



Transition to Adulthood Checklist

This resource has been created to support families as they begin to work through transitioning their loved ones. We know this may not be a complete list, but hopefully it will be a tool to help you understand what needs to be considered, what you need to prepare for, and where to go to get support. Please note that every state is different in the level of support and resources provided.

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

Early Intervention

- Begin the process of Early Intervention for your child. Check with your county to set up an evaluation.
- Develop an Individualized Family Support Plan (IFSP) for authorized support services such as respite, therapies, or personal care supplies.
- 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](#)).
- Learn about the [Individuals with Disabilities Education Act](#) (IDEA).
- Create a will and talk to someone about estate planning.
- Consider a Special Needs Trust and/or an ABL Account.
- Develop a family emergency plan.

3 years

- Develop an IEP based on comprehensive assessment in all areas of suspected disability, covering all areas 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 and seizure action plans.
- For students on a 504 plan, consider the range of services and accommodations that might be needed for your child: [Epilepsy Foundation's model 504 plan](#).
- Review: [Legal Rights of Children with Epilepsy in School and Childcare: An Advocate's Manual](#); [PESA's IEP training webinars and information](#).

5 Years

- Revise the IEP: reassessment at the transition into elementary school in all areas of suspected disability (see above) is required; goals must be measurable; progress must be made; updated **annually**. Include emergency plans and seizure action plans. (504 plan: update annually.)
- Consider a Behavior plan (FBA) by BCBA, if needed.

6-11 years

- Revise the IEP **annually**; reassessment 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**; transition assessment required every year at transition age. Include emergency plans and seizure action plans. (504 plan: update 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 the age of 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 of these areas and supportive, measurable annual goals, services, activities, instruction, and related services; update annually. The student and any needed adult service or other outside agencies must be invited to the IEP when transition planning is discussed. Assessment can include pre-vocational skills, pre-community living skills, interest inventories, and more. Transition planning and assessment required annually (for 504 plans, list reasonable accommodations that might be needed in adult settings).
- Consider a Vocational Assessment.
- Begin looking into vocational and/or recreational opportunities for your child. Teach/focus on social skills and 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 start at age 14.
- Begin health care transition readiness assessments and training; revise annually.
- Begin talking with your teen's medical providers about the transition to adult care. If your teen has complex medical issues, begin researching new medical providers now.
- Understand the Medicaid waiver and learn about Long Term Care and Home & Community-Based Services (HCBS) options in your state.
- 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 (transition portfolio/vision statement).

16 Years

- Apply for a driver's license or non-driver ID Card in order to have a convenient 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, learn about Workability and employment first laws and opportunities.
- Look into options of guardianship or conservatorship as well as other 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, advanced health care directives.
- 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.

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/conservatorship; you may need legal aid for this process. At a minimum, consider guardian ad litem to represent your child.
- Apply for SSI for your child; this is what 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 the age of 18 if their family is low income or they live in an out-of-home residential setting.
- Write a Letter of Intent, which explains your child's abilities, support needs, services, current, and future benefits, as well as your wishes for his or her future, and who will support them either legally and/or as natural supports. Revise annually.

18 Years

- Guardianship in place.
- SSI funding in place (monthly payments).
- Register to vote.

- Males must register for Selective Service (the Draft). Required by the government (but does not mean that the individual would actually be drafted); failure to register can affect eligibility for services. [Who Needs to Register | Selective Service System](#).

- IEP and transition plan (or 504 plan) revised annually. Include [emergency plans and seizure action plans](#).

- Summary of Performance must be provided by the school district upon earning a high school diploma or aging out of special education services.

- Apply for Adult Services with the supporting Federal Agency (DDS, Rehab, DMH, Vocational Rehabilitation, IHSS, HCBS, Regional Center) 6-12 months before 18th birthday; if you received services as a minor you may need to reapply as an adult.

- 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 disability population. There may be a year's long wait, but it is VERY worth the wait.

- Start researching adult medical care providers and finalizing 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 any state-specific programs or requirements (i.e. in New Jersey, apply for [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, 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

- The day after the 21st birthday should look exactly like the day before. Placements should be already visited and funding in place.

- Apply for any state waivers if you have not already done so (in some states you must be 21 to apply).

- Summary of Performance must be provided by the school district upon earning a high school diploma or aging out of special education services.



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