



Educational Transition

AFTER EPILEPSY SURGERY

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“Disability

is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities. ”

The Individuals with Disabilities Education Act



What is **TRANSITION**?

The purpose of transition planning is to look ahead at your child's future life, set goals, and decide what supports and services are needed to help them be successful.

Regardless of their disabilities, children eventually become adults – physically and legally. You may have to support your child with getting through college, finding employment, enrolling in a day program, managing medical appointments, getting around the neighborhood, or finding a place to live.

There is a major shift for students with disabilities as they leave the structured setting of high school (when they lose the support of their entire education team) and enter the 'real' world – the demands for self-determination, organization, and independence are suddenly much greater.¹ Transitioning into adulthood is an exciting time, but it can also be overwhelming – not just for the student, but for the entire family.² It's important to learn about the big changes that will occur in nearly every aspect of their lives – and the steps in

the process – especially for children with complex neurological conditions.

Under the federal Individuals with Disabilities in Education Act (IDEA), students with disabilities are entitled to a free appropriate public education (FAPE) with related services designed to meet the child's unique needs and prepare the child for further education, employment, and independent living.³ In fact, the main purpose of IDEA is to ensure that children with disabilities are "prepared to lead productive and independent adult lives, to the maximum extent possible."⁴ Transition planning should help the student with a disability exit high school ready to start the rest of their life, with a vision for their future and a plan in place.

Children with disabilities are often described as "falling off a cliff"^{5 6 7} once they leave high

school in large part due to the failure of planning and implementing effective transition plans. Unfortunately, transition planning is often an afterthought rather than what it should be: the primary focus that guides secondary special education service decisions.

Too often, transition plans fail to meet even basic legal requirements or address the particular and specialized needs of the student.^{8,9} Individualized Education Plan (IEP) teams may simply "focus on filling in the transition page of the IEP accurately without regard to the value of this requirement."¹⁰

Congress stated that "there is an urgent and substantial need ... to maximize the potential for individuals with disabilities to live independently in society" but the reality is that "... there is no federal requirement for providing supportive services in adulthood."¹²

This guide will focus on the transition from K-12 school to postsecondary life – better known as life after high school – for children who have had epilepsy surgery and have individual education plans in school. It will help you start to think about what your child will do in terms of further education, job training, employment, living arrangements, transportation, and community participation as an adult.

KEY Points



Your child will become an adult and need to make important decisions.



It is important to help your child plan for his/her future life.



Transition planning is complicated for children with neurological differences.



Transition plans are often poorly designed or implemented.

When to **START** thinking about transition

It's never too early to start thinking about transition.

Successful transition into adulthood is something to think about, discuss, and practice throughout your child's life. After epilepsy surgery, most children will need a thoughtful and detailed approach to their transition planning.

Far too often, transition conversations begin too late.¹³ "Although IDEA dictates that comprehensive transition services need not be addressed until the student is 16, there is little justification for waiting until then to begin this conversation, particularly given a context of the IEP as a strategic transition plan. Age 14 typically signals entry into high school, and students and families need to develop an awareness of graduation requirements and diploma options."¹⁴

The Individuals with Disabilities Education Act requires the transition IEP to be in place by the student's 16th birthday at the latest.¹⁵ However, most states require transition planning to begin earlier than age 16 (check your state regulations).¹⁶ Federal law allows the IEP team (which includes the parent/guardian and the student) to begin transition planning even earlier in a student's life, based on the student's needs and preferences.¹⁷ Best practices suggest that the process should begin much younger than age 16.¹⁸

Transition planning is mandatory for any child with an IEP to prepare the child for what comes after aging out of special education or earning a

diploma.¹⁹ High school may be too late to begin transition planning for a child with complex medical, academic, social, emotional, and functional needs. Insist that transition planning begins at least five years before graduation. However, even if your child is a senior in high school, they should receive a thorough transition assessment before they graduate.

Believe it or not, as early as kindergarten is not too soon to begin. You can start by researching federal and state laws and regulations that relate to transition and considering what skills will be needed to prepare your child for their future life.

If your child has significant challenges in academic or functional skills that they will need in order to live and work independently, they may need more than a few years to build those skills. School teams might not know what is needed for students who are so complex. Programs or services may need to be modified – or even created – to support your child's unique needs. It's important to involve outside agencies as early as possible; while some may not have services until the child ages out, some may have services that could be valuable along the way (see *APPENDIX: Outside Service Agencies* at the end of this guide). Some programs may have years-long waitlists and the services or funding may not be available when your child needs it most.

Start right now!

SELF-DETERMINATION: Considering Self-Advocacy, Self-Awareness and Person-Centered Planning

Before you start building your child's individual transition plan, it's important to understand self-determination — an essential skill for successful transition into adulthood. It's about believing in yourself, knowing that you are capable of, and allowed to make your own life decisions.

Students, no matter what or how significant their disability may be, are the most important people involved in transition. Research has consistently shown the correlation between early self-determination and improved post-school outcomes.^{20 21} Students who are involved in setting their own goals are more likely to achieve them.^{22 23}

Self-determination and student engagement are also supported by federal law: the IDEA states that transition-age students must be invited to their IEP meetings and participate in their own IEP development, and the IEP and transition plan must be based on the young person's strengths, preferences, and interests.

Self-determination skills include goal setting, decision making, problem solving, and self-advocacy. "Early transition activities can include training in self-advocacy skills. Such skills have been found to play a critical role in the post-school success of students with disabilities, yet a recent study found that only 3 percent of secondary students with disabilities who participate in general education academic classes have been provided with self-advocacy training."²⁴

Transition-aged youth must understand their own disability and medical needs, learn about their legal rights and how to advocate for themselves.²⁵ They must develop the ability to speak up for their wants and needs, regardless of their level

of disability.^{26 27} If your child has communication challenges, then creative approaches may need to be used, such as supported self-determination.

For many young persons who have had brain surgery for epilepsy, this transition cannot be made successfully without a great deal of support and practice. Your child should receive ongoing, specific training to participate in their own IEPs (this is a rich area for IEP goals³² – self-advocacy and self-determination are critical life skills).³³ This can include training in effective communication, social skills, appropriate personal interactions, leadership skills, disability awareness, individual rights and laws, and learning how to access community-based services to meet health, transportation, decision-making, and community living needs.

Students should also be given opportunities to learn and practice self-advocacy and self-determination skills in many different settings (school, work, community, and at home).³⁴ Starting to practice these skills in middle school is a good idea.³⁵ This process should begin early enough to have an impact on your child's future outcomes.

"Person-centered planning is putting the person with a disability at the center of all decisions that are made about their life, starting at an early age. They should be given the opportunity to make their own, informed choices.²⁸
^{29 30} "This ultimately leads to greater inclusion as valued members of both community and society." ³¹



Understanding DIPLOMA TYPES

"It is critical that high school graduates, including students with disabilities, receive a diploma that means something — that they are prepared for postsecondary education and careers. All students deserve access to the academic skills they need so that they can make their own career decisions. They should not have those decisions made for them because they did not have the academic preparation they needed or, worse, left high school with a diploma believing they had been prepared." ³⁶

Each state sets their own minimum academic requirements for graduation for all students and may have different diploma types with varying requirements to attain a diploma. ^{37,38} There could be different diplomas for students in special education (who are often thought to be unable to meet grade level standards).³⁹ It's important to understand your state's graduation requirements well before your child enters high school and to discuss your child's graduation plan with the IEP team to ensure that it is appropriate for your child.

If a student is receiving modified curriculum (rather than just accommodations that provide access to the same coursework as their general education peers), it is possible that they are on a 'certificate track.' This means that the student will receive a certificate of attendance/completion because he or she is not actually earning credits to graduate with a 'regular' diploma.

While some students may not have the ability to complete the academic requirements and statewide assessments to earn a 'regular' diploma, it's important to be aware that lack of access to a high school diploma is often a barrier to employment success.⁴⁰ Alternative diplomas may be "viewed by potential employers as confusing and of questionable value ... and they are least likely to hire persons with these certificates. Similarly, postsecondary institutions (like colleges and universities) place little value on alternative exit certificates and, in general, treat students who earn these alternative certificates as though they had dropped out of school."⁴¹

If your child does not graduate with a regular diploma by age 18 they should continue to receive special education and transition services until they 'age out' of special education (age 21-24, depending on your state law) to further develop their academic, vocational, community, social, and life skills. However, some school district transition

programs are low quality and may not have room for your child or the appropriate types of supports and services – it's important to be aware of this early in the transition process so that you can change course if needed. If you are confronted with a lack of individualized transition options that address your child's unique needs, consider reaching out to your state's Disability Rights organization or contacting a special education advocate or attorney.

The school district can be obligated to pay for outside programs: "... if a child's IEP Team determines that a child's needs can best be met through participation in transitional programs on college campuses or in community based settings, and includes such services on the child's IEP, funds provided under Part B of the Act may be used for this purpose."⁴² This can include comprehensive transition programs.

There may be limited opportunities for inclusion of students with intellectual, developmental, or other 'significant disabilities' in high school courses and school transition or job-training programs, even though research shows that students who participate in regular education, career technical, and occupation-specific classes have improved post-school outcomes.⁴³

Alternatively, **students making progress toward a diploma** may have other needs ignored if the team presumes that *unless* they are in a special

day class or on a certificate track they cannot access vocational, social skills, or community transition services (which is not the case). If your child is about to graduate with a regular or alternate diploma and be exited from IEP services, but they lack other functional skills needed to access further education, employment, and independent living, you may consider rejecting the diploma (discuss this with a special education attorney well before graduation).

Even if your child is on a 'diploma track', they may not be prepared to earn sufficient credits to graduate. Their 'course of study' leading to a regular diploma (if appropriate) must be mapped out in their transition plan.

Earning a regular diploma may not be enough to attend a four-year college (the transition services and course of study must be aligned with the long-term educational goals of the child – what additional courses are needed for the child to achieve their goals?)

During high school, there may not be enough time (with all of the academic graduation requirements) to work on soft skills, self-determination, career awareness, and training. However, if there are needs in those areas, they must be addressed. A 5th year of high school or other options can be considered. See "STEP SEVEN: GRADUATION & AGING OUT", below.

KEY Points



Start thinking about, planning for, and practicing for transition early in life.



Transition services must be in place by age 16 (and in some states 14) – but can be earlier.



Your child must be part of his/her transition planning.



It's important to understand diploma types and what is needed to achieve future educational or employment goals.

Building the TRANSITION PLAN

The entire purpose of the IEP process is to prepare your child for life after high school.

The law requires that transition is addressed in the individual education plan by specifying the activities and supports the student needs to build the skills, experiences, and connections in order to achieve their life goals.

"Although IEP documentation feels and looks linear, the planning progression should be dynamic with IEP teams approaching the transition process holistically rather than in a fragmented manner... Nothing has been finalized until all areas have been considered."⁴⁴

Under the IDEA, the first IEP after a student is 16 must include appropriate measurable postsecondary goals that are based on age appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills. The IEP now includes the transition services, including courses of study, needed to assist the child in reaching these goals.⁴⁵

The transition plan should be reflected in the student's IEP. Some states may have separate documents or forms to help streamline transition planning (such as an Individualized Transition Plan or a Transition Planning Form), but all agreements (including goals, objectives, accommodations, modifications, supplementary aids, special education, and related services, community experiences, etc.) must be documented in the student's IEP.

Regardless of what it's called, transition planning is a legally mandated part of the IEP and should not be treated as a separate process. All the rules, definitions, and safeguards of the IEP remain – the IEP must continue to provide free appropriate public education (FAPE) during transition years with the added obligation of assessing and addressing long-term, post-school outcomes.

Transition planning is a complex process. It requires time, collaboration, and open minds. The team should remain focused on the student's best possible outcomes. Transition planning should not be an afterthought or an add-on. The IEPs developed during the transition years are the most important as they have the greatest impact on your child's future life options.

Transition planning is not just about what the student can do right now, but what they could do with appropriate instruction, training, support, and experiences. The student may change direction (many times!) during the course of high school – that's okay. This process is about determining a student's potential and possibilities for their future life and making a plan for how to get there.

These are the main parts of a transition plan outlined in the IDEA.⁴⁶ Each year, make sure all parts have been completed.



TRANSITION CHECKLIST



ASSESSMENTS

Age-appropriate assessment related to training, education, employment, and, where appropriate, independent living skills assessments (including community access and recreation and leisure skills) based on the individual needs of the student to be used to determine appropriate measurable postsecondary goals. This includes functional vocational evaluation if appropriate.



MEASURABLE POSTSECONDARY GOALS

These are goals for life *after* high school. There must be one goal in each of the following areas: training/education, employment, and if appropriate, independent living skills. Evidence that the measurable postsecondary goals have been updated annually based on age-appropriate transition assessment and data collection must be provided each year.



ANNUAL IEP GOALS

Annual IEP goals must support measurable post-secondary goals to outline the steps that the student needs to take while still in high school to achieve their postsecondary goals.



PROGRESS MONITORING

Progress monitoring including benchmarks to keep track of how the student is progressing towards their goals and accessing other transition services. If the child is not making progress, reconvene the team and discuss changes to the child's instructional program.



SUPPORTS AND SERVICES

The transition plan must list the supports and services needed to help the student achieve their postsecondary goals through a coordinated set of activities, including: specially designed instruction; courses of study; related services; community experiences; employment and other adult living objectives; daily living skills; and activities for exploration and skill development.



STUDENT INVITATION

Evidence that the school invited the child to attend the meeting must be provided.



OUTSIDE AGENCIES

Involvement of outside agencies that may provide adult services, as well as evidence that a representative of any participating agency was invited to the IEP meeting with the prior consent parent or student who has received the age of majority.



AGREEMENT

Agreement of who will provide and/or pay for the activities outlined in the statement of transition services, stating who is responsible for each aspect of the process (including referral to outside agencies, work experience, on-the-job training, and follow-up).

EXAMPLES OF HOW TO COMBINE TRANSITION AND IEP REQUIREMENTS

IEP COMPONENT:	FROM A TRANSITION PERSPECTIVE, INCLUDE:
Present levels of academic achievement and functional performance	<ul style="list-style-type: none"> • A vision statement of the student's hopes and dreams for the future. • Parent and student identification of strengths, needs, interests, and preferences, including career goals. • A description of student's current skills and experiences, including transition-related assessment results where appropriate, in the following: <ul style="list-style-type: none"> » Academics, including performance on state and district requirements linked to graduation outcomes. » Effectiveness of the previous use of accommodations, modifications, and supports in achieving or progressing toward prior IEP goals. » Social/emotional/behavioral skills, especially as these relate to job seeking, job keeping, and socialization. » Communication, including any special supports the student will need to work and live independently. » Health/medical, including any condition that will necessitate medical management skills for the student. » Independent living, including community integration and participation. » Community experiences (vocational and independent living), including the nature and type of experiences the student has had. » Cognitive and learning skills, including strengths that will assist in identifying bypass strategies to compensate for disability challenges. » Self-determination skills, including self-awareness, self-advocacy, self-management, and self-motivation. » Current participation within the general curriculum and with other youths, with and without disabilities, including extracurricular participation.
Transition	<ul style="list-style-type: none"> • Current postsecondary education, employment, and independent living goals. • Diploma status and plans; participation in state/district assessments. • Anticipated course of study for secondary school. • Instruction, community experiences, related services, independent living skills instruction, and functional vocational evaluation; cross-reference to the appropriate IEP components. • Linkages; cross-reference to the appropriate IEP components.
Annual goals, objectives, and benchmarks	<ul style="list-style-type: none"> • Measurable annual goals that enable the student to make progress toward his or her long term post-school transition goals for employment, postsecondary education, and independent living. <ul style="list-style-type: none"> » Intermediate objectives or benchmarks with clear evaluation criteria and timelines that will document progress toward the annual transition goals. » Responsible person(s) for providing instructional activity or monitoring progress toward each goal and how progress will be evaluated.
Accommodations, modifications, and supplementary aids and services	<ul style="list-style-type: none"> • Job accommodations or modifications that may be needed for the student to be successful. • Job coach or assistant, if needed. • Supports ranging from intermittent to pervasive, depending on need. • Assistive technology that may enable the student to live or work more independently. • Extended school year or day, if needed to meet the student's transition goals or objectives or to access specialized services.

EXAMPLES OF HOW TO COMBINE TRANSITION AND IEP REQUIREMENTS (cont.)

IEP COMPONENT:	FROM A TRANSITION PERSPECTIVE, INCLUDE:
Special education and related services , including the frequency, location, duration, and provider of services	<ul style="list-style-type: none"> • Specialized training for staff who will provide transition services or supports, if needed. • Vocational evaluation, if needed. • Therapy/counseling services, if needed. • School health services, if needed. • Assistive technology evaluation, if needed. • Orientation and mobility services, if needed. • Community-based instruction or work experience. • Specialized instruction to meet transition goals and objectives, including occupationally specific programs. • Transportation
Least restrictive environment	<ul style="list-style-type: none"> • Inclusive services provided within the community or workplace. • Participation with youth and young adults with and without disabilities.
Periodic reporting of progress toward annual goals/ objectives	<ul style="list-style-type: none"> • Plans for monitoring and reporting to families the progress toward annual goals (including transition-related goals). • Plans for reconvening IEP team if not progressing, or if services have not been provided as agreed upon.

From IEP Transition Planning – From Compliance to Quality.⁴⁷

KEY Points



Transition services are an added component of the IEP at transition age.



The transition IEP has many parts that you must know.



The most important IEPs of your child's life are during the transition years.

STEP 1: Assessments

"Transition assessment is an ongoing process of collecting information on the student's strengths, needs, preferences, and interests as they relate to the demands of current and future living, learning, and working environments. This process should begin in middle school and continue until the student graduates or exits high school. Information from this process should be used to drive the IEP and transition planning process detailing the students academic and functional performance and post-secondary goals."⁴⁸

Assessment is how the IEP team (which now includes the student) knows which goals to target, which supports and services are needed, and is based on the student's self-defined life plan. Just as any good IEP is based on accurate present levels of academic achievement and functional performance, a good transition IEP must be based on current, accurate, and comprehensive assessment data. This data is the foundation of the student's transition plan and is a critical step in the process. It is also a required component of the law.

Transition assessments should measure the skills your child will need to develop as they relate to their goals for life after high school. These assessments must be based on the student's own interests, preferences, and strengths.

This is not an assessment done *on* the student, but *with* the student.

This is different from all of the other assessments your child has had because you are now looking at his or her ability to function as an adult. For a child who has had epilepsy surgery, multiple assessments might be needed to paint an accurate picture of your child's strengths and needs as they relate to transition.⁴⁹ Your teen must be thoroughly assessed at the beginning of the transition process, and IDEA calls for annual age-appropriate transition assessment.

How to request an assessment

At least one year before your state's mandated transition age (or earlier, if warranted and the team agrees) start to discuss transition to determine which assessments will be needed for your child and the timeline for these assessments (check your state's regulations regarding timelines). If you can coordinate your request for transition assessment with a triennial

evaluation, that is preferable (as children after epilepsy surgery often have multiple, overlapping conditions). However, if the timing isn't right, you can request a transition evaluation independent of the triennial evaluation.

Make a written request (with proof of receipt) for a comprehensive transition assessment in all areas of suspected disability outlining all areas of parental concern (see *APPENDIX: SAMPLE LETTER to REQUEST COMPREHENSIVE TRANSITION OR VOCATIONAL ASSESSMENTS*).



ASSESSMENT REQUEST CHECKLIST



ASSESSMENTS

List any specific assessments needed (for example where appropriate: vision, central auditory processing disorder, assistive technology, mobility, independent living skills, behavior, mental health disorders, autism, or functional vocational evaluation)



LETTER

Attach a letter from your child's neurologist/ neurosurgeon describing the outcomes of the epilepsy surgery (or any other concerns of the doctor, or other providers) to support the requested evaluations (see *APPENDIX: LETTER FROM NEUROSURGEON/ HEMISPHERECTOMY or TEMPORAL LOBECTOMY* for examples)



EVALUATION

Include a request for a neuropsychological evaluation. Neuropsychological evaluation is recommended for all children who have epilepsy (controlled or uncontrolled). The school will not have a neuropsychologist on staff but they must provide this evaluation, based on the needs of the child. This is the responsibility of the school district. If they refuse, ask for the refusal in writing and consider requesting an independent educational evaluation (IEE). Neuropsychological evaluation should be repeated every three years, or more often if needed.



Areas to be ASSESSED

Your transition-aged child must be assessed in education and training, employment, and independent living.

Education and Training

Assessment in education and training focuses on the student's needs, interests, and strengths related to:

- foundational skills in academics and career planning;
 - financial literacy, college readiness or other post-secondary education preparation (including vocational, continuing, and adult education);
 - study skills, communication skills, technological skills;
 - physical, instructional, and attitudinal accessibility needs (such as assistive technology, behavioral supports, accommodations, and modifications, etc.);⁵¹
 - the ability to access and engage in appropriate programs, classes, or coursework for life-long learning.
-

Employment

Assessment in employment focuses on the student's needs, interests, and strengths related to:

- career exploration and planning;⁵²
- career readiness;
- job application skills;
- job acquisition;
- stamina/endurance, frustration tolerance, work ethic;
- social skills and appropriate social interaction;
- literacy;
- motor coordination;
- mobility;
- access to transportation; and
- use of technology in real-world environments.

The assessment should also consider so-called 'soft skills' that are truly essential skills for employment such as:

- communication;
- collaboration, critical thinking, creativity, and big-picture thinking;
- navigation;
- executive functioning;
- time-management;
- self-advocacy, confidence, self-determination; and
- problem solving skills.⁵³

Career assessment should help students identify their:

- dreams;
- career goals;

- learning style;
- work values and traits;
- barriers to success in postsecondary education and/or employment;
- accommodations that might be needed in the chosen postsecondary setting;
- ability and potential to work in competitive integrated employment or supported employment (engaging in suitable and meaningful work that will provide income and/or personal satisfaction).

A functional vocational evaluation (FVE) (sometimes referred to as a comprehensive career assessment) is used to measure and predict vocational potential and may be included in your child's comprehensive transition assessment, if appropriate.⁵⁴ These evaluations use real or simulated work settings as a major part of the assessment and provide information about job or career interests, aptitudes, and skills.⁵⁵

The student might be observed in a work activity in order to write educational goals for community-based work and/or vocational education. The student does not have to have any previous work or volunteer experience for this evaluation. A functional vocational evaluation should include a detailed written report with specific recommendations for supporting progress toward the student's stated employment goals, including career exploration activities and work experiences.⁵⁶

Independent Living Skills

Assessment in independent living skills focuses on focuses on the student's needs, interests, and strengths related to:

- life skills needed to be independent (such as communication skills; study skills and organization/planning skills; adaptive skills such as functional use of assistive technology; financial literacy/personal money management; etc.);
- the ability to engage in, participate in, and access community resources (people, places, and activities like adult services, transportation, recreation and leisure activities);
- mobility skills necessary to travel independently in the community;
- the ability to contribute to the community the maximum extent possible;
- the ability to have community relationships, which requires appropriate communication and social interaction skills;
- the ability to have meaningful relationships and maintain safe relationships (understanding sexual harassment, stalking, affirmative consent, and the intentions of others);
- the ability to self-advocate, including skills in self-awareness, self-determination, and decision making;
- the ability to demonstrate safety skills (such as planning for shelter in place at school or in the community, dealing with natural disasters, or knowing how different laws apply in different settings);
- the ability to access and participate in recreation and leisure activities such as those related to sports, hobbies, special interests and/or relaxation activities;
- transition healthcare needs (see below).

These three areas of assessment are important for you to understand. Review this section often and flag it so you can refer back to it throughout the year.



Transition Health Care ASSESSMENT

Considering a student's health in the transition IEP is critical.^{57,58} Children after epilepsy surgery have very special healthcare needs that are important to address here.^{59,60,61,62,63} These needs have broad effects on the child's life and impact every aspect of the transition planning process.⁶⁴

For students with complex neurological conditions, the IEP team should consider how health issues might affect employment choices, education, and independent living.⁶⁵ "Lack of attention to health needs and health management can jeopardize goals for learning, working, and living safely in the community."⁶⁶

Your teen will need to understand or learn about:

- ✓ his/her medical condition and its symptoms;
- ✓ therapy needs (such as the importance of ongoing physical therapy);
- ✓ what is a medical emergency and what to do;
- ✓ what medications, birth control methods, or recreational drugs might interact with his/her seizure medications;
- ✓ substance abuse;
- ✓ epilepsy or visual field impairments and driving;
- ✓ social support systems (housing, travel, health insurance and Medicaid, drug coverage, dental care, mental health, access to other health care services);
- ✓ the impact of his/her disability on workplace stamina, their ability to interact with peers, and attention span;⁶⁷
- ✓ the transition to adult healthcare providers.^{68,69}

Some young adults are unable to make these types of informed decisions independently and may require significant guidance from caregivers (who may now require training in how to support their child and guide the process).⁷⁰ Most caregivers and youth with special healthcare needs are not receiving needed transition preparation.⁷¹

There are many assessments that can help determine your child's health knowledge and ability to understand health information. These assessments can also help the IEP team determine training or support that might be needed for your child.^{72,73,74}

Here are a few examples of questionnaires that assess health and health literacy (for a complete list, see *APPENDIX: HEALTH TRANSITION ASSESSMENTS*):

- Epi-TRAQ – a transition readiness assessment tool for adolescents and young adults with epilepsy^{75,76}
- Transition Readiness Assessment Questionnaire (TRAQ)⁷⁷
- All Aspects of Health Literacy Scale (AAHLS)⁷⁸
- eHEALS: the eHealth literacy scale⁷⁹
- Health Activities Literacy Scale (HALS)⁸⁰
- Rapid Estimate of Adult Literacy in Medicine (REALM)⁸¹
- Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen)⁸²
- Test of Functional Health Literacy in Adults (TOFHLA)⁸³
- Test of Functional Health Literacy in Adolescents (TOFHL-Ad)⁸⁴

Areas of assessment may include:

- health literacy – limited health literacy leads to poor health outcomes and affects patient safety, health care access and quality; includes skills needed to make appropriate health decisions and successfully navigate the healthcare system:⁸⁵
 - » health literacy requires:
 - ◊ print literacy/reading – the ability to use printed and written health information;
 - ◊ oral literacy – the ability to communicate with and understand your medical provider(s), state health concerns, describe symptoms accurately, and ask relevant questions, understand medical advice or treatment directions, personal health issues, medical jargon, scientific terms, and the complexities of the health care system;
 - ◊ visual literacy – the ability to understand graphs or other visual information;
 - ◊ computer literacy – the ability to search the

Internet for medical information, evaluate websites for accuracy; access medical records and test results;

- ◊ information literacy – the ability to obtain and apply relevant information; understand risks and benefits of treatment options; interpret test results; assess the credibility and quality of information received;
- ◊ numerical/computational literacy – the ability to reason numerically; calculate medication dosages;
- medical self-advocacy (the ability to understand your own disabilities, conditions, and routine health care needs; speak up for yourself if you disagree or need assistance, accommodations, or environmental modifications; share your developmental or communication needs);
- self-care skills (the ability to demonstrate preventative health behaviors and responsible sexual activity; manage medical appointments & medications; develop symptom awareness; understand what constitutes an emergency; access community resources, health records, health insurance, transportation; etc.)

What is measured in a comprehensive evaluation

While the broad areas of assessment that are required for transition are stated above, it's important that the evaluations consider the many areas of your child's function and how they impact education and training, employment, and independent living.⁸⁶

If **all** of your child's disabilities have not been fully assessed in the past, this is the time to make sure it happens!

Central auditory processing disorder (CAPD) evaluation: any child with temporal lobe resection or damage (including after posterior quadrant resection/disconnection, hemispherectomy/hemispherotomy) and corpus callosotomy requires a central auditory processing disorder (CAPD) evaluation from a licensed audiologist.⁸⁷

Vision evaluation: any child with an occipital lobe resection (including after posterior quadrant resection/disconnection, hemispherectomy/hemispherotomy) requires a thorough vision examination to include visual fields, visual motor, and visual processing skills. Temporal and parietal lobe resection can sometimes result in quadrantanopia and/or visual processing deficits as well.⁸⁸ Diagnosis with one of these impairments may open up opportunities for school-based or adult services from deaf, blind, or deaf-blind agencies.

Autism evaluation: signs of autism spectrum disorder can change from childhood to adulthood and for some, autism signs become obvious only in adolescence. An autism diagnosis can guide needed supports and help a student receive services in adulthood that they would otherwise be unable to access. Autism and epilepsy, even if seizures are controlled, are often comorbid conditions.

Assistive technology evaluation: school districts must provide assistive technology evaluations and equipment if needed for the student to access the "free and appropriate public education" (FAPE) required under IDEA.

Neuropsychological evaluation: recommended for all children who have epilepsy (controlled or uncontrolled). Neuropsychology focuses on the relationship between the central nervous system (the brain or spinal cord) and mental functions. Neuropsychological tests look at the brain's ability to carry out these functions (such as language, memory, perception, or attention)⁸⁹ and help understand how seizures influence brain development from a functional point of view and provide information about how seizures affect a child's behavior and learning abilities.⁹⁰



A comprehensive evaluation should include a thorough review of the following areas (dependent on the individual child and their needs):

- ✓ Academic achievement (reading, spelling, math), including how the student performs on required district or state assessments that impact graduation outcomes;
- ✓ Cognition including an estimate of the overall cognitive function (may or may not include IQ), strengths and weaknesses of the student, learning styles;
- ✓ Executive functions are cognitive processes that are necessary for the cognitive control of behavior (skills such as planning, organization, self-monitoring, cognitive inhibition, working memory, and ability to shift thinking patterns flexibly);
- ✓ Attention;
- ✓ Processing speed;
- ✓ Learning and memory;
- ✓ Social and behavioral skills development, especially those related to seeking and maintaining a job, and socialization skills;
- ✓ Psychological function (emotional and personality disorders);
- ✓ Autism;
- ✓ Adaptive and compensatory skills, including the level of support needed, effectiveness of previous accommodations, modifications, and supports, functional academic skills, physical and functional daily living skills;
- ✓ Independent living skills, including community integration and participation;
- ✓ Leisure function (including the ability to access and participate in recreation and leisure activities and any need for therapeutic recreation services);
- Communication and speech & language development, including social skills/pragmatics, AAC, and any special supports the student will need to work and live independently;
- ✓ Motor skills, including gross, fine, and functional motor skills;
- ✓ Vision, including acuity, visual motor skills, visual efficiency, orientation and mobility, visual fields (must be considered for occipital, parietal, and/or temporal lobe resection);
- ✓ Visual perception and nonverbal information processing;
- ✓ Central auditory processing (must be considered in the case of temporal lobe resection, hemispherectomy, posterior quadrant resection, or corpus callosotomy);
- ✓ Sensory processing (sensory integration problems may interfere with age-appropriate life activities such as learning to drive, making vocational choices, engaging in leisure activities, and developing independence and romantic relationships);⁹¹
- ✓ Occupational competencies and work-ready skills/behaviors, which may need to include a functional vocational evaluation;
- ✓ Self-determination skills, including self-awareness, self-advocacy, self management, and self-motivation;
- ✓ Transition health care needs, including any condition that will necessitate medical management skills for the student;^{92,93}
- ✓ Any areas of concern that are unanswered.

NOTE

- If the child is 16 or older, use of adult normative assessments can be helpful.
- Assessment and disability documentation may be needed for postsecondary institutions (colleges and universities) as they typically will not provide accommodations or services to students who do not have “documented” disabilities.
- Current data may be required of adult service agencies.

Academic Achievement

"Academic achievement" refers to the student's performance in academic areas such as language arts, math, science, and history. The definition may vary depending on a child's circumstances or situation.⁹⁴

Is your child progressing from grade to grade in all academic subjects, or are they significantly behind their peers? Some students may not be able to achieve challenging content standards, while others might be struggling because they are receiving the wrong type of instruction, or not enough instruction. Comprehensive assessment can help to determine what supports are needed. The IEP must include "academic and functional goals, designed to meet the child's needs that result from the child's disability to enable the child to be involved in and make progress in the general education curriculum."^{95 96}

It is essential to prepare your child for postsecondary life. What skills does your child need to achieve their education or career goals?

- **Basic academic skills that will help prepare your child to transition into the 'real world' include mathematical computation, reading, writing and composition, keyboarding, and public speaking.**
- **Your child must read well enough that they will be able to get and keep a job.**
- **Basic math skills are needed in order to function independently (to create a budget, manage personal finances, split a check at a restaurant, etc.)**

According to the Workforce Innovation and Opportunity Act (a federal law designed to help individuals access employment, education, training, and support services to succeed in the labor market) there is a basic literacy and numeracy level required to be considered

employable.⁹⁷ The Act states that "basic skills deficient" means: "with respect to an individual—

(A) who is a youth, that the individual has English reading, writing, or computing skills at or below the 8th grade level on a generally accepted standardized test; or

(B) who is a youth or adult, that the individual is unable to compute or solve problems, or read, write, or speak English, at a level necessary to function on the job, in the individual's family, or in society."⁹⁸

If your child's goal is to attend college, they will need to understand college level texts, read about 200 pages per week, and be able to clearly summarize a college-level reading assignment. Most community colleges require a regular high school diploma (see "Understanding the Diploma"). Without meeting high school graduation requirements, your student can still attend a junior college, but they may be required to take remedial classes at the college level first, which may be substandard and lack needed supports (and may not be covered by financial aid). Goals and services in the transition IEP should reflect this.

Research on the relationship between numeracy, literacy, and education status demonstrates that 10th grade numeracy and literacy skills are required to enable an individual to safely manage their own medications and nutrition.⁹⁹ And, the research shows that in general 7th grade skills are required to participate in activities of democracy (e.g. voting, reading materials about candidates). Also, 5th grade literacy and numeracy skills is the average for those who receive some form of social supports.

Remember the IDEA says that at transition age, transition services must be "focused on improving academic and functional achievement... to facilitate the child's movement from school to post-school activities." If the goals and services

are not designed to successfully launch your child into adulthood then you need to get back to the IEP table, or consult with an advocate or special education attorney.

Functional Performance

According to the Department of Education, the term “functional” is “generally understood to refer to skills or activities that are not considered academic or related to a child’s academic achievement.” They go on to state that “the range of functional skills is as varied as the individual needs of children with disabilities.”¹⁰⁰ “Functional” is used in the context of routine activities of everyday living.

Functional daily living skills can include:¹⁰¹

- self-care skills (the ability to groom, clean, dress, toilet, and feed yourself);
- household management (cooking, cleaning and maintenance, laundry);
- health care management (maintaining personal fitness, taking medication appropriately, seeking medical care when needed, accurately describing your medical concerns);
- social skills (making friends and communicating with others);
- emotional needs;
- self determination skills (making informed decisions such as “deciding and directing the kinds of assistance or supports needed or wanted, including using assistive devices and/or technology in the home and community,”¹⁰² accessing services/supports, voting);
- behavior skills (knowing how to behave across a range of settings, self regulation);
- mobility skills (navigating stairs, accessing your environment via walking or using a wheelchair, utilizing transportation in the community);
- time management and planning (self-direction, initiating, multi-tasking, keeping and managing a schedule);
- money management (personal finance, creating

a budget, banking, paying bills);

- participating in leisure and recreational activities;
- personal safety awareness (both in the home, in the community, and with strangers and in dating relationships; knowing how to appropriately share personal information (e.g., name, gender, address, etc.) and behave during an emergency); and
- any other skills needed in order to function in society.

According to the IDEA, a student with a disability must have academic and functional goals, and, by transition age, measurable postsecondary goals, in order to meet their unique needs and prepare them for further education, employment, and independent living.¹⁰³ Therefore, students who have an IEP must be provided not only an opportunity to earn a diploma, which is a measure of academic success, but also achieve their functional and postsecondary goals.¹⁰⁴

The Team Must Use Different Assessment Tools

How your child functions in these areas must be measured using different tools. These may include:

- Observation, testing, ratings scales, records, work samples, rubrics, checklists;
- Informal measures – interviews or questionnaires, direct observations, anecdotal records, environmental or situational analysis, curriculum-based assessments, interest inventories, preference assessments, transition planning or skills inventories/aptitude assessments (vocational/career interests, exploration, and career development tools);
- Formal measures – adaptive behavior and independent living assessments, intelligence tests, achievement tests, on the job or training evaluations (functional vocational evaluation), and measures of self-determination;
- Comparison with past findings and assessment

results (from psychologist, teachers, assistive technology specialists, occupational therapist, physical therapist, speech and language provider, etc.), reports from other experts, explanation if scores are grade- or age-normed;

- Review of records and health status to determine long-term health care needs;
- Observations in a variety of settings (which resemble actual potential vocational training, employment, independent living, or community settings), detailing the setting(s), dates, and duration of observations;
- Situational assessments in environments related to the student's vision and goals to collect meaningful data;
- Vocational evaluation, if relevant, must be done in the setting where the vocational training would occur;
- Task analysis of the critical attributes of a specific job, including environment, skills and social demands;
- Clear measurements of frequency and level of support or dependence and use of accommodations;
- Student information regarding strengths, preferences, interests; including sensory preferences, learning styles, leisure & recreation skills;
- Information and observations from the parent, teacher, or other professionals (coaches, mentors, extracurricular & club advisors, etc.) regarding any concerns, student functioning and skills; utilizing questionnaires and interviews; these should be detailed and dated;
- Technology skills (request an assistive technology (AT) evaluation at transition – existing AT tools should be transferred with the student when they leave school, and they should be assisted in receiving new technology for college and work);¹⁰⁵
- Assessments must use any needed

accommodations that allow the student to demonstrate their abilities and potential (communication devices, visual aids, etc.).

It is important that the assessments are user-friendly for students, parents, and school staff as they will be used to design the transition IEP. School staff should work with the student and family to select the best tools and strategies to evaluate. Tools should also consider the student's cultural and native language. There are countless formal and informal measures to choose from – both can provide valuable information which leads to writing measurable postsecondary goals¹⁰⁶ and help develop a plan to support the student's transition needs.¹⁰⁷

BEWARE!

Transition 'screening' for most students involves an interview with their high school counselor to identify career interests. Students may take a commercially developed interest inventory or aptitude test (tests that are generally found online and not standardized – there is no validity or reliability of these tests). An interest inventory and parent/teacher questionnaires are not transition assessments! These instruments require self-report only and are opinions, not evaluations.

Many measures used in career assessment are designed with the general population in mind (and standardized or normed using the general population), therefore these measures may not be accessible or appropriate for some students with disabilities. Here are a few examples of instruments that have been designed specifically for assessing career directions for individuals with certain types of disabilities:

- Brigance Life Skills/Employability Skills Inventories (Curriculum Associates, Inc.)
- Career Thoughts Inventory (Psychological Assessment Resources, Inc.)
- Reading-Free Vocational Interest Inventory 2 (Elbem Publications.)¹⁰⁸
- Transition Resources for Students with Significant and Multiple Disabilities (Zarrow Center)¹⁰⁹

If the student is unable or unwilling to discuss his/her own needs, preferences, strengths, or interests then age-appropriate transition assessment may be based on teacher and/or parents observations, with input from the student's family, and information contained in the student's records.¹¹⁰ Supported decision making may also be utilized (see *CONSIDERATIONS AT THE AGE OF MAJORITY*, below).¹¹¹

Legal Requirements For Assessments

All evaluations under IDEA, including transition assessments, must meet the following criteria:¹¹²

- use a variety of assessment tools and strategies to gather information (functional, developmental, and academic); include information provided by the parent/caregiver;
- include information about how the child will be involved in and progress in the general education curriculum;
- not use any single measure or assessment as the only data point for deciding whether the child meets eligibility criteria for a disability category, or determining an appropriate educational program for the child; and
- use “technically sound instruments” – tools that are researched and valid – to look at a combination of cognitive, behavioral, and developmental factors.

School districts must also make sure that assessments and other evaluation materials used to assess a child meet the following criteria:

- They are not racially or culturally discriminatory;
- They are provided and administered in the language and form most likely to yield accurate information on what the child knows and can do academically, developmentally, and functionally, unless it is not feasible to do so (that means that the assessments and activities should be

appropriate for the chronological and cognitive age of the student – this is the “age-appropriate assessment” piece);

- They are used in the way the creator of the test intended so that they are valid and reliable;
- They are administered by trained and knowledgeable personnel;
- They are given in the way the creator of the test instructed;
- They provide relevant information that directly assists in determining the educational needs of the child;
- The child is assessed in all areas of suspected disability.

Once the assessments and other evaluation measures are complete:

- A team of qualified professionals (including the parent/legal guardian and the student) determines whether the student qualifies as a child with a disability (including which eligibility categories are appropriate) and their educational needs;
- The parent/legal guardian and the student receive a copy of the evaluation report and the documentation of determination of eligibility.

The “summary of findings” should include:

- The student’s rate of progress; how it will impact their future learning; and their unique needs;
- Formal assessment of any specific area(s) of concern (e.g. executive functioning, self-determination, adaptive functioning, and/or vocational interests/functional vocational evaluation);
- Description of the student’s academic achievement and functional performance to identify and address ongoing needs, goals, services, and methods of measuring progress;
- Recommendations* for instruction (What type of instruction do they need? How much? In what setting?), related services, community experiences, the development of employment and other post-school adult living objectives,

acquisition of daily living skills, training, further education needed, and even potential employers;

- If there is a question about the child’s future educational placement or independent and assisted living options, recommendations* based on their assessment must be provided.

** If the evaluator is a member of the National Association of School Psychologists (NASP) (or NASP certified) then they must put their opinions in writing. An evaluation without recommendations is a violation of the ethical obligations of NASP.*

Who evaluates?

Finding professionals qualified to provide appropriate transition assessment may be challenging. IDEA states that all evaluations should be “administered by trained and knowledgeable personnel.” Don’t be afraid to ask what knowledge, experience, and training the evaluators have in transition assessments, and what knowledge they have of your child’s disability combined with their neurological, social, emotional, medical, or other needs.

- Comprehensive transition assessments may be conducted by a team, generally led by the school psychologist or vocational specialist.
- Related service providers provide meaningful input into the child’s skills and function, and they may need to consult or co-evaluate to support appropriate assessment (for example, a child with a visual impairment may need the support of the teacher of the visually impaired for valid assessment, a child with auditory processing disorder may need the involvement of the school district audiologist, etc.).
- For a Functional Vocational Evaluation, some school districts “may employ vocational evaluators or assessment specialists who are trained to provide these services, but many do not. In such cases, counselors may want to refer students ... to programs that

employ vocational evaluators (preferably ones who are certified by the Commission on Certification of Work Adjustment and Vocational Evaluation Specialists, www.ccwaves.org). These professionals, Certified in Vocational Evaluation (CVE), are qualified to provide all levels of assessment services” (from screening to functional Vocational Evaluation).¹¹³ The student may be referred to their Vocational Rehabilitation center for evaluation (this generally occurs only after graduation as the school district is responsible for all assessments until then).

- Neuropsychologists conduct the neuropsychological evaluation. Neuropsychological evaluation is recommended for all children who have a history of epilepsy surgery. The school will not have a neuropsychologist on staff but they must provide this evaluation if requested, based on the needs of the child. This is the responsibility of the school district. If they refuse, ask for the refusal in writing and consider requesting an independent educational evaluation (IEE). Neuropsychological evaluation should be repeated every three years, or more often if needed.

Transition assessment can be conducted as a standalone evaluation or as part of a comprehensive (triennial) reevaluation or initial eligibility assessments. Current evaluations may be needed by postsecondary institutions (e.g. colleges or trade schools) or agencies providing adult services, so if your child's triennial is due during high school do not waive the school's obligation to conduct these evaluations.

Independent Educational Evaluation (IEE)

If you disagree with the school's evaluation, or if the assessment is not comprehensive, then it is not valid, which might warrant an Independent Educational Evaluation (IEE).¹¹⁴

The purpose of transition assessment is to answer the following questions:

- Where am I now? (strengths, interests, capacities—the Present Levels of Performance in the IEP)
- Where do I want to go? (aspirations, dreams, expectations—Transition Plan Goals in the IEP)
- How do I get there? (transition services, courses, activities, supports, service linkages, community connections, help to overcome barriers—Annual Goals, Accommodations and other provisions included in the IEP)¹¹⁵

If these questions are not answered by the evaluation, go back to the IEP table and ask that additional, appropriate measures and strategies be used, or request an IEE.

“IDEA requires that in addition to parents, the child, and school personnel, that other agency representatives participate in the transition planning process as needed. At age 16, or younger, if appropriate, the student must be invited along with representatives of any other agency that is likely to be responsible for providing or paying for transition services.”¹¹⁶

Who Must Attend The Transition IEP Meeting?

The transition IEP is student driven. The IEP team should include the people who know the student well and who believe in his/her potential. The student and caregiver are equal participants in all decisions made.

The IEP Team must include all required attendees of a regular IEP meeting:¹¹⁷

- Parents/caregivers;
- At least one regular education teacher (if the child is, or may be, participating in the regular education environment);
- At least one special education teacher;
- Related service providers;
- A representative of the school district who is qualified to provide/supervise specially designed instruction; is knowledgeable about the general education curriculum; and is knowledgeable about the availability of resources of the school district;
- An individual who can interpret the instructional implications of evaluation results;
- If the parent or district choose, they can invite any other people who have knowledge or special expertise regarding the child;

At transition age:

- The student must be invited to participate in their IEP planning and meetings (if the student chooses not to/cannot attend the IEP meeting, then the IEP team must gather information about the student's interests and preferences to present at the IEP meeting);¹¹⁸
- Any outside agencies that may be providing transition services (both during high school and after graduation/aging out) also participate in the planning and decision-making regarding transition services (see APPENDIX: Outside Agencies for other agencies to consider).
- Other school staff: school-to-career personnel, school counselor, guidance counselor, coaches, etc.;
- If possible, include a 'transition specialist,' an education professional with specialized knowledge of transition services, agencies, programs, and potential employers.

The parent/guardian can excuse any team member (with written consent for the excusal) if that team member provides written input into the development of the IEP prior to the meeting.

KEY Points



Age-appropriate transition assessment is the foundation of the IEP – this is the most important step in the process!



You must understand your child's academic achievement & functional performance.



Transition Assessment should be person-centered, individualized, and in response to the student's stated vision of their future life; occurs annually.



Always request evaluation in writing, with proof of delivery; include a letter from your child's neurosurgeon.



Neuropsychological assessment should be included for any child with a neurological condition; this is the school district's responsibility.



Include transition health care readiness & health literacy assessments.



A functional vocational evaluation may be needed.



The assessment must be comprehensive (assessing all areas of suspected disability) and valid; must include recommendations. If not, request an IEE.



At transition age, additional IEP team members (notably, the student and outside agencies) are required to attend the IEP meeting.

STEP TWO:

Develop Transition Goals

“Measurable postsecondary goals are not to be confused with the annual IEP goals. Without measurable postsecondary goals, the Team doesn’t know what to work towards. Without a target, it becomes difficult to fulfill the remaining criteria for transition planning. This is key to transition planning, requiring a shift in thinking – away from the way annual IEP goals are developed.”¹¹⁹

Now that transition assessments have helped to determine your child’s baseline – known as the present levels of academic achievement and functional performance – the team can and must develop goals and objectives that consider the child’s strengths, preferences, and interests.

There are two types of goals that be considered at transition age: measurable postsecondary goals in education, employment, and independent living –

what the student will do after graduation, not what they will achieve while still in high school – and annual goals that focus on skills that will allow the student to meet their identified postsecondary goals.¹²⁰

Print the Indicator 13 Checklist and bring it to your child’s transition IEP meeting to make sure that relevant goal areas are being addressed.¹²¹

ANNUAL GOALS	POSTSECONDARY GOALS
Short-term	Long-term
Occurs during high school	Occurs after graduation from high school
Determined by the IEP Team	Determined by the student
Designed to be measured at least quarterly	Supported by annual goals
Stated in specific terms	Initially stated in broad terms, becoming more specific and refined each year
Must be related to postsecondary goals, present levels of performance, and transition activities	Must be related to student’s strengths, interests, and preferences and aligned with transition assessments

*from Annual Goals vs. Postsecondary Goals*¹²²

Some states also require use of an Individualized Learning Plan as a graduation requirement. The Individual Learning Plan is a strategic planning tool intended to help youth identify and achieve postsecondary goals. Families should ask their school district if they require this process.¹²³

Measurable Postsecondary Goals

Measurable postsecondary goals are not to be confused with annual IEP goals. MPGs are statements of what the child will do after high school. Without MPGs, the team won't know what to work towards. MPGs should include benchmarks (which break down the annual goal into smaller action steps) to help measure progress and support specific skill development.¹²⁴

Goal Areas

Measurable postsecondary goals must be made for three goal areas - education and training, employment, and where appropriate, independent living.

- **Education/training** – Most careers or jobs have a defined career path which may require on-the-job training, vocational school, apprenticeships, training or internships, a few college courses, or a college degree. Define what direction the student is headed in so you know what training they will need.
- **Employment** – Career goals can help the student take practical steps toward their intended destination. Although teens may change their minds along the way, if they choose one career goal to explore this allows the team to develop a course of study that aligns with that goal. The employment goal can be revised based on the student's performance and preferences when reviewed each year (or more often if needed).
- **Independent Living** – Some IEP teams may presume that goals in this area are only for students with intellectual disabilities, significant or multiple disabilities, or autism. However, many

students have difficulty with independent living skills and may require additional training or instruction. Don't let a specific disability type be a limitation as to whether or not your student requires these goals – the determination should be based on the comprehensive evaluation. Students with nonverbal learning disorder, dyslexia, emotional disorders, or executive functioning deficits may need significant support in the area of independent living.

Annual Goals

Postsecondary goal example:

Judy wants to be a nurse when she grows up and the transition assessments have revealed that she has the capacity to reach this career goal. Relying on the transition assessments, the transition IEP team helps Judy define three measurable postsecondary goals. These are:

- **Education and training:** Judy will attend a community college to obtain her associate degree in nursing;
- **Employment:** Judy will work in a hospital setting as a nurse;
- **Independent living:** Judy will live independently in a community no more than ten miles from the hospital where she works as a nurse.

Annual goals are different from measurable postsecondary goals:

- Annual goals are written to help the student make progress toward their measurable postsecondary goals.¹²⁵
- Annual goals describe what the student can reasonably be expected to accomplish within a 12-month period in their special education program.
- Annual goals should not be repeated year

after year; they should change over the years, becoming more specific as the student matures.

- Students and parents should be involved in developing these goals.

It is important to establish clear and meaningful connections between what the student is learning in high school and what he or she will be doing after leaving high school:

“It is not enough to simply state that a linkage exists, e.g. ‘In order to be an auto mechanic, the student must read and write for a variety of purposes.’ The linkage must be direct, specific, and genuine, e.g., ‘In order to be an auto mechanic, the student must be able to read automotive theory and skills manuals, which are written at an 8.0 GL.’” ¹²⁶

Goal Areas

Annual IEP goals can address any of your child’s academic, social, emotional, and functional needs so long as they have some bearing on transition and help the child achieve their postsecondary goals.¹²⁷

FOCUS OF ANNUAL GOAL	CONNECTION TO ADULT OUTCOMES
Organizational and study skills	Postsecondary Education: Ability to organize and complete assignments in college within allotted deadlines.
Word processing skills	Employment: Ability to use word processing required for desired employment in retail management.
Follow a schedule to complete a task or routine	Independent Living: Ability to use a schedule to complete a routine such as dressing, cleaning, cooking, medication administration, etc.
Accept and use constructive criticism	Postsecondary Education and Employment: Ability to respond appropriately to and follow through with suggestions for improved performance will assist in school and on the job.
General filing skills, phone skills and how to take and deliver a message	Employment: Skills needed for desired clerical job.
Academic skill development related to literacy or numeracy (read with grade-level comprehension, write proficiently, solve complicated math word problems)	wAll Outcome Areas: basic literacy and numeracy are required to access further education, to get and keep a job in competitive employment settings, understand and access healthcare, safely manage medications and nutrition, participate in a democracy, manage personal finances, navigate social supports.
Independently request assistance to complete a task or problem solve a situation in the expected manner for the environment	All Outcome Areas: Ability to request assistance could be safety for independent living, or related to an employment environment or related to assistance in postsecondary education.

Here are some examples of annual goals and the connection to post-school outcomes:

Annual goal example:

Judy, who wants to be a nurse, may have annual goals in the following areas to help her reach her postsecondary goals:

- *college readiness* (research the difference between college and high school, college disability services and how to access them, university policies regarding disability, disability documentation, scholarships for students with disabilities)
- *employment skills* (develop appropriate work habits, career/employment awareness, how to seek and maintain employment, physical/manual skills, specific job skills)
- *self awareness* (know about your own disability, be aware of personal preferences, interests, strengths, and limitations)
- *self-determination* (independence, decision-making, problem solving, goal setting, creativity, and persistence)
- *self advocacy* (know how to request reasonable accommodations in college, understand laws and rights of students with disabilities in college and the workplace, develop knowledge and self-confidence to advocate for your needs and navigate through bureaucracies)
- *daily living skills* (manage personal finances and household tasks, plan and prepare meals, develop responsible citizenship, access and participate in leisure activities, develop technology skills and organization skills, manage a personal schedule)
- *communication* (develop communication skills so that wants and needs are met throughout adulthood, communicate effectively in one-on-one, small-group, and large-group situations, use communication skills such as negotiation, compromise, and persuasion)
- *interpersonal skills* (develop self-awareness, self-confidence, socially responsible behavior, appropriate social interaction, safety in

relationships, understand the intentions of others, conflict resolution)

- *social emotional needs* (build and maintain friendships, manage anxiety, practice self-care)
- *behavior* (self-regulation, impulse control, anger management, appropriate behavior)
- *functional needs* (eat independently, use public transportation, communicate with an augmentative communication device, use assistive technology)
- *health-related needs* (have proficient health literacy and communication skills/strategies in order to make health decisions, identify community health resources, and discuss, understand, and ask questions about their disability and/or healthcare needs)^{128 129 130}

School districts are required only to ensure that the student's IEP contains measurable postsecondary goals based on age-appropriate transition assessment and that there are relevant transition services. They are not required to ensure that goals of further education, employment, or independent living are achieved.¹³¹ This is why it's imperative in high school that parents and other caregivers are very involved in their child's IEP and transition planning to make sure that transition services are being provided and that annual and postsecondary goals are addressed.

KEY Points



The present levels of educational achievement and functional performance form the foundation from which all other IEP decisions are made.



Appropriate measurable postsecondary goals (MPGs) are what the student will do in adulthood.



Annual goals support students' in meeting their postsecondary goals; should include academics, social, emotional, and functional needs; should not be repeated.



Each MPG should have at least one annual goal tied to it.

STEP THREE:

Identify Transition Services

“Transition services teach students with disabilities life and work skills while they are still in school. These services provide the student with a plan of what their best future could look like and instruction that moves the student forward towards those post-secondary goals. ... IDEA says that transition services must help students with disabilities move from life in school to life after school towards their goals. Transition services are tailored to meet a student’s individual strengths, preferences and interests.”¹³²

Transition services are “a coordinated set of activities” for a child with a disability that is:

- designed within a results-oriented process,
- focused on improving the academic and functional achievement of the child, and
- helps facilitate the child’s movement from school to post-school activities.¹³³

Post-school activities include:

- postsecondary education
- vocational education
- integrated employment (including supported employment)
- continuing and adult education
- adult services
- independent living
- community participation (including community based instruction)

Post-school activities must be based on each student’s needs, strengths, preferences and interests. Transition services help the student move into their adult life and reach their annual goals.¹³⁴

What is a coordinated set of activities?

Transition services are a series of activities, programs, and specially-designed instruction that prepares students to move from the world of school to the world of adulthood. Activities must be coordinated with each other – so taking a one-semester life skills class or one career interest inventory is not a transition service because it is not a coordinated set of activities. If your child requires goals, supports, services, accommodations, or the resources of outside agencies to be able to function in any of the above areas as an adult, these should be specified in the IEP. Which specific services a student receives is determined by the IEP team (which includes the parent and the student).¹³⁵

These activities can be a combination of the following:¹³⁶

- Instruction
- Related services
- Community experiences

- The development of employment and other post-school adult living objectives; and
- If appropriate, acquisition of daily living skills and
- Functional vocational evaluation

Instruction

Course of Study

Transition services include a “course of study needed to assist the child in reaching” their postsecondary goals.¹³⁷ This could be a vocational education program* or advanced placement classes for college.

Be sure that your child's course of study includes meaningful opportunities to achieve their postsecondary goals. If the student plans to attend college, the course of study should be based on the college, university, or technical school entrance requirements, not just the requirements for high school graduation (student and family should review the entrance requirements for any colleges being considered). The transition plan should list the courses the student has taken or plans to take, and document the connection between the class and how that will reasonably enable a student to achieve their MPGs. You must know whether your child's course of study leads to a diploma or a “certificate of completion.”

Students with disabilities should take courses in many disciplines: arts, science, math, vocational/technical subjects, etc. They should not be excluded from any subject because of their disability.

Specialized Academic Instruction

This is the “specially designed instruction” (special education) your child requires to access the general education curriculum (this may include communication aids, intensive reading instruction to improve comprehension, travel training, vocational education, etc.) or instruction in specific skills (such as life skills for adult living).¹³⁹

Related Services

These are supports such as psychological counseling, vision or orientation and mobility services, physical therapy, occupational therapy, speech therapy, audiological services, and assistive technology needed for the student to access more integrated work, education, and living environments. If the student will need any of these services as an adult, the IEP team should identify and link the student with the appropriate adult agencies or providers before the student leaves school.

Related service providers play an important role at transition age to “promote students’ functional abilities and participation in daily routines.”¹⁴⁰ With newly identified postsecondary goals, there may be a need for related services that were previously not necessary, or had ended.

For example:

- a student wants to pursue a career in fashion design but has a fine motor disability, so he/she may now require weekly occupational therapy services;
- speech & language services may focus more on social skills such as pragmatics and inferencing, or increasing expressive language abilities, or more nuanced language skills (literal vs. figurative language);
- occupational therapy may be needed to learn to use assistive technology for note taking;
- counseling services may support anger management and self-regulation;
- academic services may focus on interpreting nonfiction texts rather than narrative texts;
- auditory goals may address critical listening skills and metalinguistics.

“The primary ‘occupations’ of older children and teens are integrating educational instruction in and outside of school, forming and maintaining productive friendships, and beginning the transition to work and more independent, higher education. Occupational therapy interventions for this population often expand to include such items as adapting or modifying curricula, the environment, or activities to support participation in educational routines and learning activities; navigating more complex social relationships, including dating; assessing the skills needed to learn to drive or assisting with alternative community mobility options; strengthening self-determination and decision making skills, and enhancing overall independence; helping with vocational planning and transitions, including employer supports; and planning for transition to college, including time management, study habits and routines, and independent living skills.”¹⁴¹

Community Experiences

IDEA emphasizes the importance of community experiences, which allows the student to learn in the actual environments in which they will use needed skills. A child who has had brain surgery for epilepsy may be unable to generalize skills well, meaning they can’t learn a skill in one setting then instinctively know how to apply it in other settings. Therefore, explicit instruction in multiple real-life settings may be required.

Vocational and social instruction should take place in the community (off the high school campus) as much as possible. Community activities may include career and job activities (e.g. job shadowing, internship, work experiences) as well as social, recreational, leisure, shopping, banking, transportation, or opportunities to access community-based services. For students pursuing postsecondary education, they may require support in touring local colleges, meeting with the disability services office to learn how to advocate for accommodations, or attending summer or dual-enrollment programs offered by colleges and universities. Students should be encouraged to try a variety of activities and jobs to help them develop their self-determination skills.

Least Restrictive Environment

Like all special education services, transition services must be provided in the least restrictive environment (LRE), which may be the school, community, employment site, or in vocational technical schools. In addition, the school “must ensure that, to the maximum extent appropriate, children with disabilities are educated with children who are nondisabled ... this includes nonacademic and extracurricular services and activities.”¹⁴² The location of the services should be spelled out in the IEP.

There is nothing in the law that states any related service must occur on school grounds or during

the school day. In fact, the statute focuses on a continuum of settings, services and experiences in order to “facilitate the child’s movement from school to post-school activities...”¹⁴³ and specifies that “community experiences” are a mandated component of transition activities.

Employment and other post-school adult living objectives

Employment activities

Employment activities focus on developing “work-related behaviors, job seeking and keeping skills, career exploration, skill training, apprenticeship training, and actual employment. ... The focus for postsecondary employment goals for all students with disabilities is integrated, competitive employment, which is defined as employment at a competitive wage or at least minimum wage.”¹⁴⁴ Volunteer work also provides important skills and experiences that could lead to integrated or supported employment. Career counseling, exploration and guidance are transition services that can be written into the IEP.

Activities may include: the student meeting with a job coach in classroom and community settings, the school providing a vocational rehabilitation referral, or the family contacting their state’s Developmental Disabilities office for a list of local day programs.

PLEASE NOTE:

- *The federal Workforce Innovation and Opportunity Act (WIOA) prohibits school districts from placing students in local sheltered workshops to perform work for subminimum wages.*
- *Employment First is a national movement (supported by the U.S. Department of Labor, Office of Disability Employment) based on the premise that all citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life. Check your state’s Employment First initiative.*¹⁴⁵

Post-school adult living activities

Post-school adult living activities are those “that are done occasionally such as registering to vote, filing taxes, obtaining a driver’s license, renting or buying a home, accessing medical services, obtaining and filing for insurance, planning for retirement, and accessing adult services such as Social Security.”¹⁴⁶

Activities may include: driving lessons, financial literacy support, or meeting with an SSI representative to determine possible adult benefits.

Families should discuss transportation options with their IEP teams. It is important to determine the student’s transportation needs in adulthood to get to and from work, school, and recreational activities.

- Will your teen learn to drive?
- Is public transportation accessible and affordable (many cities offer significantly discounted transit cards for the person with a disability and an attendant)?
- Does your teen know how to call and pay for a cab in emergencies, or is training needed?
- Does your teen require travel training, specialized driver’s education, or ADA door-to-door transportation services?
- How will families communicate with their teen when he/she is spending time out and about in the community?

Any needs in these areas should be added as transition services in the IEP. Lack of access to appropriate transportation can limit the young person’s future life options.

Daily Living Skills

Daily living skills activities (and a functional vocational evaluation, see above under “STEP ONE: ASSESSMENT”) are included “if appropriate” to support the student in being able to perform activities of daily living.

Activities may include: exploring community agencies that provide daily living skills training to adults, connecting with adult housing options and getting on a waitlist, developing a ‘care network,’ creating a personal fitness routine, learning emergency procedures for use at home, taking courses in food preparation, child development, or life management.

All of these above activities “may be special education, if provided as specially designed instruction, or related services if required to assist a child with a disability to benefit from special education.”^{147,148}

Failure to provide transition services has consistently been viewed as a violation of the substantive requirement of IDEA.¹⁴⁹ The process must focus on results – mere inclusion of language is not enough.

Print out the portions of the IDEA that relate to transition¹⁵⁰ and bring them with you to your child’s IEP meeting (<https://www.pacer.org/transition/learning-center/laws/idea.asp> lists all sections of IDEA regulations that specifically relate to transition).

Don’t be afraid to stop the meeting and ask the team:

- How is this plan a coordinated set of activities?
- How are we improving the academic and functional achievement of my child to help them move into their adult life?
- What are the employment and living objectives? How will they be addressed?
- Does my child require a functional vocational evaluation?
- And any other questions you may have.

Which agency is responsible?

“Both IDEA and The Vocational Rehabilitation Act of 1973 as amended in the Workforce Investment Act of 1998 require a formal interagency agreement to specify the responsibilities of providing transition services to individuals with disabilities.”¹⁵¹

Upon graduation from high school (or exiting special education services) the IEP team will no longer coordinate disability related services (accommodations, transportation, therapy, or vocational services). Services may be provided by different government agencies, each with its own application process and eligibility standards. Young adults and their families must take responsibility for evaluating, applying for, and coordinating these services at this time.

Transition services are a coordinated set of activities, provided under IDEA and other disability

and employment laws, and coordinated between the school district and outside agencies. While your student is still in high school, it’s important to include the representatives from adult service agencies in all IEP planning meetings.

The IDEA requires that transition services are provided for students with disabilities regardless of which agencies provide the services (such as vocational rehabilitation, employment and training agencies, day programs, supports for people with intellectual or developmental disabilities, public mental health services, supplemental security benefits, housing, supported living, recreation, or other agencies relevant to an individual student’s needs.)¹⁵² Even if the coordinated set of activities in the transition plan can be filled by all of these outside agencies/providers, the responsibility for ensuring they are effective, appropriate, and comprehensive rests on the district.

Schools should help students and families find these providers and programs and complete applications so that services are in place as early as possible (some services may be able to start before the student graduates). Many agencies that offer adult services have eligibility criteria and waiting lists. All members of the IEP team should be familiar with postsecondary resources and other agencies that could support the student.¹⁵³

If outside agencies will provide or pay for services (even if that agency will not provide or fund services until age 18 or graduation), then a representative must be invited to the IEP meeting so that both school and post-school services can be identified and included in the IEP as part of transition planning.¹⁵⁴ A statement of interagency responsibilities or any needed linkages, as well as who pays for what service must be spelled out in the transition plan.¹⁵⁵ The IEP must define who is responsible for the activity and when each activity will begin and end.

It is the responsibility of the state's vocational rehabilitation (VR) program to coordinate with the local schools in developing transition services as part of the IEP and to provide those services. Services may overlap. There are instances in

which some special education and related services under the IDEA may also be services provided under the VR program. Decisions as to which agency is responsible for providing and/or paying for pre-employment transition services or transition services considered to be both special education (or a related service) and a VR service must be made at the state level.¹⁵⁶

The school district is ultimately responsible for ensuring that transition services (instruction, experiences, supports, and services outlined in the IEP) are provided. However, this does not allow any agency to avoid their responsibility to provide services for individuals who meet that agency's eligibility criteria.¹⁵⁷ If a participating agency agrees to provide transition services and then fails to do so, the school district must hold a meeting of the IEP team as soon as possible to identify alternative strategies for meeting the postsecondary goals.¹⁵⁸

Unfortunately, transition services are often poorly understood by school teams and frequently not well-coordinated.¹⁵⁹ Do not assume the school district will meet their obligations and take the lead. Parents, caregivers, advocates, and the student must be proactive and stay closely involved throughout the transition process.

KEY Points



Transition services should help the student make progress toward their



Interagency collaboration and IEP attendance is mandatory, as well as a statement of who will pay for what service.



Transition services should address any area of need that may prevent your child from accessing their desired post-school activities.



Transition must be a "coordinated set of activities."



The school district is ultimately responsible for making sure the services are effective, appropriate, and comprehensive.



Students, parents, and caregivers must not take a passive role in the transition planning process.

STEP FOUR:

Progress Monitoring

“The primary focus of progress monitoring is improving the educational results and functional outcomes of children with disabilities.”¹⁶⁰

Progress monitoring is the scientifically-based practice of measuring a student’s progress in a specific area of need. In order for students with disabilities to achieve their goals, the IEP team needs to know what progress the student has made in academic, behavioral, vocational, functional, and other transition-related skills. Providing instruction and transition services is not enough – the team must use data to monitor progress. Using data to make decisions will support the student’s needs as it relates to their post-school outcomes.¹⁶¹

Families must insist that the IEP contains information about what data will be collected, who will collect the data, how often, and how and when it will be shared with the family. Request ongoing, consistent communication and documentation regarding your student’s academic and functional progress. Progress monitoring is required by the IDEA, which affirms that each child’s IEP must contain a description of how and when the child’s progress on goals will be measured.¹⁶²

Follow up regularly to ensure that your student is achieving their annual and postsecondary IEP goals. At transition age, you cannot let an entire school year go by and then find out that your child did not make expected progress or that services were not delivered. You can request an IEP meeting any time you have concerns – don’t wait for the annual IEP.

Teens may change significantly in a short period of time, and they are certain to at least change their mind about many things. Postsecondary or annual goals may need to be changed or services may need to be added or altered if your child’s interests change, if your child meets a goal, or your child is not making expected progress. Students and their families should participate as active members of the IEP team so that no unilateral decisions are made for the student.

KEY Points



Progress monitoring is mandatory.



Call an IEP meeting at any time to discuss needed changes; don’t wait a year!



You must be regularly informed of your child’s progress with clear, consistent data and regular team communication.



The school district is obligated to implement an appropriate and meaningful transition plan for each child with a disability.

STEP FIVE:

Update the IEP and transition assessment each year

“In order for IEP teams to integrate transition planning and services into the IEP framework, there must be a shift in the culture of special education and in the perception of the purpose of the IEP to one of considering the IEP as an annual action agenda for a strategic long-term plan. Each year, then, the annual IEP review can provide a benchmark toward one or more long-range goals. ... Every special education decision that is made regarding a student with a disability potentially affects how that student will experience his or her life after school completion. Ultimately, the goal of the IEP is to empower the student to set his or her own long-term goals, even if the team may sometimes disagree.”¹⁶³

The Transition IEP must be updated at least annually, just as with any IEP (more often if needed!). However, the law at transition age now requires annual transition assessment to form the basis of the transition plan. The IDEA requires:

- appropriate measurable postsecondary goals that are annually updated,
- based upon an age appropriate transition assessment,
- transition services, including courses of study, that will reasonably enable the student to meet those postsecondary goals, and
- annual IEP goals related to the student's transition services needs.¹⁶⁴

Transition plans must be based on the student's current interests, abilities, and challenges. Adolescents are often unsure of their future plans, which is part of the reason why ongoing transition assessment is required. This does not mean that a student will repeat the same set of assessments every year, but perhaps a skills inventory given to a student in 9th grade might be revisited in 11th grade to determine what skills the student has acquired during that time.¹⁶⁵

At least annually, when reviewing the IEP:

- Update your student's present levels based on current assessments;
- Review the progress on goals, including

the data that was collected (if no data was collected, that is a red flag); if your student is not making expected progress toward the annual goals and in the general curriculum, the team must revise the IEP (what additional or different services and supports would enable the student to meet his or her goals?);

- Revise the annual and postsecondary goals: the school is required to update goals annually in response to ongoing, updated transition assessment data and planning.¹⁶⁶ Goals should change as your student gains experience and training. As students mature, their goals mature with them.
- Review the course of study and make sure your student is on track to graduate (with either a diploma or certificate of completion) and headed toward their postsecondary goals (considering attendance, grades, credit status and other educational performance measures);
- Ensure that the transition activities are taking place, that they are meaningful and appropriate, and that they are aligned with your child's goals.
- Review linkages with outside agencies and renew those connections annually (waiting lists for some adult services can be long, and it may take several years for funding to be allocated).
- Revise the transition plan to address any unmet needs.

KEY Points



Annual transition assessment is required.



Measurable postsecondary goals (MPGs) must be updated annually to reflect the student's current strengths, preferences and interests.



Annual goals must be updated annually and support progress towards the MPGs

STEP SIX:

Age of Majority

“There’s a very simple and common sense reason why IDEA 2004 requires that students with disabilities be invited to attend every IEP meeting where postsecondary transition goals will be considered: It’s their lives. And those lives are changing. Adulthood is approaching, and with it will come a world of responsibilities and choices. Who’s the primary stakeholder in that life ahead? The student. Who better to choose the path ahead, the job or the next schooling, than the student? Who better to ponder what career, what leisure pastimes, what community participation? Student involvement in planning ahead makes all the sense in the world.”¹⁶⁷

The “age of majority” is the legal age established by state law when a person is no longer a minor; in most states this is age 18.¹⁶⁸ At this age, your child will have control over (and responsibility for) their own educational, medical, financial and other legal decisions and actions – whether or not they are ready for this responsibility.

Depending on your state’s regulations, many rights as legal guardian may automatically transfer over to the student (including educational decision-making authority).¹³³ In addition, the student’s IEP becomes confidential; the caregiver will no longer have access to it unless the student specifically authorizes it. The school district is obligated to inform the student and caregiver of this transfer of rights at least one year before it takes effect. The school should support the family in applying for federal benefits, obtaining an ID or driver’s license, registering to vote, applying to housing programs, etc.

Considerations at the age of majority

Your child will become an independent adult decision-maker at the age of majority¹⁶⁹ unless they have been deemed incompetent under state law). In some states, only some of the educational rights transfer at the age of majority. To find out the rules in your state, [contact your state’s department of education](#).¹⁷⁰ Your local [Parent Training and Information Center](#) should also have this information.¹⁷¹

IDEA’s Special Rule

All states have a legal process to determine if a student who receives special education and has reached the age of majority continues to need help in planning her or his IEP.¹⁷² This special rule¹⁷³ relates to young adults who do not have the ability to provide informed consent to their educational programs, but who have not been determined by

a court to be “incompetent.” In such cases, states may adopt policies that allow parents, guardians, or a surrogate to continue representing the student even after the age of majority is reached. Parents or guardians would continue to represent their young person during the entire time the student is eligible for services under Part B of IDEA (until they are 18 and earn a diploma, or until they age out of special education transition services at age 21 or 22, depending on their state).^{174 175 176}

Alternatives for Decision-Making Support

You may have concerns about how to best support your child's self-determination at age 18; they might not be capable of making competent and informed decisions independently, or they might need more time to develop those skills. There are informal as well as more formal, legal decision-making support options that you may consider to help your child in making decisions for their own health care, education, financial, and legal management in a way that fits with their ability level. It is important to know all of the options before deciding which one to pursue as every young person has a unique situation and individual needs for support.

Families should meet with an attorney to discuss these options at least a year before the student's 18th birthday as it can take time to set up legal agreements and plan for the student's financial protection as adults. The laws can vary by state. Special needs attorneys, financial planners, and medical experts can help a family in determining the best legal decision-making arrangement for their child.

When it comes to determining what is the best option, the “least restrictive” ones may best support and promote the young adult's decision-making skills and rights.¹⁷⁷ Below are some examples of different options to consider.¹⁷⁸

Guardianship

Some young people may not be capable of managing their own rights, or understanding the consequences of their actions, even though they are now legally adults. Families will have to consider if their adult child is capable of making these kinds of life decisions and managing their own care and safety. You may consider guardianship, which is a court-ordered arrangement in which one or more people are given legal authority to make all decisions (educational, financial, medical, and legal) on behalf of the young person.¹⁷⁹

A person under guardianship is considered to be legally incompetent and is stripped of the authority that is granted to adults to make their own decisions: “An incapacitated or incompetent person is someone who the courts determine is unable to make “informed decisions” about his or her personal care or the care of his or her affairs due to a mental illness, physical illness, disability, or other condition. These decisions can include decisions about the person's finances, residence, education, vocational programs, behavioral programs, medical or dental care, or legal matters. The level of incapacitation is a threshold issue that determines what level of guardianship is granted.”¹⁸⁰

Guardianship is one of the most legally restrictive forms of support. Taking away the decision-making rights from any individual can have negative effects, including lack of practice in needed life skills, a sense of helplessness, and passive dependence.¹⁸¹ You may want to consider other forms of guardianship that can provide temporary or specific decision-making support while not completely denying participation in that decision. However, not all young adults are able to make their own decisions, especially those choices with more far-reaching impact on their lives.

Conservatorship

Many states offer limited guardianship, sometimes called conservatorship or limited conservatorship. People who are granted conservatorship for another individual are assigned limited decision-making responsibility based on the individual's needs, detailed in a court order. Conservatorship allows the individual to keep as many of his or her rights as possible. A person under conservatorship is not considered to be legally incompetent; he or she retains as many rights as deemed appropriate by the court. Different people have different limitations under conservatorship, depending on their individual vulnerabilities.¹⁸² (Note that most courts will not grant social relationship or marriage rights to be assigned to the conservator unless the child has a history of being abused or demonstrated predatory behavior.)

Supported Decision-Making

Supported Decision-Making is another alternative to guardianship in which the adult with a disability selects supporters who will help them make decisions about their life choices.¹⁸³ This team of trusted supporters (adult friends, family members, professionals, and others) can help them understand issues and choices, ask questions, and communicate his or her own decisions to others.¹⁸⁴ (See the [National Resource Center for Supported Decision-Making](#)¹⁸⁵ and [Supported Decisions Site](#)¹⁸⁶ from the Center for Public Representation.)

Educational Power of Attorney (EPOA)

Another option if you suspect your child might not be an informed decision maker by age 18 is to obtain an Educational Power of Attorney (EPOA) to protect your ability to participate in critical decisions affecting your young adult's future.¹⁸⁷ Students can delegate their educational decision-making rights to their parent/guardian or another adult, such as an [educational advocate](#).¹⁸⁸ An EPOA grants the agent authority to act only in the educational realm, allowing the family to

continue making educational decisions for their child. This can be done for a short period of time to allow your young adult more time to develop skills without making a mistake along the way. A power of attorney is simpler and less costly than guardianship or conservatorship, and it allows more independent decision making for the individual with a disability.

A young adult can also assign their educational decision-making rights without an EPOA, please see the *APPENDIX: CONSENT TO AUTHORIZE ADVOCACY AND RELEASE OF INFORMATION*.

Plan for Health Care Needs

Families should start discussing transition to adult care with their child's medical providers at age 12.^{189, 190} Caregivers can help their child take on more responsibility as they get older by encouraging them to make their own medical appointments, prepare and ask questions of their doctor, and take medications as directed. They may need to learn health management strategies (such as using a pill organizer, creating a filing system for medical records, keeping a calendar specifically for medical appointments and prescription refill alerts). Specific goals should be added to the IEP in preparation for transition to postsecondary life that address the child's ability to manage their own medical care and decision making.¹⁹¹ (See *APPENDIX: HEALTH TRANSITION GOALS*).

In some states, children can access certain services (mental health, prenatal care, substance abuse treatment) without parental consent as young as age 12. At the age of majority, all medical decision making rights transfer to your child. Look up your state's regulations regarding their medical rights and timelines. You may consider getting permission to make medical decisions on behalf of your child.

Medical Power of Attorney or Durable Power of Attorney

A medical POA is a legal document that enables any individual to appoint a trusted relative or friend to handle specific healthcare decisions on their behalf. Other powers of attorney can be set up for financial or other decisions.

Health Care Proxy

A health care proxy is another legal instrument which allows the individual to give medical decision making authority to a caregiver if they are

incapable of making and executing the healthcare decisions (as spelled out in the proxy). One way this is different from a POA is that the healthcare agent is only able to make medical decisions for the individual during the time when that individual is incapacitated.

End of Life Decisions

By the age of majority, your child may need a living will or advance plan of care to inform end of life decisions should the individual become incapacitated.

KEY Points



Caregivers should learn the age of majority for their state and learn about the legal ramifications of becoming an adult.



School districts must notify the student/ caregiver one year before the transfer of rights occurs.



It's also important to plan for your child's transition to adult healthcare providers and help your child develop skills to manage their own healthcare as an adult.



Schools should support young adults with this transition.



There are many options for continued parental support in making educational and other decisions for your child.

STEP SEVEN:

Graduation and Aging Out

“The failure to provide adequate transition services has consistently been viewed as a violation of the substantive requirement of IDEA. Such failure denied students a FAPE and resulted in tuition reimbursement and compensatory education. Insufficient time to plan adequate transition services may result in litigation alleging a denial of FAPE.”¹⁹²

Graduation with a regular high school diploma is a change in educational placement that requires an IEP team meeting and written notice in a document called a Summary of Performance. The IEP team (which includes the parents/caregivers and the student) should review the comprehensive transition goals and decide whether or not the student is ready to graduate.

NOTE: The school district does not need to evaluate prior to service termination at graduation – whether by diploma or aging out.¹⁹³ But – if the school district attempts to exit your child from special education services before graduation, then the district must evaluate to make the determination that the student is no longer a child with a disability.¹⁹⁴

Summary of Performance

A “Summary of Functional Performance” (SOP) must be provided when IDEA services are to be ended (due to graduation with a regular diploma or exceeding the age of eligibility for IEP services–

generally between the 21st and 24th birthday, check your state statute).¹⁹⁵

While each state develops its own Summary of Performance form, under federal law, the SOP must include:

- an academic achievement summary,
- a functional performance summary, and
- recommendations on how to assist the child in meeting post-secondary goals.

The summary should provide specific, meaningful, and easily understood information to help the student, family, and agencies or institutions that may provide services to the student after transition (including postsecondary schools).^{196 197} Schools are not required to conduct any new assessments or evaluations in order to provide the summary, but the information in the SOP should include documentation of the student’s disability – which may be needed to access adult services or accommodations in college. This is something to consider well before special education services come to an end.

Here are some sample Summary of Performance templates/guides:

- [Summary of Performance](#) from the Transition Coalition.¹⁹⁸ It may be helpful to compare with a sample [completed version](#).¹⁹⁹
- [Nationally Endorsed Summary Of Performance Template](#) developed by the National Transition Documentation Summit with the Association on Higher Education and Disability (AHEAD), the Council for Exceptional Children's Division on Career Development and Transition (DCDT), and Division on Learning Disabilities (DLD), the National Joint Committee on Learning Disabilities (NJCLD), the Learning Disability Association (LDA) and the National Center on Learning Disabilities (NCLD).²⁰⁰
- U.S. Department of Education, Office of Special Education Programs: [Summary of Performance Packet](#)²⁰¹

Check your [Department of Education](#) for specific SOP information that may be required by your state.²⁰²

Regular Diploma

Once a student with a disability graduates with a regular diploma and has reached the age of majority, they are no longer eligible for special education services and a free appropriate public education (FAPE), even if they are not prepared to transition into work or further schooling. However, earning sufficient academic credits to graduate with a diploma is not a transition plan – both academic and functional goals and supports are necessary to achieve the “results oriented process” required by IDEA. “If the school has not provided appropriate and individualized transition services, s/he may continue to be eligible for special education services.”²⁰³

Legal cases in which students who were able to earn an academic diploma had not received specially designed instruction addressing their

other transition needs (such as vocational skills or independent living skills) resulted in the court ordering the district to provide transition services.

Refusing the diploma

Refusing the diploma may allow your child to access services that should have been provided earlier, even if he or she has met the academic requirements for graduation. Yes, you want your teen to have a diploma and graduate with his or her peers, but additional time to focus on vocational or functional living skills that were not provided, to continue working on unmet transition-related goals, and to receive the transition services required to meet these goals may be needed. The student may still participate in graduation with their peers without accepting a diploma, then have a 5th or even 6th year to work on transition-related goals.

Students with disabilities often need realistic training on how to function in the workplace. There should be a balance between rigorous academic standards and the opportunity for vocational training and exploration during high school. If the student is working hard on the academic components needed to earn their diploma, they may have little time left for vocational training, experiences, or learning important ‘soft’ skills.

The student can utilize their legal rights, such as Stay Put, but they must reject the diploma in writing.²⁰⁴ If this is something you are considering, it’s important to consult with a special education attorney as soon as possible, before the student graduates or ages out! However, if a student rejects their diploma after aging out of IDEA eligibility, they may still be able to pursue due process claims for compensatory education.

Alternate diploma/certificate of completion

A student who graduates with an alternate diploma (sometimes referred to as a certificate of achievement, attendance or completion or an IEP/special education diploma) that is not fully aligned with the state's educational requirements for a diploma remains eligible for FAPE as long as they are also age-eligible (up to age 24, depending on your state).²⁰⁵

Transition programs

School districts must provide transition services addressing the student's needs related to education, employment and independent living until they 'age out.' Families may be given only one option for transition programming after age 18 when other options may be available. School districts tend to offer one-size-fits-all transition programs regardless of the young adult's individual transition needs. There may be little connection between Vocational Rehabilitation services, other adult service agencies, and school districts (although making and maintaining these connections is a required component of the law). Again, utilize your student's procedural safeguards to ensure that appropriate transition assessment and planning occurs for your teen before they graduate or age out of special education services.

Options to consider

- Consider a summer program or a Comprehensive Transition Program (CTE)²⁰⁶ after graduation that would allow your young adult to learn independent living skills and even earn credits towards a college diploma²⁰⁷ (these programs can be funded by school districts using Part B funds).^{208 209}
- If the school district fails to provide transition services which are written in the student's IEP, an individual or organization can file a complaint

with their state Department of Education (file within one year from the date that the school district stops the services).²¹⁰

- If the student did not meet their transition goals, the student may be entitled to compensatory services (file within two years from the date that you knew or had reason to know of the facts for your complaint).
- If there were no appropriate measurable postsecondary goals based on age appropriate transition assessment, the transition plan was not individualized, or the transition plan was inappropriate for the student (i.e. a generic program or service was offered that did not meet the students' identified needs) then there may be a due process issue due to a denial of FAPE to the student (file within two years from the date that the school district stops the services).²¹¹
- If the connection to adult services providers/agencies was either not provided or the family was not educated as to what the agencies provide, what their limitations are, and when they should contact them, the district may have violated the transition services portion of the law and prevented the young adult from accessing needed vocational and living supports (file within two years from the date that the school district stops the services).
- If there were procedural violations only (such as missed timelines, failure to disclose records, failure to invite the student or outside agency to meetings, etc.) this may still be considered a denial of FAPE if "the procedural inadequacies impeded the child's right to a free appropriate public education, significantly impeded the parents' opportunity to participate in the decision making process, or caused a deprivation of educational benefit."^{212 213}

KEY Points



Graduating with a regular diploma at the age of majority ends the student's right to special education services. Students who are earning an alternate diploma or certificate can access transition services until up to age 24 (check your state law).



Graduation is considered a change of placement.



Evaluation is not required when the district ends services due to graduation/aging out but if the district wants to terminate services before graduation they must evaluate to determine that the student is no longer a child with a disability.



There may be legal remedies or other options if the school fails to provide appropriate transition services.



Both academic and functional goals and supports are necessary to achieve the "results oriented process" required by IDEA.



A Summary of Performance (SOP) is required before exiting special education and should be sufficient to determine eligibility for adult services.

CONCLUSION

Successful transition to adulthood is the essence of the IDEA. Graduating from high school is just the beginning. The intention of the law is to ensure that all students with disabilities have the opportunity to reach their full potential and to lead productive lives.

- Don't wait to start learning about transition.
- Evaluations are the key to understanding your student's needs and abilities.
- Transition goals must be student-centered, measurable, and easily monitored.
- Transition goals and services must be detailed, specific, and consider all areas of life after high school, including employment, further education, independent living, and community engagement.
- A meaningful transition plan (detailed in the student's IEP) must be individually tailored to address the student's unique needs and be based on his or her strengths, preferences, and interests.
- Outside agencies are key at transition age as they will be providing transition and adult services.
- This process can be overwhelming, and there is a lot to know and do. Establish priorities by making lists and setting a timeline.
- Ensure that your child can see their own potential and advocate for themselves in whatever way possible.

“The transition practices literature recognizes that educators, service providers, and families must help students develop their skills and abilities, provide services and supports that enhance and facilitate these abilities, and develop opportunities through which students can apply those abilities. “One size fits all” and “check the box” transition planning strategies do not effectively prepare students with disabilities—who all have unique needs—for successful, fulfilling adult roles. Through continued attention to establishing effective transition services flexible enough to meet individual student needs, we can arm students with information and opportunities on which they can build their futures.” ²¹⁴

| Appendix

Appendix A: Successful Transition Tips

- Begin planning early;
- Learn about the transition process and all available community resources;
- Help your child build skills needed in adulthood (self-care, functional living skills);
- Build self-determination and decision-making skills by giving your child an opportunity to make choices and understand the consequences of their choices and actions;
- Continuously ask your child to think about their goals for the future;
- Help your child become a self-advocate, to understand their own disability and medical needs, and know what happens when they become an adult;
- Engage the IEP team early in the process; do not wait until high school;
- Use the assessment process annually to build/revise a person-centered plan that identifies your child's strengths, needs, interests, & preferences and defines measurable postsecondary goals addressing all of the areas where skills are needed to maximize your child's independence;
- Know and accurately state how the student performed today (updated present levels);
- Understand your child's needs across environments (home, school, community, workplace);
- Identify what your child will learn and do while in school to achieve their dreams and goals;
- Confirm the date of your child's graduation; diploma type; and that your child will be able to fully participate in the graduation ceremony;¹⁵⁴
- Identify and provide supports and services your child needs for success during high school;
- Connect with and explore outside agencies for training and adult living supports, and postsecondary educational institutions.
- Ensure that your child learns to the maximum extent appropriate within the general curriculum in the least restrictive environment;
- Ensure that your child attains improved academic and functional results;
- Ensure that your child is prepared for postsecondary education, employment, and independent living (including community access and participation and leisure and recreation);
- Attend all IEP team meetings and ensure your child attends as well; foster a team approach; don't be afraid to ask questions; remember you are an equal participant in the IEP team;
- Monitor your child's progress towards meeting goals and benchmarks with clear measures;;
- Review plans often; request an IEP meeting at any time;
- Discuss your child's transportation needs; request travel training or transportation services if needed;
- Consider your child's adult living situation (supported? independent?) and get on waiting lists;
- Request information about social/recreational opportunities for young adults with disabilities in your community; including support groups or other help from community organizations;
- Help your teen find work and volunteer opportunities in the community;
- Help your teen develop and stick to a plan to maintain their personal fitness;
- Begin looking for adult health care providers and support the transfer of medical care from pediatric to adult services;
- Help your teen manage their own medical care (appointments, questions for doctors, etc.)
- Teach your child emergency preparedness and personal safety with strangers and in relationships;

- Finalize health care financing with your young adult (private insurance, medicaid, etc.);
- Consider guardianship, power of attorney, and/or supported decision making options and discuss with your child;
- Help your young adult apply for SSI and other adult services;
- Build a file with all disability & accommodation documentation, medical records, etc.
- Celebrate successes often!

Appendix B: Transition Checklist by Age

AGE	ACTION ITEM
0-5	<ul style="list-style-type: none"> • Start to imagine your child's adult life. • Teach self care, self determination, and living skills. • Develop a family emergency plan; inform the local fire and police department of necessary accommodations; update annually. • Develop an IEP based on comprehensive assessment in all areas of suspected disability; update annually. • Develop present levels of functional and academic performance in the IEP based on accurate, comprehensive assessments covering all areas of skills development where the student may need support: academic; functional; daily living; social; emotional; recreational; behavior; sensory; communication; mobility; occupational and vocational; update annually.
6-10	<ul style="list-style-type: none"> • All of the above, plus: • Begin to discuss your child's hopes and dreams; write a vision statement. • Ensure that your child is meeting challenging standards and will be prepared to earn a regular high school diploma (or understand and agree as to why they will not). • Discuss potential careers with your child based on their interests and talents. • Build self-determination skills by providing opportunities for decision making and understanding the consequences of their decisions. • Teach financial literacy.
10-13	<ul style="list-style-type: none"> • All of the above, plus: • Learn about the transition planning process. • Learn about diploma options and requirements; discuss options with your child and the IEP team; understand your child's graduation plan and timeline for graduation. • Learn about requirements to attend a university or community college. • Begin transition planning by requesting age appropriate transition assessment related to training, education, employment, and, where appropriate, independent living skills to develop measurable postsecondary goals; update annually. • Consider adding pre-vocational goals to your child's IEP (training in specific skills such as the ability to organize & plan, stay on task in class, etc.)²¹⁵ • Encourage your child to participate in and/or lead their own IEP meetings. • Ensure that your child understands the impact of their disability/diagnosis. • Teach your child to advocate for their wishes, needs & accommodations. • Utilize person-centered planning regardless of ability level. • Have your child practice life skills: ask for directions, make appointments, pay for items at the store; use a cell phone; initiate social activities, etc. • Help your child find a safe place to talk about their disability (family discussions, support groups, counseling, adult mentor; role model with a disability, etc.). • Talk to your child about puberty, sexuality, and family planning issues.

AGE	ACTION ITEM
14-15	<ul style="list-style-type: none"> • All of the above, plus: • The IEP must include transition assessment, goals, and services by age 16 (14 in some states) which reflect the student's current needs, strengths, preferences, and interests; start this process as early as possible; update annually. • If your teen is assessed after age 15 they should be assessed using adult norms. • Measurable Postsecondary Goals (MPGs) must be developed in education, training, and employment, and, if necessary, independent living skills; update annually. • Annual goals support MPGs; update annually. • Your teen must be invited to their IEP meeting at transition age; they must be prepared to participate; if they cannot attend, their interests and preferences must still be considered. • Outside agencies must be invited to the IEP meeting (with student/parent written consent) at transition age. Parents should learn about potential adult and community support agencies. • The IEP team must reconvene if an outside agency is unable to meet the transition objectives in the IEP; the team should identify alternate strategies to meet the transition plan. • Review and revise course of study annually; courses taken have an impact on college, vocational, and other postsecondary options. • Determine graduation path (university, state college, community college, technical/trade school, military, workforce, day program, etc.). • Discuss vocational training vs. postsecondary education with your teen; learn admission requirements and funding options for any college or vocational training program your child is interested in. • Consider dual enrollment at a local community college (open to many high school students after they have earned 2 years of high school credits). • Consider classes that your teen may prefer to take online (online programs must follow IEP/504 and provide credit that is transferable to the student's high school transcript). • Encourage your teen to engage in self-exploration; explore careers and skills; developing self-advocacy skills; identify learning style and classroom strategies; develop their own organizational system; explore opportunities (clubs, teams, student government etc.); get a summer job or volunteer; build a resume; manage time wisely. • If your teen will take standardized testing needed for college, apply for SAT/ ACT accommodations EARLY – don't expect the school to do this for your child. • Make sure your teen satisfies any internship graduation requirements of their high school. • Encourage your teen to become independent in living skills such as laundry, managing weekly allowance, getting up in the morning, etc.).
16	<ul style="list-style-type: none"> • All of the above, plus: • Determine what adult services your teen is eligible for (adult education and training programs, day programs, residential placements/supported living, Vocational Rehabilitation, Developmental Disability Services, Department of Human Services, transportation services, etc.) and apply for them at least two years before graduation/aging out. • Make sure your teen is receiving WorkAbility and life skills training as part of their transition plan. • Begin talking with your teen's medical providers about the transition to adult care. If your teen has complex medical issues, begin finding new medical providers now. • Ensure that your teen understands his/her healthcare needs and how to manage them; help your teen keep medical records, manage medications and appointments. • Teach your teen how to handle emergency vs. non-emergency medical situations; how to communicate appropriate information; healthy vs. high risk behaviors. • Help your teen obtain a state ID or driver's license. • Ensure that your teen learns how to use public transportation (this should be an IEP goal). • Help your teen register to take one or more college entrance tests; request a copy of the test and review results; retake the exam(s) if necessary.

AGE**ACTION ITEM**

17

- All of the above, plus:
- Parents and student must receive notice regarding the Transfer of Parental Rights at least one year before the student reaches the age of majority (age 18 in most states).
- Encourage your student to continue to explore and enhance their work skills via a summer job or internship, volunteer experience, etc.; emphasize community experiences.
- If your teen is pursuing a diploma, ensure that s/he is on target to earn adequate course credits.
- Encourage your teen to continue to do the best they can in their classes and take the most challenging course load they can.
- Your teen should be able to clearly identify what accommodations s/he needs and is entitled to in college; what to do if accommodations are denied; the difference between high schools and college; the laws and rights for individuals with a disability.
- Encourage your teen to attend transition or college fairs and explore colleges online.
- Visit colleges with your teen; include the school's disability services offices; find out what services they offer to students with disabilities (such as "Student success" or "College success" courses; tutoring centers/labs providing academic support for coursework or executive functioning support; education plans including support with course selection and registration; AT support, help accessing accommodations, campus orientation, assessment; etc.);
- Find out if the college does their own psychoeducational evaluation (some do).
- Learn what accommodations are available at different schools and what disability documentation is required (not all IEPs/504 plans contain the necessary information needed to establish eligibility).
- Teen should make a college list with help from case manager/college counselor; solicit letters of recommendation; write personal statements needed for college applications.
- Help your teen create accounts for the common application and any state applications.
- Consider financial options (DOR/VR may fund college or trade school tuition, financial aid programs are available, and there may be scholarships based on your disability).
- Student-athletes should sign up with ncaa.org and contact coaches at colleges that s/he plans to apply to.
- Organize your child's medical records and other documents.
- Determine any age cutoff for therapies; get recommendations for adult providers.
- Help your teen apply for Supplemental Security Income.
- Help your teen apply or reapply for Medicaid.
- Find adult medical and dental providers.
- Get legal advice about conservatorship, guardianship, and/or power of attorney.
- Set up a Special Needs Trust (SNT) or other financial plan (such as an ABLÉ account).
- Check with your health insurance provider about medical coverage for your adult child.
- Check with Durable Medical Equipment (DME) vendors and home care agencies regarding age cutoffs; determine agencies that can continue to provide care.
- Talk about end-of-life plans with family and other caregivers, such as advanced directives, including Allow Natural Death/Do Not Resuscitate (AND/DNR) orders.

18-20

- All of the above, plus:
- Utilize IDEA-funded special education services that run through age 21, particularly transition services:
 - » Students who are diploma-bound but have not completed the required number of units may complete their units at a Comprehensive High School site until age 22 (in most states).
 - » Students who are not on a diploma track may choose to focus on job and life skills with emphasis on building the student's independence.

AGE	ACTION ITEM
21	<ul style="list-style-type: none"> • All of the above, plus: • Your young adult can independently or with help: plan future living arrangements; develop a long-term financial plan; create a care team – bring together people who care about the young person to plan and help reach goals (person centered planning).
22-26	<ul style="list-style-type: none"> • All of the above, plus: • Your young adult should: transition to adult education and training programs; continue to build social networks and maintain friendships; take on as many independent living responsibilities as able; create a list of necessities for emergency preparedness (medication, equipment, supplies).
26	<ul style="list-style-type: none"> • All of the above, plus: • Access health insurance or Medicare (your young adult is no longer covered by parents health insurance unless negotiated with a private carrier).

Appendix C: Sample Letter to Request Comprehensive Transition/Vocational/ Triennial Evaluation – Letter A

Parents names/Address/date

TO: Name / Title (Director of Special Education Services)
Special Education Department/
ADDRESS/FAX #

RE: Request for Comprehensive Triennial Re-Evaluation
(Child's name, DOB)

Dear Ms./Mr. (name of Special Education Director) ,

This letter serves as our written request that our child, <Child's FULL name>, receive a comprehensive triennial re-evaluation in all areas of suspected disability, including a comprehensive transition assessment (at age 14, rather than waiting until age 16, due to his complex neurodevelopmental history). The ultimate purpose of his education is to prepare him to be a functionally independent, contributing member of society. We need to understand his potential in order to determine an appropriate educational plan for high school. <Child's name> would like to attend a 4-year college and we want to ensure that the services and supports are in place to enable him to access the needed curriculum to achieve that goal. We intend to align his triennial evaluation with his annual IEP (as discussed at his last triennial and previous IEP team meetings), so these assessments should be completed by <date>.

As a reminder, <Child's name> is in X grade at <name of school> and is eligible for special education under visual impairment, OHI, orthopedic impairment, and specific learning disability. <Child's name> underwent a right hemispherectomy at 2 years of age due to refractory seizures related to a prenatal stroke. <Child's name> has also been diagnosed with hydrocephalus (shunted at age 7), a left homonymous hemianopsia, a left hemiplegia, a central auditory processing disorder (CAPD), and a social communication disorder (SCD).

There are a significant number of assessments that are crucial to understanding <Child's name>'s unique profile of strengths and weaknesses. Please see the attached letter from his neurologist describing the permanent, unavoidable side effects from the disconnection of the right hemisphere of his brain, which also supports the need for the requested assessments.

We request that the following assessments comprise his comprehensive triennial re-evaluation:

- Neuropsychological (including social-emotional)
- Psychoeducational (including detailed assessment of literacy/specific learning disabilities)
- Audiology
- Speech, language, and communication (including receptive and expressive language; social skills)
- Behavior
- Vision
- Orientation and mobility
- Gross motor (PT)
- Fine motor (OT)
- Sensory
- Assistive Technology
- Educationally Related Mental Health (including

emotional health needs)

- Medical and Health (including health literacy; self-advocacy; personal safety)
- Transition (including self determination and adaptive

skills)

- Functional Vocational Evaluation
- Here are details about each requested assessment and why each is needed:

Neuropsychological: Due to <Child's name's> brain injury, it is critical that a neuropsychologist (with specialized knowledge of brain surgery for epilepsy and its effects) assess his multiple domains of impairment and cognitive consequences of <type of surgery> including: attention; speeded information processing; spatial cognitive skills; executive functioning (including initiation, inhibitory control, planning, mental flexibility, and utilization of feedback, which are employed in service of solving problems and reaching future goals); communication and language; nonverbal and auditory processing; learning and memory; visual-motor and visual processing; social-emotional functioning; general cognitive ability; and any new learning problems, to pinpoint specific areas of deficit and instructional needs. This assessment should be executed by a clinician who can work with the school team to offer expert guidance to teachers regarding effective teaching methods and supports for <Child's name>.

Psychoeducational: to assess his academic skills in math, reading, spelling, oral and written expression, and how these skills are impacted by the brain-based issues outlined above. We need to understand any gains he may have made, or any new areas of deficit, to ensure that he is receiving the most appropriate supports, services, and accommodations. This assessment should include repeating previous measures in order to provide a comparison of his progress over time, including (list specific measures such as: WISC IV, TAPS-3, NEPSY-II and KTEA, GORT, DTLA, PPVT-4) and/or another look at ___ (list any previous concerns or issues).

Audiology: <Child's name> has a diagnosed Central Auditory Processing Disorder. We request an audiology re-evaluation to examine his brain's ability to localize, lateralize, and discriminate sounds and recognize patterns after undergoing <type of surgery>. It is imperative that a qualified examiner using a sound booth perform separate testing of each ear, binaural testing, and testing in the sound field. Assessment should include sound in quiet, sound in noise, filtered sound, frequency (pitch) patterns, and dichotic listening. Only audiologists can diagnose CAPD. Typically, an audiologist would recommend repeat testing every two years up to about 13-14 years of age for children with typical neurological case histories, as there is a known improvement in auditory neuromaturation that plateaus by that age. The key to <Child's name> is that his history is not typical. So re-evaluation is important to assess <Child's name>'s neurodevelopment, which will have an atypical pattern due to the intractable epilepsy and the radical brain surgery. This moves the focus from solely the auditory processing diagnosis to looking instead at: what are <Child's name>'s auditory functional abilities, what areas are improving but still weak, and what areas have significant deficits? This is relevant in understanding how <Child's name> is learning, but also what coping mechanisms may be in play, how can he utilize them maximally to improve his everyday performance in and out of the classroom, and in adjusting accommodations so that they are useful and effective. We do not want to focus on areas that have already improved when other areas may be in greater need.

Speech and language: to assess <Child's name>'s speech, articulation, spoken and non-spoken language, social, and communication skills. <Child's name> has been diagnosed with a Social Communication (Pragmatic) Disorder, has receptive and expressive language deficits, as well as difficulties with sustained attention and error awareness (which may contribute to pragmatic weaknesses). Since <Child's name>

also has confirmed CAPD, a comprehensive battery of testing to determine the scope of his linguistic deficits is warranted.

Functional Behavior Assessment: to determine the reason for behaviors such as checking out, work refusal, putting his head on his desk, etc. and provide appropriate alternatives and a supportive behavior intervention plan.

Vision: to assess how <Child's name> uses his remaining vision in everyday life, and to identify areas of concern (for example: in safety, navigation, and reading). Homonymous hemianopsia is a type of cortical vision impairment that includes a loss of half the foveal (central) field and the entire opposite parafoveal field. After hemispherectomy, components of a comprehensive vision assessment should include: visual acuity; field of vision; contrast sensitivity; oculomotor control (including saccades and tracking, analyzing reading from left to right); and depth perception.

Orientation and mobility: to assess how the homonymous hemianopsia affects his ability to travel safely both indoors and outdoors, with or without assistance, and consider sensory, navigational, visual, and mobility skills. <Child's name>'s orientation skills are particularly affected by his hemianopsia and profound left hemispacial neglect. <Child's name> often bumps into things or trips on objects on the floor that are in his left field, has fallen off of curbs due to reduced depth perception, and he may be startled when something suddenly appears in his remaining field of vision.

Physical Therapy/gross motor: to examine <Child's name>'s locomotor skills, body coordination, ambulation, balance, vestibular reflexes, as well as agility, core strength, and postural control. The hemispherectomy disconnected his motor strip and left him with left hemiparesis and profound left hemispacial neglect.

Occupational Therapy/fine motor: to examine object control, specifically in the areas of fine manual control, visual-spatial, visual-motor and fine motor skills. In addition to his left hemiparesis, <Child's name> displays dysgraphia and tremors in his right hand (disconnection of the motor strip impacts both the contralateral and ipsilateral pathways).

Sensory: to measure the sensory integration processes that underlie learning and behavior, including proprioception, self-regulation and self-modulation. The hemispherectomy surgery removed the sensory cortex of the left side of his brain, and <Child's name> displays numerous sensory processing issues (tactile, auditory, visual, etc.).

Assistive Technology: to further assess what aids and devices can enhance <Child's name>'s communication/writing, help him maintain focus, provide access to his curriculum, and minimize academic demands.

Educationally Related Mental Health: to determine whether the <Child's name>'s disability warrants continued mental health and therapeutic interventions to enable him to make friends, socialize appropriately, and develop self esteem.

Medical and Health: to include health literacy; self-advocacy; personal safety; health transition readiness.

Transition (including self determination and adaptive skills): Adolescents with neurological impairments like <Child's name> need more time to learn skills, including those related to postsecondary transition, so

we must understand his strengths, needs, preferences, and interests as they relate to the demands of his current and future living, learning, and working goals; and his academic achievement and functional performance (adaptive functioning, life skills, self care, relationships, communication, housing, money management, career and education planning, and self advocacy, etc.) in order to design an appropriate transition plan.

Functional Vocational Evaluation: to assess <Child's name>'s ability to work in his desired work settings and determine what supports might be needed to help him meet his career goals. He should be assessed across several areas including career awareness, career exploration, and career experiences. Assessment should take place on the job, in the neighborhood, and in the community.

We trust that the above assessments will be performed by qualified individuals and that the testing protocols used will be appropriate for a child with <Child's name>'s vision, hearing, orthopedic, fine motor, and attention challenges.

Each evaluator should have an understanding of the following:

- Homonymous hemianopsia (including the loss of half the central/foveal field and the entire left parafoveal field), and its impact on visual information processing, visuospatial attention and eye-movement control issues (examiner should be seated on <Child's name's> right and present materials in his right central field of vision);
- Central Auditory Processing Deficit (assessor should speak into his right ear; he should be assessed in a silent room unless the test is to measure his ability to function in a multiple noise environment or how his abilities may be impacted in typical environments);
- Motor deficit (left hemiparesis): some assessment measures expect a student to have bilateral hand use – the results of these assessments should reflect his struggles and needs for further adaptation;
- Attention deficits;
- Social communication (pragmatic) deficits.

We request an assessment process that yields the most effective teaching methods and supports for <Child's name>; that the evaluator be well-versed in extending the assessment beyond office-bound tests to help reveal what <Child's name> can do independently, in the classroom, and in real-world settings with and without supports. In a 1:1 assessment setting, his prefrontal cortex is optimally supported, and his most serious disabilities may be overlooked by the evaluator.

We look forward to signing an assessment plan within 15 days.

Sincerely,
Parents' names

CC: principal, case manager, special ed supervisor, etc.

Appendix D: Sample Letter to Request Comprehensive Transition/Vocational/ Triennial Evaluation – Letter B

Parents names/Address/date

TO: Name / Title (Director of Special Education Services)
Special Education Department/
ADDRESS /FAX #

RE: Request for Comprehensive Triennial Re-Evaluation
(Child's name, DOB)

Dear Ms./Mr. (name of Special Education director),

This letter serves as our written request that our child, <Child's FULL name>, receive a comprehensive triennial re-evaluation in all areas of suspected disability, including a comprehensive transition assessment and a functional vocational evaluation. In order to address her unique needs as early as possible we are requesting that transition planning begin now rather than waiting until _____ (state mandated age for transition planning) due to her complex neurodevelopmental history. We intend to align her triennial evaluation with her annual IEP (as discussed at her last triennial and IEP team meetings), so these assessments should be completed by <date>.

We need to prepare and plan for where she is going after high school and how she will get there to ensure that she has a satisfying and purposeful life after school. We need to fully understand the range of her needs in order to develop appropriate postsecondary goals and the services she needs to meet those goals.

As a reminder, <Child's name> is in X grade at <name of school> and is eligible for special education under multiple disabilities, visual impairment, and orthopedic impairment. <Child's name> underwent a left hemispherectomy (or <type of surgery>) at <age> due to refractory seizures related to a cortical dysplasia (or <diagnosis>). <Child's name> has also been diagnosed with <other known disabilities>. She is nonverbal and uses a wheelchair.

There are a significant number of assessments that are crucial to understanding <Child's name>'s unique profile of strengths and weaknesses. Please see the attached letter from her <neurologist/neurosurgeon> describing the permanent, unavoidable side effects from the disconnection of the left hemisphere of her brain (or <type of surgery>), which also supports the need for the requested assessments.

In total, we request that the following assessments comprise her comprehensive triennial re-evaluation:

- Developmental/cognitive profile
- Psychoeducational: Academic achievement
- Speech, language, and communication
- Receptive and expressive language
- Augmentative communication
- Social skills
- Social, emotional, behavioral needs
- Audiology

- Vision
- Orientation and mobility
- Gross motor and physical mobility (PT)
- Fine motor (OT)
- Sensory needs
- Adaptive skills
- Assistive Technology
- Medical and Health (including health literacy; self-advocacy; personal safety)
- Transition (including self determination and adaptive skills)
- Functional Vocational Evaluation

Here are details about each requested assessment and why each is needed:

Developmental/cognitive profile: to measure <Child's> ability to reason, solve problems and use cognitive processing.

Psychoeducational: to assess academic achievement and functional skills.

Speech, language, and communication:

- Speech and language: to assess <Child's name's> functional and verbal skills, spoken and non-spoken language and communication skills, receptive and expressive language skills.
- Augmentative and Alternative Communication to determine alternative means for expressing her wants and needs
- Social skills
- Social, emotional, behavioral and adaptive skills assessments: to help determine behavior patterns, emotions, feelings, and potential academic and social issues.

Audiology: to examine the remaining hemisphere's ability to localize, lateralize, and discriminate sounds and recognize patterns. Since behavioral CAPD testing might not be possible we request a CAEP (cortical auditory evoked potential).

Vision: to assess how <Child's name> uses vision in everyday life, and to identify areas of concern (for example: in safety, navigation, and reading).

Orientation and mobility: to assess the ability to travel safely both indoors and outdoors, with or without assistance, and consider sensory, navigational, visual, and mobility skills.

Physical Mobility / gross motor: to examine <Child's name's> locomotor skills, body coordination, ambulation, balance, vestibular reflexes, as well as agility, core strength, and postural control. The hemispherectomy disconnected her motor strip and left her with right hemiparesis and right hemispatial neglect.

Fine motor: to examine object control, specifically in the areas of fine manual control, visual-spatial, visual-motor and fine motor skills.

Sensory needs: to evaluate how sensory input is received and perceived through sight, sounds, touch, taste, smell, movement and balance, body position and muscle control and sensory integration processes that underlie learning and behavior (including proprioception, self-regulation and self-modulation).

Assistive Technology: to further assess what aids and devices can enhance <Child's name>'s communication, help her maintain focus, provide access to her curriculum, and minimize academic demands.

Medical and Health: to include health literacy; self-advocacy; personal safety.

Transition: to form the basis for defining goals and services to be included in the IEP, we request the use of formal and informal transition assessment procedures, including direct observations in a variety of real-world situations and environmental analyses. Adolescents with neurological impairments like <Child's name> need more time to learn skills, including those related to postsecondary transition, so we must understand her strengths, needs, preferences, and interests as they relate to the demands of her current and future living, learning, and working goals; and her academic achievement and functional performance (adaptive functioning, life skills, self care, relationships, communication, housing, money management, career and education planning, and self advocacy) in order to design an appropriate transition plan.

Functional Vocational Evaluation: to assess <Child's name>'s ability to work in her desired work settings and determine what supports might be needed to help her meet her career goals. She should be assessed utilizing situational assessment. Typical assessment methods such as paper and pencil or computer-based interest inventories may be ineffective. Assessment should take place in the community.

We trust that the above assessments will be performed by qualified individuals and that the testing protocols used will be appropriate for a child with <Child's name>'s vision, hearing, orthopedic, fine motor, and attention challenges.

Each evaluator should have an understanding of the following:

- Homonymous hemianopsia (including the loss of half the central/foveal field and the entire right parafoveal field) and resulting visual information processing, visuospatial attention and eye-movement control issues (examiner should be seated on <Child's name's> left and present materials in her left central field of vision);
- Central Auditory Processing Deficit (assessor should speak into her left ear; she should be assessed in a silent room unless the test is to measure her ability to function in a multiple noise environment or how her abilities may be impacted in typical environments);
- Motor deficit (right hemiparesis): some assessment measures expect a student to have bilateral hand use – the results of these assessments should reflect her struggles and needs for further adaptation;
- state **any** of your child's specific assessment needs>

We look forward to signing an assessment plan within 15 days.

Sincerely,

Parents names

CC: principal, case manager, special ed supervisor, etc.

Appendix E: Sample Letter to Request Transition Assessment – General – Letter C

Parents names/Address/date

TO: Name / Title (Director of Special Education Services)
Special Education Department/
ADDRESS /FAX #

RE: Request for Transition Assessment
(Child's name, DOB)

Dear Ms./Mr. (name of Special Education director),

Our child, <Child's name>, is approaching transition age. We are writing to request transition-specific evaluations to update her present levels of functioning in order to develop measurable postsecondary goals for her in employment, education or training, and independent living.

In preparation for the meeting, we would like to review the transition-specific assessments that the school district uses. We would also like to meet with the transition coordinator or the person responsible for conducting transition-specific assessments to discuss which evaluations will be used, and why.

We want to ensure that assessments are conducted in the following areas:

- functional skills
- adaptive behavior
- communication skills
- social skills
- independent living skills
- motor skills
- vocational skills

As a reminder, our child has vision, hearing, orthopedic, fine motor, and attention challenges.

We look forward to signing an assessment plan within 15 days and scheduling a time to meet with the transition coordinator.

Sincerely,
Parents names

CC: principal, case manager, special ed supervisor, etc.

Appendix F: Letter from Neurosurgeon/Hemispherectomy

Re: [Child's Name]

To whom it may concern:

[Patient] is a young [boy/girl] with a history of drug-resistant seizures. S/He underwent a [hemispherectomy/hemispherotomy] - a procedure where half the brain is removed and/or completely disconnected to stop drug-resistant epilepsy. Here, the [right/left] side of [Child's] brain was [removed/disconnected] to stop [his/her] drug-resistant epilepsy as a result of [hemimegalencephaly/ cortical dysplasia/ stroke etc.]. [Child] is now seizure-free, but there are permanent, unavoidable side effects from the removal/disconnection of the [right/left] hemisphere of [his/her] brain.

These are:

Visual Impairment

[Child] has a permanent cortical vision impairment known as homonymous hemianopsia. This vision loss is in half of [his/her] visual field. In other words, [he/she] is totally blind beginning from approximately the nose (midline) all the way to the ear opposite from the side of surgery. This includes loss of half the central (foveal) vision as well. This visual field loss affects both eyes and is a result of surgical disconnection of the occipital lobe of the brain. Please note that this vision loss is not correctable using glasses because it is unrelated to focusing of the lens of the eye. Homonymous hemianopsia can severely affect the [Child's] orientation and mobility in school in various static and dynamic environments, as well as [his/her] ability to view text and reading materials. In language read from left to right, right hemianopia can have a profound effect on the child's ability to read/learn to read.

Hearing Impairment

Cortical auditory impairment (also referred to as central hearing loss or central auditory processing disorder/CAPD) are known results of hemispherectomy. The extent and severity of the impairment and perceived communication handicap can vary from child to child, but typically results in mild-to-severe dichotic listening deficits, poor sound lateralization, difficulty understanding speech in the presence of noise, and sound localization challenges. For example, because there is massive suppression of auditory input into the ear on the same side of the removed hemisphere, children may neglect conversational partners of the side of the missing hemisphere when experiencing different types of speech inputs to both sides simultaneously. Please note that cortical auditory impairment cannot be detected by a pure-tone hearing test which mainly assesses detection of sounds as a peripheral hearing function.

Orthopedic Impairment

[Child] has significant loss of gross motor function on his/her [left/right] side known as hemiparesis. This also manifests as a loss/limitation of fine motor skills essential for highly coordinated movements of the [left/right] hand and fingers, as well as a complete hemispatial neglect in most children (a lack of awareness that the [left/right] side of the body even exists). This is part of the overall upper motor neuron syndrome caused by the surgery.

Please note that fine motor function in the “good hand” is affected as well. This may manifest as difficulty with writing, drawing, force production, and pressure sensitivity.

Other Health Impairments

- Fatigue – [Child] may have general fatigue, as well as decreased cognitive and physical stamina as a result of the surgery. Additionally, please note the child may have a return of seizures at any time. S/He should have a seizure action plan and a complex care plan in place.
- Hydrocephalus – [Child] is at an increased risk of hydrocephalus [or presently has shunt and concerns about shunt failure]. The warning signs of hydrocephalus [or shunt failure] include, but are not limited to, headache, vomiting, sleepiness, cognitive decline, blurry vision, seizures, and/or behavioral changes. [or if the child already has a shunt, describe shunt and failure warning signs]. The risk of developing hydrocephalus is throughout the lifespan.
- ADHD – [Child] may also have challenges with higher executive function skills because one prefrontal cortex has been removed or disconnected, regardless of auditory skills. We often see heightened auditory distractibility, attention concerns, or attention deficit hyperactivity or inattentive disorder (ADHD/ADID) post-operatively. Child may have hyperkinesia, perseverate, and/or self-stimulate.
- Thermoregulation – Some children after hemispherectomy surgery are unable to regulate their body temperature appropriately.
- Reduced sensitivity to heat, cold, and pain – Sensitivity to heat, cold, and pain is impaired in the hand, forearm, and upper arm opposite the removed hemisphere. The reduced sensitivity is most significant in the hand. Children are at risk of unknown broken bones after falls because their pain reaction is significantly reduced, or burns. After a fall or exposure to extremely hot or cold surfaces, they should be checked by the school nurse for broken bones or burns even if they are not complaining of pain. Additionally, sensitivity to hot and cold is impaired in the arm on the same side of the removed hemisphere in the upper arm.

Most, but not all, children after hemispherectomy surgery have the following challenges discussed below. Because my observation of [Child] is limited by the brief amount of time we have during clinic visits, I am unable to provide diagnosis of the following; however, if parents are concerned, proper assessments should be done to address these potential issues:

- Specific Learning Disability / Intellectual Disability – Hemispherectomy surgery and removing anti-epileptic drug use is known to increase intellectual quotient by approximately ten points over time; however, most children after hemispherectomy surgery will have specific learning disabilities or intellectual disability. Specific learning disabilities postoperatively often affect reading, mathematics, visual and auditory processing, and other areas. A neuropsychological evaluation is recommended to fully understand these challenges as respects [Child] and to see if he/she is a child identified as having specific learning disability or intellectual disability.
- Autism – Autism and epilepsy, even if seizures are controlled, are often comorbid conditions. If parents are concerned, [Child] should be evaluated to see if he/she is a child identified as having autism.
- Behavior – Approximately 27% of children after hemispherectomy have significant behavior problems affecting school or social life. 10% require constant supervision due to behavior problems. If parents are concerned, proper evaluations should be conducted to determine if the child's behaviors affect his/her ability to access the educational environment or present safety concerns.

- Finally, like a traumatic brain injury, epilepsy surgery is often associated with impairments in the following areas: cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech.

If you have any questions, please do not hesitate to contact me.

<signed> Neurologist or Neurosurgeon

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Appendix G: Letter from Neurosurgeon/Temporal Lobectomy

Re: [Child's Name]

To whom it may concern:

[Patient] is a young [boy/girl] with a history of drug-resistant seizures. [S/He] underwent a [left/right] [partial/complete] temporal lobectomy [including resection of the left/right amygdala/hippocampus] to stop seizures caused by [cortical dysplasia/hippocampal sclerosis/tuberous sclerosis/etc] (or <surgery type>).

[Child] is [now/not] seizure-free, [but/and] there may be permanent, unavoidable side effects from the surgery. These include:

Visual Impairment

[Child] may have a permanent visual field impairment in the upper quadrant of the opposite visual field from the removed temporal lobe. This is known as superior quadrantanopia and may include loss of up to ¼ of the foveal vision as well. This visual field loss affects both eyes and is a result of possible disconnection of Meyer's loop in the brain. Assessment to determine this condition should be made using a perimetry test (not confrontation examination alone) as patients often report no visual field issues but perimetry test confirms a visual field loss despite unremarkable confrontation examination.

Please note that this vision loss is not correctable using glasses because it is unrelated to focusing of the lens of the eye. Superior quadrantanopia can affect the [child's] orientation and mobility in school in various static and dynamic environments, as well as [his/her] ability to view text and reading materials. In languages read from left to right, right quadrantanopia may affect a child's ability to read/learn to read.

Additionally, because the surgery disrupted both the dorsal and ventral visual streams of the brain, the child may have visual processing challenges. A comprehensive visual assessment, including for cortical vision impairment and orientation and mobility, should be performed to determine if the child is identified as having a visual impairment.

Hearing Impairment

Cortical auditory impairment (also referred to as central hearing loss or central auditory processing disorder/CAPD) is a known challenge after temporal lobectomy. This is because one auditory cortex - the part of the brain that processes sound - has been removed.

The extent and severity of the impairment can vary from child to child, but typically results in mild-to-severe dichotic listening deficits, poor sound lateralization, difficulty understanding speech in the presence of noise, and sound localization challenges. Research shows that the probability of a decreased performance in a non-dominant-side dichotic test after surgery was 7.5-fold greater in patients who underwent surgery on the dominant temporal lobe compared with the nondominant temporal lobe.

Please note that cortical auditory impairment cannot be detected by a pure-tone hearing test which mainly assesses detection of sounds as a peripheral hearing function. A comprehensive auditory assessment, including pure tone hearing test as well as central auditory processing evaluation, should be performed to determine if the child is identified as having a hearing impairment.

Speech and Communication Impairment

The temporal lobe holds the primary auditory cortex, which is important for the processing of semantics of speech and plays a key role in speech comprehension. [Child] may have receptive or expressive speech and communication challenges, related either to the epilepsy or temporal lobe resection, or both. A comprehensive speech evaluation is thus recommended to determine if the child is identified as having a speech and/or communication impairment.

Other Health Impairments

- Fatigue [Child] may have general fatigue, as well as decreased cognitive and physical stamina as a result of the surgery.
- Seizures [Child] may have a return of seizures at any time. [S/He] should have a seizure action plan and a complex care plan in place
- Hydrocephalus [Child] is at a small risk of hydrocephalus [or presently has shunt and concerns about shunt failure]. The warning signs of hydrocephalus [or shunt failure] include, but are not limited to, headache, vomiting, sleepiness, cognitive decline, blurry vision, seizures, and/or behavioral changes.
- ADHD [Child] may have challenges with higher executive function skills, We often see heightened auditory distractibility, attention concerns, or attention deficit hyperactivity or inattentive disorder (ADHD/ADID) post-operatively. Child may have hyperkinesis, perseverate, and/or self-stimulate. If parents are concerned, a comprehensive evaluation to determine whether the child is identified as having ADHD should be performed.
- Specific Learning Disability or Intellectual Disability – Children with temporal lobe epilepsy are at risk of reading difficulties involving accuracy and comprehension. Verbal memory, semantic memory, naming, emotional perception can be impacted as well. Please note that temporal lobe surgery and removing anti-epileptic drug use is known to increase intellectual quotient over time in most children. [Child] may experience a drop in intellectual quotient immediately following surgery, followed by a slow upward trend as far as six years after or more, with a possible significant jump in IQ eight years or more after surgery.
- If parents are concerned about specific learning disability or intellectual disability, a neuropsychological evaluation is recommended annually to fully understand these challenges as well as IQ trajectory as respects [Child], and to see if he/she is a child identified as having specific learning disability or intellectual disability requiring intensive instructional interventions.
- Autism – Autism and epilepsy, even if seizures are controlled, often occur together. If parents are concerned, [Child] should be evaluated to see if he/she is a child identified as having autism.
- Behavior – Children with epilepsy often have behavior challenges, even after surgery, or if medications are weaned. Surgery, however, often improves behaviors in most children. If parents are concerned, proper evaluations should be conducted to determine if the child's behaviors affect [his/her] ability to access the educational environment or present safety concerns.

If you have any questions, please do not hesitate to contact me.

Very truly yours,
Neurologist or Neurosurgeon

To the clinician – sources for the content of this letter include:• Dutton, G.N. (2009), 'Dorsal stream dysfunction' and 'dorsal stream dysfunction plus': a potential classification for perceptual visual impairment in the context of cerebral visual impairment? *Developmental Medicine & Child Neurology*, 51:170-172.

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Appendix H: Postsecondary Goals

Post-secondary Education/Training

- Complete on the job training for [desired occupation].
- Earn an occupational certificate in [desired occupation].
- Attend courses designed to provide vocational training in culinary arts, cosmetology, pet grooming, heavy equipment operation, etc. [desired occupation]
- Enroll in adult education course/program (i.e. “ ... participate in daily instruction on social skills, self advocacy skills and self-care skills at a center-based adult education program.”)
- Enroll in a college or university to study [desired occupation], (i.e. “... attend college to obtain an undergraduate degree in science and education to become a high school science teacher.” or “... take courses at a local community college to earn an associate’s degree and then transfer to a 4-year university to obtain a bachelor’s degree in world languages.”)
- Participate in remedial education courses at the local community college focusing on life skills instruction, functional reading, functional math, productivity and basic employability skills.
- Enter the military for training in [desired occupation].
- Enter an apprenticeship in the field of [desired occupation].

Employment

- Get a competitive job – work full time / part time [desired occupation]
- Obtain a supported employment position – work full time / part time [desired occupation]
- Get a job that is integrated competitive employment [desired occupation]
- Start a business [desired occupation]
- Do volunteer work in the community [desired volunteer position]
- Attend a Day Program to participate in prevocational activities, habilitative and functional skill training.
- After obtaining her degree from college, Judy will be a [desired occupation].

Independent Living

- Live independently
- Live with family, roommates
- Live independently with supportive services
- Live in residential settings
- Manage finances, household
- Access community – independently
- Use public transportation
- Independently prepare for each day, including dressing, cleaning, preparing meals. etc.
- Participate in the community (vote, access recreation and leisure, develop relationships, etc.)

A Helpful Formula from the National Secondary Transition Technical Assistance Center (NSTTAC)²¹⁶:

<i>After High School</i>	<i>Student</i>	WILL	<i>Behavior</i>	<i>Where and How</i>
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Appendix I: Annual IEP Goals

Make sure that each goal includes the due date, any 'givens' (such as setting, instruction, prompting, etc.), how the goal will be measured, how often data will be collected, and what % of accuracy determines the goal has been met (more detail in the goal makes tracking progress easier).

Education/Training :

- Given daily instruction and use of high-interest materials, Jonette will increase her inferential reading comprehension scores by one grade level as measured by classroom assessments in order to improve this skill for increased success with postsecondary education and training.
- Judy will demonstrate an understanding of her daily schedule and class routines by making entries on an electronic calendar to manage her schedule and assignments.
- Ben will set reasonable expectations for his academic, social, and career development by attending and participating in his IEP to provide input on desired and needed goals.
- Akinde will demonstrate the ability to self-advocate for needed accommodations by contacting the Student Services specialist at the local community college for an appointment and discuss his needed accommodations.
- In order for Renee to achieve her postsecondary goal of attending motorcycle mechanic's school, she will independently utilize a Livescribe pen to acquire classroom notes.
- Makenna will read with grade-level comprehension, write proficiently, and solve complicated math word problems (break this into 3 separate goals) in order to pass the SAT/ACT and apply to a four-year college to pursue her desired career path of becoming a science teacher.
- Silas will research the difference between laws in high school, college, and the workplace.
- Jameka will research and understand college

disability services and how to access them, university policies regarding disability, what disability documentation is needed by each school, and scholarships for students with disabilities in order to determine which 4-year colleges to apply to.

- Frank will learn self-advocacy skills to request reasonable accommodations in college and develop the knowledge and self-confidence to advocate for his needs on the college campus.

Employment

- John will rank his preference of career opportunities using a picture symbol rubric after completion of community-based instruction at three different community sites for at least two 2-hour sessions every week for 6 weeks.
- In order to decide what career path to pursue, Jose will analyze and explore his personal characteristics related to educational and career planning.
- To assist him in reaching his postsecondary employment goal of working as an automotive mechanic, Andrew will be able to convert standard units of measurement to metric units of measurement with 80% accuracy in 5/5 trials on teacher-made tests of 20 questions.
- In order to participate in a vocational training program at the local adult day center, Kayla will transition between activities with one visual prompt 100% of the time for 2 consecutive weeks.
- In order for Micah to meet her postsecondary goal of working at Walmart as a greeter, she will develop appropriate work habits such as proper grooming and work attire, appropriate social interaction, and being on time for all required activities (as measured by _____).
- In order for Jacob to meet his postsecondary goal of working in the community he will learn how to seek and maintain employment by visiting three job sites of interest, observing

employees in his desired role(s), and meeting with the hiring manager to find out what the requirements are to obtain the job (___ times, as measured by _____).

- In order to achieve her specific job goal to be a home healthcare aide, Lisa will demonstrate improved physical/manual skills by being able to deadlift 100 lbs. (as measured by _____).

Independent Living

- In order to achieve her postsecondary goal of living alone in an apartment, Sarah will increase her reading Lexile score from 680 to 920 as assessed by the Read 180 curriculum.
- Given fading prompts, Bernard will demonstrate appropriate oral hygiene by brushing and maintaining teeth two times per day with 100% accuracy.
- Given direct instruction on saving money and balancing a checkbook, Marsha will open a bank account, write checks, and make deposits and withdrawals.
- Bonnie will perform basic household tasks and plan and prepare simple meals.
- In order to demonstrate functional communication, given daily training and explicit instruction, Shondra will read international symbols and survival words.
- Janice will increase conditioning skills by developing her own exercise program with 10 exercises and will utilize the program 5 times per week as measured by a student log.
- Henry will access and participate in leisure activities in his community.
- Given coaching and scaffolded support, Byron will improve social interaction by staying on topic and engaged during non-preferred conversation, and will take notes if he can't remember key points of important

conversations.

- Given explicit training and practice sessions, Jane will make and keep plans to see at least two friends once each week.
- In order to develop effective communication, leadership skills, and disability awareness, Micha will volunteer to speak at community youth groups about disability awareness topics 5 times, developing his own presentation, coordinating the presentation, and transporting himself independently.
- Sally will utilize her self advocacy skills to remove herself from a noisy situation and/or advocate for an assistive technology tool or a quiet setting for instruction.
- In order to access his goal to attend community college and determine appropriate college course selection, Jessie will describe his own disability, personal preferences, interests, strengths, and limitations.
- Gabe will demonstrate the ability to obtain needed items available at a grocery store by composing a list of 10 needed grocery items; asking an employee for assistance if needed; and selecting appropriate items based on preference, freshness, nutritive value and cost.
- Given direct instruction and guided practice, Jackie will identify which public bus route to take from her apartment to the grocery store and community college.
- In order to manage her epilepsy and hydrocephalus when she is living in an apartment with friends next year, Leticia will manage her own health-related needs by demonstrating adequate communication skills/ strategies in order to make health decisions, identify community health resources, and discuss, understand, and ask questions about her healthcare needs.

A Helpful Formula from National Secondary Transition Technical Assistance Center (NSTTAC)²¹⁷:

GIVEN	_____	_____	WILL	_____	_____	_____
	<i>condition</i>	<i>student</i>		<i>behavior</i>	<i>criteria</i>	<i>time frame</i>
	<small>(i.e., direct instruction, modeling, peer tutoring)</small>			<small>(i.e., 80%)</small>		<small>(i.e., by June, 2015)</small>

Appendix J: Connecting Postsecondary Goals to Annual Goals

POSTSECONDARY GOAL	ANNUAL GOAL	CONNECTION
Upon graduation from high school, Gary will attend Williams County Community College.	Given Williams County Community College information, Gary will demonstrate knowledge of the admission requirements by describing requirements and identifying admission deadlines with 90% accuracy.	Learning about the college’s admission requirements will help Gary meet his goal of attending Williams County Community College; this can be completed during the school year.
Following high school, Jenny will attend a four-year college to obtain a degree in computer science leading to employment in a professional position in the field of computer science.	Jenny will independently organize her academic work for all classes and homework using a planner, highlighters, dividers, and other organizational tools at least twice a week for the duration of this IEP.	Independent organizational skills and proficient use of organizational tools is a skill that Jenny will need in order to complete college assignments in a timely manner.
	Jenny will prepare questions in writing to ask her teachers to clarify assignments and required course content, once a week for the duration of her annual IEP.	Preparing questions for her teachers is a skill Jenny will need in order to be able to successfully interact with college professors and clarify requirements and otherwise understand important information in college courses.
After graduating high school, Janice will obtain a part-time position in a community retail environment.	Janice will identify her likes and dislikes related to retail employment options by participating in at least three retail job shadowing experiences and select her preferences using pictures, words, and affect by ____ date ____ .	Participating in job shadowing will help Janice identify her likes and dislikes about the job and help to ensure that the job she pursues is one that she is motivated to continue. This experience will also help the team to identify needed skills and supports to be targeted during the high school years.
After finishing high school, Jacob will increase his work hours in the business department of a local office supply store to work full time.	Given a list of possible scenarios at work, Jacob will identify those that require a meeting with his supervisor with 90% or better accuracy once a week for the duration of the IEP.	This annual goal primarily focuses on teaching Jacob a skill that will help him make appropriate decisions on the job, avoid mistakes during employment and, therefore, will assist him in maintaining employment.
	Given his OOD caseworker’s contact information, Jacob will call or email him independently to share information and discuss issues at his job at least two times a month for the duration of the IEP.	Learning to independently contact his adult service caseworker while in high school is a skill that will prepare Alex for his continued employment postsecondary goal.
After graduating high school, Miguel will live in the family home with natural supports and use public transportation to commute to work four to five days per week.	Given visual supports, social narratives, and video modeling, Miguel will demonstrate how to safely wait for, board, ride, and depart the public transportation from his home to a community site one time per week for three consecutive weeks by ____ date ____ .	This annual goal prepares Miguel to independently use transportation following high school to accomplish both the postsecondary goals of living at home and being employed in the community.

from: *Transition Planning and the IEP: Aligning Postsecondary Goals and Annual Goals. The Ohio Center for Autism and Low Incidence (OCALI)*²⁸

Appendix K: Health Transition Assessments

Assessment tools (measures/checklists):

- [Epi-TRAQ](#) – a transition readiness assessment tool for adolescents and young adults with epilepsy²¹⁹
- [Transition Readiness Assessment Questionnaire \(TRAQ\)](#)²²⁰
- [GoToTransition.org](#): A comprehensive website about transitioning from pediatric to adult health care. Includes various health transition assessments
 - » [Sample Transition Readiness Assessment for Youth](#)²²¹ | [En Español](#)²²²
 - » [Sample Transition Readiness Assessment for Parents/Caregivers](#)²²³ | [En Español](#)²²⁴
- [SELF-CARE ASSESSMENT \(YOUTH/YOUNG ADULTS\)](#)²²⁵
- [Transition Health Plan for Youth with Disabilities and Their Families](#)²²⁶
- TRANSITION HEALTH ASSESSMENT, Colorado Department of Education
<https://www.cde.state.co.us/healthandwellness/transition-health-assessment-tch>²²⁷
- The UNC TRANSITION Scale [A Clinical Tool to Measure the Components of Health-Care Transition from Pediatric Care to Adult Care](#)²²⁸

Health Literacy Assessments:

- [All Aspects of Health Literacy Scale \(AAHLS\)](#)²²⁹
- [eHEALS: the eHealth literacy scale](#)²³⁰
- [Health Activities Literacy Scale \(HALS\)](#)²³¹
- [National Assessment of Adult Literacy \(NAAL\)](#)²³² – health-related assessment questions are embedded in the main NAAL assessment booklet; they can be scored along each PDQ (prose, document, and quantitative) scale as well as the separate health literacy scale.
- [Rapid Estimate of Adult Literacy in Medicine \(REALM\)](#)²³³
- [Rapid Estimate of Adolescent Literacy in Medicine \(REALM-Teen\)](#)²³⁴
- [Short Assessment of Health Literacy—Spanish and English \(SAHL-S&E\)](#)²³⁵
- [Test of Functional Health Literacy in Adults \(TOFHLA\)](#)²³⁶
- [Test of Functional Health Literacy in Adolescents \(TOFHL-Ad\)](#)²³⁷

Incorporating HealthCare needs and goals in the IEP:

- [Health in the Individualized Education Plan](#)
<https://depts.washington.edu/healthtr/documents/iep.pdf>
- Health Transition Planning and the Individualized Education Program (IEP)
<https://www.pacer.org/transition/learning-center/health/planning-and-iep.asp>
- What Does Health Have to Do with Transition? Everything!²³⁸
<https://files.eric.ed.gov/fulltext/EJ1140315.pdf>

Helpful Tools for Youth and Families:

- Child Neurology Foundation: [Transition of Care](#)²³⁹
- [Dependent Disabled Adults: Continuation of Private Health Care Coverage](#)²⁴⁰ – state laws that allow parents to continue health coverage for their disabled adult children.
- [Getting Ready for Healthcare at the Age of Majority](#)²⁴¹ – a tip sheet by the National Secondary Transition Technical Assistance Center and the National Post-School Outcomes Center offers helpful strategies and notes pros and cons of guardianship.
- [GotTransition.org](#)²⁴²
 - » [Guardianship and Alternatives for Decision-Making Support](#)²⁴³
 - » [Understanding Guardianship: an archived broadcast of a 2012 Got Transition webinar](#)²⁴⁴
 - » [Preparing for the Transition from Pediatric to Adult Health Care: Parent Guide](#)²⁴⁵
 - » [Sample Medical Summary and Emergency Care Plan](#)²⁴⁶
 - » [Six Core Elements of Healthcare Transition](#)²⁴⁷
- [Healthy Transitions | Moving from Pediatric to Adult Health Care](#)²⁴⁸
- [HIPAA release form](#)²⁴⁹
- [How and Why you should apply for Medical Assistance for your Disabled Child](#). A Day In Our Shoes²⁵⁰
- [Making the Move to Managing Your Own Personal Assistance Services \(PAS\): A Toolkit for Youth with Disabilities Transitioning to Adulthood](#)²⁵¹ – toolkit designed to help transition-age youth with significant disabilities, as well as their family and friends, navigate the complex world of personal assistance services (PAS).
- [Preparing for Adulthood: Taking Charge of My Own Health Care](#)²⁵² – 4-part series on transitioning from pediatric to adult health care developed by PACER's Youth Advisory Board.
- [Transition Summary](#). University of Chicago²⁵³
- [Transition to Adult Health Care: Training Guide in Three Parts](#)²⁵⁴
- [Transition to Adulthood: A Health Care Guide for Youth and Families; The Autistic Self Advocacy Network \(ASAN\)](#)²⁵⁵
- [The Transition to Health Care Checklist: Preparing for Life as an Adult](#)²⁵⁶
- [TRANSITIONS CHECKLIST](#) – Young Adults With Neurologic Disorders; Child Neurology Foundation²⁵⁷

Child-friendly resources:

- [Medikidz Explain Epilepsy: Bringing Information about Epilepsy to Young Patients and Their Families](#)²⁵⁸ – animated superheroes to explain medical conditions to children by providing accurate and engaging information for young people and their families. <https://www.advancingepilepsycare.com/medikidz/overview>
- [Transition Quick Guide: Take Charge Of Planning And Managing Your Own Health And Career Goals](#)²⁵⁹ – for youth and young adults from age 12-30; checklist provides information and resources about health insurance coverage, self-care, health care transition, decision-making, and career planning and management.
- [The Workbook for Youth: Wisconsin Community of Practice on Transition Practice Group on Health](#)²⁶⁰

Appendix L: Health Transition Goals

- Student will learn about her seizure disorder, surgical history, shunt and shunt failure/hydrocephalus warning signs, and/or other health needs to ensure good health, in order to live safely in the community.
- know (be able to say aloud and/or spell out and/or enter into her cell phone) the name(s) of the foods and/or medications she is allergic to;
- know the name(s), dosages, and what time to take her medication(s); identify, read, and follow the directions on their medication; contact her doctor's office or pharmacy to ask about medication refills;
- learn 2-3 side effects of her medication and when to report any changes in side effects or new symptoms to her doctor;
- learn 5 facts about her seizure disorder and surgical history & make a 10-minute presentation in health class;
- know the name/type of shunt and shunt setting; know when it's not working;
- know and state the signs and symptoms of hydrocephalus and/or shunt failure, know when to report any changes or new symptoms to her neurologist or neurosurgeon, and how to advocate with the neurosurgeon (as post epilepsy-surgery hydrocephalus is poorly understood);
- know and understand her different subspecialists (i.e. neurologist, epileptologist, neurosurgeon, orthopedist, orthotist, physiatrist, endocrinologist, psychologist, etc.) and how each one addresses her specific healthcare needs;
- know where to find a copy of her most recent MRI;
- prepare a medical binder with a one-page outline of her medical history and current medications, names and contact information of all doctors and other specialists involved in her care, and recent imaging on CD to bring to the hospital for an emergency or routine appointment;
- develop an emergency plan for when she is living on her own (know where her emergency binder is, know what constitutes a medical emergency, determine 2-3 local friends or family knowledgeable about her health conditions who she can contact in the event of an emergency, etc.);
- identify and interview 2-3 physicians to choose from to help manage adult health care and determine which specialists are needed (i.e. neurologist, epileptologist, neurosurgeon, orthopedist, physiatrist, endocrinologist, psychologist, etc.);
- prepare and practice asking a few questions to her doctor or specialist at her next appointment, conducting research to help formulate questions, review previous lab work or tests (MRIs/EEGs, etc.);
- input all of her doctors' contact information on phone; name and identify all doctors when asked;
- know how to call doctor's office or use an online portal to schedule a future appointment and identify which accommodations she needs to request in advance;
- plan transportation to the doctor's office ahead of time;
- keep insurance card safely in wallet/backpack (or take a photo of it and store it on her phone) and be able to retrieve the insurance card when asked;
- Student will name his learning differences, disability, medical, or mental health diagnosis (e.g. diabetes, depression, ADHD) and how the impact him in the community;

- know (say aloud and/or spell out and/or enter into a cell phone) the name(s) of learning differences, disabilities, medical or mental health diagnosis(es)
- describe the impact of their learning differences, disabilities, medical or mental health diagnosis(es)
- name 2-3 people who can help with intellectual differences, disability, medical, or mental health needs in an emergency
- input emergency contacts' information on his phone and name/identify contacts when asked
- identify the impact of illness or disability on his life
- understand the impact of his disability in his postsecondary setting
- know what accommodations are needed in different settings and how to advocate for them

See [Sample Goals for the Health Care Transition](#).

[Readiness Assessment for Students with an IEP261](#)

Appendix M: Outside Service Agencies

Outside agency representatives who could be invited to the IEP meeting may include:

- Department of Vocational Rehabilitation (age 14-16 depending on your state; don't wait until 18 to access pre-employment transition services);
 - Developmental Disabilities agencies (may not be IQ based, individuals with neurodevelopmental disabilities may qualify for services);²⁶²
 - Regional Center (some states) or county social workers;
 - School district transition programs or other post-high school programs;
 - Day training and habilitation staff;
 - Career and vocational school representatives;
 - Community college or college representatives;
 - Student accessibility/disability services from college or technical schools;
 - Postsecondary transitional living programs (e.g. College Internship Program, College Living Experience); ^{263 264}
 - College-based [Comprehensive Transition Programs](#) (CTPs); ²⁶⁵
 - Assistive technology providers;²⁶⁶
 - Disability-specific agencies (National Alliance for the Mentally Ill (NAMI), Easter Seals, The Arc, state organizations for the Blind and Visually Impaired, Deaf-Blind Services, etc.)*
 - Independent and assisted living facilities and programs;;
 - Community Based Independent Living Skills
- Providers (integrated community services, independent living centers²⁶⁷) (some have summer programs for middle and high school students, or postsecondary/transition programs);²⁶⁸
 - Disability-supportive employers within the community;
 - Transportation providers (to access job and community);
 - Probation officer or teacher from a juvenile justice center;
 - Community parks and recreation staff;
 - Medicaid or Medical Assistance (MA) expert/representative (in particular, a to help the team understand the transition to adult waivers);
 - [Social Security Administration \(SSA\)](#) - to help the team understand the rules and limitations that are involved when discussing Social Security and Supplemental Security Income (SSI);²⁶⁹
 - Protection and Advocacy Agencies, Parent Training and Information Agencies, and other community advocacy organizations that provide information about disability rights legislation & acts; policy & state regulations; housing, transportation, leisure, and employment;
 - The individual's personal care, health care, or mental health care providers
 - Other personal or professional support networks.

***PLEASE NOTE:** If your child has not already been fully assessed in vision, CAPD, autism, or other areas be sure to get these evaluations before transition to ensure access to these adult services agencies, if applicable.

Appendix N: Consent to Authorize Advocacy and Release of Information

I, _____ (adult student's name),
hereby authorize _____
School District to release/exchange information with my parents,
_____ which pertains to my school
program, grades, placement, behavior and/or discipline.

I also wish that my parents be invited to any and all meetings about me, and I
do not want any decisions made without their input.

If the school has any documents I need to sign, my parents must sign first,
before I will sign.

This authorization, unless otherwise revoked by me in writing, is intended to
remain in effect for the duration of time I receive special education services or
until my twenty-seventh birthday, whichever comes first.

_____ signature of adult student

_____ name of adult student

_____ date

Appendix O: Federal Benefits and Entitlements

At the age of majority, your child may qualify for state or federal benefits as a result of disability and/or limited financial resources. Confidentiality policies and the transfer of rights at the age of majority may create a barrier between families and these services.

The Social Security Administration (SSA)²⁷⁰ manages two different disability programs: Supplemental Security Income (SSI) and Social Security Disability Income (SSDI). SSI is needs-based, available only to people with fewer than \$2,000 in assets; SSDI is an entitlement program, which means that assets do not determine eligibility but the earnings are generally distributed after the parent's death. Both programs provide a monthly income for people with disabilities, but the eligibility rules are different.

SSI is also the eligibility gateway to other important programs, such as Medicaid health care, vocational training, and group housing programs. Even if your child had SSI, Medicaid, or Medicare as a child because of their disability they must apply as an adult and be evaluated based on the definition of disability for adults.²⁷¹

- Rules are in place that dictate how many hours a person can work if receiving SSI, Medicaid or Medicare (this includes paid internships while still in high school). There are work incentive programs but you need to understand the rules.²⁷²
- The young person's living arrangement is used to determine how much Supplemental Security Income (SSI) they can receive. Parents can charge rent for young adults who reside at home.²⁷³
- There are both federal and state subsidized housing programs. Housing and supervision may be appropriate during different periods of your young adult's life.
- If your child receives SSI or SSDI, the SSA funds the Ticket to Work program²⁷⁴ to provide career development services to beneficiaries between age 18 to 64 to assist these individuals to become financially independent.

A Note About Legal Blindness

Certain epilepsy surgeries, stroke, brain tumor, or other trauma to the occipital lobe of the brain can cause homonymous hemianopia, a type of vision loss to half of the visual field (or loss of vision in the right halves or the left halves of both eyes). This is considered a loss in peripheral vision, which can occur along with or independently of central visual acuity loss (20/20 vision). A person with homonymous hemianopia is considered legally blind under the Social Security Act.

Please see our guide [*Vision After Hemispherectomy, TPO Disconnection, and Occipital Lobectomy: An Introductory Guide*](#)²⁷⁵ for more information on the types of visual impairments that can result from these surgeries.

Legal blindness simply means that, under social security law, you have at least one of the following:

1. central visual acuity for distance of 20/200 or less in your better eye with use of a correcting lens; or
2. a visual field limitation in your better eye, such that your visual field is 20 degrees or less in your better eye (visual field); or
3. loss of visual efficiency – a percentage that combines both your visual field efficiency (peripheral vision) and your central visual acuity (straight-ahead vision), in your better eye.

AND the vision loss is for a period that lasted/is expected to last at least 12 months.^{276 277}

To be considered for disability under peripheral vision loss, you will need to have a visual field efficiency test. To meet Social Security's required severity for decrease of visual fields, you must have test results that match one of the following, in the better eye:

- visual field efficiency of 20% or less
- widest diameter of the visual field no more than 20 degrees from the point of fixation, or
- mean deviation of -22 or worse, measured by automated static threshold perimetry.

Vision Loss Affecting Your Functional Capacity

If you don't qualify for disability benefits under poor peripheral vision, poor visual acuity, or a combination of the two, the SSA is required to consider the effect of your peripheral vision loss (and any other symptoms) on your capacity to complete daily activities and your regular work (this is called a medical-vocational assessment). For instance, your decrease in peripheral vision may make it too dangerous for you to continue working around hazardous machinery or working at unprotected heights. If you can't do your regular job, the SSA will then determine whether there is any kind of work you could do.²⁷⁸ A medical-vocational assessment takes into account your **functional limitations** (such as not being able to drive), your age, your job skills, and your education level.²⁷⁹

If your young adult has a visual impairment, but is not blind according to the rules defined above, they may still be eligible for SSI benefits on the basis of disability (if their vision problems alone, or combined with other health problems, prevent them from working.)

Higher monthly income

Social Security disability income for someone who is legally blind is higher (as much as \$2,110 per month in 2020 vs \$1,260 a per month for disabled workers who aren't blind). The earnings limits usually change each year. Additionally, if you're legally blind and self-employed, they don't evaluate the time you spend working in your business as they do for people who aren't blind. This means you can be doing a lot of work for your business, but still receive disability benefits, as long as your net profit averages \$2,110 or less a month in 2020.

A Note About Driving

Please note that qualifying for federal benefits and obtaining a driver's license are not evaluated in the same way. You could have a driver's license and still qualify for SSI, or vice versa. The determination about obtaining a driver's license is made on a state level, and requirements can vary widely.

All states have best corrected visual acuity (BCVA) requirements for licensure of at least 20/40 (Georgia requires 20/60; New Jersey and Wyoming require 20/50). Visual field requirements are more varied: 16 states have no required visual field testing unless the individual has also failed a visual acuity test; 34 states with a visual field requirement stipulate different degrees of remaining vision (from 105 to 150 degrees). Some states explicitly state that they will not issue any driver's license to a person with a homonymous hemianopia.²⁸⁰ In addition, some state regulations require a continuous visual field of a certain size. This requirement is met with an intact visual field of at least one eye, but not with visual field loss in both eyes. With disconnected visual fields, it is a lot harder to keep a continuous field of view over the affected side.²⁸¹

Lastly, it's important to note that there are other physical and mental conditions that may impair a patient's ability to drive. See [Driving Restrictions per State](#)²⁸² to find out your state's low vision and visual field requirements for passing.^{283 284 285}

Appendix P: Financial Planning

Special needs trusts and other estate planning

Often, families choose a special needs trust or a supplemental needs trust for their eligible child in order to provide financial security without jeopardizing their government benefits (such as Supplemental Security Income payments, Medicaid or food stamps). Parents don't need to be wealthy to require this estate planning. As little as \$2,000 could make the child ineligible for federal programs until all of that money is spent. While the loss of the monthly SSI disability payment may not be significant, losing [Medicaid](#) health benefits could be huge for someone with complex medical problems.²⁸⁶

ABLE accounts

In 2014, Congress passed the Achieving a Better Life Experience (ABLE) Act, allowing states to create ABLE accounts for eligible individuals. An ABLE account is a tax-free savings account (similar to a 529 savings account) that allows people with certain disabilities, diagnosed before age 26, to save money and still access federal benefits such as SSI, Medicaid, and housing supports.

The money in an ABLE account can be used for any qualified disability expense (QDE), or those expenses that improve or maintain health, independence, or quality of life. These can include housing, transportation, health care expenses, even vacations. The funds can pay for the individual's education, employment, and other disability-related expenses without the individual losing their federal benefits. ABLE accounts can help with transition services and postsecondary education. Most ABLE programs allow eligible individuals to participate regardless of their state of residence (if there is no ABLE program in your state, you can register an ABLE account in another state).²⁸⁷

In general, family members can contribute up to \$15,000 a year to the accounts tax-free, and recipients can keep their government benefits until the accounts exceed \$100,000. After that, they would lose SSI but remain eligible for Medicaid. These accounts are less restrictive than a special needs trust, though some people with disabilities may need both.²⁸⁸

Appendix Q: Documents For Adulthood

Job Portfolio

- Job history, including dates and contact information
- Letters of reference
- Resume
- Vocational assessments
- Volunteer experiences
- Examples of academic or job accommodations used successfully in the past
- Examples of effective assistive technology used in the past (including prices, suppliers, and potential funders if possible) for personal use.

Health History

- Allergies
- Documentation of any relevant medical diagnosis (plus all surgical reports & MRIs etc.)
- Documentation of disabilities that may entitle the individual to additional services or funding (motor, vision, hearing, cognitive impairments)
- Immunization records
- Medications (type, date started or stopped, and any side effects)
- Contact information and names of doctors, dentist, specialists, and therapists
- Pharmacy contact information

Personal Documents

- Birth certificate (copy)
- Passport (copy)
- Current community service providers
- Emergency contact information
- Health and other insurance information (copy)
- Social Security card (copy)
- Identification card or driver's license (copy)
- Letters of recommendation
- Report card and progress reports; standardized testing results (ACT/SAT etc.)
- Samples of academic, art, or design work
- Examples of effective accommodations and assistive technology
- Summary of Performance (required upon graduation with a regular diploma or when a youth exceeds the age of eligibility for special education services at 21)
- School Records
- Copies of Individualized Education Programs (IEP) for last several years
- Current evaluation reports (over the past three years, especially psychoeducational/ neuropsychological assessments before the student turned 18)
- Diploma (copy)
- High school transcript (copy)
- Postsecondary contact information

Adapted from [Documents to Keep for Youth Transitioning to Adult Life](#), PACER publication "Mapping Dreams: A Transition to Adulthood" ²⁸⁹

Appendix R: State Transition Guides

STATE	STATE EDUCATION DEPARTMENT TRANSITION WEBSITE AND/OR GUIDE (if your state does not have a transition guide, your state department of education is listed, and another organization's transition guide is also listed, if available)
Alabama	Transition Services https://www.alsde.edu/sec/ses/ts/Pages/tshome.aspx https://www.alsde.edu/sec/ses/ts/Resources/Engagement%20Series%20Handbook%20Number%201.pdf
Alaska	Alaska Transition Handbook http://dhss.alaska.gov/gcdse/Documents/TransitionsHandbook.pdf
Arizona	Exceptional Student Services https://www.azed.gov/specialeducation/transition/ Secondary Transition Resources https://padlet.com/SecondaryTransition/transitionresources
Arkansas	Arkansas Transition https://www.arkansastransition.com/index.php/component/content/article?id=20
California	Secondary Transition Planning - Special Education (CA Dept of Education) https://www.cde.ca.gov/sp/se/st/ Secondary Transition Planning: The Basics https://6abb391c-dbc9-4e2e-9cd4-f10c9c4bb967.filesusr.com/ugd/c055a4_f1b186d9ab24411eb8971d6583e849b5.pdf
Colorado	Secondary Transition Resources CDE https://www.cde.state.co.us/cdesped/transition_resources Charting a Course for the Future - A Transition Toolkit CDE https://www.cde.state.co.us/cdesped/transition_tk
Connecticut	Secondary Transition - Planning from School to Adult Life https://portal.ct.gov/SDE/Special-Education/Secondary-Transition https://ctserc.org/about/serc-programs/transition
Delaware	Special Education / Transition Planning https://www.doe.k12.de.us/Page/2342
Florida	Secondary Transition http://www.fl DOE.org/academics/exceptional-student-edu/secondary-transition.stml http://www.fl DOE.org/core/fileparse.php/7764/urlt/0084240-transition.pdf
Georgia	Transition https://www.gadoe.org/Curriculum-Instruction-and-Assessment/Special-Education-Services/Pages/Transition-.aspx Special Education Transition Manual 2015 https://www.gadoe.org/Curriculum-Instruction-and-Assessment/Special-Education-Services/Sp-Ed-Transition-Manual.aspx

Hawaii	<p>Individualized Education Program (IEP) http://www.hawaiipublicschools.org/TeachingAndLearning/SpecializedPrograms/SpecialEducation/Pages/IEP.aspx</p> <p>Transition Services: Moving from High School to Further Education and Work https://careerkokua.hawaii.gov/re/fp/article.cfm?id=353</p>
Idaho	<p>The Idaho IEP Guidance Handbook - August 2018 https://www.sde.idaho.gov/sped/sped-manual/files/chapters/chapter-5-individualized-education-programs/The-Idaho-IEP-Guidance-Handbook.pdf</p> <p>SECONDARY TRANSITION STUDENT (16-21) IEP FILE REVIEW CHECKLIST 2019 https://www.sde.idaho.gov/sped/program-monitoring/files/g sfr/2019-GSFR-Ru-bric-Secondary-Transition.pdf</p>
Illinois	<p>Indicator 13: Secondary Transition https://www.isbe.net/Pages/SPP-APR-Indicator-13.aspx</p> <p>IDHS: Transition Services Program Manual https://www.dhs.state.il.us/page.aspx?item=117408</p>
Iowa	<p>Secondary Transition - Guidance for Quality IEPs https://educateiowa.gov/pk-12/special-education/guidance-quality-ieps/secondary-transition-guidance-quality-ieps</p> <p>WHAT IS POSTSECONDARY EDUCATION AND WHY SHOULD STUDENTS, FAMILIES AND IEP TEAMS CONSIDER IT? https://www.transitioniowa.org/about/learning</p>
Kansas	<p>https://www.ksde.org/Agency/Division-of-Learning-Services/Special-Education-and-Title-Services/Special-Education/Secondary-Transition</p> <p>High School Transition to Work https://kcdcinfo.ks.gov/life-resources/school</p>
Kentucky	<p>Transition for Students https://education.ky.gov/specialed/excep/transition/Pages/Transition-for-Students.aspx</p> <p>Transitions to Postsecondary https://www.prichardcommittee.org/transitions-to-postsecondary/</p>
Louisiana	<p>Louisiana's Transition to Higher Expectations https://www.louisianabelieves.com/academics/common-core-state-standards/louisiana's-transition-to-higher-expectations</p> <p>Transition - High School to Adulthood https://fhfofgo.org/transition-high-school-to-adulthood</p>
Maine	<p>Regulation Framework for New Chapter 101 https://www.maine.gov/doe/sites/maine.gov/doe/files/inline-files/State%20Regulation%20Chapter%20101MUSER.pdf</p> <p>A Guide to TRANSITION Services in Maine https://www.maine-yc.org/wp-content/uploads/2016/03/MSK.HandbookWEB-1.pdf</p>
Maryland	<p>Md Secondary Transition Planning Guide http://marylandpublicschools.org/programs/Documents/Special-Ed/SecondaryTransition/MdSecondaryTransitionPlanningGuide.pdf</p> <p>Transitioningyouth http://mdod.maryland.gov/education/Pages/transitioningyouth.aspx</p> <p>The Maryland State Department of Education Transition Planning Guide for Individuals with Disabilities www.mdcoalition.org/LiteratureRetrieve</p>

Massachusetts	<p>Transition - Special Education http://www.doe.mass.edu/sped/secondary-transition/</p> <p>The LINK Center Transition Brochures FCSN https://fcsn.org/linkcenter/transition-resources/brochures/</p>
Michigan	<p>Transition Planning: A Guidebook for Young Adults and Family https://www.michigan.gov/documents/mdch/trans_final_308093_7.pdf</p> <p>Transition To Adulthood Topics https://www.michiganallianceforfamilies.org/transition/</p>
Minnesota	<p>Secondary Transition https://education.mn.gov/MDE/dse/sped/sec/</p> <p>Minnesota Secondary Transition Toolkit for Families: A Guide to Preparing Your Child with a Disability for Life Beyond High School https://www.pacer.org/publications/MDE-Toolkit-2017.pdf</p>
Mississippi	<p>Secondary Transition Services https://www.mdek12.org/OSE/STS</p> <p>Secondary Transition - The Mississippi Department of Education mdek12.org</p>
Missouri	<p>Transition Services https://dese.mo.gov/adult-learning-rehabilitation-services/vocational-rehabilitation/transition-services</p> <p>For Parents https://dese.mo.gov/special-education/effective-practices/parents</p>
Montana	<p>Forms/Guides https://opi.mt.gov/Educators/Teaching-Learning/Special-Education/Special-Education-Forms-Guides</p> <p>Montana Parent's Handbook on Transition: http://pluk.org/Pubs/PLUK_Transition_High_School_04_2008.pdf</p>
Nebraska	<p>Transitions for All Students https://www.education.ne.gov/nce/transitions-for-all-students/</p> <p>NDE Transition: Home http://transition.ne.gov/</p>
Nevada	<p>Secondary Transition http://www.doe.nv.gov/Inclusive_Education/Secondary_Transition/</p> <p>Transition Services Planning Handbook http://www.ndalc.org/wp-content/uploads/2016/09/IEP-disputes-FINAL.pdf</p>
New Hampshire	<p>Secondary Transition https://www.education.nh.gov/who-we-are/division-of-learner-support/bureau-of-student-support/special-education/secondary-transition</p> <p>Family Engagement Toolkit https://nextsteps-nh.org/everything-about-transition/family-involvement-practices/next-steps-tools-family-involvement/</p>
New Jersey	<p>Transition from School to Adult Life https://www.nj.gov/education/specialed/transition/</p> <p>The Family Guide to Transition Services in New Jersey https://www.chatham-nj.org/cms/lib/NJ01000518/Centricity/Domain/1294/Family%20Guide%20to%20Transition%20Services_0.pdf</p>

New Mexico	<p>College and Career Readiness Bureau https://webnew.ped.state.nm.us/bureaus/college-career-readiness/</p> <p>New Mexico Public Education Department Special Education Bureau https://webnew.ped.state.nm.us/wp-content/uploads/2018/03/Developing-Quality-IEPs.pdf</p>
New York	<p>Transition Home:Special Education:EMSC:NYSED http://www.p12.nysed.gov/specialized/transition/home.html</p> <p>Transition Services & College Planning Guide https://www.advocatesforchildren.org/sites/default/files/library/transition_guide.pdf?pt=1</p>
North Carolina	<p>Secondary Transition https://ec.ncpublicschools.gov/disability-resources/intellectual-disabilities/secondary-transitions</p> <p>A Parents' Guide to Special Education in North Carolina https://law.duke.edu/childedlaw/docs/Parents'_guide.pdf</p>
North Dakota	<p>Special Education https://www.nd.gov/dpi/education-programs/special-education</p> <p>Parent Guide to Special Education http://www.pathfinder-nd.org/pdf/res/920.pdf</p>
Ohio	<p>Secondary Transition and Workforce Development for Students with Disabilities http://education.ohio.gov/Topics/Special-Education/Federal-and-State-Requirements/Secondary-Transition-and-Workforce-Development</p> <p>Secondary Transition for Students with Disabilities Modules Ohio Department of Education http://education.ohio.gov/Topics/Special-Education/Federal-and-State-Requirements/Secondary-Transition-and-Workforce-Development/Secondary-Transition-for-Students-with-Disabilities</p>
Oklahoma	<p>https://sde.ok.gov/secondary-transition</p> <p>Special Ed Transition Handbook.indd https://www.4rkids.com/uploads/9/6/1/7/96171342/special-ed-transition-handbook.pdf</p>
Oregon	<p>Oregon Department of Education : Secondary Transition for Students with Disabilities : Education Programs & Secondary Transition https://www.oregon.gov/ode/students-and-family/SpecialEducation/SecondaryTransition/Pages/Secondary-Transition-for-Students-with-Disabilities.aspx</p> <p>A transition guide for students with disabilities leaving high school https://www.ocdd.org/wp-content/uploads/2017/12/Transition-Guide.pdf</p>
Pennsylvania	<p>Transition Support Documents and Downloads Special Education Services https://www.iu1.org/departments/special-education-services/documents-and-downloads</p> <p>School https://www.secondarytransition.org/topic/school</p>
Rhode Island	<p>Secondary Transition for Students with Disabilities https://www.ride.ri.gov/StudentsFamilies/SpecialEducation/SecondaryTransition.aspx</p>
South Carolina	<p>Post-Secondary Transition https://ed.sc.gov/districts-schools/special-education-services/programs-and-initiatives-p-i/post-secondary-transition/</p>

South Dakota	<p>IEP – South Dakota Department of Education doe.sd.gov</p> <p>Transition IEP Plans https://tslp.org/writing-ieps/</p>
Tennessee	<p>Special Education Secondary Transition https://www.tn.gov/education/student-support/special-education/special-education-secondary-transition.html</p> <p>https://transitiontn.org/site-index/</p>
Texas	<p>Secondary Transition Guidance Texas Education Agency https://tea.texas.gov/academics/special-student-populations/special-education/programs-and-services/state-guidance/secondary-transition-guidance</p> <p>Transition in the IEP http://texasprojectfirst.org/node/225</p>
Utah	<p>Special Education: School to Post-School Transition https://www.schools.utah.gov/specialeducation/programs/schooltransition</p> <p>Transition from School to Adult Life https://utahparentcenter.org/wp-content/uploads/2019/07/Transition-Parent-Handbook-Final-07.2019.pdf</p>
Vermont	<p>Postsecondary Transition Planning Presentation 2020 Agency of Education https://education.vermont.gov/documents/edu-postsecondary-transition-planning-presentation-2020</p> <p>Family Guide to Transition Services in Vermont https://www.vermontfamilynetwork.org/wp-content/uploads/2019/10/VFN-Family-Guide-to-Transition-Services-in-VT.pdf</p>
Virginia	<p>VDOE :: Special Education Transition Resources http://www.doe.virginia.gov/special_ed/transition_svcs/resources.shtml</p> <p>Transition Guide https://www.vadars.org/downloads/publications/Transition-ServicesGuide.pdf</p>
Washington	<p>Transition Services (Ages 16–21) https://www.k12.wa.us/student-success/special-education/guidance-families-special-education-washington-state/transition</p> <p>Guidelines for Aligning High School & Beyond Plans (HSBP) and IEP Transition Plans https://www.k12.wa.us/sites/default/files/public/specialed/programreview/monitoring/secondarytransition/Guide-Align-HSBP-IEP-Transition.pdf</p>
West Virginia	<p>Overview https://wvde.us/diversion-transition-programs/transition/overview/</p> <p>WEST VIRGINIA TRANSITION GUIDE http://www.pathwayswv.org/docs/WVDE%20Transition%20Slide%20Guide%20web-1.pdf</p> <p>Transition Through School And Into Life: A Handbook For Students And Parents https://ced.hsc.wvu.edu/media/1086/transitionbooklet.pdf</p>
Wisconsin	<p>Transition Planning for Students with Disabilities https://dpi.wi.gov/sped/topics/transition</p> <p>A Guide to the Transition Process https://specialed.madison.k12.wi.us/files/specialed/TransitionPlanningResourceGuide.2014_0.pdf</p>

Wyoming	<p>College & Career Readiness https://edu.wyoming.gov/beyond-the-classroom/college-career/</p> <p>Secondary Transitions https://wyominginstructionalnetwork.com/additional-resources/transition/</p>
District of Columbia	<p>Transition Services, Programs and Supports dcps https://dcps.dc.gov/service/transition-services-programs-and-supports</p> <p>Transition Services and Programs and Supports https://dcps.dc.gov/sites/default/files/dc/sites/dcps/publication/attachments/DSI%20Transition%20Services%20Programs%20and%20Supports.pdf</p>

Appendix S: Education, Disability, and Employment – Transition Age Youth

Expectations for people with disabilities have evolved over the years. As a result, there have been many changes in the laws and policies that support the opportunities and independence of individuals with disabilities (including increased legal requirements for transition planning). It is important for families and students to understand the federal laws that protect and provide certain rights to individuals with disabilities (related to education, transition, workplace, and living needs).²⁹⁰ A guide to all of the laws affecting people with disabilities can be found here: [A Guide to Disability Rights Laws](#).²⁹¹

The Rehabilitation Act of 1973

The Rehabilitation Act of 1973²⁹² is the foundation of disability-related legislation. This federal law prohibits discrimination on the basis of disability in federally funded programs and authorizes state vocational rehabilitation (VR) programs, client assistance programs, and independent living centers. Sections of this law are often referred to by their Title or Section number, e.g., Section 504 or Title I.²⁹³

The Americans with Disabilities Act of 1990

The Americans with Disabilities Act of 1990 or ADA is a civil rights law that prohibits discrimination based on disability. It covers access to employment; state and local government programs and services; access to public places such as businesses, transportation, and nonprofit service providers; and telecommunications. It provides similar protections against discrimination to Americans with disabilities as the Civil Rights Act of 1964, which made discrimination based

on race, religion, sex, national origin, and other characteristics illegal.^{294 295}

The ADA and Section 504 both protect access and equity

Both Section 504 of the Rehabilitation Act of 1973 (Section 504) and Title II of the Americans with Disabilities Act of 1990 (Title II) prohibit discrimination against individuals with disabilities in higher education and the workplace. Most educational institutions and private schools are covered by Title II and Section 504, depending upon the type of government funding they receive. (Religious educational institutions that do not receive government funding are exempt from these laws.)²⁹⁶ Postsecondary schools are not required to provide FAPE (free and appropriate public education) as IDEA no longer applies. Rather, schools are required to provide appropriate academic adjustments (accommodations) as necessary to ensure that it does not discriminate on the basis of disability. Also, if a college provides housing to nondisabled students, it must provide comparable, convenient, and accessible housing to students with disabilities at the same cost. Most postsecondary schools are required to have a Disability Services Coordinator (may also be referred to as a Section 504 Coordinator or ADA Coordinator) who coordinates the school's compliance with Section 504, Title II, or both laws.

“Students with disabilities, including those eligible under IDEA, have rights under Section 504 of the Rehabilitation Act, which prohibits disability discrimination by recipients of Federal financial assistance, including public elementary and secondary schools. Section 504 requires that a free appropriate public education, as defined in the

Section 504 regulations, be provided to elementary and secondary students with disabilities through the provision of regular or special education and related aids and services that are designed to meet their individual educational needs as adequately as the needs of nondisabled students are met. Section 504 does not specifically require that eligible students receive transition services as defined in IDEA. However, implementation of an IEP developed in accordance with the IDEA is one means of meeting the Section 504 FAPE standard.”²⁹⁷

Section 504 and Vocational Rehabilitation

The Vocational Rehabilitation (VR) Services program provides services that, among other things, help individuals with disabilities (including students) obtain employment (including counseling and training). To be eligible, one must be an “individual with a disability” (have a physical or mental impairment which constitutes or results in a substantial impediment to employment and can benefit in terms of an employment outcome from vocational rehabilitation services).

Under the VR program²⁹⁸ “transition services” means a coordinated set of activities for a student or youth with a disability—

- Designed within an outcome-oriented process that promotes movement from school to post-school activities, including postsecondary education, vocational training, competitive integrated employment, supported employment, continuing and adult education, adult services, independent living, or community participation;
- Based upon the individual student’s or youth’s needs, taking into account the student’s or youth’s preferences and interests;
- That includes instruction, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills

and functional vocational evaluation;

- That promotes or facilitates the achievement of the employment outcomes identified in the student’s or youth’s individualized plan for employment (IPE); and
- That includes outreach to and engagement of the family, or, as appropriate, the representative of such a student or youth with a disability.

The Department of Education published guidance for “Increasing Postsecondary Opportunities for Students and Youth with Disabilities”²⁹⁹ which clarifies that vocational rehabilitation funding may be used to support more than just workplace readiness, and may include:

- postsecondary education programs while still in high school (such as dual enrollment programs);
- comprehensive transition or other postsecondary programs for individuals with disabilities after leaving high school;
- receiving transition-related services under the IDEA and the VR program; and
- financial aid available to students with disabilities enrolled in comprehensive transition and postsecondary education programs for students with intellectual disabilities offered at Institutions of Higher Education (IHEs) under the Higher Education Act of 1965, as amended (HEA).

Workforce Innovation and Opportunity Act (WIOA)

The Workforce Innovation and Opportunity Act (WIOA)³⁰⁰ amended the Rehabilitation Act of 1973 (Rehabilitation Act) in 2014 to require states to additionally provide a defined set of activities called pre-employment transition services (pre-ETS).³⁰¹ The Act requires the Department of Rehabilitation (via State Vocational Rehabilitation agencies) to spend 15 percent of their budget on pre-employment transition services for students ages 14 and 21. WIOA emphasized providing services to students with disabilities³⁰² to ensure that they have meaningful opportunities to

receive training and other supports and services in order to achieve their employment goals. Pre-ETS services include both providing services and participating with IEP Teams to assist in developing transition plans in IEPs for students.

VR agencies must provide (or arrange for the provision of) pre-employment transition services for all students with disabilities in need of such services. Students may qualify for the Department of Rehabilitation (DOR) pre-employment services by showing documentation of significant impact on their ability to get employed. VR agencies must provide these services in collaboration with LEAs.³⁰³ However, there are inconsistencies across states and municipalities regarding the provision of these services. Individuals may be misinformed that they cannot receive pre-ETS and VR services simultaneously or that they have to wait until graduation or the age of majority, which is not the case. Students who require VR services do not need to wait until graduation/exit from special education before applying to their Department of Rehabilitation.

The Pre-ETS services required by WIOA³⁰⁴:

1. Job exploration counseling – Discussing local labor market information, including in-demand industry sectors and occupations, as well as nontraditional employment and career pathways of interest to the students, as well as administering vocational interest inventories.
2. Work-based learning experiences – Coordinating such experiences as a school-based program of job training and informational interviews to research employers; work-site tours to learn about necessary job skills, job shadowing, or mentoring opportunities in the community; internships, apprenticeships, short-term employment, and fellowships (paid or unpaid), or on-the-job trainings located in the community.
3. Post-secondary activity counseling – Providing information on course offerings, career options, and the types of academic and occupational training needed to succeed in the workplace, and postsecondary opportunities associated with career fields or pathways.
4. Workplace readiness training – Helping students with disabilities develop social skills and independent living skills (financial literacy and travel skills); job-seeking skills; and an understanding of employer expectations for punctuality and performance, as well as other “soft” skills necessary for employment.
5. Self-advocacy – Teaching students about their rights and responsibilities, including how to request accommodations or services and supports and communicate their thoughts, concerns, and needs in the area of education or employment interests.

There are unfortunately many challenges in providing pre-ETS and VR services to students with disabilities, which include: fitting services into the school day; low expectations of students; lack of capacity to serve all students; shortage of trained VR counselors; school budgets; difficulty finding job opportunities and work experience for students with significant disabilities; students with disabilities may be denied access to regular school district vocational programs; services are often based on available programs rather than on students’ abilities, needs, preferences, and interests; skills are obtained at school and not in the community; lack of integrated employment experiences for students who are still in school; lack of knowledge and training about pre-ETS/VR services; teachers not trained in employment services; VR counselors may not understand different training and accommodations needed by job seekers with autism as compared to those with cerebral palsy, for example; agencies get involved too late; VR agency is not at the table to help develop the IEP; little collaboration about responsibility for services that could be considered covered under IDEA or the Rehab Act.^{305 306 307}

The Department of Rehabilitation (via state VR agencies) can provide counseling, medical and psychological services, job training, tuition, assistive technology, equipment, uniforms, advocacy, and other supports (including assistive technology assessment and functional vocational assessment). Generally these supports are provided after graduation as the school district is responsible for these services until then. Eligibility is not based on income, but rather the severity of the disability and how that affects the individual's ability to work.

Frequently Asked Questions on the Workforce Innovation Technical Assistance Center (WINTAC) website reflects guidance provided to state vocational rehabilitation agencies that are responsible for developing pre-employment transition services now required by the Workforce Innovation and Opportunity Act (WIOA). Advocates for transition-age youth may find these questions helpful during this stage.³⁰⁸

The Carl D. Perkins Vocational and Technical Education Act of 2006

The Act provides an increased focus on the academic achievement of career and technical education students, strengthens the connections between secondary and postsecondary education, and improves state and local accountability.

Higher Education and Opportunity Act

The Higher Education Opportunity Act includes provisions to increase access and opportunities for youth and adults with intellectual disabilities who are interested in participating in higher education programs.³⁰⁹ "Not only does the HEOA allow students with intellectual disabilities to qualify for Pell Grants, Supplemental Educational Opportunity Grants, and the Federal Work Study Program for the first time, it also establishes a new grant program that will fund the development of programs tailored specifically to college students with intellectual disabilities across the country."³¹⁰

Information about the transition to life after high school for students, parents, and professionals.
<http://www.ncset.org/>

National Center for the Study of Postsecondary Educational Supports (NCSPEs) <http://www.rrtc.hawaii.edu/>

Navigating the Transition from High School to College for Students with Disabilities, Meg Grigal, Joseph Madaus, 2018.

Online Colleges, Online Degrees, And College Scholarships Website <https://www.college-scholarships.com>

Appendix T: Select College Resources

[Accommodations and English Learner Supports for US Students \(ACT testing\)](http://www.act.org/content/act/en/products-and-services/the-act/registration/accommodations.html) <http://www.act.org/content/act/en/products-and-services/the-act/registration/accommodations.html>

[Accommodations for Test Takers with Disabilities – The College Board \(SAT testing\)](https://accommodations.collegeboard.org/) <https://accommodations.collegeboard.org/>

[Affordable Colleges.com](#) – Resource guide on Scholarships and Financial Aid available to students with Disabilities

[Association on Higher Education and Disability](https://www.ahead.org/home) <https://www.ahead.org/home>

[Autistic Self Advocacy Network](https://autisticadvocacy.org/) – Works to educate communities, support self-advocacy in all its forms, and improve public perceptions of autism. <https://autisticadvocacy.org/>

[Best Colleges Overview of College Resources for Students with Disabilities](https://www.bestcolleges.com/resources/students-with-disabilities/) <https://www.bestcolleges.com/resources/students-with-disabilities/>

Black, Disabled and Proud <http://www.blackdisabledandproud.org/>

[College Finder](https://www.petersons.com/) – Peterson’s college search; <https://www.petersons.com/>

College Guide for Students With Learning Disabilities

<https://www.bestcolleges.com/resources/college-planning-with-learning-disabilities/>

[College Navigator](https://nces.ed.gov/collegenavigator/) – The US Department of Education website for students who are choosing a college or applying for financial aid; includes information about colleges’ disability services offices. <https://nces.ed.gov/collegenavigator/>

Colleges with Programs for Students with Learning Disabilities, Fifth Edition (1997), edited by Charles T. Mangrum II and Stephen S. Strichart. Peterson’s Guides, Princeton, NJ.

Comparison of the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act (Section 504), & The Americans with Disabilities Act (ADA) <https://access.ku.edu/sites/disability.drupal.ku.edu/files/docs/Comparison%20of%20the%20IDEA%2C%20Section%20504%2C%20ADA.pdf>

From Disability to Diversity: College Success for Students with Learning Disabilities, ADHD, and Autism Spectrum Disorder Lynne C. Shea, Linda Hecker, et al. | Mar 31, 2019

From High School to College: Steps to Success for Students With Disabilities, Elizabeth Hamblet (Author), 2017

[Getting Ready for College: Advising High School Students with Learning Disabilities](#)

Vickie M. Barr, Rhona C. Hartman, Stephen A. Spillane, LD Online <http://www.ldonline.org/article/6132>

Hauser, J. [How High School and College Differ for Students with Disabilities](https://nesca-newton.com/college-high-school-differences/?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+blogspot%2FiMfKT+%28NESCA+Notes%29) https://nesca-newton.com/college-high-school-differences/?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+blogspot%2FiMfKT+%28NESCA+Notes%29

HBCU Disability Consortium! This project involved a group of colleagues working in disability services at Historically Black Colleges and Universities (HBCUs) and Predominantly Black Colleges and Universities (PBCUs), working in partnership with the Taishoff Center at Syracuse University. <https://www.hbcudisabilityconsortium.org/>

HEATH Resource Center – An online clearinghouse of information for college students with disabilities. <https://www.heath.gwu.edu/>

Higher Education Opportunity Act - 2008 <https://www2.ed.gov/policy/highered/leg/hea08/index.html>

Learning Outside The Lines: Two Ivy League Students with Learning Disabilities and ADHD Give You the Tools for Academic Success and Educational Revolution, *Jonathan Mooney, David Cole, et al. 2000.*

McCormick, J. Psy. D. [When it Comes to the College Transition, Sweat \(some of\) the Small Stuff](http://www.nesca-news.com/2018/05/when-it-comes-to-college-transition.html?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+blogspot%2FiMfKT+%28NESCA+Notes%29) http://www.nesca-news.com/2018/05/when-it-comes-to-college-transition.html?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+blogspot%2FiMfKT+%28NESCA+Notes%29

NCCSD – National Center for College Students with Disabilities (NCCSD) <http://www.nccsdonline.org/>

National Center on Secondary Education and Transition (NCSET) – A national center with information about the transition to life after high school for students, parents, and professionals. <http://www.ncset.org/>

National Center for the Study of Postsecondary Educational Supports (NCSPES) <http://www.rrtc.hawaii.edu/>

Navigating the Transition from High School to College for Students with Disabilities, *Meg Grigal, Joseph Madaus, 2018.*

Online Colleges, Online Degrees, And College Scholarships Website <https://www.college-scholarships.com/>

PACER Center: [Transitioning to Life After High School](https://pacer.org/students/transition-to-life/) <https://pacer.org/students/transition-to-life/>

Princeton Review the K&W Guide to Colleges for Students with Learning Disabilities or Attention Deficit/Hyperactivity Disorder, Marybeth Kravets, Amy F. Wax. Princeton Review.

The Taishoff Center for Inclusive Higher Education: [What is Inclusive Higher Education?](https://taishoffcenter.syr.edu/)

<https://taishoffcenter.syr.edu/>

Taking Flight: College for Students with Disabilities, Diverse Learners and Their Families, Perry LaRoque, PhD, 2019.

Taymans, J.M., & West, L.L. (Eds.). (2000). *Unlocking potential: College and other choices for people with LD and AD/HD*. Bethesda, MD: Woodbine House.

Teaching, Including, and Supporting College Students with Intellectual Disabilities, Kelly Kelley, 2019

Think College – a national initiative dedicated to developing, expanding, and improving research and practice in inclusive higher education for students with intellectual disability. <https://thinkcollege.net/>

Think College! Postsecondary Education Options for Students with Intellectual Disabilities, Meg Grigal Ph.D., Debra Hart M.S., 2009.

Transition Programs for Students with Intellectual Disabilities (TPSID) <https://www2.ed.gov/programs/tpsid/index.html#:~:text=The%20Model%20Comprehensive%20Transition%20and,inclusive%20model%20comprehensive%20transition%20and>

Transitioning to College: A Guide for Students with Disabilities (a six-page, quick-reference laminated guide), Elizabeth Hamblet

Understood.org: **Are There IEPs and 504 Plans in College?** <https://www.understood.org/en/school-learning/choosing-starting-school/leaving-high-school/are-there-ieps-and-504-plans-in-college>

U.S. University Directory State Universities, Online University Degree Search and College Rankings
StateUniversity.com features information about all Universities and Colleges in the United States.
<https://www.stateuniversity.com/>

Winning in College: A Guide for Students with Disabilities
<https://www.edsmart.org/students-with-disabilities-college-guide/>

Appendix U: Selected Resources & Tools

Ability Path's [The Journey To Life After High School](https://abilitypath.org/wp-content/uploads/2015/12/life-after-high-school.pdf) <https://abilitypath.org/wp-content/uploads/2015/12/life-after-high-school.pdf>

[ADA Technical Assistance Program](https://adata.org/) <https://adata.org/>

[American Association of People with Disabilities \(AAPD\)](https://www.aapd.com/) <https://www.aapd.com/>

[The Americans with Disabilities Act of 1990, Titles I and V](http://www.eeoc.gov/policy/ada.html) <http://www.eeoc.gov/policy/ada.html>

[AutismSpeaksTransitionToolKit](https://www.autismspeaks.org/sites/default/files/2018-08/Transition%20Tool%20Kit.pdf)<https://www.autismspeaks.org/sites/default/files/2018-08/Transition%20Tool%20Kit.pdf>

[Autism Speaks Financial Planning Transition Tool Kit](https://www.autismspeaks.org/sites/default/files/2018-08/Financial%20Planning%20Tool%20Kit.pdf) <https://www.autismspeaks.org/sites/default/files/2018-08/Financial%20Planning%20Tool%20Kit.pdf>

Bridging the Gap Across Transition – training module that provides information to youth on their rights under the Americans with Disabilities Act (ADA) to help them navigate their way from the school system to the world of work, post-secondary education, or training; self-advocacy, disability disclosure, sufficient medical documentation, and accommodations.

Module <http://webcast.askjan.org/transition>

Accessible transcript <https://askjan.org/modules/transition/Transition%20Webcast%20Script.doc>

Charting the Life Course [LifeCourse Framework – LifeCourse Nexus](https://www.lifecoursetools.com/lifecourse-library/lifecourse-framework/) <https://www.lifecoursetools.com/lifecourse-library/lifecourse-framework/>

Disability Access Information and Support (DAIS), [Transition Topics](http://www.janejarow.com/public_library/dsshetopics/transition.html) http://www.janejarow.com/public_library/dsshetopics/transition.html

[Equal Employment Opportunities Commission \(EEOC\)](https://www.eeoc.gov/disability-discrimination) <https://www.eeoc.gov/disability-discrimination>

[Disability and Business Technical Assistance Centers \(DBTAC\)](https://worksupport.com/documents/ADA_DBTACbrochure.pdf) https://worksupport.com/documents/ADA_DBTACbrochure.pdf

[Federal Student Aid: Home](http://studentaid.ed.gov) <http://studentaid.ed.gov>

[The Go To Guide for College Financial Aid](http://www.finaid.org) <http://www.finaid.org>

[Financial Aid for Students with Disabilities, HEATH's annually revised resource paper](https://www.heath.gwu.edu/sites/g/files/zaxdzs2346/f/downloads/2014_2015_heath_financial_aid_publication.pdf) https://www.heath.gwu.edu/sites/g/files/zaxdzs2346/f/downloads/2014_2015_heath_financial_aid_publication.pdf

[GUIDANCE AND CAREER COUNSELORS' TOOLKIT](https://www.heath.gwu.edu/sites/g/files/zaxdzs2346/f/downloads/Toolkit%202014.pdf) <https://www.heath.gwu.edu/sites/g/files/zaxdzs2346/f/downloads/Toolkit%202014.pdf>

[Job Accommodation Network \(JAN\)](https://askjan.org/) <https://askjan.org/>

[Key Provisions on Transition: IDEA 1997 compared to IDEA 2004 http://ncset.org/publications/related/ideatransition.asp](http://ncset.org/publications/related/ideatransition.asp)

The Knowledge Translation for Employment Research (KTER) Center at American Institutes for Research (AIR) presents the results of three recent focus groups with VR counselors and recipients. <https://kter.org/resources/technical-brief-7-2017>

[IDEA 2004 Close Up: Transition Planning http://www.schwablearning.org/articles.asp?r=998](http://www.schwablearning.org/articles.asp?r=998)

[The Independent Living Research Utilization \(ILRU\) program http://www.ilru.org](http://www.ilru.org)

[Mapping Your Future : Transition Planning for Students with Disabilities https://www.kcdsg.org/files/content/transitionHS.pdf](https://www.kcdsg.org/files/content/transitionHS.pdf)

[National Alliance for the Mentally Ill \(NAMI\) https://nami.org/Blogs/NAMI-Blog/September-2019/Supporting-Youth-Mental-Health](https://nami.org/Blogs/NAMI-Blog/September-2019/Supporting-Youth-Mental-Health)

[The National Business and Disability Council \(NBDC\) https://www.viscardicenter.org/nbdc/about/](https://www.viscardicenter.org/nbdc/about/)

[National Career Development Association http://www.ncda.or](http://www.ncda.or)

[National Center on Secondary Education and Transition http://www.ncset.org](http://www.ncset.org)

[National Council on Disability \(NCD\) https://ncd.gov/policy/education](https://ncd.gov/policy/education)

[National Information Center for Children and Youth with Disabilities \(NICHCY\) https://www.washington.edu/doit/national-information-center-children-and-youth-disabilities-nichcy-0](https://www.washington.edu/doit/national-information-center-children-and-youth-disabilities-nichcy-0)

[National Library Services for the Blind and Physically Handicapped \(NLSBPH\) https://www.loc.gov/nls/](https://www.loc.gov/nls/)

[National Network: information, guidance and training on the Americans with Disabilities Act \(ADA\). https://adata.org/](https://adata.org/)

[Open Doors for Multicultural Families provides a Transition Resource Guide available in 10 languages https://www.multiculturalfamilies.org/product-category/transition-guide/](https://www.multiculturalfamilies.org/product-category/transition-guide/)

[PACER Center – Parent Advocacy Coalition for Educational Rights. Includes publications and resources related to transition planning for life after high school, including college. https://pacer.org/](https://pacer.org/)

[Parent-to-Parent of the United States http://www.p2pusa.org](http://www.p2pusa.org)

[Post-ITT Website http://www.postitt.org](http://www.postitt.org)

[Self Determination Synthesis Project at the University of North Carolina at Charlotte http://project10.info/files/TWSelfDeterminationv.7.8.13.Final2.pdf](http://project10.info/files/TWSelfDeterminationv.7.8.13.Final2.pdf)

[Technical Assistance Alliance for Parents http://www.taalliance.org](http://www.taalliance.org)

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