

Preparing for Transition: A Checklist

by Sarah C. Wayland, Ph.D.
Guiding Exceptional Parents | Forever Parenting Project

General transition resources

- For residents of Prince George's County:
<https://www.thearcofpgc.org/our-programs/children-and-youth/transitioning-youth/>
- For Maryland residents:
 - Maryland State Department of Education's Technical Assistance Bulletin on Transition Planning – Legal Policy, Implementation and Tools
 - <https://www.marylandlearninglinks.org/secondary-transition-planning-guide/>
 - Guide for Implementing the Secondary Transition Process
 - <https://mdtransitions.org/>
 - <http://mdod.maryland.gov/education/Pages/transitioningyouth.aspx>
 - https://www.ppmmd.org/resource_category/transition/
- For USA:
 - Eric Jorgensen, CFP® has created a truly incredible resource [Sage – an AI-powered disability planning consultation tool](#) to help you figure out what supports your child is eligible for and when to apply. It helps you figure out what you need to do to access SSI, Medicaid, DAC, Waivers, Trusts, and many other aspects of long-term planning.
 - The Arc's [Center for Future Planning](#) provides terrific guidance for families.
 - [National Technical Assistance Center on Transition](#)
 - [National Youth Transitions Center](#)

Things to do before 18:

- Set up a [Maryland 529](#) (to save for college tax free) or [Maryland ABLE](#) (to save for disability-related expenses tax free) account for your child. You don't have to use the plans administered by Maryland, but you do get a tax write-off if you are a Maryland resident.
 - To compare different states' ABLE accounts, the [ABLE National Resource Center](#) is a terrific resource.
 - Note that on the death of the beneficiary some states require that ABLE funds be used to reimburse the state for Medicaid-related expenses prior to being distributed to their estate. (This is not true in Maryland or Virginia, but it is true in Washington, D.C.)
- Open a bank account with your child as one of the account holders, with an associated debit card.
 - I like having an account that my child can access that I can easily transfer money into in case they need money quickly.

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- If you think your child may need to apply for SSI when they turn 18, it is critically important that the sum total of cash in their name does not exceed \$2000.
 - If family members want to give more than \$2000 to your child, it may be best to create a trust into which they can deposit money for the benefit of your child (consult a lawyer before accepting the money.)
- Get official State ID.
 - You will need a [copy of your birth certificate](#).
 - A copy of your [Social Security Card](#) (and a Social Security number if you don't have one).
 - Another form of ID (school ID counts if you are still in school).
- Register to vote.
- [Get a passport](#) (if you think it's necessary). It gets harder to get your first passport after you graduate (because you can no longer use your school ID for proof of identity).
- Figure out what your child wants to do when they graduate. [Create a plan for helping them reach their goals](#). This should be part of the IEP process starting at age 14.
 - Employment outcomes are [better for people who get job experience](#) before graduating from high school. (And while I knew this to be true, my kids were not able to juggle fulfilling their graduation requirements while also working. So they are both getting work experience through internships and programs funded by [DORS](#) (Division of Rehabilitative Services) post-graduation. More on that below.)
- [Prepare for college](#) (PACER - Minnesota Parent Training and Information Center)
 - If considering college, [Howard Community College's Project Access](#) is a college preparatory program designed to facilitate the transition of high school students with disabilities into post-secondary education.
 - Apply for accommodations if you want to take AP Exams, or if the schools you are considering applying to require the ACT or SAT.
 - The [ACT is usually reasonable about granting accommodations](#).
 - The College Board (SAT, AP Exams) often requires multiple appeals, so start [the accommodation request process](#) early.
 - Consider applying to schools that are "[test optional](#)" if your child doesn't want to deal with taking the SAT or ACT.
- [Prepare for employment](#) (PACER - Minnesota Parent Training and Information Center)
 - [O*NET OnLine](#) is an online tool for career exploration and job analysis.
 - Sign up for [services for High School Students](#) and especially [Pre-Employment Transition Services \(Pre-ETS\)](#) through [DORS](#) (Division of Rehabilitative Services).
- If diagnosed with a developmental disability, [apply for the DDA waitlist](#) as soon as possible, and definitely before graduation.

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- Once your child has been approved for the wait list, you need to choose an agency that serves your area to [Coordinate Community Services](#). (You can find the DDA's list of CCS Agencies for each region in Maryland [here](#).)
- People with mental illness are eligible for supports through [Maryland's Behavioral Health Administration](#). These supports are not as well-funded in Maryland, so if you qualify for DDA services, you should work to obtain funding for supports through the DDA.
- People with other health issues are supported through [Maryland's Public Health Administration](#)
- According to Shannon Caisie at the now defunct company, *Planning Across the Spectrum*, the sooner your child's credit file gets started, the easier it will be for them to participate in the credit system if they are in a financial position to do so. If you want your child to build their credit score, and you think they are capable of managing their money, consider the following:
 - Add them to the account for your oldest credit card in good standing. Do this before you freeze their credit (see below).
 - Educate them on the concept of credit until they can use it responsibly. That is, they should only charge what they can afford to pay off each month in full.
 - Make sure they pay bills on time. One person I know has it set up so the minimum payment is automatically paid from the main account each month, and they pay the remaining balance monthly as well. (This protects them in case they forget to make a payment.)
 - Credit cards offer protection if you buy anything online.
 - Know your kid well enough to know what approach you need to teach them, and be honest with yourself and with them about what habits they can develop in regard to money.*
- [Freeze your child's credit report](#) so no one can steal their identity.
 - [Equifax](#)
 - [TransUnion](#)
 - [Experian](#)
 - Make sure your child will be able to unfreeze their accounts if necessary in the future. This means saving the PIN that each credit agency gives you to allow you to unfreeze the account. Make sure your child has a copy of the PINs for each agency.
- Work with a financial planner who ***understands the issues for disabled people*** so you can make sure your child will be okay when you are no longer able to support them. (This is REALLY important, and you don't need to be wealthy to develop a financial plan. And the earlier you do it, the better.) Some advisors who will help you with your personal financial

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planning, while also helping you coordinate those plans with your child's government benefits are:

- Elizabeth (Liz) Yoder at Dependent Financial Planning
- Maedi Tanham Carney at [M&L Special Needs Planning](#)
- Annette Hines at [Special Needs Companies](#)
- Michael Beloff at [Belvedere Wealth Partners](#)
- Mike Walthers at [Oak Wealth Advisors](#)
- Elizabeth Larson, founder of [Special Needs Advanced Planning](#)
- Chase Philips at Merrill Lynch
- Paratransit (transportation for people with disabilities)
 - If in Prince George's or Montgomery Counties, customers with disabilities may be eligible to ride Metrobus and Metrorail at a discounted rate. Apply for a [Reduced Fare SmarTrip® photo ID card](#).
 - [MetroAccess](#) is a shared-ride, door-to-door, paratransit service for people whose disability prevents them from using bus or rail.
 - [Abilities-Ride](#) allows MetroAccess customers to move some of their trips to local taxicab companies, sedan and van companies, and national transportation network companies.
 - Montgomery County has [three transportation options](#) for people with disabilities, including Metro (as described above), [Ride On](#), and [Call'n'Ride](#).
 - Howard County, Anne Arundel County, City of Laurel and Northern Prince George's County are served by [Regional Transit Authority \(RTA\)](#). [RTA Mobility](#) is a curb-to-curb, shared ride transportation service for Riders who are unable to ride [RTA fixed route transit system](#) due to a disability or age.
 - This service, [Go Go Grandparent](#), originally created for older adults – to help them access Lyft, Uber, Doordash, Instacart and more – can also be helpful for people with disabilities who have trouble navigating apps on their cell phones.
- Before graduating, make sure to have the school (or an independent neuropsychologist) conduct an assessment that documents your child's disability. (Make sure the report includes an assessment of their ability to do Activities of Daily Living (ADLs).) You can use this to:
 - Document your child's needs when you apply for SSI benefits
 - Document a need for accommodations in college
- Make sure you and your child understand the type of supports provided by the school system so you can implement them in the community after your child graduates.
- Accessibility equipment
 - Make sure you and your child understand the equipment that is being provided by the school system, and how to use it.

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- If your child uses equipment provided by the school system (e.g., an AAC device for communication), work with your healthcare provider to get these devices for personal use after graduation. Your child will need to return any school-issued device when they graduate.
- Here are some [ideas for funding sources for equipment](#), compiled by Brilly Semenova.

Things to do at (or after) 18:

- (assigned male at birth) Register for [Selective Service](#).
- If you haven't already, register to vote!
- Remember that after 18, NO ONE WILL TALK TO YOU unless your child has signed legal paperwork allowing you to talk with them. You don't need guardianship, you just need permission. (More on this below.)
- Make sure you are set up to **transition your child's healthcare** to the adult world.
 - <https://www.gottransition.org/six-core-elements/>
 - Because of HIPAA your child will need to sign Medical Healthcare Proxy releases for insurance, all healthcare providers, and all pharmacies so that you can continue to communicate on behalf of your child if needed.
 - Have your child create an Advanced Healthcare Directive: <http://www.marylandattorneygeneral.gov/Pages/HealthPolicy/AdvanceDirectives.aspx> and have them name a Health Care Agent in that document so that the Agent can make decisions on their behalf if they are unable to do so.
 - Teach your child how to take care of their medical needs. If they can't do the following, you will need to figure out how to support them in these matters. *I cannot overemphasize the importance of taking this seriously.*
 - Take medications independently, without reminders.
 - Handle the refill process, including talking to doctors and picking up from the pharmacy.
 - What to do when they are feeling poorly. When should they call the doctor?
 - Understand their underlying medical conditions and how to manage them.
 - If you are a Federal Employee, your child can continue to be covered by your health insurance after the age of 26 if OPM has determined that they are [incapable of self-support](#) because of a mental or physical disability. This coverage continues even after you die, if you are enrolled for *Self Plus One* or *Self and Family* at the time of your death, though your child will have to pay their premiums after you die.

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- Note that Medicaid and Medicare are available for many people with disabilities, and for some of those people it does not make sense to have additional coverage. In our case, the insurance available from the US Government covers many more services and other health-related costs than Medicaid, so we have opted to keep our kids on our insurance.
- Vision and Dental benefits end at 22 unless you [apply to extend them](#) (which requires you to document the disability). If your child is incapable of self-support, your agency or retirement system must contact BENEFEDS within 60 days of your child's enrollment or 22nd birthday (if already enrolled) to confirm their eligibility. If not, your child's enrollment will be voided.
- If your child will not be employable, or if they are underemployed because of disability, **apply for Supplemental Security Income (SSI)**.
 - Apply before age 22 if your child will be permanently disabled.
 - The [Social Security Blue Book](#) documents the medical criteria that social security uses to evaluate impairments in adults age 18 and over so you understand how disability determinations are made.
 - If your child qualifies for SSI, they automatically qualify for Medicaid, though you should check to make sure it actually happens.
 - If your child is living with you, you can have them pay for their part of your housing costs. Have your child sign a rental agreement with you that begins when they start receiving benefits and submit this agreement with your application. The amount of SSI coverage for rent is one-third of the annual benefit. [Learn more](#) on the SSA website.
 - I found it helpful to have someone guide me through this process who understood the financial repercussions of different decisions regarding how I wanted to support my boys.

For example, you will need to decide whether you will want to rely solely on governments benefits, use your own private resources to pay for supports, or some combination of the two. Understanding the implications of these decisions can help you avoid making mistakes that will rob your child of important supports once you are no longer able to support them. Some businesses that can help with the SSI application process and also with helping you evaluate your support options are:

 - Rebecca Rubin at [Disability Support Solutions](#) (Maryland)
 - Maedi Tanham Carney at [M&L Special Needs Planning](#) (Maryland)
 - The team at [Incl\(us\)ion Consultants](#) (Virginia)
 - A [representative payee may be appointed by the Social Security Administration](#) for your child if they determine that your child needs help managing their Supplemental Security Income benefit payments.

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- Some people are denied SSI benefits to which they are entitled. You can appeal. Depending on your situation, it may be wise to hire a lawyer. They can be reimbursed from your child's benefits, and the amount they can collect is capped, so you can arrange it such that you do not incur out-of-pocket expenses.
 - [Cervoni Disability Law](#)
 - [Fierst & Fink](#)
- SSI or SSDI?
 - Your child [may be eligible for SSDI benefits](#) if a parent is deceased or starts receiving retirement or disability benefits. The benefit is paid based on the parent's Social Security earnings record. The disabled "adult child" must be unmarried, age 18 or older, have a disability that started before age 22, and meet the definition of disability for adults.
- If your child qualifies for SSI, consider applying for:
 - [Supplemental Nutrition Assistance Program \(SNAP\)](#) to help with food costs.
 - [Rental Subsidy programs](#) (including [Housing Choice Voucher \(Section 8\)](#) rental assistance), to help with housing costs.
- Sign up for [Medicaid](#) (which funds [Waiver services](#) administered through [Maryland's Developmental Disabilities Administration \(DDA\)](#), [Maryland's Behavioral Health Administration \(BHA\)](#), and [Maryland's Public Health Administration \(PHA\)](#).)
 - Once your child is 18, they become a household of 1, and your income will no longer count against them (as far as receiving services is concerned.)
 - You do not need to receive SSI to qualify for Medicaid.
 - The [Employed Individuals with Disabilities \(EID\) Program](#), administered by the Maryland Department of Health (MDH), provides Medical Assistance (also called Medicaid) to working Marylanders with disabilities.
- Consider whether your child will need help managing their affairs (financial, legal, medical). Consult with an [attorney who understands special needs](#) if you are concerned about this to discuss:
 - [Supported Decision Making](#) (not available in all states),
 - Power of Attorney (financial, legal, medical),
 - Advanced Directives, or
 - Guardianship (reserved for people who are incapable of making their own decisions.)
 - If child will be on SSI, work with a lawyer to set up a Special Needs Trust and make sure any assets left to your child will go into the Trust and not directly to your child. (If more than \$2000 is left to the child, they will lose their benefits.)
 - [First Maryland Disability Trust](#), [Advocacy Trust](#), [HOPE Trust](#), and [Cumberland Trust](#) are companies that can serve as Trustees if no one in your circle of support is willing to do so. Some banks can do this as well.

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- Pooled Special Needs Trusts (e.g., [Shared Horizons](#) in Maryland or [Visible National Trust](#), nationwide) are a good option for families who can't find a corporate trustee to serve them.
- Make sure to create a [Letter of Intent](#) so people will know how to support your child after you are gone. Update this letter regularly and make sure the executor of your estate knows how to get the most recent copy. [The Dani Plan](#) is an online tool that will allow you to create such a letter, and will make it easy for you to keep it updated.
- Consider including an advocacy agency in your plans who will monitor and address your loved one's concerns when you no longer can. A personal advocate can serve as a trusted confidant, guide, and advocate, in addition to communicating financial concerns to your chosen Trustee (e.g., [By Their Side](#) in Maryland, or [DC Quality Trust](#) in Washington DC).
- Some attorneys in the DC area that consistently get excellent recommendations include:
 - [Fierst & Fink](#) (Montgomery County, MD)
 - [Stephen Ellville & Associates](#) (Maryland & Northern Washington, DC)
 - [Ally Legal Planning](#) (Howard County, MD)
 - [Sinclair Prosser Gasior Law](#) (Anne Arundel, Prince George's & Calvert County, MD)
- Meet with your [DORS \(Division of Rehabilitative Services\)](#) counselor to discuss career plans (this includes college) and what support your child is eligible for. (For example, you may qualify for tuition assistance.)

After graduation

- Explore job opportunities through the [Maryland Department of Labor Workforce Development and Adult Learning](#).
- Apply for an internship through the [Maryland Apprenticeship and Work Training Program](#).
- The [American Job Centers](#) have programs for youth ages 18 – 24 to get experience working.
- Work with the [Maryland Work Incentives Network](#) to coordinate benefits if you get a job.
- If attending college, sign FERPA releases. (May need a separate release for different departments even within the same university.)
- Meet with your [DORS \(Division of Rehabilitative Services\)](#) counselor to discuss career plans (this includes college) and what support your child is eligible for.
 - Explore the [list of Specialized Services](#) for people with different disabilities on the DORS website.

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- Contact your Coordinator of Community Services (CCS) to determine what Waiver supports are available to your child. This chart will help you understand [what kinds of supports are available under each waiver](#).
 - The [Family Supports Waiver](#) is only available to families supporting a disabled person 21 or younger.
 - The [Community Supports Waiver](#) and the [Community Pathways Waiver](#) serve people with disabilities of all ages.
 - The Community Supports Waiver helps participants to live more independently in their homes and communities with Day and Support Services that promote community living.
 - The Community Pathways Waiver provides the same services available through the Community Supports Waiver, but it also provides Residential Services for people who need substantial in-home support or live-in caregivers.
 - There are two service models for coordinating these services: Self-directed services and traditional, agency-based services.
 - This page on the Maryland DDA website [describes the different service models](#), and also lists the [types of services available](#). My family uses this page to cue us to think through which options will be helpful to our kids as they build a life that works for them.
 - In Maryland, you can find [providers to deliver the different services](#).
- Find local support for yourself with other parents of kids with disabilities like your child's. In Prince George's County we have the [Adults with Developmental Disabilities Citizens' Advisory Committee](#). Montgomery County has the [MC-Transitions](#) list.
- You can find groups on social media that can help you navigate all this, e.g., [Parents of College Bound Kiddos with ADHD](#)

Possible Paths after High School:

- Work experience in area of interest.
- Work experience at anything!
- Trade school or apprenticeships.
- Community college
 - Certifications
 - Degree (AA)
 - Workforce Development (non-credit courses)
 - [Prince George's Community College](#)

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- [Howard Community College](#)
- [Montgomery College](#)
- [Northern Virginia Community College](#)
- College Transition Programs specifically for people with disabilities.
 - [Howard Community College – Project Access.](#)
 - [Northern Virginia Community College – College Steps Program.](#)
- In Maryland if you are receiving Social Security benefits (SSI or SSDI) you may be able to attend Community College tuition-free. Talk to a Benefits Counselor to find out if you are eligible.
- Programs like [College Living Experience](#), [College Internship Program](#), [Landmark College](#) (in MA), [Beacon College](#) (in NY), [The Summit Center](#)(ages 18-23), or [ClemsonLIFE](#) (in SC, for students with intellectual disabilities).
- College – with supports.
 - [College Web LD](#) can help you find an appropriate fit.
 - Guides
 - [The K&W Guide to Colleges for Students with Learning Differences](#)
 - [Colleges That Change Lives](#)
 - Contact the Disability Support Office at each of the colleges/universities you are considering to find out what supports are available and the documentation required to qualify, as well as the cost of the programs. These supports can range from simple accommodations (free) to separately funded support programs (costs money).
 - There are services specifically to help parents of kids with disabilities figure out which post high school programs will work best for them. Some good options include:
 - [Bass Educational Services](#)
 - [College Consulting Collaborative](#)
 - [Spectrum Transition Coaching](#)
 - Make sure to get tuition insurance.
- Supervised year abroad.
- Gap year (programmed).
- Helping out with family at home.
- Volunteering.

Where will they live?

Consider a living situation where your child can easily access support services, transportation, employment, and recreation. The options that Medicaid Waiver programs cover in Maryland include:

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- Supported Living – beneficiaries live independently in homes of their choice. For some innovative inclusive communities, consider:
 - [Main Street](#) in Rockville
 - [Integrated Living Opportunities \(ILO\)](#)
 - [Makom](#) in Central Maryland and Northern Virginia.
 - [Best Buddies Living Program](#) (nationwide)
- [Shared Living](#) – beneficiaries live in either the provider’s home/apartment, in their own home/apartment with a provider, or in a shared home with a roommate.
- Community Living in a Group Home – beneficiaries are acquiring the skills necessary to maximize independence while living in a provider owned group home setting.
- Community Living With Enhanced Supports – beneficiaries require enhanced supervision and have challenging behaviors. They live in a provider owned group home setting.
- Depending on your child’s financial situation, consider applying for [Rental Subsidy programs](#) (including [Housing Choice Voucher \(Section 8\)](#) rental assistance), to help with housing costs. [This article from ProPublica](#) describes how to navigate the application process for Section 8 housing.
- [Maryland Inclusive Housing Corporation](#) can help your child access and maintain inclusive, affordable, and accessible housing of their choice by creating opportunities, identifying resources, connecting people, and providing services.
- [Guidance to the process of accessing housing](#), either via a Waiver or via Affordable Housing. OSG is in Northern Virginia, but the principles apply no matter where you live.