

Transition to Adulthood/Life Stages Checklist

This resource has been created to support families as they think about various transitions for their loved ones. We know this may not be a comprehensive list, but we hope it will serve as a helpful tool to guide you through what needs to be considered, what preparations you should make, and where to seek support. Please note that every state differs in the support and resources it provides.

If we have left anything out, please feel free to contact us at info@epilepsysurgeryalliance.org

Early Intervention (Age 0–3)

- Begin the Early Intervention process for your child. Contact your county to arrange an evaluation. If relevant, get a referral to the Deaf-Blind Project for your state.
 - Develop an Individualized Family Support Plan (IFSP) for authorized support services, such as respite care, therapies, personal care supplies (including diapers and pull-ups), or in-home assistance with activities of daily living.
 - Join a local or national advocacy group to help educate yourself on what you may need ([Pediatric Epilepsy Surgery Alliance](#), [The Epilepsy Foundation](#), [the ARC](#), [Easter Seals](#), [Global Genes](#), [NORD](#), [EveryLIFE](#), etc.). Seek parent support: surround yourself with people who get it!
 - Learn about the [Individuals with Disabilities Education Act](#) (IDEA).
 - Create a will and talk to an attorney about estate planning.
 - Consider a Special Needs Trust and an ABLE Account.
 - Develop a family emergency plan.
 - Get on [Medicaid Waiver waitlists](#) for your state.
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3 years

- Develop an IEP based on *comprehensive assessment in all areas of suspected disability*, covering all areas in which the student may need

support: academic, functional, daily living, social, emotional, behavioral, sensory, communication, mobility, occupational, recreational, and vocational; goals must be measurable; progress must be made; updated annually. *Include emergency plans, seizure action plans, and 1:1 support if needed.*

- For students on a 504 plan, consider the range of services and accommodations that might be needed for your child: see the [Epilepsy Foundation's model 504 plan](#).
 - Review: [Legal Rights of Children with Epilepsy in School and Childcare: An Advocate's Manual](#); [PESA's Navigating The IEP Process, School and Learning](#), and [Programs & Resources](#).
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5 Years

- Revise the IEP: Reassessment is required at the transition into elementary school in all areas of suspected disability (see above). Goals must be measurable, progress must be documented, and the plan must be updated **annually**. Include emergency plans and seizure action plans. (504 plan: update annually.)
 - Consider a Behavior plan (FBA) by a BCBA or a family safety plan, if needed.
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6–11 years

- Revise the IEP **annually**; reassessment is required every 3 years unless the student has a

change in status or an IEP team member requests an earlier assessment (no more than one assessment per need area per year). Include emergency plans and seizure action plans. (504 plan: update annually.)

12 – 14 Years

- Revise the IEP **annually**; a transition assessment is required yearly at transition age. Include emergency plans and seizure action plans. (The 504 plan should be updated annually.)
- Learn about diploma options and requirements; discuss these options with your child and the IEP team; understand your child's graduation plan and the timeline for graduation.
- Develop a transition plan as part of your child's IEP (the transition plan complements the IEP but does not replace it). Federal Guidelines require a written transition plan that includes the student's needs, strengths, and preferences by age 16 (some states require transition planning by age 14). Begin by requesting age-appropriate transition assessment in **training & education**, **employment**, and, where appropriate, **independent living skills** to develop measurable postsecondary goals in all these areas and supportive, measurable annual goals, services, activities, instruction, and related services updated annually. When transition planning is discussed, the student and any necessary adult services or other outside agencies must be invited to the IEP meeting. Assessment can include pre-vocational skills, pre-community living skills, and interest inventories, among others. Transition planning and evaluation are required annually for 504 plans, listing reasonable accommodations that may be needed in adult settings. See PESA's course, [Transition Roadmap for Youth with Neurological Conditions](#), and our [100+ page guide, Educational Transition For Youth With Neurological Conditions](#).
- Consider a Vocational Assessment.
- Begin looking into vocational and/or recreational opportunities for your child. Teach/focus on social

skills, community participation, transportation, daily living skills like cooking and financial literacy, decision-making, self-advocacy, and self-determination.

- Connect with your state's Vocational Rehabilitation department; pre-employment Transition services can start at age 14.
- Initiate health care transition readiness assessments and training, revising them annually.
- Discuss the transition to adult care with medical providers. If your teen has complex medical issues, begin researching new medical providers now.
- Consider your teen's needs regarding their sexuality and relationships and seek appropriate support.
- Understand the Medicaid waiver and learn about your state's Long Term Care and Home & Community-Based Services (HCBS) options.
- Develop a personalized 'future plan' for your young adult (like an IEP, only for all aspects of their life), following the rules in place in your state (might be called a person-centered plan, transition portfolio, vision statement, or letter of intent).

16 Years

- Apply for a driver's license or a non-driver ID Card to have a form of government ID.
- IEP and transition plan must be revised annually: update annual age-appropriate transition assessments in training & education, employment, and, where appropriate, independent living skills; review and revise the course of study (ensure that courses taken have an impact on the student's college, vocational, and other post-secondary options); update goals and services; include travel training and life skills training in the IEP. Include emergency plans and seizure action plans. (504 plan: update annually.)
- Determine if your child will graduate with a diploma or a certificate of completion.

- Explore work-based learning or volunteer opportunities, and learn about Workability and employment first laws and opportunities.
- Look into guardianship/conservatorship options, person-centered planning, durable power of attorney, naming a representative and payee for governmental benefits, opening and maintaining a joint bank account, medical power of attorney, and advanced health care directives.
- Ensure that your teen understands his/her healthcare needs and how to manage them; help your teen keep medical records and manage medications and appointments.
- Teach your teen how to handle emergency vs. non-emergency medical situations, communicate appropriate information, and healthy vs. high-risk behaviors.

17 Years

- IEP and transition plan (or 504 plan) revised annually. Include emergency plans and seizure action plans.
- Learn about the transfer of parental rights and other legal changes at the age of majority.
- Prepare to assume guardianship or conservatorship; you may need legal aid. At a minimum, consider a *guardian ad litem* to represent your child.
- Consider your child's desire and ability to participate in relationships or marriage, and what protections are needed.
- Apply for SSI for your child; this will qualify your child for Medicaid when he/she turns 18. Make sure the applicant does not have more than \$2,000 in assets (excluding their primary residence). This benefit may be available to some individuals before age 18 if they reside in an out-of-home residential setting or their family has a low income.
- Write a "Letter of Intent" explaining your child's abilities, support needs, services, current and future benefits, and your wishes for his or her

future and who will support them, legally and/or as natural supports. Include end-of-life wishes/plans. Revise annually.

18 Years

- Guardianship in place.
- SSI funding in place (monthly payments).
- Register to vote.
- Males must register for the Selective Service (required by the government – does not mean the individual would be drafted). Failure to register can affect service eligibility. [Who Needs to Register | Selective Service System](#).
- IEP and transition plan (or 504 plan) revised annually. Include [emergency plans and seizure action plans](#).
- The school district must provide a "Summary of Performance" when the student earns a high school diploma or ages out of special education transition services.
- Apply for Adult Services with the supporting Federal Agency (Department of Developmental Services, Vocational Rehabilitation Services, Home and Community Based Waiver Services) **6-12 months before your 18th birthday**; if you received services as a minor, you may need to reapply as an adult.
- Apply for [Social Security Income \(SSI\)](#) on the first day of the month after you turn 18 (you must reapply as an adult).
- Connect/reconnect with your state's Vocational Rehabilitation department to develop an individualized plan for employment (IPE); can pay for assistive technology, college tuition, other training programs, textbooks, provide Paid Work Experience (PWE), job shadowing, coaching, and more.
- Visit day and residential programs.
- Apply for Section 8 Housing.

- Apply for local and regional housing lists. Ask if there are any portable vouchers for the disabled. There may be a year's wait, but it may be worth it.
- Start researching adult medical care providers and finalizing the transition from a pediatrician to an adult primary care physician and any needed specialists. See PESA's [Guide To Health Care Transition After Pediatric Epilepsy Surgery](#)
- Check with your state for state-specific programs or requirements (e.g., in New Jersey, apply for the [Personal Preference Program](#)).
- Revise your Letter of Intent annually (see above).

19–20 Years

- IEP and transition plan (or 504 plan) revised annually. Include emergency plans and seizure action plans.
- Focus on functional life skills in work, school, community, safety, and travel training.
- Ensure work-based learning or further education/training is occurring.

- Ensure transportation options are in place before school district services end.
- Revise your Letter of Intent annually (see above).

21 Years (or later in some states)

- The school district must provide a "Summary of Performance" upon earning a high school diploma or aging out of special education services.
- The day after the 21st birthday (or end of transition programs in your state) should look exactly like the day before. Adult placement should be determined with funding in place.
- If you have not already done so, apply for [state Medicaid waivers](#) (in some states, you must be 21 to apply).
- Transfer of care: Transfer all healthcare to adult providers with a supported handoff based on the youth's healthcare transition plan.

For more information, please visit our [Transition Roadmap for Youth with Neurological Conditions course](#). This free, self-paced course includes over ten hours of training modules covering all aspects of transition. In this series, you will find the steps you need to take to build your child's education transition plan, the transition to adult healthcare, future planning, decision-making, and financial support, among other topics.

This course supplements our 100+ page guide, "[Educational Transition for Youth with Neurological Conditions](#)." This guide helps youth with neurological conditions use the individual education plan (IEP) to support the transition process. It also includes information about healthcare transition, college resources, template letters, checklists, and more.

[The \(Almost\) Everything List](#) is our comprehensive resource list, which includes almost everything you need to know about making decisions, school, adult life, financial assistance, and family support.



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