.

OK – I'm Prepared – Now How Do I Get Started?

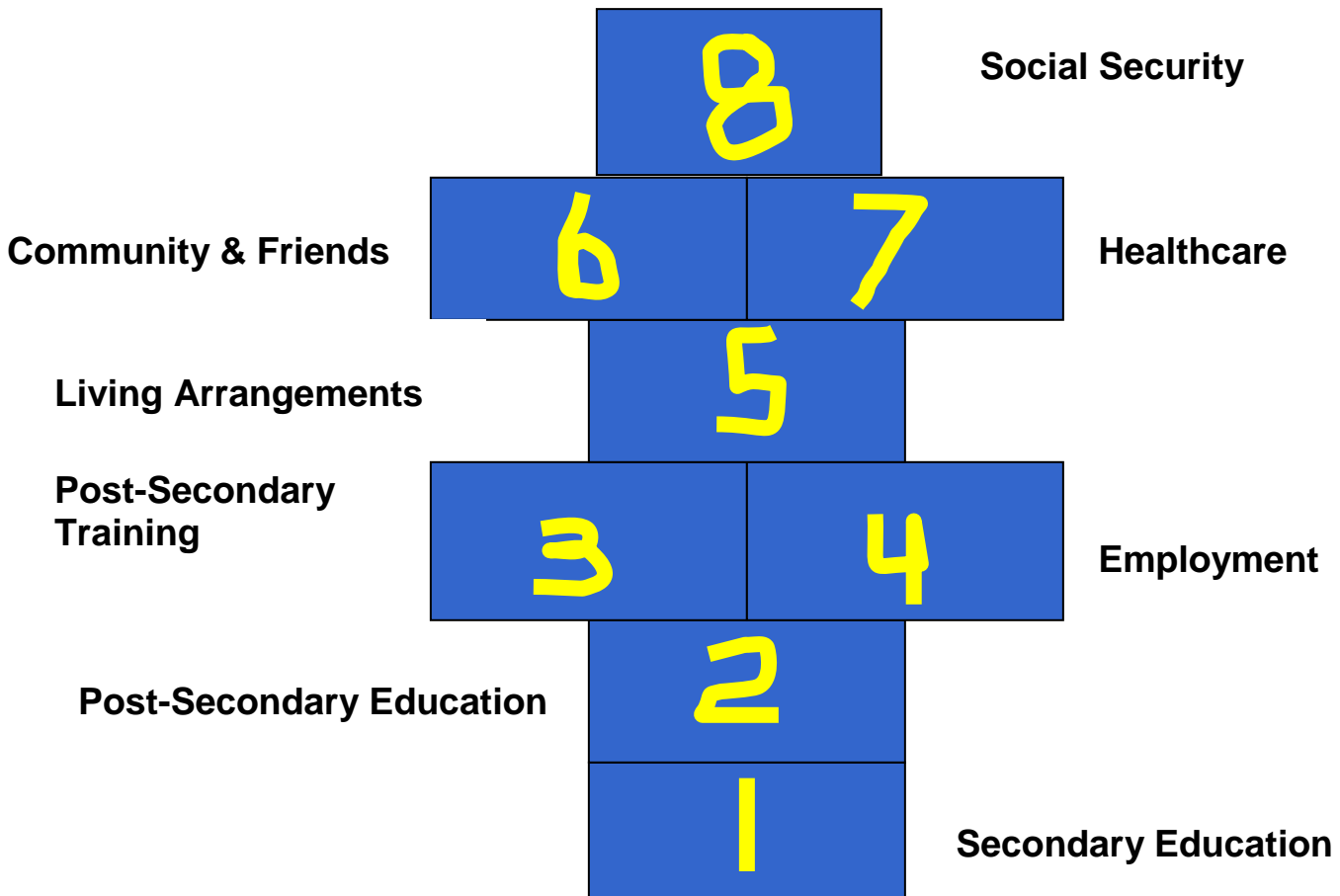
Before playing the Transition Hopscotch game, begin by asking yourself five basic questions:

- Where will my daughter live?
- What will my son do all day?
- What will she do for fun?
- How will he make friends?
- Will she need supports to live, work and play? If so, who will provide them?

If some of these questions are already answered (e.g., if you know that your daughter will reside with you), use those answers to help shape the responses to the other questions. For example, will living at home affect how your daughter spends her free time or how she makes friends?

As you deal with the confusing array of services, agencies, rules, guidelines, funding sources, insurances, etc., use these questions to keep your balance and focus. Don't get lost in the jargon of the education or healthcare system. **Everything** boils down to these five questions.

The Transition Game's "Court"



Each of the squares on the court represents a major component of your child's transition process. Depending on your situation, you may be able to "skip over" a square or two. To use a previous example: If a decision has already been made that your child will live at home, the "Living Arrangements" square won't apply,

and you can move on to another component. The sections below raise questions for each of these squares.



Secondary Education

When does transition planning begin? As previously stated, in Pennsylvania, transition planning must begin at age 14. A key component of transition planning is the assessment process. Assessments can be done in a number of areas, including behavioral, aptitude, interest and work values, intelligence, self-determination and others. Good transition assessments will help guide the entire process.

What is the IEP's role in transition planning? The IEP is the planning document for the transition process. The IEP contains a section on transition (currently Section III – Transition Services). This section spells out your child's post-school goals for Post-secondary education/training, employment and independent living.

These goals should drive the rest of the IEP. The IEP annual goals need to tie back to the transition goals so that the IEP's goals and activities produce a coordinated set of building blocks leading to the successful attainment of your child's post-school transition objectives.

When do secondary education services end? The services provided by the secondary educational system end when one of two conditions are met:

1. When your child receives a diploma and **graduates** from high school, **or**
2. When she reaches 21 (if she turns 21 during a school year, she is allowed to complete that year, but if she turns 21 between school years, she cannot begin another term and she actually is done at age 20).

What other government agencies or service providers are involved in transition planning? The answer to this question depends on what area of the Commonwealth you live in, but may include such agencies as your county MH/MR office or the Office of Vocational Rehabilitation (OVR), the Bureau of Blind and Visual Services (BBVS), or a job placement agency such as Shadowfax in York, PA (www.shadowfax.org).

What laws apply after your son reaches 21? At the age of 21 years, the law changes for the student and they are no longer under the IDEA (Individuals with Disabilities Education Act) “**entitlement**” law but under Section 504 of the

Rehabilitation Act and the ADA (Americans with Disabilities) “**eligibility**” laws. Unlike elementary school and high school, IEP’s and 504 Plans are not part of the process in providing services to those over 21. In addition, the university does not provide services that are “personal in nature.” There are many services that are offered in high school but not in college.



Post-Secondary Education

What services must the post-secondary institution provide for my daughter who is deafblind? All students with disabilities in a university setting are protected under the ADA (Americans with Disabilities Act) and Section 504 of the Rehabilitation Act of 1973. These laws were made to **protect the civil rights of individual with disabilities and ensure equal access to education.**

These laws state that “no otherwise qualified individual with a disability shall, solely by reason of his/her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity of a public entity.”

In a post-secondary education setting, the term "otherwise qualified" means "a person who meets the academic and technical standards requisite to admission or participation in the education program or activity, with or without reasonable modifications to rules, policies or practices; the removal of architectural, communication or transportation barriers; or the provision of auxiliary aids and services."

A "person with a disability" is defined as "any person who 1) has a physical or mental impairment which substantially limits one or more major life activities [including walking, seeing, hearing, speaking, breathing, learning, and working], 2) has a record of such an impairment, or 3) is regarded as having such an impairment."

What responsibilities will my son have in obtaining these accommodations? Students with deafblindness will need to take on a new and active role upon entering college and need to register with the Disability Services Office (DS) at their college or university. Responsibility and self-advocacy are so important to acquiring and maintaining accommodations.

All accommodations are individualized and based upon the student’s documented disability. Once documentation has been approved, students meet with a DS counselor to determine accommodations. The DS counselor works with the student to identify appropriate and reasonable accommodations for each

semester. Below are examples of accommodations that may need to be made for a student with deafblindness:

- Assistive Technology
- Classroom and or desk location
- Foreign Language Substitution
- Interpreting Services
- Note Taking Services
- Testing (extended time)
- Text books in Alternate Format.

Who pays for services and accommodations? Under Federal legislation, students with disabilities are entitled to reasonable and appropriate accommodations to ensure equal access to education. The university **does not** provide accommodations of a “personal nature.” **Students are responsible for their own transportation, assistance with homework, coaching, mobility training, personal care attendants, and activities outside the university.**



Post-Secondary Training

If my child is not going to college, what types of job training are available to him? There are many types of training, administered by a number of governmental agencies and private groups. The specific types of training available to your child will depend on the decisions that are made during the transition planning that you and the educational team implement. There are a number of private, non-profit organizations that work with those who are disabled to provide training, support services and linkages to possible employers. Some examples of such agencies include: Gateway Employment Resources, serving southeastern PA (www.gatewayemployment.org), Shadowfax in York, PA (www.shadowfax.org), and AHEDD, serving the Pittsburgh area (www.qpsea.org/AHEDD%20Page.htm)

What is the role of the Pennsylvania Office of Vocational Rehabilitation (OVR) and when does it become involved? OVR “assists eligible individuals with disabilities to obtain and keep a job, and promotes economic and social independence in their daily life activities. Services may include counseling and guidance, job training, and physical and mental restoration.”⁴

⁴ See the OVR description in the Department of Labor and Industry’s section on the Commonwealth’s website: www.dli.state.pa.us

One of the key criteria for OVR is determining whether the individual can obtain and keep productive employment. OVR's charter, however, does not extend to individuals who don't meet this criterion.

OVR can become involved in the IEP transition planning as early as two years before graduation, and occasionally sooner.

Is the training organization required to provide services and accommodations to my daughter? The organization follows the same rules as colleges and universities regarding accommodations.



Employment

What will my daughter “do for a living?” The assessments that are done during the transition planning will go a long way in answering questions about your daughter's interests, abilities, aptitudes and temperament.

Remember, however, that 70% of adults who are deafblind are not employed. Thus, finding paid employment for your child can be one of the longest, most grueling tasks in the entire game of transition hopscotch. Explore your child's eligibility for OVR services, work with your team at school to find other agencies and providers that may help your daughter, and identify all possible avenues, including volunteer work if it turns out that paid employment is not an option.

What level of supports will my daughter require in her job? Again, use your child's assessments to determine the types of supports she will need, and work with your team at school to identify agencies and funding sources that can provide those supports.



Living Arrangements

Will our son live independently, with us or other family members, in a group home, in a personal care home or in a skilled facility? Will he need support services? If so, whom should we contact?

Where your son resides will depend partly on personal choice and partly on the degree of supports he will need to live as independently as possible. These supports will need to be stitched together from various programs and agencies.

In Pennsylvania, a good place to start is your county's Mental Health/Mental Retardation (MH/MR) agency. If your son has mental retardation (MR), a Prioritization of Urgency of Need for Services (PUNS) should be submitted to your county's MH/MR agency. The PUNS will help determine if your son qualifies for various Waiver Programs under the Medical Assistance program. A waiver provides funding for mental retardation supports and services to assist your son to live as independently as possible.

For a complete discussion of Medicaid-funded waivers, see the **Transition Health Care Checklist**, published by the Pennsylvania Department of Health. Waivers are found in Appendix H (pp. 25-28) of the Checklist. Contact the Department of Health to obtain a copy, or at: www.health.state.pa.us/transitionchecklist.



Community Involvement

What can be done to ensure that our daughter will have friends, will be involved in the community, and will have fun in her leisure time?

To be part of a community, to have friends and to know how to have fun during leisure time are all skills that people learn as part of growing up. If a person who is deafblind has not developed these skills prior to age 21, it is not likely that she will naturally develop them after transition ends. This makes it all the more necessary to begin transition planning as early as possible. The school/home teams will want to build on skills and relationships as they are occurring in natural settings, such as school, church and community in order to carry over into a life beyond educational programming.

Being mindful of the basic need for all to belong to something is an important consideration in developing the IEP as your daughter moves through school. Social assessments, volunteering and recreational interests can be used to expose her to the community and the community to her. Again, the earlier that this exploration is started, the more likely it is that she will be involved and have friends once she reaches adulthood.



Healthcare

What type of health insurance does my son qualify for? What age limits apply for health insurance? Do my son's current healthcare providers have "age restrictions" for their patients? The answers to these questions will vary

widely, depending on a number of factors. However, these questions are critical to your son's transition to adulthood, especially if he has complex medical needs. To assist you in finding the answers, we recommend that you read the **Transition Health Care Checklist**. This checklist does an excellent job of guiding parents through the process for transitioning their child with disabilities to the adult healthcare system. The website address is:

www.health.state.pa.us/transitionchecklist



Social Security

Does my daughter qualify for Social Security benefits? Supplemental Security Income (SSI) is the major income program under the Social Security Act. SSI is designed to help people who are aged, blind and disabled, and who have little or no income. SSI is meant to meet basic needs, such as food, clothing and shelter.

The **Transition Health Care Checklist** (Appendix F, pp. 19-21) identifies other Social Security benefits that your daughter may qualify for, including:

- **Social Security Benefits as a Disabled Adult Child (SSDAC)** – An adult child who is disabled may be eligible for SSDAC based on the parent's work history if the parent retires, becomes disabled or dies.
- **Social Security Disability Benefits (SSDI)** – Your daughter may qualify for SSDI if she has sufficient Social Security work credits to be "insured" for disability and meets medical criteria.
- **Ticket to Work** – This program provides services to people who are disabled and receive SSDI and/or SSI benefits. The Ticket Program provides employment, vocational and other services to assist those who are disabled to go to work and earn more money. The goal of the program is for the recipient to earn sufficient money so that Social Security cash payments are not needed. More information on the program can be found at www.yourtickettowork.com

When and where should my daughter apply for benefits? She may apply for disability benefits on the first day of the month she turns 18 years old. Almost every form can be completed online **except** for SSI. She (or you, acting on her behalf) must apply for SSI in person at the local Social Security Administration office. You can find that office by calling 800-772-1213, or you can begin the process online at www.ssa.gov/

If she already receives SSI, does she have to reapply? She must reapply for SSI, because, at age 18, she now must meet eligibility criteria for adults.

Conclusion

In thinking about your child's transition to the adult world, try to keep the following in mind:

- **Start EARLY! Start EARLY! Start EARLY!**
- Don't try to reinvent the entire wheel – develop a network of other parents and professionals, friends and relatives who can help you do research, pose questions and develop plans
- Use the questions in this document to develop your own.
- **Focus** on getting answers to the key questions for your situation.
- You may want to **organize your thinking** around the eight squares on the transition “court.” You may need to add a square or two to reflect your situation, or you may be able to skip a square because it doesn't apply to your child, but don't forget the importance of each square.
- Remember that the transition process is not a 100-yard dash, but a marathon. Keep your eye on the prize – your child's future depends on it!

Resources

Learn more about:

Pennsylvania Partnership for the Deafblind (PPDB) – www.papdb.org

National Family Association for Deaf-Blind (NFADB) – www.nfadb.org

The Pennsylvania Deafblind Initiative, see www.pattan.net and click on Deafblindness in the left column

Transition training for parents, educators and providers, see the Pennsylvania Training and Technical Assistance Network (PaTTAN) at www.pattan.net

Publications (including those on transition) specifically for those who are deafblind, see the National Consortium on Deaf-blindness at <http://nationaldb.org>

Healthcare issues in transition, see the Pennsylvania Department of Health's publication, **Transition Health Care Checklist**, rev. June 2008, at www.health.state.pa.us/transitionchecklist

There are many more resources, but these should get you started.