



Statewide Parent  
Advocacy Network  
35 Halsey Street  
Newark, NJ 07102  
(973) 642-8100  
[www.spannj.org](http://www.spannj.org)

# Transition to Adult Life for Youth with Deaf-Blindness: A Parent Mini-Guide



Developed by the Statewide Parent Advocacy Network  
In collaboration with the Perkins School for the Blind  
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Dear parent of a youth with deaf-blindness:

As the parent of a youth with deaf-blindness, you face many challenges every day. You have hopes and dreams for your youth, and you want their educational services to help them develop and learn.

In 2008, the Perkins School for the Blind worked with experts in deaf-blindness, including state deaf-blind projects, to develop Deafblindness: Educational Service Guidelines (the Guidelines). These guidelines provide state and local education agencies a framework to support the development of meaningful, appropriate programming for students with deaf-blindness. They also identify the knowledge and skills educators need to help their students who are deaf-blind reach their full potential and become successful, contributing members of our society.

In 2010-2011, the Perkins School for the Blind collaborated with the Statewide Parent Advocacy Network (SPAN), state deaf-blind projects, and families of children with deaf-blindness, to develop resource materials for families of children with deaf-blindness based on the Guidelines. The resource materials include fact sheets, mini-guides, and an IEP Meeting Checklist. You can access the resource materials and the Guidelines on the websites of SPAN ([www.spannj.org](http://www.spannj.org)), the Perkins School for the Blind ([www.perkins.org](http://www.perkins.org)), and the National Consortium on Deaf-Blindness ([www.nationaldb.org](http://www.nationaldb.org)). You can also find many other resources that will help you maximize your child's education and development on these websites. For additional assistance in advocating for your child with deaf-blindness in the education system, contact your state Parent Training and Information Center (PTI). You can find contact information for your PTI at [www.parentcenternetwork.org](http://www.parentcenternetwork.org). For additional assistance in advocating for your child with deaf-blindness in the healthcare system, contact your state Family to Family Health Information Center (F2F). You can find contact information for your F2F at [www.familyvoices.org](http://www.familyvoices.org).

We would like to thank the Conrad N. Hilton Foundation for funding these resources. We would also like to thank the New York and New Jersey deaf-blind projects for their assistance in facilitating parent focus groups; the state deaf-blind project staff and parents of children with deaf-blindness who participated in focus groups and provided feedback on the resources; and the Perkins School for the Blind for their ongoing support.

## TRANSITION TO ADULT LIFE FOR STUDENTS WITH DEAF-BLINDNESS

This mini-guide has been developed to guide you through the transition to adult life process of your youth with deaf-blindness. It is based on the recommendations in Deafblindness: Educational Service Guidelines (the Guidelines).<sup>i</sup>



The Individuals with Disabilities Education Act (IDEA) protects the rights of children with disabilities, including children with deaf-blindness, ages 3-21, to a free, appropriate public education. IDEA ensures *“that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and **prepare them for further education, employment, and independent living.**”*

Transition is the planning process that helps youth with disabilities plan for college, vocational training, employment, independent living, and health/wellness. Transition planning should start no later than the school year during which the youth turns 16 (or earlier if appropriate). (Some states start the transition process at age 14. Check with your state’s PTI to find out the rules in your state). In addition, no later than at age 15, the IEP team must provide information about the transfer of decision-making responsibility to your youth when they reach the age of majority (18). Without effective transition, too many youth with deaf-blindness leave school with little chance for employment or community living. The Guidelines have recommendations that will help you and your youth with deaf-blindness prepare for transition and adulthood.

Your youth must be invited to the IEP meeting whenever transition is being discussed, and the letter that you receive regarding the meeting must indicate that transition will be discussed. The IEP team must fully include you and your youth in developing the transition plan as part of the IEP.<sup>ii</sup> Deaf-blindness impacts your youth’s social and communicative connections and her/his ability to develop as a person. You and your youth can contribute information and learn through participation in the process of developing the transition plan. Your youth needs to learn about his/her disability, accommodation needs, and how to articulate what s/he needs before leaving high school. Attending and participating in transition planning is a vital part of this process. Even if your youth with deaf-blindness will not be able to be fully independent, the transition process will help you plan for their future.

Your youth’s IEP should include assessments to determine appropriate post-secondary (post-high school) outcomes. These may include vocational evaluations, interest inventories, and independent living assessments as well as psychological and educational testing. Person-centered planning strategies can help you, your youth, and the school identify strengths, preferences, and specific skills needed for successful transition.<sup>iii</sup> Independent living assessments help identify the supports your youth with deaf-blindness will need to live and work in the community, including communication support service providers, interpreters, or augmentative communication systems.<sup>iv</sup>

The transition plan within the IEP has to include appropriate measurable post-secondary goals based on age-appropriate transition assessments. Age appropriate assessments might include interest inventories or community-based vocational assessments that help your youth identify career interests. The IEP for your youth in transition should be driven by these goals.

The transition plan within the IEP must address whether consultation is needed from adult agencies such as vocational rehabilitation, developmental disabilities, or agencies serving adults with deafness/hearing loss or blindness/vision loss, and how it will be obtained. Often, there is no one service agency that assumes responsibility for adults with deaf-blindness and the other disabilities that often accompany the conditions that lead to deaf-blindness (such as cognitive and physical disabilities).<sup>v</sup> More than one agency may need to be involved in your youth’s transition process. The school may need to establish interagency agreements with these adult service providers to ensure the development of an appropriate transition plan and the provision of the supports and services needed to implement that plan.

You and your youth with deaf-blindness need to consider four important domains when thinking about life after high school:

**Post secondary education.** What kind of post secondary education is realistic and appropriate? What skills are necessary to be successful? The IEP should identify and implement steps to make sure that, when college is identified as the appropriate post secondary goal, the student has taken courses in high school that will help secure choices of college. Is your youth expected to pass the high school graduation test? Will s/he be taking the S.A.T. or A.C.T? Will s/he need accommodations under U.S. non-discrimination laws such as Section 504 of the Vocational Rehabilitation Act (Section 504) or the Americans with Disabilities Act (ADA) to have equal access to these assessments, or to participate in postsecondary education?<sup>vi</sup>

### **Employment**

Does the IEP discuss career goals? Will your youth need to develop skills for a specific career? Possible choices for career and vocational education are critical to explore. Preparation for employment may include career awareness activities, job sampling, attendance at career seminars or conferences, and contact with adults with deaf-blindness. Such adults can serve as positive role models and enhance expectations for your youth.<sup>vii</sup> The IEP should also address vocational skills that will deal with your youth's ability to know where to begin to find an available job, complete a job application, and handle a job interview. Vocational evaluations which help determine career interests and capabilities can be an appropriate request in transition planning.

### **Independent living**

Your youth with deaf-blindness lacks the information typically obtained through the use of vision and hearing, but the possibility of independent living still exists. To maximize this possibility, your youth must learn concepts and skills in natural settings beyond the school building, the school day, and the school year. Independent living skills include:

*Transportation:* What transportation is needed for your youth? Will s/he have to take public transportation, and if so, does she need direct instruction to learn how to use it? Does s/he need accessible transportation? How will s/he get needed orientation and mobility training, in the environments that s/he currently navigates and those that s/he may be navigating after s/he

leaves high school? As s/he progresses, orientation and mobility classes will take more time, so these classes should be offered during both daylight and evening hours. Your youth with deaf-blindness may have severe night blindness, and may need opportunities to learn skills when it's dark.<sup>viii</sup>  
*Other independent living skills:* Does s/he need direct instruction in food shopping and meal planning and preparation, using money/making change, or personal hygiene? Are there social skills needed so s/he can function within the community? Will s/he eventually be able to live independently, or will s/he need a group home or other type of residential support? If s/he is eligible for support from other agencies, the transition plan should address how you will apply and access those services, and the district will need to provide assistance to help obtain them.



### **Health**

Lack of attention to health needs and health management can jeopardize your youth's goals for learning, working, and living safely in the community. Health needs to consider as part of transition planning include appropriate nutrition; proper hygiene; importance of exercise as a life skill; effects of adverse chemicals (alcohol, tobacco, other substances); and reproductive education.

If your youth has more specialized health care needs, this area of transition planning is even more critical. Transferring responsibility for self-care to your youth requires consideration of factors such as complexity of health needs, physical and intellectual abilities of your youth, and your – and his/her - cultural values, health care practices, and beliefs about disability. Be sure to include your youth's doctor and specialists in transition planning.

Your youth must receive appropriate transition services. IDEA defines transition services as a coordinated set of activities designed within a results-oriented process, focused on improving your youth's academic and functional achievement to facilitate their movement from school to post-school activities. Services must be based on your youth's needs, and take into account their strengths, preferences, and interests. Post-school activities could include post-secondary, vocational, or adult education; integrated employment (including supported employment); adult services; independent living; and/or community participation.



Transition services include:

- **Instruction:** This includes courses of study and/or skill development.
- **Related services;** Many services may be required to help your youth benefit from special education. These may include services such as transportation; speech-language pathology and audiology; interpreting; psychological; physical and occupational therapy; recreation/ therapeutic recreation; social work; school nurse; counseling, including rehabilitation counseling; orientation and mobility; and medical services for diagnostic and evaluation purposes only. However, the term does not include a medical device that is surgically implanted or its replacement.
- **Community experiences:** These are provided outside the school or in the community, such as community work experiences/exploration, job site training, banking, shopping, transportation, counseling, recreation.
- **The development of employment and other post-school adult living objectives:** These are services leading to a job or career or those that support activities done occasionally such as registering to vote, filing taxes, renting a home, accessing medical services, filing for insurance or accessing adult services such as SSI.

- **If appropriate, acquisition of daily living skills:** These services improve your youth's ability to do activities that adults do every day - preparing meals, paying bills, maintaining a home, grooming, caring for clothes).
- **Functional vocational evaluation** (assessment process that provides information about job/career interests, aptitudes, and skills, gathered through situational assessment, observations or formal measures.

Transition services should be delivered through curricular and extracurricular activities across many settings – *in academic and vocational classrooms, at home, and throughout the community* – to practice and reinforce skills in real life situations, so that your youth feels comfortable in those settings.

As your youth approaches adult life, it is critical for him/her to be aware of his/her support needs. College, work, and community settings must provide reasonable accommodations *only* if they are made aware that they are needed. Your youth must be prepared to disclose his/her disability and the accommodations needed to participate in education, work, or community life.

The IEP team must provide information about the decision-making changes that occur at the age of majority at least three years before your youth turns 18. Your rights regarding IEP decisions transfer to your youth when they turn 18, unless you or another adult are appointed as your young adult's legal guardian. This requirement in the law does not consider ability of the student, so you need to consider whether you will pursue full or partial guardianship prior to the IEP meeting after your youth turns 18. This should also trigger a discussion of how to build services into the IEP to help your youth learn the skills to be able to make IEP decisions for him/herself. This "transfer of rights" does not mean that you are no longer a part of any IEP team; your young adult can choose to actively invite you to continue to help with decisions at the IEP meeting with a simple letter.

### **Last Evaluation**

Your youth must be evaluated at least every three years to determine whether s/he continues to have a disability and whether his/her strengths and needs have changed. This re-evaluation is called the "triennial evaluation." You and the school together decide which assessments should be conducted as part of the triennial evaluation. If you and the school agree that a reevaluation is unnecessary, the reevaluation may be waived.

For students in transition, it is important to discuss and plan for a final evaluation to have current documentation of your youth's disability and levels of academic and functional performance. A reevaluation is not required before termination of your youth's eligibility due to graduation or exceeding age 21, unless it is written into the IEP. Identify when the last evaluation should take place as a transition strategy toward post-secondary goals when your youth is 16 and beginning the transition process to help eliminate conflict during the last school year.

## Summary of performance

IDEA requires that your youth receive a Summary of Performance (SOP)<sup>ix</sup> (academic achievement and functional performance and recommendations on how to assist her/him to meet postsecondary goals) upon graduation or "aging out" (usually at age 21). The SOP can be part of the documentation required under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act to help establish your youth's eligibility for reasonable accommodations and supports in post-high school settings. This information helps employers, colleges, etc. consider accommodations for access. Submission of the SOP does not automatically mean that your youth will qualify for accommodations, as these decisions are made on a case-by-case basis, but it is helpful information. It is also useful for the Vocational Rehabilitation Comprehensive Assessment process, required to determine your youth's eligibility for vocational rehabilitation services. For more information about the transition to adult life process and components of the transition plan, contact your state PTI ([www.parentcenternetwork.org](http://www.parentcenternetwork.org)). For more information about transition for youth with deaf-blindness, access the Guidelines on-line;<sup>x</sup> for other resources, go to the website of the National Dissemination Center for Children with Disabilities.<sup>xi</sup> To find your state deaf-blind project, go to the website of the National Consortium on Deaf-Blindness at [www.nationaldb.org/](http://www.nationaldb.org/) and click on your state, or call 800-438-9376.

## Conclusion

The development of an effective transition to adulthood plan for your youth with deaf-blindness will serve as a "roadmap" for your youth's future. The National Consortium on Deaf-Blindness has a range of resources and inspiring stories, including information on self-advocacy by youth and young adults with deaf-blindness<sup>xii</sup> that will help you develop and implement a meaningful transition plan for your youth.

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<sup>i</sup> [Deafblindness: Educational Service Guidelines, www.perkins.org/resources/educational-publications/deafblindness-educational-service-guidelines](http://www.perkins.org/resources/educational-publications/deafblindness-educational-service-guidelines)

<sup>ii</sup> Chapter 4 Issue I

<sup>iii</sup> For more information on person-centered planning, visit the Cornell University ILR School Employment and Disability Institute Person-Centered Planning Education Site at <http://www.ilr.cornell.edu/edi/pcp>

<sup>iv</sup> Chapter 4 Issue VII

<sup>v</sup> Chapter 4 Issue VII

<sup>vi</sup> [www.nichcy.org/Laws/ADA/Pages/Default.aspx](http://www.nichcy.org/Laws/ADA/Pages/Default.aspx)

<sup>vii</sup> Chapter 5 Issue VI

<sup>viii</sup> Chapter 5, Issue IX

<sup>ix</sup> The National Secondary Transition TA Center has a sample of a meaningful SOP at [www.nsttac.org](http://www.nsttac.org).

<sup>x</sup> **Deafblindness: Educational Service Guidelines Related to Transition**

### Chapter 1 Foundations

**Issue VI.** Educators should be knowledgeable about appropriate service options and supports needed by students who are deafblind throughout their education and transitions.

### Chapter 4 Services and Placement Options

**Issue I.** The educational team must fully include the family and student in developing the Individualized Education Program (IEP) and Individualized Transition Plan (ITP).

**Issue IV.** The educational team should ensure that goals and objectives addressing the development of communication and social relationships are included in the IEP and ITP to meet the individual needs of the student who is deafblind.

**Issue VII.** Educators must ensure that transition planning for students who are deafblind is collaborative and involves all appropriate adult service agencies.

### Chapter 5 Supportive Structures and Administration

**Issue II.** State and local education agencies (SEAs and LEAs) should ensure that every student who is deafblind is served by a well-coordinated educational team with the specialized knowledge and skills to fulfill its responsibilities for developing and meeting the requirements of the Individualized Education Program or Individualized Transition Plan (IEP/ITP).

**Issue VI.** State and local education agencies (SEAs and LEAs) should implement planning strategies for the important transitions that students who are deafblind will experience throughout their education.

<sup>xi</sup> [www.nichcy.org/EducateChildren/transition\\_adulthood/Pages/Default.aspx](http://www.nichcy.org/EducateChildren/transition_adulthood/Pages/Default.aspx)

<sup>xii</sup> [www.nationaldb.org/FFSelfAdvocacy.php](http://www.nationaldb.org/FFSelfAdvocacy.php)