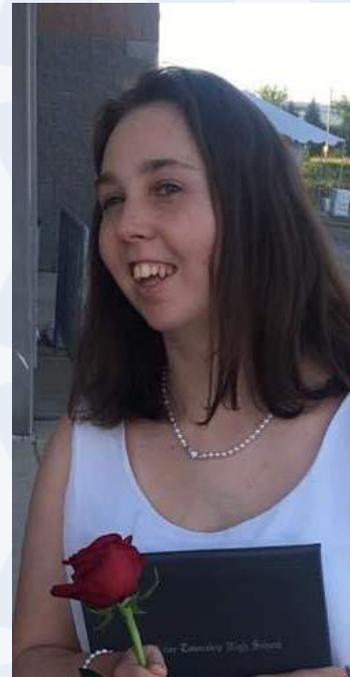


TRANSITIONING

FROM SCHOOL

TO ADULTHOOD

PLANNING GUIDE



Dravet Syndrome  
Foundation

# Introduction

Transition to adulthood is a complex, confusing, and often emotional process. For each Dravet patient family, the process will look and feel very differently because our wants and needs for our young adult differs, as well as their abilities.

While Estate Planning and a Special Needs Trust should be the first step in your long term planning, the purpose of this booklet is to assist parents through the often intimidating process of transitioning out of high school/educational entitlement into the world of adult services. Life is challenging enough when caring for a loved one with Dravet syndrome, and we hope this booklet will provide some helpful and timely guidelines to make the process more manageable.

It's important to recognize, not only are each of our experiences different, but each state/county we live in has different rules, timelines, and disability entitlement programs. Please understand this document is just a guide, and some topics may require outside legal or financial assistance. You will also want to research your individual state programs and eligibility. Many of the steps outlined in this booklet could take weeks or months, so we encourage families to start the process early. If possible, connect with parents in your community to learn from their experience. Create a team including school teachers, therapists, case management agency contacts in your state and anyone else who knows and understands your young adult with Dravet syndrome.

We encourage everyone to lean on your family, friends, and the broad Dravet patient community to help you navigate this new journey. And please share your experiences and learnings!

*-From the Parents of Adults with Dravet Syndrome Advisory Committee*

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## Age 15 (Freshman Year / Grade 9)

- Research/Connect with parent disability groups in your community to start to build a network of resources to help you with the transition process.
- Consider a Special Needs Trust and/or ABLE account in order to protect assets saved in your child's name and ensure eligibility for SSI and Medicaid.
- Review banks and financial planning to ensure no money is being saved in the child's name in preparation for SSI application when the child turns 18.
- If your child is already enrolled in a state waiver program, begin discussions on what changes to programming may take place after age 18 with your state agency case manager.
- If not in a waiver program, complete or update applications with your state disability services agency for adult disability waivers or programs.
- Begin exploring day programming and housing options because waiting lists can be several years long.
- Explore recreational opportunities or special rec programs in your area, including Special Olympics, Best Buddies, art, music, and theater programs.
- If you do not already have respite providers, explore options either through your waiver program or other community services.
- Make sure your child is receiving life skills planning, and if appropriate, vocational training as a part of their IEP/transition plan.
- Contact the DSF Family Network Liaison to learn ways to get connected with Dravet Families starting this transition process.

### Notes :

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## Age 16 (Sophomore Year / Grade 10)

- Obtain a State ID from your local Department of Motor Vehicles (DMV).
- Review your estate plan to evaluate eligibility for governmental benefits, including special needs trust and/or ABLE account.
- Review parents' wills (or other family members' wills) if appropriate, to ensure any inheritance money is not directly placed in the child's name. Receiving the funds directly may cause the child to lose public benefits, such as Supplemental Security Income (SSI) and Medicaid.
- Evaluate Guardianship and Power of Attorney (prior to your child turning age 17). Consult with your state agency case manager/educational team for guidance, including who should be guardian. You may also want to discuss this with healthcare providers.
- Check with your attorney to see if a health care proxy, also known as a durable medical power of attorney, is recommended or required in your state.
- Familiarize yourself with the educational process in your school district once your child completes the traditional high school program (post high school programs will vary by age and scope for each state).
- Discuss with your child's educational team the timing to complete neuropsychological evaluation, behavioral testing, and other tests needed for guardianship.
- Work with your educational team to start to create peer mentor relationships with high school students. These students can sometimes, longer term, become great respite workers.
- Begin to discuss day programming, residential, and work program options with educational staff.
- Identify community programs and services in your area and state.
- Join the DSF Facebook group for Caregivers of Adults 16+ to learn from other parents and share advice.



## Age 17 (Junior Year / Grade 11)

- Identify professionals needed to allow you to complete Guardianship and/or Power of Attorney paperwork (MD, social worker, and clinical psychologist).
- Complete Guardianship and/or Power of Attorney for financial and medical decisions. You will not be able to petition the court for guardianship until the date of your child's 18th birthday. Forms will expire, so you can't do them more than 180 days in advance.
- Begin to tour post high school day and residential programs, and get on waiting lists if necessary, for when your child ages out of their school system (this varies state to state).
- Organize all of your child's medical records and other important documents (social security card, birth certificate, IEP, behavior plans, Trust documents, SSI papers, guardianship papers, care plan, etc.)
- Complete neuropsychological evaluation, behavioral testing, and any other tests required for guardianship, SSI and/or day program placement.
- If your child has private insurance, review the policy regarding your child's coverage after the age of 18. Under the 2010 Patient Protection and Affordable Care Act ("Obamacare"), private insurance policies typically covers children under your policy until age 26, but with proof of disability your child can remain on your policy after age 26.
- If your child already receives Medicaid, be aware that some programs change at age 18.
- Setup respite services in your home to begin acclimating your child to support being provided in the home by someone other than a parent or family member.
- Work with your child's educational team (and your state disability/vocational service agency) to begin to understand potential vocational opportunities and job coaches.
- Find out if there is an age cutoff for any of the therapies your child receives. If so, get recommendations for providers working with adults.

## Age 17 (Junior Year / Grade 11)

- .Keep detailed notes of your child's seizure activity and care requirements throughout the day. Documenting their multiple daily needs will support your SSI application and for waiver programs.
- Check with Durable Medical Equipment vendors and home care agencies to see if there are age cutoffs, and if so, what agencies can continue to provide the necessary care.
- If required by your state, begin the Certified Family Home process if your child will be receiving residential funding for in-home care.
- For military families - make sure your child has a military ID card and that it is updated as service status changes, and that you add the disabled dependent to your military survivor benefits.

### Notes :

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## Age 18 (Senior Year / Grade 12)

- Apply for SSI and Medicaid the month your child turns 18 years of age. If previously on SSI, complete phone interview.
- Set up a joint bank account to hold and track SSI payments. Begin to track SSI spending as required by your state.
- If your child does not already receive medicaid, consider applying after obtaining SSI. In most states, if you are an SSI recipient, you may be automatically eligible for Medicaid.
- Contact your state's disability agency - ask your school for a referral to determine eligibility. Once approved, work to secure funding and programming. Inquire if agency has transition coordinators on staff.
- If your child qualifies for adult services through your state, consider adding one of the parents as a primary care provider in order to be compensated. Consider adding another adult in household (could be a sib or grandparent), in addition to parents, as a primary care provider.
- Share Guardianship paper with schools, health care providers, etc. Also add a copy to your estate and financial files.
- If you have a son, they must register for Selective Service, regardless of disability. He may register at the post office or online at [www.sss.gov](http://www.sss.gov).
- If you have a daughter, arrange for her to have a gynecological exam with a gynecologist who understands Dravet syndrome/Developmental and Epileptic Encephalopathies.
- Consider getting on a housing waitlist. Section 8 waitlists are long and can be up to 10+ years. This includes Adult Family Homes (A.F.H.s) which are residences where three or four adults who are not related to the operator reside and receive care, treatment or services that are above the level of room and board. They adhere to state regulations and are built or modified with accommodations including but not limited to wheelchair ramps, wider doorways, and lower countertops.





## Age 19-22 (Transition Services)

- Research and work with your state agency case manager to identify potential vocational opportunities and day programming options.
- Work with your child's transition team at their school to finalize IEP/transition goals to ensure focus on skills needed for adult life.
- Find adult medical providers to replace your current pediatrician and pediatric specialists.
- Create a Letter of Intent or Care Binder that documents your desires and long-term plans for your child's daily care, finances, medications, caregivers, housing, etc.
- Begin dialogue with immediate family members on goals/plans for your adult child's future and family involvement in this process.
- Continue to monitor the waitlists for day programming and residential services that you are interested in.
- Contact state disability agency to ensure all adult entitlements are in place. If state has an adult disability registry, ensure your case manager knows criticality of receiving services.
- Participate in informational sessions/presentations for services for adults with disabilities, often presented by local non-profit disability awareness agencies (such as The Arc) or centers for independent living.
- Address transportation needs and explore options.
- Complete annual guardianship report, as required by your state.
- If your child is receiving SSI, track spending and submit an annual SSI report, as required by your state.
- At the beginning of the last year of transition, begin moving into adult programs. Complete necessary paperwork for transition and develop overall strategy for transition.



## Glossary of Terms

**ABLE Accounts:** Tax-advantaged savings accounts for individuals with disabilities and their families, were created as a result of the passage of the Stephen Beck Jr., Achieving a Better Life Experience Act of 2014 or better known as the ABLE Act. Currently you can deposit \$15,000 per year for a maximum of \$350,000.

**Age of Majority:** The age when a person becomes a legal adult. The rights of the parent of a student with a disability transfer to the student when he/she reaches the age of majority.

**Americans of Disabilities Act of 1990 (ADA):** Guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state, local government and telecommunications.

**The Arc:** Connect with your local chapter of The Arc. Chapters provide a wide variety of services, supports, and advocacy for people with intellectual disabilities and their families. This varies by chapter and includes but is not limited to: individual and public policy advocacy; residential, educational, and vocational services; person-centered and financial planning; recreational activities; and other supports that meet the unique needs of the community.

**Beneficiary:** One who is lawfully entitled to the proceeds of property, the title to which is vested in another, such as a trustee or an executor.

**Community Integrated Living Arrangement (CILA):** A flexible service arrangement for people with developmental disabilities or chronic mental illness which focuses on the needs of the individual in his/her home.

**Daily Living Skills:** Skills/activities that are required for a day-to-day functioning within the home and the community

**Disabled Adult (For SSI/SSDI):** An individual who is unable to perform substantial gainful employment due to a physical, mental, or a combination of conditions.

**Durable Medical Equipment (DME):** Equipment and supplies ordered by a health care provider for everyday or extended use. This may include oxygen, wheelchairs, walkers, adaptive/hospital beds, etc.

**Department of Health and Human Services (HHS):** This is the federal agency that oversees the federal Medicare and Medicaid programs. Most families will work with their State Department of Human Services for funding for these programs.

**Division of Vocational Rehabilitation Agency (DRS):** Assists people with cognitive, sensory, physical, and/or emotional disabilities to attain employment and increase independence. Funded by Federal and state money, VR agencies typically operate regional and local offices. VRs typically last for a limited period of time and are based on an individual's rehabilitation plan.

**DHS/DRS Certification:** Process of referral, interview, and certification making clients eligible for particular services/resources available through the Department of Services/Division of Rehabilitation Services. These services can include residential, home and/or employment services.

**Estate Planning:** The process of creating and preserving one's property during one's lifetime and arranging for its transfer at one's death. Most frequently, the term is associated with advantageous investment and tax planning that does not sacrifice personal/family security and welfare.

**Family Support Services:** Services provided to families that enable them to provide the extra care needed to keep their child with a disability at home with the family. Examples include respite care, counseling, adaptive equipment, specialized transportation, financial support, support groups, and training.

**Functional Skills:** Skills that are important for everyday living such as shopping for groceries, how to speak to one's boss, balancing a checkbook, laundry, etc. Also known as Activities of Daily Living (ADLs).

**Guardian:** A person appointed by the court to control and manage another person's affairs and/or property. Most typically, a guardian is appointed by the court to control and manage another person's affairs of a minor or of an adult who is incapable of looking after his/her own affairs.

**Health Care Proxy:** Also known as a durable medical power of attorney, is a document that allows you to appoint another person(s) as your health care agent to make health care decisions on your behalf if you are no longer able to do so. You may give your health care agent authority to make decisions for you in all medical situations if you cannot speak for yourself. Thus, even in medical situations not anticipated by you, your agent can make decisions and ensure you are treated according to your wishes, values and beliefs.

**High School/Transition Paperwork File:** Keep all important paperwork which may be necessary for applying for adult services in one place. This should include high school IEPs, assessments, behavior plans, medication summaries, medical reports, neuropsychological evaluations, recreation enrollment waivers, guardianship papers, seizure logs, SSI documentation, state entitlement documentation, residential waiting list applications, etc.

**Home Based Support Service Program:** Services to help individuals stay in their homes and become independent.

**IDEA: Individuals with Disabilities Education Act:** The most important US law regarding the education of students with disabilities. The law ensures that eligible children with disabilities have a free, appropriate education in the least restricted environment.

**Inclusion:** Incorporating persons with disabilities to their greatest possible benefits in all aspects of life.

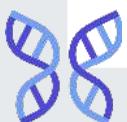
**Independent Living with Support:** A residence of an individual's choice where he/she lives with support services such as assistance with budgeting, shopping, cleaning, etc.

**Intermediate Care Facility for Developmentally Disabled (ICFDD):** A licensed group residence with close supervision. Training and supervision are provided to achieve adequate social and daily living skills. ICFDD 15 or fewer: as above, but residents may work or attend a day program.

**Job Coach:** A person who trains persons with disabilities on the job. Coaches have special training to help them both instruct the person with disabilities to the job and to aid him/her to become fully integrated in the workforce.

**Letter of Intent:** A "letter of intent" or "letter of instruction" is a document that ensures your trustee knows your child's functional abilities, routines, interests, and particular likes and dislikes. In addition to describing your special child, the letter of intent identifies specific doctors, services and resources that will help your child enjoy the highest level of independence and self-reliance. The document is a valuable tool that communicates knowledge only parents may know, including specific hopes and desires for their child's future well being, to the very people who will be caring for the child after the parents no longer are able to do so.

**Living Trust:** A legal arrangement by which property is managed and held for the good or benefit of a person, to take effect before the death of the creator.



**Medicaid:** A state-administered medical assistance program for those individuals who are 65 years or older, blind or disabled and eligible for Supplemental Security Income (SSI), or a recipient of Aid to Families with Dependent children (AFDC).

**Medicare:** National social insurance program administered by the US Federal government. It provides health for Americans age 65 or older who have worked and paid into the system through the payroll tax. It also provides health insurance to younger people with some disability status as determined by the Social Security Administration.

**Paratransit:** A public shared ride system that provides transportation services that supplements larger public transportation services without a fixed route and timetable to individuals with a disability who are unable to ride the public route independently.

**Power of Attorney:** Students over the age of 18 may sign these to give their parents the right to legally make financial and healthcare decisions on their behalf.

**Related Services:** Supportive and therapeutic activities and services during and after high school to achieve and maintain post-school goals and rehabilitation. Can include transportation, physical therapy, occupational therapy, rehabilitative counseling, etc.

**Respite Care:** Provides temporary relief for caregivers from the ongoing responsibility of caring for an individual of any age with special needs.

**Supplemental Security Income (SSI):** The SSI program provides monthly payments to adults and children with a disability or blindness who have income and resources below specific financial limits.

**Social Security Disability Insurance (SSDI):** Social Security benefits payable to an individual with a work history, or their family, in the event the individual becomes disabled.

**Special Needs Trust:** Special needs trusts are made specifically for the benefit of disabled or mentally ill beneficiaries who lack the mental capacity to manage their own finances. The trust is created with the specific needs, lifestyle, and future of the beneficiary in mind. Oftentimes these trusts are used to ensure that the beneficiaries don't lose government benefits they are receiving. The trustees of special needs trusts can be family members or, if an appropriate and trustworthy family member is unavailable, a third party will be appointed by the court.

**State Registration Database:** Used by some states to track individuals with developmental disabilities to assess upcoming needs for services. If available in your state, it is important to be added to this list as soon as possible, and this often can be done long before age 18.

**Summary of Performance (SOP):** A final summative document to be completed by the school, student, and family as a communication tool that provides important linkages to any adult services. The document should include academic achievement, functional performance, secondary goals and how to achieve them and recommendations for accommodations. Transition law indicates that a SOP is to be completed for every student who graduates, exits due to age, or drops out of school.

**Supported Living Arrangements (SLA):** A group residence where the individual lives with supervision by paid staff members. Residents are expected to self-administer medications, to have basic social and day living skills, to function independently in the community, and to work or attend a day program.

**Transition:** A results oriented process involving a partnership of students with disabilities and their families, school-aged services, post-school services and local communities which results in maximum levels of employment, independent living, and community participation. Community participation includes, but is not limited to, access to health, leisure, legal and social services, transportation, adult education and social integration.

**Transition Plan:** A transition plan is the section of the Individualized Education Program (IEP) that outlines transition goals and services for the student. The transition plan is based on a high school student's individual needs, strengths, skills, and interests.

**Transition Planning Inventory (TPI):** A comprehensive transition assessment that is completed by school, family, and the student.

**Transition Planning Meeting:** Meeting to be scheduled prior to the IEP in order to discuss and identify specific transition goals and activities to be put into place in the upcoming IEP and address the individuals transition to post-school life and services.

**Transition Services:** Activities that prepare students with disabilities to move from school to post-school life. The activities must be based on the student's needs, preferences, and interests, and shall include needed activities in the following areas: instruction, related services, and community experiences.



