

The Family Guide to Transition Services in New Jersey

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Dear Families and Youth/Young Adults with Disabilities:

SPAN is pleased to provide you with this *Family Guide to Transition Services in New Jersey*. By providing one cohesive document on the transition process, services, and supports, we hope to make the journey easier for everyone. Transition can be a complicated time—this guide can answer your questions and can make transition a successful period for families and youth/young adults with disabilities.

SPAN would like to thank the <u>Massachusetts Federation For Children</u> <u>with Special Needs</u> for their contribution to the development of this Transition Guide. SPAN regularly collaborates with all the federallyfunded Parent Centers in the Northeast US to continue our effort to positively impact families and youth/young adult with disabilities.

SPAN's vision is that all families in New Jersey will have the resources and support they need to ensure that their children become fully participating and contributing members of our community and society.

FOR FURTHER ASSISTANCECALL: (800) 654-SPAN (7726)VISIT: spanadvocacy.org

The Family Guide to Transition Services in New Jersey



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What Is Transition?

N ew Jersey students with disabilities who receive special education services are entitled under federal and state laws to receive appropriate transition services to support their movement beyond school, beginning no later than age 14, or earlier if appropriate. New Jersey has a long tradition of providing transition planning for students to access appropriate adult services as needed under <u>Chapter 6A:14</u> of the Special Education Administrative Code. *The Family Guide to Transition Services in New Jersey* is intended to help parents, students, and the professionals who serve them better understand these requirements and improve their access to appropriate transition services.

Transition is the time when a student with disabilities and/or special healthcare needs moves on from high school to adult life. This passage takes place when the student exits high school because they have either graduated from high school with a diploma or have completed the year of schooling during which they have turned 21, the age when a school district is no longer required to provide special education services.

What Are Transition Services?

** Transition services" are a coordinated set of activities designed as part of a results- or outcome-oriented process; this process focuses on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to "post-school activities." These include postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services (including adult healthcare), independent living, and community participation. Results- or outcomes-oriented processes start with the desired end (result or outcome) in mind, and then identify the knowledge, skills, services, and supports needed to achieve those desired results or outcomes.

Services must be based on the child's needs, taking into account their strengths, preferences, and interests. Transition services include instruction, related services, community experiences, the development of employment and other post-school adult living objectives and, if appropriate, the acquisition of daily living skills and a functional vocational evaluation.

Transition services must be provided in the "least restrictive environment" (LRE). LRE is likely to be the "real world"—the community in which the student will live and work after high school graduation. A student's transition goals may include learning to ride a bus, shop for groceries, access community-based recreational activities, handle money, partner with healthcare providers, and apply for a job.

Who is Eligible for Transition Services?

n New Jersey, students between the ages of 14 and 21 who receive special education services and have an Individualized Education Plan (IEP) are eligible for transition services.

In New Jersey, transition planning begins no later than the school year in which a student will be 14. At that time, the IEP must include a statement of the graduation requirements that the student is expected to meet. In addition, it must include a statement of the student's strengths, interests, and preferences, along with a course of study and related strategies and activities designed to help the student develop or attain post-secondary goals.



What Does IDEA 2004 Say about Transition?

The federal special education law known as the <u>Individuals with</u> <u>Disabilities Education Act (IDEA)</u> defines Transition Services as "a coordinated set of activities for a student, designed within a resultsoriented process, which promotes movement from school to postschool activities, including:

- Postsecondary education
- Vocational training
- Integrated employment (including supported employment)
- Continuing and adult education
- Adult services
- Independent living
- Community participation

These activities are based on the student's needs, taking into account the student's strengths, preferences, interests, and vision for adult life."

What Does the Rehabilitation Act Say about Transition?

The federal <u>Rehabilitation Act</u> defines transition services similarly, using an outcome-oriented approach with a focus on career development, competitive employment in the integrated labor market, and self-sufficiency of the individual. The coordinated set of activities "shall include instruction, community experiences, the development of employment and other post-school adult living objectives and, when appropriate, acquisition of daily living skills and functional vocational evaluation."

What Is Chapter 6A:14, the New Jersey Special Education Code?

C hapter 6A:14 is the New Jersey Special Education Code that, together with IDEA, provides children with disabilities a free and appropriate public education (FAPE) that meets their unique needs. For students eligible for special education, an Individualized Education Program (IEP) is developed by a team that includes several parties.



Possible members of the IEP team are as follows:

- The parent(s)/guardian(s)
- <u>The student</u> (no later than age 14, and earlier if the parent wishes)
- School personnel—at least one general education teacher, someone qualified to provide or supervise special education, someone who can interpret evaluation results, someone who can make commitments on behalf of the district

The team may also include other agencies:

- Division of Developmental Disabilities (DDD)
- Division of Vocational Rehabilitation Services (DVRS)
- Commission for the Blind and Visually Impaired (CBVI)
- Division of Mental Health and Addiction Services (DMHAS)

The team may also include any individuals invited by the parent or school district. For transition-age students, this includes representatives of any involved adult agencies who have been given consent by the parent(s)/guardian(s) or the student to attend.

The student must be invited to any meeting in which transition will be discussed. The student may choose not to attend, but it is *highly recommended* that they do. This is critical both for the IEP to reflect their interests and preferences and to build their advocacy skills.

The IEP for a student who is 14 must include a statement of the state and local graduation requirements that they are expected to meet. If the student is exempted from, or there is a modification to, local or state high school graduation requirements, the IEP must include a rationale for the exemption or modification and a description of the alternate proficiencies to be achieved in order to qualify for a state-endorsed diploma.

The IEP for the school year during which the student turns 16 must include measurable post-secondary goals based upon age-appropriate transition assessments. Appropriate transition services designed within a "results oriented" process to facilitate the student's movement from school to post-school activities—including post-secondary education, vocational education, integrated employment, continuing and adult education, adult services, independent living, and community participation—must also be included.

At least three years prior to a student reaching the age of majority (18), the IEP team must meet with them and provide information to them about their rights. Regardless of ability, students become their own decision-makers upon reaching age 18.

Parents who believe their child will need assistance should consider <u>Supported Decision Making and Alternatives to</u> <u>Guardianship</u> (see page 22) before their student turns 18.

> Two years prior to graduation, students should register with the <u>Division of Vocational</u> <u>Rehabilitation Services (DVRS)</u> to determine eligibility for adult services. A student who receives Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) is automatically eligible for DVRS services.

Workforce Innovation Opportunity Act (WIOA)

The Workforce Innovation Opportunity Act (WIOA) was signed into effect in 2014 and the regulations were issued in 2016. WIOA provides for Pre-Employment Transition Services (Pre-ETS) to students with disabilities who are eligible or potentially eligible for Vocational Rehabilitation (VR) services; these begin during the school year that a student turns 14 years old.

There are five activities available under Pre-ETS:

- Job exploration counseling
- Work-based learning experiences, which may include in-school or community-based opportunities
- Counseling on opportunities for enrollment in comprehensive transition or postsecondary educational programs
- Workplace readiness training to develop social skills and independent living
- Instruction in self-advocacy, including peer mentoring

After exiting school, if a youth with disabilities chooses to be placed in a setting that pays subminimum wage, there must be documentation that they received appropriate Pre-ETS or transition services under IDEA for the placement to be allowed by WIOA.

The Pre-ETS that are provided by DVRS to a student who is eligible for special education need to be coordinated with other transition services provided by the school district and others, since Pre-ETS are not meant to replace the transition services in a student's IEP, but rather to enhance them. Each local education agency (LEA) needs to collaborate with DVRS to ensure

that the provision of Pre-ETS is complementary to the transition services being provided.

The IEP team must also consider the need for consultation from other agencies beginning when the student turns 14, or younger if appropriate.



What Is the Parent's Role in Transition Planning?

Parents have a key role in preparing their child for the transition from school to work and adult life. Hopefully, the process was already started when the student was in elementary and middle school, and the student has begun to learn about different jobs and participate in community and



school activities. Parents need to provide increasing opportunities for their child to develop the skills needed to become as independent as possible in areas such as performing household chores, taking care of hygiene needs, making choices, and advocating for themselves and their own needs in school, community activities, and their own health care.

In New Jersey, transition planning starts no later than the school year in which the student will turn age 14 (age 16 under federal law). The best advice for parents beginning this process is to *START EARLY!* There is a lot of information available about the transition process and the child's rights under special education laws as well as about post-school options and adult agencies. It can all seem overwhelming, especially at the beginning, but help and support is available from a variety of places—local school districts, state agencies, community and family organizations like SPAN, and other families who have been through this process with their children.

An activity that can help educate parents about available transition resources is the <u>"Transition from School to</u> <u>Adult Life" Transition Workshop</u> offered by SPAN at various locations across the state during the school year.

Parents have so much to share about their child's strengths, needs, interests, and dreams. This is important information to discuss at annual IEP meetings and to use in designing appropriate transition services.

Parents are essential partners with the school district throughout the entire special education process; this is especially true during transition planning. A parent's most important role in the transition process is to ensure that the student's *voice* is heard and that all team members listen and support the student in developing the skills they need to live an adult life that is as independent and meaningful as possible.

What Is the Student's Role in Transition Planning?

Students are at the center of the transition planning process and need to be encouraged and supported to take an active role in this process. This can be done through activities such as:

- Participating in, or even leading, their annual IEP meeting
- Developing their own Vision Statement to share at the IEP meeting
- Identifying career options that match their interests and skills
- Taking courses in school to prepare them for postsecondary life
- Participating in extracurricular activities relevant to their interests

A great tool to aide in this planning is "The Positive Student Profile" found on the SPAN website. First refer to the <u>Sample Profile</u> and then <u>Create Your Own Profile</u>.

Regardless of a student's disability, they must be invited to any meeting in which transition will be discussed. Although the student may choose not to attend, they should be supported and encouraged to actively develop self-advocacy skills.

Creating opportunities for choices and preferences at an early age encourages decision-making skills. Early participation in the IEP process prepares students for their expected participation at age 18, when they will be a decision-making member of the IEP team.

Students need to begin exploring post-school options while still in school. This may include developing a portfolio of interests and experiences, visiting college programs, job-shadowing at a work-site, or contacting an adult agency to apply for services.

One of the most helpful activities that students can pursue while still in school is gaining work experience—a summer job, an internship, a volunteer position at a local community organization, and so on.

Research shows that students who have work experience during high school are more likely to get and keep a job after high school and will earn more money after they leave school. This is where networking with family, friends, neighbors, teachers, and local businesses can help with locating job possibilities in the community. The student will have the opportunity to learn work habits and new skills as well as develop self-confidence and friends in the workplace.

What Is a Self Advocate?

An effective self-advocate is someone who is good at letting other people know what they think, feel, and need. Sometimes self-advocacy means asking lots of questions and continuing to ask them until one really understands the answers. It can also mean helping other people understand what is important to oneself. Sometimes it means asking for help when it is really needed.



Self-advocacy does not mean a person will always get exactly what they want exactly how they want it, but having the skills and confidence to communicate one's strengths, wants, and needs is an important first step in reaching one's goals.

> SPAN has several webinar recordings to help families and young adults understand the importance of selfadvocacy and self-determination:

spanadvocacy.org/content/reachtransition-webinars-0

Self-advocacy skílls need to be taught and practiced at home, ín school, and ín the community as early as possible so that students have the opportunity to learn how to problem-solve, make choices, and advocate for themselves.

What Is the Student's Vision for the Future?

The student's vision of their own future drives the transition planning process. The Transition statement is part of the Transition Plan within the IEP. This statement reflects the student's strengths, preferences, interests, future plans, and longterm goals. The long-term goals then become part of the student's IEP. These postsecondary goals should include the student's future



plans in three outcome areas: Education/Training, Employment, and Independent Living.*

* Independent Living is a broad area that spans civic engagement, housing, recreation, health care, friendships, and community participation.

Because it is sometimes difficult for students to determine what they want to do "when they grow up," a good starting point can be a discussion about their **interests**, **strengths**, **and dreams**. At this stage, age-appropriate transition assessments can be helpful for developing measurable postsecondary goals.

For example, there may be a need to do career exploration through **Career Interest Inventories** before it is possible for a student to identify potential jobs in which he or she may be interested. It may also be helpful to use a process called **"Person-Centered Planning"** to help develop the student's vision.

With the help of a facilitator, this process gives the student an opportunity to share their hopes and dreams for the future with the important people in their life, who then work together to develop an <u>Action Plan</u> to help move the student toward their vision.

Transition Planning in Fligh School

How and When do | Begin Transition Planning with My Son or Daughter?

Work with your school team to ensure that transition planning begins with the IEP no later than when your child turns 14. Every school year until they graduate or turn 21, there needs to be a thoughtful and comprehensive transition planning discussion either at the IEP meeting or in conjunction with it. This transition discussion must be documented annually in the Transition Plan. The Transition Plan is a section within the IEP that is updated on an annual basis, during the annual IEP meeting.

No later than when a student turns 14, the school district will begin to invite them to the team meeting. It is important to discuss with the student how they want to participate in the transition planning process and make these planning meetings meaningful. It is helpful to prepare the student for the meeting by reviewing the participants, discussing the purpose of the meeting, and determining the student's role in the meeting.

SPAN recommends that parents bring their child to some or all of the IEP meetings starting from the very first one. Children with disabilities at any age need to understand their disability, their strengths and needs, and how to participate in the partnership and advocacy process.

Utilizing a Transition Checklist is always helpful.

For some students it is also helpful to have a pre-meeting with a member of the team to prepare a **Vision Statement** about their interests and goals for the IEP meeting. Utilizing a tool such as the **Positive Student Profile** can also be helpful.

The Transition Plan will document the transition planning discussion and includes the following sections:



<u>Postsecondary Vision</u>: Reflecting the student's strengths, preferences and interests, and desired outcomes for postsecondary education/training, employment, and adult living. (Corresponds to the vision statement in the IEP.)

Disability-Related Needs: Documenting the skills that require IEP goals and/or related services. This section identifies the skills that students need to develop or improve in order to achieve their postsecondary goals and that require special education and/or related services. IEP goals/objectives need to be developed for these skill areas. (For example, the student may need to develop skills in the area of travel training, resume writing, or healthcare decision-making.)





Action Plan: Outlining how the student will develop selfdetermination skills and be prepared both academically and functionally to transition to post-school activities in order to achieve the postsecondary vision.

Specific Areas to Be Addressed in the Action Plan Include:

- Instructional Needs: Specific courses or a course of study in high school that enables the student to reach postsecondary goals
- <u>Employment</u>: Providing work opportunities and skill development in activities such as resume writing, interviewing, and other "soft skills"
- Community Experiences/Post-School Adult Living: A listing of the roles and actions of the involved school personnel, family members, adult service providers, peers, and others in the community who can help the student develop necessary skills



How Does the IEP Address the Student's Transition Needs?

n order for transition services to be provided by the local school district, they must be documented in the student's IEP. The Transition Plan can help to identify the transition services needed by the student, specifically using the student's postsecondary goals and their disability-related needs.

There needs to be a clear link between the student's annual IEP goals and postsecondary goals. The Transition Plan should document the student's disability-related skills that require IEP goals and/or related services. It is important to remember that the IEP is a legal document guaranteeing services to the student. This discussion may generate IEP goals/objectives based on the student's disability-related needs and postsecondary goals that should be incorporated into the student's IEP.

Transition planning is an ongoing process throughout the high school years, and all IEP goals/objectives should be reviewed and updated or changed on an annual basis.

What Are Postsecondary Goals?

Oostsecondary goals are measurable goals that focus on three specific areas:

- 1) Postsecondary Education/Training: Where and how is the student going to continue to learn new skills after graduation?
- 2) Employment: Where is the student going to work or engage in productive activities after graduation?
- 3) Independent Living: Where is the student going to live, and how are they going to access adult services and participate in community activities and civic engagement, including voting and adult healthcare?

These are long-term goals that will be achieved by the student after leaving high school. They need to be appropriate to the student's needs and based on age-appropriate transition assessment. The IEP team must be able to measure progress toward these goals, which are part of a student's IEP beginning at age 14 and need to be reviewed annually until the student graduates or turns 21.



What Are Transition Assessments?

Transition assessments are used in the process of collecting data on the individual's needs, preferences, and interests as they relate to the demands of current and future working, educational, living, and personal and social environments. Assessment data serve as the common thread in the transition process and form the basis for defining goals and services to be included in the IEP.

The results of age-appropriate transition assessments provide the student, parents, and other members of the IEP team with information about how the student is currently functioning.



They form the basis for the development of measurable postsecondary goals and the transition services needed to help the student achieve them.

Transition assessments should be individualized based on the student's strengths, preferences, interests, needs, and desired post-school outcomes. It is often helpful to use multiple assessments rather than a single test to ensure that the assessment(s) chosen supports the student's learning style. Like other assessments, the request for transition assessments should be put in writing by the parent(s)/guardian(s) or adult student to the school district.

A transition toolkit can help: transitionta.org/system/files/toolkitassessment/ AgeAppropriateTransitionAssessmentToolkit2016_COMPLETE_11_21_16.pdf

The Role of Outside Agencies in the Transition Planning Process

The IEP team must consider the need for consultation with other agencies such as the <u>Commission for the Blind and Visually Impaired (CBVI)</u>, <u>Division of</u> <u>Mental Health and Addiction Services (DMHAS)</u>, <u>Division of Vocational</u> <u>Rehabilitation Services (DVRS)</u>, <u>Division of Developmental Disabilities (DDD)</u>, <u>Division of the Deaf and Hard of Hearing (DDHH)</u>, and <u>New Jersey Consortium</u> <u>on Deaf Blindness (NJCDB)</u>.



Transition Timeline: Things to Consider

Adapted from: Parent Brief, Winter 1996, National Transition Network (with amendments by Education Law Center, September 2011)

Prior to Transition (Birth-12 years old)

- Envision a future for your child as an adult. Have a conversation with your child about what they envision for themselves.
- 2. Consider what skills it will be necessary to develop to help make your child more independent.
- 3. Seek out opportunities for skill building. Encourage your child's interests and build on strengths. Give your child responsibilities/chores as much as possible at home (opportunities for success).
 - 4. Encourage social engagement outside of school.
- 5. Look for volunteer opportunities.

Ages 15-16

- Identify community support services and programs (vocational/rehabilitation/county services, Centers for Independent Living, etc.).
- Invite adult service providers and/or peers to the IEP transition meeting.
- Match career interests and skills with vocational course work and community work experiences.
- Gather more information on postsecondary programs and the support services offered, and make

Ages 13-14

- Identify personal learning styles and the necessary accommodations to help your child become a successful learner and worker.
- Identify career interests and skills, complete interest and career inventories, and identify additional education or training requirements.
- 3. Explore options for post-secondary education and admission criteria.
- Identify interests and options for future living arrangements, including supports.
- Learn to effectively communicate interests, preferences, and needs.
- Be able to explain the disability and the needed accommodations.
- 7. Learn/practice informed decision making skills.
- 8. Investigate assistive technology tools that can increase community involvement and employment opportunities.
- Broaden experiences with community activities and expand friendships.
- 10. Pursue and use local transportation options outside of family.

arrangements for accommodations to take college entrance exams.

- Identify healthcare providers and become informed about sexuality and family planning issues.
- Determine the need for financial support (Supplemental Security Income (SSI), state financial supplemental programs, Medicare, etc.).
- 7. Begin a resume and update it as needed.

- 11. Investigate money management and identify necessary skills.
 - 12. Acquire identification card and develop the ability to communicate personal information.
- 13. Identify and begin learning skills necessary for independent living.
- 14. Learn and practice personal health care.
- Learn and practice appropriate interpersonal, communication, and social skills for different settings (employment, school, recreation, with peers, etc.) œ.
- Explore legal status with regard to decision-making both prior to and once having reached the age of majority. 6.
 - 10. Practice independent living skills (budgeting, shopping, cooking, housekeeping, etc.)
- 11. Identify needed personal assistant services and, if appropriate, learn to direct and manage these services.

One Year before Leaving the School District

- Apply for financial support and other programs (SSI, independent living services, vocational rehabilitation, personal assistant services, etc.) as appropriate.
- Identify public transportation options and apply as needed (New Jersey Transit reduced fare application; Access Link; county para-transit, etc.). ц Сі
- Identify and apply for appropriate postsecondary education options, and arrange for needed accommodations. т. т
- Practice effective communication by developing interview skills, asking for help, and identifying necessary accommodations in postsecondary and work environments. 4.
- Specify desired job and obtain paid employment with supports as needed. <u>л</u>.
- Take responsibility for arriving on time to work, appointments, and social activities. <u>ن</u>
- Identify health insurance coverage options and apply for Medicaid (if applicable) when student turns 18. ~
 - Assume responsibility for health care needs (making appointments, filling and taking prescriptions, etc.). ώ.
 - 9. Register to vote and, if male, register for Selective Service.

What Is Age of Majority?

A t least three years prior to when the student begins the transition process and reaches the age of majority (18), the IEP team must meet with the student and provide them with information about their rights upon reaching age 18.

Parents should understand that youth make their own IEP decisions once they turn 18. Parents can continue to participate with the consent of their adult child. Only stripping the adult of their legal rights through obtaining guardianship takes away the young adult's right to be an IEP decision-maker.

Supported Decision-Making

Parents of children (and adults) with disabilities and self-advocates need to know that supported decision-making is a preferred alternative to guardianship. While parents may have legitimate concerns about their youth/young adult's ability to make decisions about their own healthcare, education, finances, living situation, etc., youth and young adults with disabilities have the right to be involved in and make their own decisions about their lives.

Families of individuals with disabilities and self-advocates need to be aware of supported decision-making and make the choice that best fits their needs and maximizes the dignity and independence of their youth/young adults with special needs.



Principles of Supported Decision-Making: For more information on this topic see "Supported Decision-Making and Alternatives to Guardianship" Webinar: <u>tinyurl.com/sup-decis-make-alt-guard</u>

Reasons Parents Might Seek Guardianship

- Medical and health concerns, including seeking care and following medical advice
- Financial and legal (decision-making) concerns, including signing of contracts
- Educational concerns, including advocating to obtain services
- Self-care and safety concerns, including matters of sex/sexuality
- Program and placement matters, including accessing vocational/adult services and living arrangements
- Mistaken belief that it is required in order to be eligible for services from New Jersey Department of Human Services Division of Developmental Disabilities
- Fear of the young adult's lack of decision-making capacity
- Misinformation that they "must" get guardianship
- Fear of what will happen when parents are no longer around

Reasons Parents Might Want to Avoid Guardianship

- To not make a public declaration of incompetence
- To limit how involved the courts are in their lives
- To discourage people from dealing only with the guardian and ignoring the individual
- To promote independence, dignity, and freedom of choice
- Guardianship is difficult to modify or terminate
- Attorneys, hearings, and evaluations are expensive

Children with special needs should have as much input as they can based on their capacity. Parents must begin at an early age to help their child—regardless of their disability or special healthcare needs—engage in decision-making about their own care and prepare them to make independent decisions as they become adults.

Principles of Supported Decision-Making

- All individuals of legal age are persons before the law and have a right to self-determination and respect for their autonomy, irrespective of disability.
- All adults are entitled to the presumption of capacity and identity, irrespective of disability, and to the decision-making supports necessary to exercise capacity and reveal identity.
- Decisions made interdependently with family, friends, and trusted others chosen by the individual will be recognized and legally validated.
- All individuals have a will, and this will is capable of being interpreted and forming the basis for competent decision-making and identity.
- Individuals are entitled to the supports and services necessary for full participation and equality. The provision of such supports will lessen the need for legal intervention in decision-making.
- Third party interests and liability concerns do not provide a valid justification for removing a person's decision-making rights.

Shared decision-making is one of the key concepts in healthcare. When patients and their families partner with health providers, they get better outcomes.

One of the six core outcomes the Maternal/Child Health Bureau highlights is the importance of shared decision-making: "Families of children and youth with special healthcare needs partner in decisionmaking at all levels and are satisfied with the services they receive."

One of the main ideas behind another core outcome for children with special needs—the medical home—is that care needs to be patient- and family-centered.

To protect the civil rights and dignity of youth and young adults with disabilities and special healthcare needs, it is critical that parents use supported decision-making as an alternative to guardianship for their young adults with special needs.

Even if parents decide that guardianship is the only alternative that will work for their family, it is important that they minimize the extent of their guardianship and use options such as limited guardianship so that their young adult with special needs can make as many of their own decisions as possible. In terms of healthcare decision-making, an important alternative to guardianship is a **Healthcare Power of Attorney**, which allows parents to participate in healthcare decision-making for their young adult with special needs without guardianship. Links to relevant forms, resources, and contacts are listed below.

Forms

Sample Healthcare Power of Attorney & Advance Directive Forms

- American Academy of Family Practitioners (AAFP)–Advance Directive/Power of Attorney: www.aafp.org/afp/1999/0201/p617.html
- NJ Department of Health–Palliative and End of Life Care: What is an Advance Directive (see Healthcare Proxy): <u>www.state.nj.us/health/advancedirective/whatis.shtml</u>
- Disability Rights Idaho–"Self Advocacy Guide to Guardianship" (see Chapter 2): www.disabilityrightsidaho.org/images/content/docs/Self-Advocacy%20Guide%20to% 20Guardianships.pdf

Resources

Alternatives to Guardianship Resources

- SPAN: <u>spanadvocacy.org/content/supported-decision-making-and-alternatives-guardianship</u> / (800) 654-SPAN (7726)
- Alternatives to Guardianship: <u>ruralinstitute.umt.edu/transition/</u> <u>NewsletterVol5_lss3_text.pdf</u>
- Guardianship-Family Options (see Power of Attorney): <u>nj.gov/humanservices/ddd/</u> services/guardianship
- Guardianship & Alternatives to Guardianship: <u>www.ridlc.org/media/publications/ridlc-guardianship-booklet.pdf</u>
- Guardianship and Its Alternatives (see Chapter 3): <u>mcdd.kennedykrieger.org/guardianship-and-its-alternatives-handbook-2011.pdf</u>
- Thinking about Guardianship?: <u>www.gcdd.org/images/Reports/guardianship%20guide%</u> <u>20-%20gcdd.pdf</u>
- SPAN: Transition materials for health care practitioners, including power of attorney for medical decisions, can be found at <u>www.spannj.org/keychanges/</u> <u>TransitionResourcesHealthPractitioners.pdf</u>

Helpful Contacts

- Centers for Independent Living (CILs): CILs maximize the skills needed for independent living, the supports needed to achieve this goal, and the potential of individuals who may not live independently. County CILs can be found at <u>www.njsilc.org</u>
- SPAN Family Voices/Family-to-Family Health Information Center: <u>www.spanadvocacy.org/content/family-family-health-information-center-family-voices-nj</u>

What Does "Healthcare" Mean?

"Healthcare" is one of the life domains to be considered during the transition process along with post-secondary education, employment, and independent living. Healthcare for youth with disabilities includes things like managing their own health, financing health care and health insurance, interacting with healthcare providers, and advocating for their own health and healthcare.

Some young adults have been dealing with health problems for many years, and for them this time of transition may be even more complicated. They may feel like they are tired of dealing with health issues and would rather just think of other things, like going out with friends or finding a summer job. They may be nervous about leaving doctors they are familiar with and getting to know new ones.

Addressing Healthcare Needs and Integrating Them into the Transition IEP

t is important for youth with special healthcare needs to be able to understand their own condition and needed treatment, explain their condition and needed treatment to others, monitor their health status on an ongoing basis, and ask for guidance from adults, including health care providers.

Additionally, they should understand formal and informal advocacy services and learn about systems that will apply to them as adults (health insurance, social security, and power of attorney for healthcare).

The IEP should address all healthcare needs within the **Present Levels of Academic Achievement and Functional Performance** and through measurable goals. Goals and objectives within the IEP should include as much self-care and independent management of health conditions as possible to optimize adulthood employment, independent living, and community participation.



SPAN has several webinars for more information: <u>www.spanadvocacy.org/content/reach-transition-webinars-0</u> Independent living skills should be addressed in the Transition Plan. These are skills or tasks that contribute to the successful independent functioning of an adult in the domains of leisure/recreation, home maintenance, personal care, and community participation. Goals and objectives should include as much self-care and independent management of health conditions as possible to optimize adulthood employment, independent living, and community participation.

Health and Transition to Adulthood

eaving school and creating an adult life present new opportunities and new challenges for everyone; how people respond to those opportunities and challenges depends on many things. Having a disability is just one factor of many that can have an impact on someone's transition to adulthood; a person's strengths and needs, likes and dislikes, family's expectations of what adult life should look like, and where they live are all things that will help shape the choices a person makes.

There are ways, however, that having a disability can create unique challenges

when someone is in the process of transitioning to adult life. For example, depending on the specifics of the disability, some young adults have had little experience doing things alone. In other cases, because they have needed specialized supports for many years, other young adults wonder if that means they will never really be "grown up."



One thing to keep in mind is that no one is completely "independent." The idea that adulthood means that people are able to do everything on their own is a myth. All people, regardless of whether or not they have a disability, need help reaching their goals. When we ask people we know and admire, they tell us they didn't achieve their successes without some help along the way. Just watch someone winning an Oscar or an athlete getting a big sports awards—they always spend time thanking those people who have helped them get to where they are.



A t 18, most people have the legal right to make their own decisions about their health care. However, while taking responsibility for one's own health is a part of growing up, being 18, or being an adult of any age, doesn't mean a person suddenly understands everything they need to know. Nor does it mean they are expected to make big decisions all by themselves.

Many young adults choose to have their parents or another trusted adult provide at least some guidance when they are making medical decisions, especially if they are complicated. Some people have a guardian who has the legal responsibility of making certain decisions for them.

Understanding one's disability is an important step in growing up and taking responsibility for reaching the goals that matter to a person. The more a student understands themselves—strengths, interests, likes, dislikes, dreams for the future, as well as their disability and any health issues they might have—the easier it will be for them to meet new challenges successfully.

If young adults with disabilities do not understand what they need, it will be much harder for other people to understand and provide the supports and accommodations that will be most useful to them. Being a good self-advocate means knowing oneself best of all.

Talking with a Healthcare Provider

All a child's young life, they have seen a pediatrician who is trained to care for children and their healthcare needs. When a child becomes an adult, they should see someone who is trained to care for adults.

Moving from pediatric to adult healthcare services for a teen or young adult with special needs involves more than just switching to adult specialists (which can be difficult enough); it can also involve switching to new programs. Parents must not only continue to advocate on behalf of their teens, but must also help their teens speak up for themselves to the best of their ability—this includes talking to their doctors.

There are many questions surrounding healthcare that a student may have when it comes to seeing a doctor:

- How do I talk to a doctor about my health?
- How do I ask my doctor questions?
- How do I make doctor appointments?
- Do I understanding the directions for taking my prescriptions?

It is important for a student to know that there are lots of different kinds of supports, and that which supports they choose will depend on what exactly they need help with. Here's one way to think about the kinds of supports they may find helpful:

- "Natural" supports—family and friends;
- "Community" supports—resources that are there for everyone, with or without a disability, like libraries, YMCAs, and public transportation;
- "Disability-specific" supports—resources like Medicaid, Social Security, and para-transit;
- Assistive technology—includes wheelchairs, screen readers for the computer, and recording devices.

Again, depending on what a person needs, they may use one or a combination of these kinds of supports.

Planning ahead, learning what they need to do to stay healthy, and having a health care provider and people to support them will make it much easier for youth to transition to adulthood and a life in the community.

Post-School Options

As students begin to plan for the future, they need to explore post-school options in the areas of postsecondary education, employment, and adult living while they are still in school. Transition planning in high school should include preparation in all three of the following areas:

Postsecondary Education: Students with disabilities who are interested in postsecondary education and training may want to apply to 2-year or 4-year college programs or pursue specialized training at a vocational or technical school. Like all students, they will need to consult with their guidance counselor, visit college programs, learn about financial aid options, register for SATs or other entrance exams (with needed accommodations), and fill out college applications during high school. It will also be important for students and their parents to understand the important legal and programmatic differences between high school and college.

There Is No IEP/Special Education in College

While laws such as the <u>Americans with Disabilities Act (ADA)</u> and <u>Section 504 of</u> <u>the Rehabilitation Act</u> provide access with accommodations, college-level students must meet admission criteria defined as "otherwise qualified." These are *civil rights protections*, not entitlements to services.

At any institution of higher education, the student will be considered an adult who is expected to make their own decisions and to self-advocate when they move on to college. Learning these skills is essential in the transition planning process.

In college, services are based on eligibility. Students must disclose their disability and provide documentation to demonstrate their need to receive accommodations and supports in college. Deciding whether to disclose a disability is a personal decision. It is important for youth to know what their disability is and understand how it affects them. Youth must also learn how to communicate that information to their college Disability Services office or their employer's Human Resources office.

A qualified student cannot be denied admission on basis of disability as long as the student is able to meet the academic and technical standards for participation in the program.

The college must also make necessary academic adjustments to provide equal access and the opportunity to participate to students with disabilities. In elementary and secondary education, the supports students with disabilities receive are often called "related services" or "accommodations" and "modifications." In postsecondary education, these supports (such as a note-taker) are sometimes referred to as "academic adjustments" or "auxiliary aids," and they must be requested from the Disability Services office at the college.

Auxiliary aids should support the student to ensure that communication is as effective as it would be for students without disabilities. The college must provide an appropriate, but not necessarily the most sophisticated, aid or service that will provide equal opportunity and access for the student with a disability. Although the college should give primary consideration to the student's preference, an effective alternative is permissible.

Colleges are not required to provide more general personal services—such as personal care attendants or assistive technology devices for personal home use—to students with disabilities. SPAN's transition webinars have more information:

spanadvocacy.org/content/reach-transition-webinars-0

* Students with intellectual and developmental disabilities who are interested in exploring college options can get more information at <u>thinkcollege.net</u>.

Employment: After leaving high school, some students may choose to begin working right away. Hopefully, they have been provided with career exploration activities during high school to help them match their interests and skills with an appropriate job. A comprehensive vocational assessment may be necessary to assess the student's current vocational skills and need for accommodations such as assistive technology.

If individuals have a physical, mental, emotional, or learning disability that interferes with their ability to work, they may be eligible for vocational rehabilitation (VR) services from the <u>New Jersey Division of Vocational Rehabilitation Services (DVRS)</u>. If eligible for VR services, the student may receive vocational counseling, evaluation, job placement, and/or job coaching to help them become competitively employed.

Another area to explore is how working will impact benefits from the Social Security Administration such as SSI or SSDI and health insurance from Medicaid and Medicare. It may be helpful to contact a benefits planning counselor at the Social Security Administration to obtain individualized help with these questions.

Independent Living: A part of the transition planning process for students is thinking about where they want to live after they leave school and what residential supports, if any, they will need in order to live in their own apartment or in a supported living situation.

The student needs to learn the skills necessary to live as independently as possible. Independent living skills include money management and paying bills, preparing meals, doing laundry, managing medications and health care, using public transportation, and much more.

Adult Services: Entitlement vs. Eligibility

What Is the Difference between Entitlement to Special Education Services and Adult Eligibility for Services?

Entitlement is a guarantee of access to services for everyone who qualifies. Under state and federal law, special education services are an entitlement. This entitlement to special education services in New Jersey terminates when a student graduates with a high school diploma or completes the school year during which they turn 21, whichever comes first.

When students receiving special education services in New Jersey graduate from high school and/or turn 21, their *entitlement* to special education ends. They may then be *eligible* for adult services if they meet the eligibility criteria for adult agencies and programs. It is important to understand the difference between **entitlement** to special education services and **eligibility** for adult services.

Adult eligibility for services is *not* necessarily an entitlement, so youth and young adults who are eligible for services from an adult agency are not guaranteed access to services. Unlike special education, human services for adults with disabilities are contingent upon program availability and funding, and there may be waiting lists for services. That is why it is important to start the application process for agency eligibility early.

(Note: If your child has been receiving children's services from an agency such as Division of Disability Services or Division of Children and Families, you will need to reapply because the criteria for adult services can be different from the criteria for children's services.) t is important for youth/young adults to start applying for adult services and programs several months before they turn 18, or even earlier, depending on the program/service. Parents should keep copies of health, education, and social services records (i.e., medical records, IEP, habilitation plan, etc.) handy, since their child may be asked to submit them when applying for adult services.

In general, when applying for any programs or services, parents should remember to jot down the names and contact information of agency representatives and keep copies of any applications they submit. When mailing important documents, they should use a return receipt method and follow up, as they should get a letter stating their child's eligibility status and/or start date.

It is strongly recommended that the eligibility process begin two years prior to the projected date of high school graduation or turning 21 to allow for sufficient planning and budgeting by the adult agency. Contact the appropriate agencies if there are questions about their eligibility processes:

- NJ Division of Developmental Disabilities nj.gov/humanservices/ddd/home
- NJ Department of Children and Families state.nj.us/dcf
- NJ Division of Mental Health and Addiction Services (DMHAS) nj.gov/health/integratedhealth
- NJ Commission for the Blind and Visually Impaired state.nj.us/humanservices/cbvi/home/index.html
- NJ Department of Labor and Workforce Development lwd.dol.state.nj.us

Each agency's website contains information about the programs and services offered by the agency and the eligibility process for obtaining services. Most state agencies have local Area Offices around the state, so parents can contact their local Area Offices for more information. It is often helpful to learn more about an agency's programs and services by calling or visiting the local office and discussing the child's future needs.

What Other Community-Based Services are Available?

There are many community-based services available that can provide information, resources, and services for transition-age students. Here are a few examples:

<u>One Stop Career Centers</u>: These centers provide assistance to anyone seeking employment, including people with disabilities, and offer job search workshops, local job postings, and career counseling. They also offer job fairs with local employers and are a good resource for job information.

<u>Centers for Independent Living</u>: CILs offer a range of services to people with disabilities including peer mentoring, skills training, information and referral, and advocacy. Young adults with disabilities can get help with housing, employment, transportation, equipment, and other transition-related issues.

NJCILS: www.state.nj.us/humanservices/dds/resources/cntrindlivindex.html

Helpful SPAN Links

Reach for Transition

www.spanadvocacy.org/content/reach-transition-resources-employmentaccess-community-living-and-hope

Center for Parent Information & Resources

www.spanadvocacy.org/content/center-parent-information-resourcesnational-span-project

Basic Rights in Special Education

www.spanadvocacy.org/content/basic-rights-special-education-workshop

Look to the Future: Transition from School to Adult Life

www.spanadvocacy.org/content/look-future-transition-adult-lifeworkshop#overlay-context=content/look-future-transition-adult-lifeworkshop

Partners in Transition



Center Parent Information & Resources

spanadvocacy.org/content/ center-parent-informationresources-national-span-project spanadvocacy.org



spanadvocacy.org/content/ national-raise-technicalassistance-center



spanadvocacy.org/content/ reach-transition-resourcesemployment-accesscommunity-living-and-hope

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