The Arc
Northern Virginia

Getting the Most From Special Education

Preschool through High School

A Guide for Parents of Students with Disabilities in Northern Virginia

This guide is one of six developed for parents of children with intellectual and developmental disabilities under the auspices of The Arc of Northern Virginia's Transition POINTS program. Transition POINTS focuses on key life decision points: receiving a diagnosis and having a child with a disability enter an early intervention program; school and special education; transitioning out of the school system; securing employment or day services; finding a place to live outside the caregiver's home; and aging with a disability.

All of the guides can be found at https://thearcofnova.org/program/transition-points.

As information changes, updated content and resources may be found in the Resource Library on our website at https://thearcofnova.org/resource-library.

This is not a legal document and does not spell out your or your child's rights and responsibilities under the law. Every effort has been made to verify the information in the document, but please be aware that items such as program regulations, deadlines, and contact information can change. Referrals to organizations and individuals are for informational purposes and do not constitute an endorsement of their services.

www.thearcofnova.org

INTRODUCTION

As your child grows and begins their school journey, you may discover that they need additional supports to learn and thrive. Learning that your child may require special education services can bring a range of emotions—pride in who they are, along with questions, uncertainty, and a desire to ensure they have every opportunity to succeed. This is a new chapter, and while it may feel complex at times, you are not alone.

This guide is designed to support you as you navigate the world of special education. Schools, services, and processes may feel unfamiliar at first, but with the right information and guidance, you can become a strong and confident advocate for your child, and encourage them to be strong advocates for themselves. Along the way, you will discover your child's unique strengths, celebrate their progress, and build meaningful partnerships with educators and professionals.

The Arc of Northern Virginia's Transition POINTS Guides were created to serve as a practical and compassionate resource for families at every stage of the educational journey. This guide focuses on understanding special education, including how to access services, what your rights are, and how to work collaboratively with your child's school team. You'll find clear explanations of key processes such as evaluations, Individualized Education Programs (IEPs), and accommodations, along with strategies for effective communication, advocacy, and planning for the future.

Every child and family is different, and there is no single path through special education. This guide offers flexible, step-by-step information that you can use in a way that fits your needs, whether you are just beginning to explore services or looking to strengthen an existing plan.

You do not need to have everything figured out right away. What matters most is taking one step at a time and knowing that support is available. With knowledge, preparation, and the right partnerships, you can help create a positive and empowering educational experience for your child, and a strong foundation for their future.

ABOUT TRANSITION POINTS

Families need realistic, actionable information with which they can make a wide range of decisions as their child grows. Providing this information is the mission of The Arc of Northern Virginia's Transition POINTS program (Providing Opportunities, Information, Networking and Transition Support).

Transition POINTS focuses on six key decision points in the lifetime of an individual with an intellectual disability:

1. Receiving a diagnosis and having a child enter an early intervention program
2. Starting school and entering the special education system
3. Transitioning out of the school system to adulthood and adult services
4. Entering the world of work and meaningful community engagement
5. Exploring housing and supportive living options
6. Aging with a disability and planning for long-term quality of life

Transition POINTS
Providing Opportunities, Information, Networking and Transition Support

For each transition point, we provide guides in both print and digital formats, online resources, workshops, and webinars, and practical tools to help families navigate complex systems and make informed decisions with confidence.

Many of these resources can be found on our website at www.thearcofnova.org. The Arc of Northern Virginia maintains a library of informative life-planning videos and webinars on our YouTube Channel at https://www.youtube.com/user/VideosatTheArcofNoVA.

The information in this guide is intended to support individuals with intellectual and developmental disabilities and their families broadly, although some resources referenced are specific to Northern Virginia and the Commonwealth of Virginia. To explore resources specific to your local community, contact the Community Services Board (CSB) in your region. You can find your local CSB by visiting DBHDS (Department of Behavioral Health and Developmental Services) at https://dbhds.virginia.gov/community-%20services-boards-csbs. The CSB is the point of entry into the public funded system of services for people with mental health needs, intellectual and developmental disabilities. Also, visit The Arc of Virginia at www.thearcofva.org to find the local Arc chapter in your community.

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When you first open Getting the Most From Special Education, it's natural to feel overwhelmed by the amount of information it contains. This guide is meant to be a resource you can return to again and again—not something you need to read or act on all at once. Every family's journey is different, and not every section will apply to your child or your situation right now. Think of it as a toolbox: use the pieces that are most relevant today, and know that you can come back later as your child grows and your family's needs change. Take it step by step, focus on what feels most important, and allow this guide to support you rather than add pressure.

GENERAL NOTES

A CHECKLIST FOR PARENTS

A CHECKLIST FOR PARENTS

STEP TO TAKE BY AGE	CHECK IF DONE	NOTES
ASAP		
Organize key documents **pg. 70**		
Create a will **pg. 110**		
Establish a Special Needs Trust **pg. 110**		
Apply for a Medicaid DD Waiver to get on the waiting list **pg. 103**		
Determine if your child is eligible for Supplemental Security Income and Medicaid **pg. 95**		
Write a letter of intent **pg. 92**		
ANNUALLY		
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Update list of teachers **pg. 34**		
Update letter of intent **pg. 92**		
Every 3 Years: Triennial review of eligibility for Special Education **pg. 33**		

STEP TO TAKE BY AGE	CHECK IF DONE	NOTES
AGE 3 YEARS		
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If your child has not been in Early Intervention, contact your local Child Find program. Begin eligibility. **pg. 52**		
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Discuss child's needs with local therapeutic recreation department and explore other recreation options **pg. 116**		
BEFORE KINDERGARTEN		
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Work on developing self-determination so your child can explain their disability and begin to self-advocate **pg. 60**		

STEP TO TAKE BY AGE	CHECK IF DONE	NOTES
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Obtain Metro reduced-fair or MetroAccess ID cards and begin travel training. Ask if there are local public transportation options made free for high schoolers (e.g., Cue, DASH, ART) **pg. 120**		
Invite DARS (Department of Aging and Rehabilitative Services) to IEPs for Pre-Employment and Transition Services (Pre-ETS) **pg. 65**		
Explore eligibility for adult services with school and CSB; complete applications and release of information forms **pg. 107**		
Attend The Arc of Northern Virginia's virtual Transition Lunch and Learn Sessions and/or Annual Transition Series and join our Transition Parent Support Group **pg. 19**		
Learn about The Arc of Northern Virginia's Tech for Independent Living Program to build independent living skills **pg. 75**		

STEP TO TAKE BY AGE	CHECK IF DONE	NOTES
AGES 16-18:		
Deepen transition planning. If there is a Support Coordinator or service provider through Waiver, invite them to IEPs (notify school in advance). **pg. 50**		
If college-bound, research schools, visit campuses, and meet with disability support service offices. Research financial aid. **pg. 62**		
Decide on diploma tract. **pg. 65**		
Begin to explore and discuss employment service programs and meaningful day options for post-graduation. If the goal is independent employment contact DARS for Vocational Rehabilitative (VR) services **pg. 65**		
Build a Supported Decision Making Team and explore our SDM library at thearcofnova.org/sdm **pg. 82**		
Start to pivot toward our Transition POINTS: Transition from School to Adult Life Guide and related resources **pg. 5**		
AGE 17 (OR 12-18 MONTHS BEFORE GRADUATION):		
If college-bound, take required tests and apply in final year of school. **pg. 62**		
Explore employment/day options more deeply and discuss post-graduation funding options **pg. 66**		

STEP TO TAKE BY AGE	CHECK IF DONE	NOTES
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If your child already has Medicaid, start the Disability Determination Process. Visit the Medicaid section at thearcofnova.org/resource-library to learn more **pg. 98**		
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18TH BIRTHDAY AND SOON AFTER:		
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Apply for Supplemental Security Income (SSI) and Medicaid **pg. 95**		
If your child is male, register for the Selected Service at www.sss.gov/register		

STEP TO TAKE BY AGE	CHECK IF DONE	NOTES
AGES 18-22:		
If not already done, apply for Medicaid Waivers and meet with CSB for intake **pg. 103**		
If not already done, apply for DARS services **pg. 65**		
If not already done, obtain Metro reduced-rate transition fare cards/ID cards. Apply for MetroAccess if needed. Continue travel training. **pg. 120**		
Before graduation, determine the service provider that suits your child's needs for either employment or day support services. Apply, coordinate funding and start date. **pg. 66**		

GENERAL NOTES

GENERAL NOTES

THE BASICS OF SPECIAL EDUCATION

THE BASICS OF SPECIAL EDUCATION

Navigating special education can feel overwhelming at first, but understanding the process and knowing where to begin can help you feel more confident and prepared. Special education services are designed to meet the unique needs of children with disabilities, ensuring they receive meaningful access to education and opportunities to succeed.

If your child is between ages 2 (by September 30) and 5, start by exploring preschool options through your local school district. Contact your local Child Find coordinator to begin the process. At age 5, you will register your child for kindergarten and continue working with Child Find if you have concerns about development.

For students entering elementary, middle, or high school, your first point of contact is typically your base school's principal or Special Education Director. No matter your child's age, reaching out early and asking questions is an important first step.

LOCAL SPECIAL EDUCATION WEBSITES

CITY OF ALEXANDRIA

https://www.acps.k12.va.us/departments/teaching-learning-leadership/office-of-specialized-instruction

ARLINGTON COUNTY

https://www.apsva.us/special-education

FAIRFAX COUNTY

https://www.fcps.edu/academics/academic-overview/special-education-instruction

CITY OF FALLS CHURCH

https://www.fccps.org/o/fccps/page/special-education

LOUDOUN COUNTY

https://www.lcps.org/o/doss/page/special-education

PRINCE WILLIAM COUNTY

https://www.pwcs.edu/support_services/special_education/index

SPECIAL EDUCATION PRINCIPLES

Special education is guided by the Individuals with Disabilities Education Act (IDEA), a federal law that ensures students with disabilities are entitled to a free appropriate public education tailored to their individual needs. These services are provided at no cost to families and may include instruction in the classroom, specialized supports, and related services such as therapies. Your child has the right to the "least restrictive environment" (LRE), meaning they have the right to be included in all areas of learning with kids without disabilities to the maximum extent possible.

While IDEA provides the framework, your child's actual educational program is developed collaboratively. You, as a parent or caregiver, are a key member of the team. Your knowledge, perspective, and involvement are essential in shaping an education plan that reflects your child's strengths, needs, and goals.

TAKING THE FIRST STEPS

1. **LEARN THE PROCESS.**
   If you are new to special education or concerned about your child's development or school performance, start by learning how the system works. This includes understanding evaluations, eligibility, and the Individualized Education Program (IEP) or 504 Plan.

2. **BE AN ACTIVE PARTICIPANT.**
   You are your child's strongest advocate. Participating in meetings, asking questions, and sharing insights about your child helps ensure their program is meaningful and appropriate.

3. **UNDERSTAND ELIGIBILITY.**
   To qualify for special education, a child must have a disability that impacts their ability to learn. The school will follow a formal process to determine eligibility.

4. **KNOW YOUR RIGHTS AND RESPONSIBILITIES.**
   Once your child is eligible, you have important rights under IDEA. These include being involved in decisions, accessing records, and agreeing to services. Understanding these rights helps you advocate effectively.

5. **FOCUS ON THE IEP OR 504 PLAN.**
   The Individualized Education Program (IEP) or 504 Plan is the foundation of your child's education plan. It outlines goals, services, and supports. Learning how to develop and monitor an effective IEP is key to your child's progress.

6. **BUILD STRONG COMMUNICATION.**
   Open, ongoing communication with teachers and school staff helps create a collaborative environment. Preparing for meetings and staying organized can make a big difference.

7. **PLAN FOR THE FUTURE.**
   While your child is in school, it's also important to think ahead. This includes planning for long-term needs such as financial security, guardianship, and transition to adulthood.

8. **CONNECT WITH OTHER FAMILIES.**
   Other parents on a similar path can help share their experiences, and you can help them learn from yours. This is a key way to build community. The Arc of Northern Virginia offers several virtual and in-person parent meet up options, especially for tweens and older children, but we can also help you find options that better fit your needs. See our offerings at https://thearcofnova.org/events and reach out at thearcofnova.org/answers for any questions along the way.

REMEMBER

- You know your child best.
- Your voice matters in every decision.
- Planning ahead makes a difference.
- You are not alone—resources and communities are available to support you.

Note: For information on what happens after your child "ages out" of the school system entirely at age 22, see Transition from School to Adult Life at https://thearcofnova.org/program/transition-points

NOTES

First IEP or 504 Plan my student joined	Date I opened this guide

My biggest dreams for my child

My child's biggest dreams for themselves

Two ideas I want to make sure we do

Family, friends, and professionals I trust to be involved

One creative idea I want to try

KEY SPECIAL EDUCATION CONCEPTS AND TERMS

KEY SPECIAL EDUCATION CONCEPTS AND TERMS

Federal law, the Individuals with Disabilities Education Act (IDEA), guides how the special education process is carried out in schools and what rights you have as a parent. This section will make you more conversant with the key principles of IDEA and with some of the basic "alphabet soup" of the law.

FREE APPROPRIATE PUBLIC EDUCATION (FAPE)

A key principle of IDEA is that children with disabilities are entitled to a public education appropriate to their needs, at no cost to their families. "Free appropriate" means that all special education and related services:

- Are provided at public expense
- Meet the standards of idea and the Virginia Board of Education
- Provide appropriate services that are based on your child's needs and allow your child to receive educational benefit from those services.

It is important to remember that the courts have said that **a child must receive meaningful educational benefit** from his education, but **schools do not have to maximize your child's potential.**

LEAST RESTRICTIVE ENVIRONMENT (LRE)

A second principle is that children with disabilities must be educated (including nonacademic and extracurricular activities) with students who do not have disabilities to the maximum extent possible and should attend the school that is closest to home.

IDEA does not use the term "inclusion," nor does it require that every student with a disability be placed in a general classroom regardless of his or her individual needs and abilities. However, it does require the IEP team to consider what kind and how many "supplementary aids and services" could be used to help your child learn in a general education classroom **before** considering a more restrictive placement.

Placement decisions must take into consideration whether your child would benefit more educationally from the general education classroom (with any supplemental services) compared to what he or she would get in a special education classroom, the non-academic benefits from interacting with their non-disabled peers; and the degree of disruption of the education of other students that may result from the inability to meet the unique needs of your student. If your child's behavior is impeding his or her education or that of other students, request a formal Functional Behavior Assessment.

Placement decisions may not be made on criteria such as your child's disability or the availability of educational or related services.

INDIVIDUALIZED EDUCATION PROGRAM (IEP)

The Individualized Education Program (IEP) is a legally binding document that describes the who, what, when, why and where of your child's special education. It sets out the rationale for providing special education supports and services to your child, specific objectives that your child is to achieve during the year and enumerates which related services (e.g., speech therapy), modifications and accommodations, if any, he or she will receive.

The IEP is written cooperatively by a team made up of the parents, educators, principal or principal's designee, the student (when appropriate) and other invited specialists who know the student (e.g., an occupational therapist or speech language pathologist).

For a full explanation of how an IEP is developed, see the section "Getting a Handle on the Individualized Education Program."

504 PLANS

IEP vs. 504

WHAT IS A SECTION 504 PLAN?

This guide will mostly focus on 504 Plans since that is what most children with developmental disabilities use. However, if your child is not found eligible for special education, he or she may qualify for accommodations under Section 504 of Rehabilitation Act of 1973. To be eligible for accommodations under this law, a person must have a

(1) mental or physical impairment that (2) substantially limits one or more daily activities (such as self-care, walking, seeing, speaking, sitting, thinking, learning, concentrating, or interacting with others).

Compared to IEPs, 504 plans:

- Offer **access to the learning environment** but not specialized instruction. Generally, a student with a 504 plan is educated in the general education classroom
- May be helpful to children with a wide range of physical or mental issues ranging from attention deficit disorder, dyslexia, or poor vision to depression, asthma, diabetes, tourette's, or cancer
- Require parental **notification** but not parental participation or consent for evaluation or for writing the plan itself
- Provide no formalized testing. Schools are not required to pay for an outside independent evaluation
- Have no required structure. Unlike an IEP, a 504 plan does not have to be a written document nor include any specific provisions
- Have no age limit. IEP protections stop when a student ages out at 22, but 504 protections may continue into college and the workplace

For a comparison of IEPs and 504 plans, see https://www.understood.org/en/school-learning/special-services/504-plan/the-difference-between-IEPs-and-504-plans

Possible accommodations in a 504 plan include:

- Highlighted textbooks
- Extended time on tests or assignments
- Preferential seating
- Frequent feedback
- Extra set of textbooks for home use
- Computer aided instruction
- Enlarged print materials
- Behavior intervention plans or contracts
- Visual aids
- Oral tests

YOUR RIGHTS UNDER IDEA

IDEA ensures that you as the parent **understand** the special education process and, with that understanding, **give your permission** for your child to participate in special education. In general, your rights are:

- To participate in any meetings in which decisions are made about your child's special education
- To be notified in writing (**prior written notice**) about every proposed action to be taken on behalf of your child or any refusal to take action. Prior written notice must clearly state the action being proposed (or refused) and the reasons for that action
- To give your permission (**consent**) in writing for evaluations of your child and placement in special education. You also have the right to revoke your consent, although not for actions already taken to review your child's school records in a timely fashion

For a more detailed breakdown of rights under IDEA, see table below.

YOUR RIGHT UNDER THE LAW	THIS MEANS YOU...	THIS MEANS THE SCHOOL...
Right to Participate	Participate in any group or meeting that makes decisions about the educational placement of your child May participate by conference call or video conferencing Mutually agree upon a time and place to hold all IEP meetings	Must provide access to evaluations at least two days prior to meeting (to give parents adequate time to review material) Must ensure parental participation in meetings regarding identification, evaluation or placement of child and the provision of FAPE Must obtain parental consent for any change in placement and services
Right to be Notified	Must be informed in a timely matter of all meetings and of any proposed changes related to your child's identification, evaluation or educational placement	Must provide written notice any time it proposes or refuses to change eligibility, requests or refuses to evaluate, or initiates or refuses to change placement of student Must provide notice in native language of parents
Right to Consent	May give or withhold consent to any evaluation OR reevaluation to determine eligibility of your child for special education May give or withhold consent for initial placement of your child in special education and for your child to continue in special education	Must ensure that parent(s) consent before conducting an initial evaluation, reevaluation or functional behavioral assessment, before changing categorical identification in the IEP, before revising services, or before terminating services
If you revoke your full or partial consent	May refuse to consent fully or partially to services proposed by the LEA (Local Education Agency)	Must stop evaluating the student or providing identified special education services BUT has to provide prior written notice before stopping Will not be considered in violation of requirement to provide a free appropriate public education Is not required to provide special education discipline protections if you revoke all services Does not have to change your child's school records to remove references to special education services, although you may request expunging of records

YOUR RIGHT UNDER THE LAW	THIS MEANS YOU...	THIS MEANS THE SCHOOL...
Right to Review Records	Must make a request for records in writing May review any record and request copies if needed	Must provide the requested records without unnecessary delay if records are part of an IEP or a hearing regarding evaluation or placement. In all other cases, records must be provided within 45 days of a request May charge a reasonable amount for making copies
Right to Submit Private Evaluations	May provide information for your child's evaluation from professionals such as psychologists, occupational or physical therapists, speech-language pathologists, etc.	Must review and consider evaluations and information provided by the parent
Right to Request Independent Educational Evaluation (IEE)	Must provide (written) request stating you disagree with the school-provided evaluation. Further explanation is not required Are limited to only one IEE (Independent Educational Evaluation) per school-provided evaluation	Must act "without unnecessary delay" to ensure that an IEE is provided at public expense or file a due process complaint Must provide the criteria by which the evaluation may be obtained
Right to an Interpreter	Must provide informed consent and therefore must be able to understand and take part in IEP decisions	Must provide an interpreter (including sign language interpreter)
Right to Have Required Members in IEP Team	May invite other individuals who have knowledge of the child to IEP meetings	Must ensure that at a minimum, the following are part of the IEP team: • parent • at least one general education teacher of the child, if receiving or will be receiving general ed services • at least one special education teacher of the child • a representative of the LEA who can address the provision of special education services • a person who can discuss the evaluations (if not one of the above) • the child (when appropriate)

** Please be sure to consult an attorney if you have questions about your rights.*

GENERAL NOTES

LEARNING ABOUT SPECIAL EDUCATION

LEARNING ABOUT SPECIAL EDUCATION:

REFERRAL, EVALUATION & ELIGIBILITY

There are five steps in the special education process, and each step builds on the previous one. Throughout the process, information is gathered and considered by a group of people, including you, within certain timelines and with certain procedural safeguards.

For more detail on the special education process, see the Virginia Department of Education's handbook at https://www.doe.virginia.gov/programs-services/special-education/information-for-families/virginia-family-s-guide-to-special-education and VDOE's Guidance on Evaluation and Eligibility https://www.doe.virginia.gov/programs-services/special-education/evaluation-and-eligibility.

STEP 1: IDENTIFICATION AND REFERRAL

There are two primary ways in which children are identified as possibly needing special education and related services: through the system known as Child Find (which Virginia must operate by law), and by referral from a parent or school personnel.

Parents are often the first to notice that their child's learning, behavior, or development may be a cause for concern. If you are worried about your child's progress in school and think he or she might need extra help from special education services, email or write to your child's teacher, the school principal, or the Director of Special Education in the school district. Although you may make this request in person or by phone, **it's best that it be in writing**, which can be email to school staff.

The special education administrator has **three business days** after receiving the referral to decide how to proceed with the request. In most cases, the administrator will refer the matter to the school-based team, which then has 10 days within receipt of the referral to convene and determine whether evaluations of the student are necessary to determine eligibility.

Parents of kindergarteners who did not receive special education services in preschool may ask for an initial screening at any time. Students may also be referred by a teacher, school administrator, Virginia Department of Education, any state agency or any individual.

NOTES

Date you contacted the school or they contacted you about a possible special education evaluation	**Date you heard from the school about next steps**
Date you heard about evaluation plans	**Which professionals will be part of the evaluation**

STEP 2: EVALUATION

Once your child is identified as possibly needing special education services, **he or she must be evaluated. This is the law** and is the only way the school system can:

- determine if your child has a disability as defined by IDEA
- determine whether your child needs special education services due to the manifestation of that disability
- make decisions (with your participation and consent) about appropriate educational programming

You must give your consent for the evaluation to proceed. The school system has **65 business days** from the date it received the initial referral to complete the testing, write an evaluation report(s), and make a decision about whether your child is eligible for special education.

By law, the evaluation must be "full and individual," looking at all areas related to the child's suspected disability: cognitive, communication, social, psychological, and physical. If there is an area of life where you know you want the school to evaluate your child (e.g., an Occupational Therapy assessment to look at their handwriting), you can request that in writing along with your request for the evaluation itself. Those requests are stronger when you give a reason for your concern, which could include family history, home observations, or things you've read and learned about developmental milestones. The school system must use a variety of tests to determine eligibility for special education. The evaluation reports must be made available to the parents at least two days before the eligibility meeting (make a written request to have a copy provided to you rather than going to the school to review the reports). Types of tests or assessments may include:

- Classroom observations
- Psychological evaluation
- Educational testing
- Functional behavioral assessment (to get a better understanding of how your child behaves in a variety of settings and situations)
- Speech and language testing
- Physical exam (on general health, vision and hearing)
- Assessments related to speech, fine motor skills, or gross motor skills
- Reviews of your child's existing school records
- Interviews with you and your child's teacher(s)
- Other information parents wish to share, such as assessments you've paid for privately. You can contribute to the process by noting the areas of educational concern to you, and giving the IEP team leader a written list
- You may consent to all or some of the recommended assessments

Once all the assessments are completed, the school writes a report that includes a list of all the tests performed, a summary of the results/scores, and an explanation of what the results mean. You can ask to have the results of any assessment explained to you before the IEP meeting (you have the right to ask for this). You will then have time to absorb the information and decide how you would like to have the IEP team use the results. **Again an evaluation does not result in a diagnosis or even in recommendations for services** (this is done in the eligibility meeting).

Once you see the evaluation report, if you disagree with the results or have questions, make an appointment to speak with the IEP coordinator. If your concerns are not answered in this meeting, send a letter or email outlining your concerns and highlight the information in the report with which you disagree.

You also have the right to request an evaluation from an outside expert at the school district's expense (called an Independent Educational Evaluation or IEE). If the school district denies your request, it must provide an answer within 5 calendar days and initiate a due process hearing. Document your request for an IEE in writing. The request need only state that you disagree with the school's evaluation and you request an IEE. The school district will then send you a letter indicating the criteria for the IEE.

TIP: **Evaluation vs. Diagnosis**

It's important to understand that evaluations for the purposes of special education do not result in a diagnosis.

Having a medical diagnosis is not needed for your child to qualify for special education. Instead, your student must qualify under one or more of the 13 categories of disability outlined in IDEA. In many cases, this "disability eligibility category" is different from a medical diagnosis.

For example, a child with cerebral palsy (medical diagnosis) may be eligible under the "Orthopedic Impairment" disability category. A child with ADHD may be eligible under the "Other Health Impairment" category.

NOTES

Date you gave consent for an evaluation	**Professionals involved in evaluation**
Date you provided information to the school for the evaluation (e.g., family history and home observations)	**Date you received the evaluation report from the school**
Questions about the evaluation report	**Any other opinions you think are missing**
Assessment findings	**Suggestions on goals/services from the assessment**

STEP 3: DETERMINATION OF ELIGIBILITY

Next, the IEP team meets to discuss the results of the evaluations and decide if your child is eligible for services. You have the right to ask about the rationale for choosing a particular test or set of tests and what the results of a test battery mean in clear and plain language. For an explanation of how data and scores are used, see https://www.understood.org/en/school-learning/evaluations/evaluation-basics/what-special-education-testing-evaluations-results-mean

To qualify for special education services, (1) your son or daughter must have one of 14 disabilities as defined in the IDEA (see list below); (2) the disability must adversely affect the his or her education; and (3) the child requires special education and related services.

IDEA'S DEFINITION OF DISABILITY.

Federal law lists 14 disability categories under which a child may be found eligible for special education and related services. These categories are:

- Autism
- Deafness
- Deaf-blindness
- Developmental delay (used for children ages 3-9)
- Emotional disturbance
- Hearing impairment
- Intellectual disability
- Multiple disabilities
- Orthopedic impairment
- Other health impairment
- Specific learning disability
- Speech or language impairment
- Traumatic brain injury
- Visual impairment, including blindness

The disability must adversely affect the student's education, including his or her academics, ability to socialize with peers and teachers, and ability to physically navigate the school, among other issues. Examples of adverse impacts include:

- Limited progress, or deficiency in cognitive areas
- Evidence of emotional or behavioral disturbance
- Problems with fine or gross motor skills

If your child's performance is NOT hindered by their disability, he or she may not qualify for services, even if he or she has one of the 14 disabilities.

If your child is not found eligible, the school MUST provide you with prior written notice; you also have the right to appeal the decision. Parents can request an IEE, mediation, or an administrative review; you may also file for due process or discuss eligibility for a Section 504 Plan.

NOTES	
Date of eligibility meeting	**IEP category for eligibility**
People in the meeting	**Questions you want to remember to ask**
General Notes	

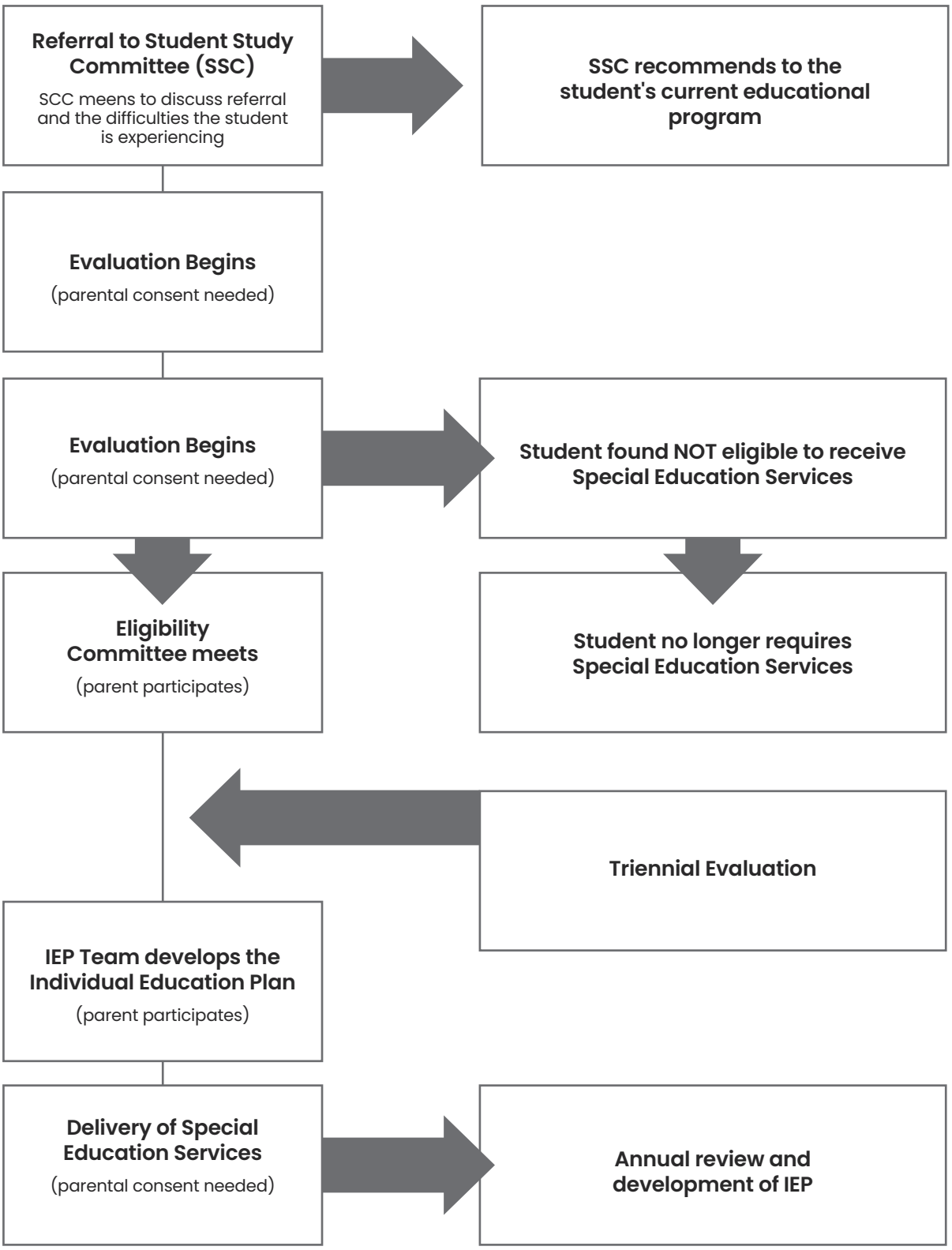
STEP 4: WRITING THE INDIVIDUALIZED EDUCATION PROGRAM (IEP)

You must consent in writing to the eligibility determination. If your child is found eligible to receive special education and related services, the team then has 30 calendar days to write an Individualized Education Program (IEP) to meet the needs of your child. The IEP must be reviewed and revised at least annually. The process of developing and implementing an IEP is described in more detail in the next section, "Getting a Handle on the IEP."

NOTES	
Day IEP meeting is scheduled	**People I want to invite to IEP meeting**
General Notes	

STEP 5: REEVALUATION

At least every three years, a team must reevaluate your child to determine whether he or she continues to need special education. Again, you must give your consent for any recommended assessments and for any continued or change in placement in the special education program.



* Adapted from Arlington County Public Schools "Special Education Cycle".

GETTING A HANDLE ON THE IEP

Once your child has been found eligible for special education services, it is time to develop his or her Individualized Education Program (IEP). An IEP is a written document developed by the IEP team (including you as the parent) that will guide your child's education based on your child's unique needs. The overall goal of an IEP is to prepare your child for further education, employment and independent living. The IEP answers the following questions:

- Why does your child need special education?
- Which special education services will be provided by the school?
- Will your child receive related services, and what are they?
- Who will be working with your child (general and special education teachers, speech therapists, or occupational therapists, for example) and how much time each week they will be spending with your son or daughter?
- What goals your child will be working on for the next year (365 days)?
- When, where and how will those goals are to be achieved?

Keep in mind that **the IEP process is guided by law and that the IEP itself** is a written document with multiple parts also required by law that **has the status similar to a contract between you and the school system.**

IEPs must by law include the following sections:

1. Present levels of academic achievement and functional performance
2. Annual goals stated in measurable terms. This section may also include benchmarks or short-term objectives
3. Measurement on how progress will be reported
4. Accommodations in assessment: how your child will participate in Virginia's Standards of Learning testing
5. Statement of how special education and related services and supplementary aids will be provided to your child
6. Service delivery: when, where and frequency with which the child will receive which services
7. Extent of nonparticipation with nondisabled peers in the classroom and other school settings
8. Transition planning included in the IEP in which your child turns 14
9. Statement on the age of majority (student must be told a year prior to the child turning 18 about the rights that will transfer to him or her at that time)

More information about the IEP can be found at www.parentcenterhub.org. More about the IEP in Virginia schools can be found at: https://www.doe.virginia.gov/programs-services/special-education/information-for-families/virginia-family-s-guide-to-special-education

IEP TEAMS

At IEP meetings, you and the rest of the team work together to write an IEP based on your child's unique needs and on which the team agrees. During the meeting, each person takes a turn in the discussion. The discussion will include talking about your child's strengths, your concerns for enhancing the student's education, the results of the most recent evaluation(s) of your child, and the student's academic, developmental, functional and behavioral needs.

Bring your own list of priorities to the meeting and share these as the meeting goes along. As a parent, you are an equal member of the IEP team and an expert on your child. **IEP team members are required to work together** to design an effective program for your child. The main purpose of the meeting is to agree on each part of the IEP so that the document can be written and services can start.

Believe in your own expertise. You are the expert on your child. While teachers are the educators, they need your insights into what works (or might work) in school with your son or daughter. Be willing to share your experiences from home and the community, as well as the kinds of teachers and tools that have worked well for your child in the past, and those that have not.

Make all requests in writing. As mentioned several times in this guide, your written request or consent starts the key timelines in the special education process. Written requests force you as the parent to be very clear in what you are asking for, and creates a "paper trail" in case of any dispute.

Make the IEP team accountable for any request you make. Under the Prior Notice portion of IDEA, if you make a request in an IEP meeting, the school must provide you with Prior Written Notice that includes, among other things: a description of what action the school is going to take (or not take) and why; what basis the school used to accept or reject your request; and what other options the school considered and why.

Spend time on understanding your child's levels of performance and on developing goals. Focus on placement at the end. Goals and objectives, which flow from present levels of performance with baseline data, must be written before a placement decision is made. Because schools must consider placement in the least restrictive environment as a first option, you and the IEP team must go through each and every goal and ask if that goal can be met in the general education classroom (with or without modifications or support).

Tip: Consider bringing other people—spouse, other family members, friends—with you to the IEP meeting to provide support. You can also hire advocates or Special Education attorneys to help you before, during, and after the meeting. They can attend with you if you would like, though schools generally ask to know who is coming in advance of the meeting. You can find a list of these professionals at https://thearcofnova.org/resource-library/#special-education

See "Ten Common Mistakes Parents Make During an IEP Meeting" for more detail.
https://kidstogether.org/10-IEP-mistakes

Are you a Fairfax resident: In Fairfax County, The Office of Special Education Procedural Support provides guidance and resources to parents and students on the implementation of and compliance with the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act. 571-423-4101
https://www.fcps.edu/academics/academic-overview/special-education-instruction/procedural-support-services

NOTES

What I most want to see in the IEP

My big dreams for my child

The therapies my child needs

What works well for my child to help them learn

What does not work well for my child

What kind of environment do I think would be ideal for my child

Partners I want at my IEP

Times I requested updates and changes, and how it went

General Notes

THE NITTY GRITTY: 9 KEY COMPONENTS OF AN IEP

Now we'll take a deeper dive into each of these parts of the IEP so you know what to look for, expect, and request for your student.

1. PRESENT LEVELS OF PERFORMANCE

The Present Levels of Performance are the most critical part of the IEP, yet experts say the importance of this section is often overlooked by parents.

Present Levels form the rationale for the rest of the IEP, describing how your child's disability affects his or her school work and his or her ability to function in the school setting (such as being able to go to the bathroom by himself or get along with peers).

With a well-written Present Levels of Performance, the IEP team is able to write the rest of the IEP, including sections on how and where your child would receive special education services, whether accommodations are needed, and which (if any) related services like speech therapy may be appropriate.

Present Levels must include information on **functional and behavioral as well as academic levels of performance**. A well-written present level will describe:

- what your child's strengths and weaknesses are academically, behaviorally, and functionally
- what helps your child learn
- what limits or interferes with his or her learning
- objective data from current evaluations of the child
- how your child's disability affects his or her ability to be involved and progress in the general curriculum

In developing this section of the IEP, the IEP team may use information from:

- **Testing and evaluations,** which may be conducted by the school or privately. If your child is new to special education, the information will come from the tests and observations done during the child's evaluation for eligibility. If your child's IEP is being revised, the information may come from evaluations done during the year
- **Observations** from teachers and others who work with the child
- Information gained during the child's day-to-day school routine (such as **classroom participation, homework, projects or test papers**)
- **Parents** also provide information that help shape the child's "present levels" statement

Academic Levels of Performance. Academic achievement generally refers to the academic subjects a child studies in school and the skills the student is expected to master in each: reading and language arts, writing, math, science, history, and so on.

Functional Levels of Performance. Functional performance refers to skills and activities of everyday living such as (1) dressing, eating, going to the bathroom; (2) social skills such as making friends and communicating with others; (3) behavior skills, such as knowing how to behave across a range of settings; and (4) mobility skills, such as walking, getting around, going up and down stairs.

TIP: **Especially for Preschoolers**

The concept of "present levels" is slightly different for preschoolers; there are no "academic" levels of functioning since your child has not yet entered school.

Instead, the present levels statement needs to talk about how your child's **disability affects activities typically done by a preschooler**. These activities include (but are not limited to):

- coloring
- using scissors
- grouping things
- playing games with peers (individually, in small groups, or in large groups)

2. ANNUAL GOALS

The importance of the Present Levels section is key to the team's ability to set annual goals for your child.

IEP goals point to what your child will be trying to achieve both academically, behaviorally and functionally in the coming school year. This can be challenging since goals may be needed in a wide variety of areas.

In thinking about a goal, the first step is to make sure there is a **direct link between a need spelled out in the Present Levels and the goal**. Then ask:

- What can my child currently do in the areas of academics, extracurricular activities, or functioning within the school day?
- What challenging, yet attainable, goal can we expect him or her to attain in a year? How can this be expressed as a measurable skill or level of performance?
- How will the school team know when my child has reached this goal? There must be a way to measure your child's progress.

To be valuable to your child, an IEP goal must (1) be directly related to one of his or her needs as described in the Present Levels of Performance AND (2) be measurable. A goal for this year might be a stepping stone to a larger goal over a number of years.

Goals may address a wide range of academic, behavioral and functional issues that may, for example, help a student:

- feed him or herself more independently
- use public transportation
- solve algebraic equations
- communicate with an augmentative communication device
- control impulses or anger
- initiate conversation
- write more legibly
- extend eye gaze
- learn basic number facts
- learn to read Braille

TIP: **The Well-Measured Goal**

Making an IEP goal measurable is the only way for you and teachers to tell whether or not your child is making progress. A well-written goal will include:

- **A timeframe:** by the end of the first grading period, in 12 weeks, by the end of the school year.
- **Conditions** under which the student will be performing: when presented with 2nd grade level text; given a story prompt; given a pencil grip; using assistive technology.
- **The desired action:** Michael will solve 2-step equations; Juan will initiate a conversation; Jen will point to her picture system; Tom will sit in his chair.
- **Performance indicator(s)** that identifies how much, how often, or to what standards the behavior must occur: solve addition problems with 90% accuracy; earn 4 or better when graded according to the 6-trait writing rubric; achieve a reading score at the 5th grade level or above, as measured by the Qualitative Reading Inventory (QRI).

From Center for Parent Information and Resources at
http://parentcenterhub.org/repository/iepgoals/#prompts

3. MEASURING AND REPORTING PROGRESS

Your child's IEP must also describe how and when the school will report progress toward meeting the annual goals.

Criteria used to evaluate progress toward a goal must reflect the measures chosen in the goal itself. If your child is to perform a task with "80% accuracy," then progress must be noted against that criterion.

Information for assessing progress may come, for example, from teachers' observations; a review of classwork and homework assignments; test and quiz results; and informal or formal standardized assessments (such as the Woodcock Johnson).

Schools must report on progress on special education goals at least as often as report cards come out.

TIPS:

The IEP is a legal document, and the school is obligated to carry it out. You can help by monitoring your child's progress and bringing up any concerns with the IEP team. To keep track of progress:

- Observe your child's behavior at home and their comments or attitudes about school
- Check your child's homework every night (or other interval, as appropriate)
- Ask for copies of any visual charts or schedules used in school
- Request a home-to-school communications log (in a notebook that goes back and forth in your child's backpack) or via email
- Look out for improvements (or deterioration) in skills, such as his or her comprehension of subject matter or ability to do homework independently
- Read carefully the progress reports from the IEP team
- Ask for the data collection that supports the progress reports

Remember that parents and the school are equal partners in the special education process. If you do not agree with the recommendations of the IEP staff or a report, it's important to talk about it with the staff. Be clear about what it is you don't agree with. If the team agrees that other services are needed or the recommendations aren't appropriate, it has the power to make different decisions.

4. SPECIAL EDUCATION SUPPLEMENTARY AIDS & SERVICES AND RELATED SERVICES

This is the nitty gritty of what constitutes your child's special education program. Again, special education is instruction designed to address a specific child's needs that result from his or her disability. Instruction, schoolwork, and homework are tailored to the needs of the child.

SUPPLEMENTARY AIDS AND SERVICES

Supplementary aids and services are intended to improve your son or daughter's access to learning and his or her participation in academic, extra-curricular, and non-academic activities and settings. You and the rest of the IEP team must determine what supplementary aids and services a child will need and specify them in the IEP.

Modifications are changes in what is being taught to or expected from the student. Making an assignment easier so the student is not doing the same level of work as other students in their grade is an example of a modification.

Sample Modifications

- **Instruction:** reducing the difficulty of assignments; reducing the reading level; highlighting key words or phrases; assigning projects instead of written reports
- **Materials:** film or video supplements in place of reading text; word bank of choices to answer questions; reword questions in simpler language
- **Scheduling:** modifying length of assignments/texts
- **Behavioral:** providing breaks between tasks; using positive reinforcement; giving daily feedback to student; charting progress

Accommodations are changes that help your child to overcome or work around the disability. Allowing a student who has trouble writing to give his answers orally is an example of an accommodation. Here, the student is still expected to know the same material and answer the same questions as fully as the other students, but he doesn't have to write his answers to show that he knows the information.

However, the school must also ensure that any special classes, separate schooling, or other removal of children with disabilities from the general educational environment occurs only if the nature or severity of the disability is such that education in general classes cannot be achieved even with the use of supplementary aids and services.

Sample Accommodations

- Scheduling: establishing a schedule; giving extra time to complete assignments; providing checklist for tracking tasks; integrating rest breaks
- Setting: sitting at front of classroom; using a special chair; working in a small group; removing distractions in classroom; providing a quiet space
- Materials: using special lined paper for writing or graph paper for math problems; providing audiotaped lectures or books; using large print or Braille texts; using a pencil grip; using calculators
- Student Response: allowing answers to be given orally; using sign language, a communication device, or Braille; using headphones when environmental stimuli are overwhelming
- Testing: allowing open book testing; having teacher read test directions or test questions; providing study guides prior to testing; breaking up testing over several days or having untimed tests http://www.smartkidswithld.org/getting-help/the-abcs-of-IEPs/examples-of-accommodations-modifications

RELATED SERVICES

To help a child with a disability benefit from special education, he or she may also need additional support in other areas, such as speaking or moving. This additional support comes in the form of related services. These services include, among others:

- speech therapy or audiology services
- interpreting services
- psychological services
- physical therapy
- occupational therapy
- recreation, including therapeutic recreation
- counseling services
- orientation and mobility services
- school health services and school nurse services
- social work services
- transportation

Evaluations conducted earlier in the process are used to determine your child's need for one or more related services. Goals can be written for a related service just as they are for other special education services. The IEP must also specify when the service will begin; frequency with which it will be provided and for what amount of time; where it will be provided; and how it will be measured.

Changes in services listed in the IEP cannot be made without parental consent and a change to the IEP.

PROGRAM MODIFICATIONS FOR SCHOOL PERSONNEL

Also part of the IEP is identifying services or supports that the school staff may need to help your student be successful. These supports may include:

- attending a conference or training related to your child's needs
- getting help from another staff member or administrative person
- having an aide in the classroom
- getting special equipment or teaching materials

MAKING A PLACEMENT DECISION

One of the guiding principles of IDEA is that children with disabilities must be educated (including nonacademic and extracurricular activities) in the Least Restrictive Environment, that is, with students who do not have disabilities.

While the law does not require that every student with a disability be placed in a general classroom, it does require the IEP team to **consider** first what kind and how many "supplementary aids and services" could be used to help your child learn in a general education classroom **before** considering a more restrictive placement.

Placement decisions may not be made on criteria such as your child's disability or the availability of educational or related services. Nevertheless, some students with disabilities may benefit from more intensified, focused programs. Local school districts have developed specialized programs to meet those needs, but parents should be aware that choosing one of these would be considered a more restrictive placement. Studies also show students, even those with significant disabilities, gain tremendous benefits from inclusive educational experiences. It is very difficult to shift from segregated educational settings back to inclusive settings, so a move toward a more restrictive environment should be made with careful consideration.

5. EXTENT OF NONPARTICIPATION

The IEP must also include an explanation of the extent, if any, to which your child will not participate with their nondisabled peers in the general class and in other school settings and activities.

The explanation of nonparticipation should reflect the child's needs and not be based on the needs or convenience of the school. Again, while inclusion is not required by law, there must be a statement in the IEP clarifying the amount (if any) a child will NOT be in the general education environment.

6. ACCOMMODATIONS IN ASSESSMENT

IDEA requires that students with disabilities take part in state and districtwide assessments. In Virginia these are the Standards of Learning (SOL) assessments given in 3rd-12th grades.

While Virginia permits accommodations during SOL testing, the IEP team must consider whether these are necessary for your student to be able to take the SOL, whether your child (and the school) are experienced with the accommodation, and whether the accommodation affects the "integrity and security" of the test.

Accommodations must be implemented throughout the school year and documented in the IEP if they are to be implemented during statewide assessments.

Accommodations in testing may include:

- Adjusting the time of day the test is administered
- Having the test read to the student
- Allowing an assistive device or organizer during the assessment
- Giving the test in Braille or sign language
- Giving the student a quiet place outside the classroom for taking the assessment
- Allowing answers to be marked in test booklet instead of an answer sheet
- Permitting breaks during the test-taking session
- Allowing extra time to complete the test

A complete list of accommodations allowed by the Virginia Department of Education can be found in *Students with Disabilities: Guidelines for Assessment Participation* at: https://www.doe.virginia.gov/teaching-learning-assessment/student-assessment/virginia-sol-assessment-program/participation-inclusion

If your student is looking toward post-secondary education, but is unlikely to pass SOL tests even with accommodations, they can pursue a Special Permission Credit Accommodation that would allow them to get full credit for high school classes that usually require passing an SOL. https://thearcofnova.org/resource-library/#special-education

ALTERNATE ASSESSMENTS

Sometimes the IEP team may determine that it is inappropriate for a specific child to participate in the state's SOL testing even with accommodations (due to a significant cognitive disability, for example).

If you believe this may apply to your child, have the team consider using the Virginia Alternate Assessment Program (VAAP). Requirements and procedures for the VAAP may be found at https://www.doe.virginia.gov/teaching-learning-assessment/student-assessment/virginia-sol-assessment-program/virginia-alternate-assessment-program-vaap Choosing the VAAP will affect diploma options.

7. DELIVERY OF SERVICES: WHERE & WHEN

This section of the IEP lists details about the delivery of special education instruction and related services:

- the frequency with which he or she will receive the service(s) (number of times per day/week/month)
- length of time each "session" will last (number of minutes)
- where services will be provided (in the general education classroom or another setting such as a special education resource room)
- when services will begin and end (starting and ending dates)
- whether they are regularly scheduled or intermittent in the special education or general education setting

EXTENDED SCHOOL YEAR (ESY) SERVICES

The IEP team should in a timely manner, also consider whether or not your child needs to receive services beyond the typical school year (e.g., during the summer, over the winter break, after school). This is called Extended School Year or ESY services.

In considering ESY for a student, the IEP team considers:

- regression/recoupment
- degree of progress the student is making on his/her IEP
- emerging skills/breakthrough opportunities
- interfering behaviors
- the nature and/or severity of the disability
- special circumstances or other factors

In essence, the team must answer the following question: will the benefits the child gained during the regular school year be **significantly jeopardized** if he or she is not provided with the ESY program? If the answer is "yes," then the child must receive ESY services in order to meet the criterion of a free appropriate public education (FAPE). For a handbook on ESY, see https://www.doe.virginia.gov/programs-services/special-education/specific-disabilities.

If you think your child may benefit from ESY, you can keep track of any regressions you see over winter or spring breaks or other notable time away from school to use as justification for the need for ESY.

8. TRANSITION PLANNING

A key component of IDEA, transition planning facilitates the student's move from school to post-school activities. The transition planning must start no later than the first IEP to be in effect when your child reaches 14; be individualized; be based on the student's strengths, preferences, and interests; and include opportunities to develop functional skills for work and community life.

The IEP team, including your child, develops annual goals that are academic and functional, as well as, post-secondary goals that focus on employment, education, and/or training, and independent living skills. As with goals developed in other IEPs, post-secondary goals must be measurable and have a timeframe.

Examples of post-secondary goals that can be worked on while in high school:

- Greet supervisor every day using appropriate eye contact, 4/5 trials, by Feb 15
- Learn to use smartphone, including calling and texting and entering needed phone numbers into contacts with no more than one prompt in 4/5 trials by June 1.
- Enroll in one technical education class per semester in chosen field of interest
- Attend two transition or employment fairs by November 30
- Draft a resume using the sample provided by the guidance counselor by October 15
- Before bedtime, check that work uniform is clean and presentable for the next day with no prompts, 4/5 trials through June 1

Examples of post-secondary training goals1:

- Complete study skills course at the community college after high school
- Complete travel training to use public transit to/from work independently
- Complete on the job training to improve work skills

Examples of post-secondary education/vocational education goals:

- Complete coursework to become a licensed home health care aide/nurse's assistant
- Complete a sign language class, with supports, at a community college
- Complete the requirements for an Associate's Degree in Automotive Technology

Examples of post-secondary employment goals:

- Work part-time as a home health care assistant
- Be employed as a ticket scanner at a sports arena
- Work part time in a retail store

Examples of post-secondary independent living goals:

- Acquire and take medication according to schedule
- Use a digital scheduler to be on time for volunteer work
- Vote in local, state, and national elections
- Plan a leisure or recreation activity

See the section in this guide on "Middle and High School: The Transition Years" for more information on the transition process.

Examples taken from "Development of Postsecondary Goals," Virginia Dept. of Education Guidance Document, 2011.

9. TRANSFER OF RIGHTS AT AGE 18

In Virginia, a person is considered an adult once he or she turns 18. Adults have the right, among others, to: vote, make a will, engage in contracts (sign a lease, sign up for cell phone service), apply for credit, get married, and make personal medical decisions. In school, 18-year-olds may sign themselves in or out of school, sign field trip permission slips, and choose their coursework.

Beginning at least one year before the student reaches the age of majority, the IEP itself must include a statement that the student has been told about the rights that will transfer to him or her at age 18. Although the student does not reach the age of majority until age 18, development of self-determination skills must begin much earlier that during the transition planning years. Self-determination must begin as early as elementary school.

GENERAL NOTES

NOTES

Things I want to make sure the school knows about my student's performance and needs at home	**Things that I want to make sure become goals in the IEP**
How I want to have the school communicate data and other updates with me? Is it in the IEP?	**Aids, services, and modifications that make a big difference for my student**
Extra therapies we want to preserve in school	**Things that I know help my student test better**

NOTES

Considering ESY—Is this a good tool for us? What skills regress most without regular use?	**First transition IEP date**
First date student attended IEP	**Main dream for transition**
Biggest social/soft skill need	**Biggest work skill need**
Biggest life skill need	**Legal authority options considered**

GENERAL NOTES

SPECIAL EDUCATION:

Entering at Preschool Through Exiting at High School

ENTERING SPECIAL EDUCATION: TRANSITIONING TO PRESCHOOL AGES 2–5

If your toddler has a developmental delay or disability, he or she may be eligible for services through a preschool program in your local school system. Toddlers may enter the special education system from an early intervention program (as early as 15 months of age) or through a referral from you (the parent) or your child's pediatrician beginning at age 3. If they are found eligible for special education services, your child may receive services in a preschool program, child care, recreation classes, private therapies, etc.

OPTION 1: IF YOUR CHILD HAS BEEN IN EARLY INTERVENTION

Your child is eligible to stay in the early intervention program until the age of 3. However, you may choose to begin special education services in the school system if your toddler reaches the age of 2 by September 30 the year that you would like to begin a preschool program.

EARLY INTERVENTION VS. SPECIAL EDUCATION

In general, the biggest change from an early intervention program to a special education program is that the focus shifts from family and developmental needs to a focus on the child and his or her educational, behavioral, and functional needs. In essence, the "rules" change on the kind of goals your child needs, and who, when, where, how, and the frequency of any special education services may be provided to meet those goals. This change has several implications.

- Special education services focus on improving academic, behavioral, and functional outcomes for your child, and are carried out at home or in a community preschool setting, early childhood special education classroom, community-based setting, etc. It is the decision of the IEP team, of which you are an integral and required member, to determine where special education and related services take place.
- The legal document guiding your child's special education services changes from an Individual Family Service Plan (IFSP) to an Individualized Education Program (IEP). In addition to the parents, a whole team works on the IEP. This team includes people like special education teachers, general education teachers, service providers like therapists, and a special education administrator. Your early intervention team members may also participate in the IEP process, if it occurs before your child turns 3 years old, but you can still request for them to join after your child turns three. You may also invite people who are familiar with your child- friends, family members, advocates, private therapists, etc.

INDIVIDUAL FAMILY SERVICE PLAN VS. INDIVIDUALIZED EDUCATION PROGRAM

ISSUE	IFSP (EARLY INTERVENTION PROGRAMS)	IEP (PRESCHOOL - AGE 21)
Age	Infant to 3	3 to 22 (may start at age 2 if child enters preschool at that age)
Legal status	Legal document	Legal document
Why you need this document	Focuses on the developmental needs of the child & services that the family needs to enhance the child's development	Focuses on the functional, behavioral, and educational needs of the child & services that can be carried out in school
What's in the document	• in-depth assessment of child's present levels of development • outcomes desired for the child and family; • services the child and family will receive to help them achieve the outcomes • methods, timelines and plan to measure progress • with the family's approval, it may also include information regarding the family's resources, priorities, and concerns related to the development of their child Family determines which outcomes will be in the plan.	• present levels of functional, behavioral, and educational performance and participation in developmentally appropriate activities • measurable annual academic, functional and behavioral goals for educational needs (academic, social, emotional, physical, etc.) • how and frequency that progress will be measured • how progress will be reported to the family • may include information about the family's concerns for enhancing the child's education • services and accommodations guaranteed under the IEP IEP team, including the parents and student, determine the goals.
Who is involved in developing the plan	Team may include: • a parent(s) of the child • other family members as requested by parent • advocate or person outside the family, if requested by parent • service coordinator • individual(s) involved in conducting evaluations and assessments	Team must consist of: • Parent(s) of child • student's general education teacher • student's special education teacher • representative from school district who can commit resources • person who can interpret results of evaluations The team may include others who have knowledge or special expertise about the student
Which services may be provided	Includes the early intervention services and supports necessary to meet the unique needs of the child and family in order to achieve the identified outcomes	Includes the special education, related services, supplemental aides and services, accommodations, modifications, and supports to be provided to help the child make progress and participate in school
Where services are carried out	In the child's home	Before school, in school and after school

TIMING FOR TRANSITIONING TO PRESCHOOL.

The timing is a bit complicated, but your service coordinator from Early Intervention can help you decide when and how to begin the transition. The referral must occur at least 90 days before your child must move into a preschool program (age 3) but no more than nine months prior to when your child may transition into preschool (age 2), which means as early as 15 months, but no later than 33 months of age. This time is spent completing the assessments and paperwork needed to move into the special education system.

Talk to the early intervention team and discuss the pros and cons of transitioning your child out of early intervention at the age of two or staying until his or her 3rd birthday. Keep in mind, if you choose to transition out at the age of two, your child can go back if you decide it was too early.

OPTION 2: IF YOUR CHILD HASN'T BEEN IN EARLY INTERVENTION

Virginia public schools offer Child Find, which provides free screenings and/or evaluations for children 2-5 years of age suspected of having developmental disabilities or delays. You may call the Child Find office yourself anytime if you feel like your child should be evaluated. You do not need a doctor's recommendation.

- **Become a specialist on your child.** If you are concerned about certain behaviors (or lack thereof), keep notes or make videos that detail what the behavior is, when it occurs and where, and how long it lasts. The goal is to get as accurate a picture as possible of how your child is reacting to you and the environment. You can then present something concrete to the pediatrician and the Child Find team.
- **Talk to your pediatrician.** Pediatricians typically ask development-related questions during well-child checkups. During this conversation, bring up your concerns with whatever documentation you have. If the doctor shares your concerns, he or she may screen your child in the office for developmental delays (ask for a copy of the results) or refer you to a developmental pediatrician or therapist. Ask for a referral to the Child Find coordinator if you haven't called yourself yet. Even if your pediatrician does not share your concerns, you can still refer your child to Child Find. Trust your instincts.
- **Consult with the specialists.** At a minimum, specialists will be able to give you a better handle on your child's issues, although you may not get a diagnosis right away. Again, it is important to share your own observations about your child's behavior and development because it provides a context for what the specialists are seeing during their own evaluations. It can take a long time to make the rounds of specialists, but your child can participate in special education while you wait for a formal medical diagnosis.
- **Use any diagnosis to your advantage.** That diagnosis is the key to ensuring your child gets access to timely interventions and supports. The sooner and more comprehensive the interventions offered, the fewer long-term needs you may see. The diagnosis is just a tool to open doors to help your child, but it doesn't change who your child is. The diagnosis will also help guide you in doing your own research and in seeking support for yourself and your family.

GETTING STARTED: REFERRAL AND ELIGIBILITY

However your toddler enters a preschool program, the steps involved include:

- Referral to a preschool special education program
- Assessment of developmental progress (which may require several assessments with different therapists)
- Determination of eligibility
- Writing of an individualized Education Program

Each of these steps is discussed in more detail in the previous sections.

Some children make enough progress in early intervention that they do not qualify for special education services in preschool or elementary school. However, if you and the IFSP team believe your child might be eligible for special education services in a preschool setting, then a referral is made to the Special Education Director in your school district. This starts the 65-day timeline for eligibility to be determined.

If additional assessments are needed to determine eligibility, the child will be reviewed by a child study team. That team includes you as the parent. Request that specialists in each area of need (educational, speech, fine motor, etc.) evaluate your child.

For students entering kindergarten from preschool, teachers usually begin scheduling IEPs in the spring to support the move into kindergarten. Children do not need to be "ready" to transition to kindergarten, as their IEP for elementary school will be designed to meet their individual needs.

However, be aware that some children are dismissed from special education at the end of preschool. Your input is critical for this process. If further testing is recommended, you must consent to the evaluations and then your child will be assessed. If you disagree with the evaluation, you have the right to request an Independent Educational Evaluation (IE), for which the school system pays.

NOTES

Date Child Find contacted	**Who contacted Child Find**
Planned date to move from Early Intervention to Child Find	**People we want at the first IEP meeting**
Date of first IEP meeting	**Planned preschool**
	Date preschool was toured
Plans to practice understanding the new schedule, bus, location, playground, etc. with my child	

CHILD FIND CONTACTS

CITY OF ALEXANDRIA

703-578-8217
1501 Cameron Street, Suite 235, Alexandria, VA
https://www.acps.k12.va.us/departments/teaching-learning-leadership/office-of-specialized-instruction/child-find-and-early-childhood-special-education-services
childfind@acps.k12.va.us

ARLINGTON COUNTY

703-228-2550
2110 Washington Blvd, Arlington, VA 22204
https://www.apsva.us/child-find
child.find@apsva.us

FAIRFAX COUNTY

https://www.fcps.edu/academics/curriculum/early-childhood-education/early-childhood-child-find
Pimmit Hills Child Find
703-506-2374
703-204-6791 for Spanish
7510 Lisle Ave., Falls Church, VA 22043

SOUTH COUNTY CHILD FIND

703-317-1400
703-317-1405 for Spanish
6520 Diana Ln
Alexandria, VA 22310

BULL RUN CHILD FIND

703-456-2200
703-456-2220 for Spanish
15301 Lee Highway Centreville, VA 20121

LOUDOUN COUNTY

571-252-2180
407 E Market Street, Leesburg, Virginia 20176
https://www.lcps.org/o/doss/page/child-find
ecidservices@lcps.org

PRINCE WILLIAM COUNTY

703-791-8857
13225 Canova Dr, Manassas, VA 20112
https://www.pwcs.edu/support_services/special_education/child_find/index

GENERAL NOTES

ENTERING SPECIAL EDUCATION:

Kindergarten (age 5) & Elementary School

ENTERING SPECIAL EDUCATION: KINDERGARTEN (AGE 5) & ELEMENTARY SCHOOL

Going to kindergarten is a big transition for all children. Even if your child has been to preschool, entering a building surrounded by "big kids" and having new teachers and activities can be a bit scary. Most of the scariness of school disappears once children meet their teachers, make friends, and settle into their new routine. Remember you can ask for multiple tours of the new school, do practice trips, create social stories and photo books to help your child prepare, or do anything that helps your child understand the new plan.

You will need to register your child at the school he or she will attend, and you can find that through the links below. Most schools host an orientation or open house for incoming students.

CITY OF ALEXANDRIA
http://www.acps.k12.va.us/enroll

ARLINGTON COUNTY
https://www.apsva.us/registering-your-child

FAIRFAX COUNTY
https://www.fcps.edu/online-registration

LOUDOUN COUNTY
https://www.lcps.org/o/doss/page/student-registration

PRINCE WILLIAM COUNTY
https://www.pwcs.edu/registration/index

AUTOMATIC SCREENINGS FOR STUDENTS

All students new to a public school are screened within 60 days of initial enrollment for possible concerns in the areas of vision, hearing, speech, voice, and language. Fine and gross motor development are screened through third grade only to determine if formal assessment is indicated. All problems noted in the screening process are to be reported to the building principal/designee who will make referrals to a Student Study Committee as appropriate.

If You Have Concerns about Your Kindergartener For some children, the expectations of kindergarten, like sitting still, learning letters and numbers or interacting with peers, may uncover cognitive, behavioral or social issues that had not previously been apparent in home or preschool environments. If you are concerned about your child, talk to your child's kindergarten teacher or contact the local Child Find coordinator. See Child Find Contacts in the previous section.

IDENTIFYING CHILDREN FOR SPECIAL EDUCATION

Local Educational Agencies (LEAs) have a legal obligation to locate and identify students who may potentially qualify under IDEA for special education services. This mandate includes children who are advancing from grade to grade. An employee of the LEA can submit a referral to begin the eligibility process.

Parents may also submit a referral to begin the eligibility process. If your child is not receiving special education services in school, and you are concerned that your child may have a disability, submit a letter to the special education coordinator or an administrator in the school stating the concerns. The letter need only state that you would like your child to be referred for special education services. **Keep a copy of this letter since it serves as the start of the IEP process timeline.** This process is the same regardless of the child's grade level.

Remember that parents and the school are equal partners in the special education process. If you do not agree with the recommendations of the IEP team or a report, it's important to talk about it with the school. Be clear about what it is you don't agree with. If the team agrees that other services are needed or the recommendations aren't appropriate, it has the power to make different decisions.

For more helpful tips on communicating with your child's school and being a partner in the special education process, see the Pacer Center's "Keys to Success in the Family-School Partnership" at https://pathfinder-nd.org/pfc/resource.php?r=161#gsc.tab=0

TIP: **Key School Documents**

- Keep the school directory handy (these have both teacher information and names and addresses of your child's classmates)
- Post key teacher or therapist contact information on the fridge, along with their preferred method of communication (phone, email, text, etc.)
- Write down or keep in a digital file all the URLs and passwords for online classroom resources, such as the school's website, Blackboard, Google Classroom, and other online communication sites.
- Have one place, digital or physical, for every evaluation, IEP, and data sent home from the school. Organize it chronological timeline or topic.

NOTES

Date Kindergarten begins	**Location of binder with all the school data/ reports and my login information**
Three things we want to do to ensure the transition is successful (e.g., tours, contacting the teacher, practicing ahead of time)	**Key Contacts at the school I want to remember**

MIDDLE AND HIGH SCHOOL: THE TRANSITION YEARS

For all adolescents, transition to middle school introduces new challenges such as navigating a bigger school, changing classrooms more often, and engaging with more students and teachers. In the spring, familiarize your rising middle-schooler with the new environment by touring the new school, meeting his or her teachers if possible, and practicing going to the new bus stop or walking to the school.

For students with a disability, middle school also means starting to plan for high school graduation and the move out of the school system. IDEA allows students with IEPs to remain in the school system until age 22 (as long as he or she does not graduate with an Advanced or Standard Diploma). After that, an individual with a disability must apply for adult services in your city or county to receive public services.

Students who are planning their transition out of the school system will find the "I'm Determined" website useful. See www.imdetermined.org (I'm Determined is funded by the Virginia Department of Education; it provides direct instruction models and opportunities to practice skills associated with self-determined behavior.) Self-determination skills should be practiced beginning from an early age. Middle school is an ideal time to start growing these skills in earnest. Students should be attending their own IEP meetings, be familiar with their IEP services, and working on asking teachers directly for help. It is a good time to set up an evening routine where you check in on grades, homework, and any missing assignments. Create a plan to communicate regularly with the many teachers now in your child's life.

TRANSITION: THE BIG PICTURE

By law, planning for life after high school must begin **with the first IEP in which the child turns 14**, and IDEA terms the period between ages 14 and 22 "transition." IDEA requires IEP teams to plan ahead with specific goals that focus on training, education and employment. Examples of such goals are on page 20. For details on what IDEA requires during transition, see http://www.wrightslaw.com/info/trans.index.htm

While transitioning out of school may seem far off when your child is "only" in 8th grade, use this time and the services the school system is required to provide to give your child a head start on his or her future. Although legally transition planning begins at age 14, transition to adulthood, employment and independence needs to begin much earlier. Transition planning starts around the dinner table, with lots and lots of discussions with your student about their vision for what they'd like to do (and where) after he or she leaves school. Questions to think about include:

- What are your biggest priorities for your loved one once they are not in school?
- What financing will be needed for post-secondary education or training and employment supports?
- Is my child comfortable talking about his or her disability?
- What concerns do you have for him or her when they are on the job or in the community?
- What is your young adult's vision of his or her future two, five, even 10 or 20 years from now?
- Does he or she have a "dream job"? What is appealing about that job and how could he or she work toward that goal?
- How important are coursework and grades to that future vision?
- What are his or her favorite subjects in school or favorite hobbies? Can these be realistically turned into a job or career?
- How can you support your family member's independence at home?
- What kind of job training would be most useful for him or her to acquire before leaving school?

- What kind of accommodations might be necessary at college or on the job? How familiar is your son or daughter with their rights to these accommodations?
- What life and self-advocacy skills does your young adult need to acquire to make their post-school goals a reality?
- Where would your family member like to live and with whom once they move out of your home?

THE FORK(S) IN THE ROAD

"Start with the end in mind," recommends Stephen Covey in Seven Habits of Highly Effective People. This is a useful way to think about transition: work backwards from your loved one's desired path—at least what you can foresee for 2-5 years after graduation—and advocate strongly for the coursework, programs and services that will support that future.

KNOW WHERE YOUR CHILD IS STRONG AND LIKELY TO THRIVE.

If your son or daughter is struggling in all academic areas, and is having difficulty passing the Standards of Learning exams, (which are required to earn a standard or advanced diploma), or takes no joy in the academic areas of school, a work-based learning or career pathway may be a better option.

LOOK AT ALL THE OPTIONS.

If your child's academic ability varies—for example, if he is very artistic or hands-on, but not good with paper-and-pencil tasks or assignments requiring extensive reading, consider participation in a technical or specialized course offered through your school system, an adult education course, or an apprenticeship.

Completion of these courses will prepare your child to sit for most state certification exams. Note: Many students participate in specialized or technical programs while working toward earning their high school diploma. All students are eligible to apply; however, some of the programs may require a strong proficiency in oral and written language as well as a strong aptitude in math, science and problem-solving skills.

Not all careers require college or community college, but they do require training or work-based learning. For some individuals, Customized Employment is a great option and begins with Discovery (an assessment to discover a person's strengths) before job development. Visit DARS (Department of Aging and Rehabilitative Servies) at https://dars.virginia.gov/#disabilities for more information on customized employment.

GENERAL NOTES

POST-SECONDARY SCHOOLING.

More and more individuals with disabilities are attending university or taking courses at local community colleges. Going to college is a big step for all young adults, and finding the right college makes all the difference.

There are some specialized programs offered for non-traditional students (See Higher Education Opportunity Act and THINK College). Ask your school division about these programs. Mason LIFE https://masonlife.gmu.edu is an example of a college program for non-traditional students.

Families contemplating college for their student with a disability need to take into account all the requirements for college. First, your son or daughter will need to meet the college's expectations for grades, test scores, and high school coursework. This information is easily obtained from the institution's website and your high school's college counselor.

Second, it's important to remember that going to college requires more than academic acumen.

Students need to be able to live independently, handle more demanding coursework, balance their academic and social life, manage money, and care for their own mental and physical health. Make sure students have self-determination skills long before transition to college. Students who have received extensive support from their parents and the school during their high school years may find the adjustment to college difficult if a similar level of support is not possible. It may be worth considering schools near home where family can be directly involved, peer mentors, or specialized tutoring and services at the school.

Third, consider taking small steps toward that degree; have your student start with a few courses at a local university or community college, possibly near home, to help acclimate him or her to new routines and demands.

All college-bound students need to start early, in 9th grade to do the required research on which post-secondary option would be best. If considering college, be sure meet with the institution's Office of Disability Services to see the kind and extent of support that may be available before applying. These offices exist at all colleges.

College Steps www.collegesteps.org offers peer to peer support for students at Northern Virginia Community College's Loudoun and Annandale campuses. For more information on post-secondary options, see "Transition to Adulthood" and "Entering the World of Work" at https://thearcofnova.org/program/transition-points.

CAREERS IN SKILLED TRADES, VOCATIONAL OR TECHNICAL FIELDS.

Many students who pursue alternatives to college—work-based training, vocational or technical careers—have very positive and productive lives.

Planning for the appropriate training and certifications for these jobs can begin early in high school. Ask your transition coordinator whether career assessments, job coaching, coursework, technical training or work experience may be available in high school and how that can translate to jobs after graduation.

Also look also into vocational programs run by the state. Ask the ETR (Employment Transition Representative) or transition coordinator if your child might be eligible for vocational assessment and employment services offered through the state's Department of Aging and Rehabilitative Services (DARS) https://dars.virginia.gov, Virginia Apprenticeship Programs, https://virginiaworks.gov/im-an-employer/hire-and-retain/registered-apprenticeship-and-on-the-job-training, or Fairfax County Adult & Community Education https://www.fcps.edu/registration/adult-and-community-education-registration.

Also in Fairfax County are the Davis and Pulley Career Centers that provide career and employment skills instruction to students with disabilities. Students receive instruction in business-based skills; career skills are practiced in a variety of community settings and businesses. For more information, visit https://www.fcps.edu/academics/curriculum/special-education/services-and-programs/career-and-transition-services-0.

In addition to the Academic Academy, Arlington's Career Center offers a range of technical courses—from culinary arts and automotive repair to engineering and information technology—for high school (and in some cases, college) credit. https://careercenter.apsva.us Also at the Career Center is Arlington's Program for Employment Preparedness (PEP) that aims to increase work readiness for students age 18-21 with IEPs. Job experiences may range from a supported on-campus program to a fully independent work experience at a local business.

Alexandria offers The Career Prep program starting in middle school and continues through high school, https://www.acps.k12.va.us/programs-services/career-technical-education. The program includes building of life skills such as travel training, money management, and workplace behavior and expectations.

GENERAL NOTES

NOTES

Programs and colleges we want to check out

Places we've considered for funding services post-graduation

Dream outcome for my student post-school

Biggest strengths that should be supported and grown

Thoughts on diplomas and graduation age

EXPANDING THE IEP TEAM

While administrators, teachers and appropriate service providers such as occupational therapists will continue to be part of the IEP team, during transition, IEP meetings should also include:

Your child. As your child approaches adulthood, it becomes more important for him or her to be an active participant in IEP meetings. In fact, IDEA requires that your child be invited to attend IEP meetings at which transition will be discussed. His or her involvement in IEP meetings can range from sitting in the meeting for a brief period to preparing a short statement that he or she reads aloud to the IEP team about aspirations, strengths and difficulties, to actively discussing and writing goals as an equal member of the IEP team.

I'm Determined www.imdetermined.org is funded by the Virginia Department of Education and provides direct instruction models and opportunities to practice skills associated with self-determined behavior.

Employment transition representative (ETR) or transition coordinators. All local high schools have transition coordinators whose job it is to provide information and advice on transition-related services and programs available to students while still in high school and beyond.

Representatives from school-based programs. Some school systems offer academic, vocational, and work experience programs that support students' transition goals.

College counselor. For students considering post-secondary education, high school counselors can provide resources to help families with the search for the right college and advice on local college's application requirements and disability services.

Representatives from local organizations that support the transitioning students' needs for vocational training, employment, recreation, life skills, or housing services.

Support coordinator (if available). If your child is eligible for services through the local Community Services Board (CSB), a case manager will help find and coordinate services for adults with disabilities in your area; he or she should be invited to IEP meetings beginning senior year of high school.

Virginia Department of Aging and Rehabilitative Services (DARS). Ask the ETR or transition coordinator if your child may be eligible for employment-related services through the state's vocational agency. If so, schedule an appointment for an intake interview and file the necessary paperwork ahead while your student is still in high school. Visit https://dars.virginia.gov.

DIPLOMA OPTIONS

Virginia school districts offer four different high school diploma options: Advanced, Standard, Standard with Credit Accommodations for students with disabilities, and the Applied Studies Diploma. Deciding which diploma to aim for depends on your student. Factors to consider include the ability to earn passing grades in his or her high school coursework and to score 400 or above on the needed number of Standards of Learning (SOL) exams.

APPLIED STUDIES DIPLOMA

This diploma is available to students with disabilities who complete the requirements of their Individualized Education Program (IEP) and who do not meet the requirements for other diplomas.

If your child is unable to meet the requirements for the latter diplomas, he/she is eligible to earn this diploma. This diploma still allows your child to pursue vocational training and/or certification.

STANDARD DIPLOMA

Some students with disabilities may be eligible for a credit accommodation, if that would support them in meeting the requirements for a standard diploma. A student with a disability can be a student with an IEP or a 504.

ADVANCED STUDIES DIPLOMA

Earning an advanced studies diploma is a personal choice. One of the major differences in the standard and advanced studies diploma is the requirement to take 3 years of a foreign language or 4 years of two different languages (2 years each). Some students have difficulty with foreign languages; therefore, they pursue a standard diploma instead. This diploma option will open more doors to the more competitive colleges and universities.

Note that **graduating with an Advanced or Standard Diploma means your son or daughter will no longer be eligible for special education services.** Students who receive a Standard Diploma with Credit Accommodations or an Applied Students Diploma may stay in the school system under age 22.

For more information on diploma options, view VDOE's webinar at their website at https://www.doe.virginia.gov/parents-students/for-students/graduation/diploma-options

EMPLOYMENT AND DAY SUPPORT SERVICES

For more information on these options, see The Arc of Northern Virginia parent guides "Transition from School to Adult Life" and "Entering the World of Work" at https://thearcofnova.org/program/transition-points.

NOTES

Diploma you think is the best fit	**Estimated year of graduation**
Career and Technical school options of interest	**Things shared and discussed in transition IEP meetings I want to remember**

GENERAL NOTES

GENERAL NOTES

STRATEGIES FOR PARENTS:

Becoming an Advocate for Your Child

STRATEGIES FOR PARENTS: BECOMING AN ADVOCATE FOR YOUR CHILD

While parenting any child has its rough spots, advocating for a child with special needs can be particularly challenging. Learning about your child's needs and abilities is an ongoing process, as is learning about what services and programs, both in and out of school that are available to meet those needs. No one program or specialist will have "the answer" for your child. Your job is to learn about what's available and how to make the most of it.

GENERAL TIPS

Learn all you can about your child's needs, strengths, and tools that help them. Being a good advocate begins with knowing your child. This may take time as you get to know how your son or daughter is reacting to the classroom setting. The more you know, the better you can advocate for the help your child needs. Take notes in a central place when they have a particularly good day or experience, and write anything you can about what drove that. Likewise, write down the challenging days and patterns you're seeing. Talk to other parents who have children with similar needs, read books on best practices for supporting your child's disability(IES), and join in on webinars and educational sessions that may benefit them. You never know when a new perspective or idea could help you unlock a path to success for your loved one.

Accept that this is not easy, but that you can do it. It can be difficult to "hear" what teachers and specialists are saying about your child's needs or their vision for your child's future, especially when you are under stress. Be aware that you are under stress and may be defensive at times because you're the parent and you see your child in a different, but totally valid light. Instead, try to be a good listener and solution-oriented. Remember you don't need to sign IEPs at the meeting, but you can take time to debrief, review at home, or think through what was discussed before signing.

Whenever possible, take someone like your spouse or a good friend, or even a paid advocate, with you to teacher conferences and IEP meetings. They may pick up on different things that are being said and provide some objectivity and perspective. They can also help you remember what you wanted to share and emphasize.

Be prepared and organized. Parenting a child with a disability requires working with lots of people, going to lots of meetings, and reading lots of documents. Find a binder, digital or physical, or other means of keeping things in one place where you can check back at any time. Flip through and realize how much progress your child has made when you need a boost!

- Come prepared to meetings with your own plan about what you want to discuss and share, along with any recent data (anecdotal or notes) you have from experiences at home and in the community.
- Bring copies of your child's most recent IEP, evaluation results, test scores, etc.
- Ask a spouse, family member or friend to come with you to be sure what is said is what you understood was said. They can take notes that you can compare later.

Keep written records. Document in ***writing*** what was agreed on in meetings. Take notes, then call or email to get clarification of things you did not understand. Make all requests to the school in writing, and write polite follow-up letters/emails. Make and keep copies of emails, letters, meeting notices, evaluation reports, and anything you send to or receive from the school district.

See also the next section, "Strategies for Parents: Keeping Good Records."

Learn your rights under the law. Federal and state anti-discrimination, health care and special education law govern many of the programs in which your child will participate during his or her school life. If you do not understand your rights, ask the school's special education coordinator or other member of the IEP team to explain them to you. You can always ask questions at thearcofnova.org/answer. Taking special education classes to help you learn the basics through groups like The Arc @ School, https://thearcatschool.org, or Wright's Law, https://www.wrightslaw.com, is also a great way to feel empowered and knowledgeable.

Develop a team mentality. For most of your child's school life, you will be working as part of the IEP team to develop educational goals for your child's school experience. You are an integral and equal member of this team. Some parents feel they must defer to teachers and therapists, but the best results come when parents take an active role in IEP meetings. You know your child best; help others to know him or her, too. Work to find solutions to difficulties your child is having. If you don't think a proposed strategy would work or that the school isn't aiming high enough, speak up and let them know you have another perspective to share. If this feels too uncomfortable, don't forget that you can bring a friend, family member, or advocate to help you in the meetings.

Monitor your child's progress throughout the year. Keep an eye on your child's progress in school, including their academic grades and whether they are reaching their IEP goals. ***Report your concerns early*** to the teacher or to the IEP team leader; don't wait until the annual IEP meeting!

NOTES

People who have attended IEPs with you, or who you want to in the future	**Things you remember that seem to make IEPs go better**
One thing that helps you feel psyched up or capable	**One class or book on becoming an effective parent advocate you want to remember**

GENERAL NOTES

MAXIMIZING INDEPENDENCE

MAXIMIZING INDEPENDENCE

SELF-ADVOCACY

Increase student involvement with the transition process. A great way to build self-determination for a young adult with a disability is through the IEP process. Begin student IEP involvement early. Assist your child in communicating his or her needs, wants and dreams, but let his or her voice be heard!

- Have the student attend all meetings.
- Assist in understanding your child's abilities, interests, needs, and preferences.
- Let the student express dreams and aspirations.
- Have the student be a part of the decision-making process.
- Practice participating and leading IEP meetings at home.
- Allow your child some freedom under safe circumstances. Yes, students might not succeed, but they need to find out how to handle adversity while you can still provide assistance.
- Allow your child to experiment and try different interventions and strategies. If one intervention, strategy, or approach doesn't work, don't give up, try another!
- Encourage your son or daughter to communicate with community agencies via email, by phone, or in-person with your support.

RESOURCES FOR SELF-ADVOCACY

The I'm Determined project is a state directed project funded by the Virginia Department of Education, focused on providing direct instruction, models, and opportunities to practice skills associated with I'm Determined behavior. The I'm Determined website offers tools for youth to learn and for parents to help teach these skills. www.imdetermined.org

IT'S MY CHOICE

By William T. Allen, PhD from the Minnesota Governor's Council on Developmental Disabilities is a self-advocacy workbook designed to help individuals with intellectual and developmental disabilities (IDD) actively participate in making choices about their lives.
www.Mn.gov/mnddc//extra/publications/choice/Its_My_Choice.pdf

"DUDE, WHERE'S MY TRANSITION PLAN?"

A guide to promote student involvement in planning for life after high school.
https://www.parentcenterhub.org/dude-wheres-my-transition-plan

THE ARC OF NORTHERN VIRGINIA PEOPLE FIRST FOR YOUNG ADULTS

The Arc of Northern Virginia offers People First for Young Adults, a social and self-advocacy group for youth with disabilities ages 15-26. The group meets in-person and virtually on the second Tuesday of every month.

People First (ALLY) Toastmasters is an adapted Toastmasters public speaking club that meets in combination with People First. The group meets virtually on the third Thursday of the month.

To learn more about these groups and to sign up, go to our website at https://thearcofnova.org/self-advocacy.

Advocacy Group is a community of self-advocates who are interested in using their advocacy skills to benefit the greater community. The group meets the third Tuesday of the month on Zoom. This group is facilitated by Christina Eagle, an educator, doctoral student, and Arc of Northern Virginia volunteer. For more information, email Christina at ceagle2@gmu.edu.

VOTING

Everyone has the right to register to vote when they turn 18, unless that right is taken away by the Court (ex. guardianship). Helping your young adult with intellectual and developmental disabilities (IDD) participate in voting is an important step in fostering their independence and civic engagement. Voting is a fundamental right, and with the right support, your young person can have a voice in decisions that affect their community and future. As a parent, you can help by providing information about voter registration, explaining the voting process, and exploring accommodations that ensure accessibility. Whether it's learning about candidates, using accessible voting machines, or practicing how to fill out a ballot, your guidance can empower them to make informed choices.

You can register online, in person, or by mailing in a registration, and details are at https://www.elections.virginia.gov/registration/how-to-register.

Voting accessibility is a protected right under the Americans with Disabilities Act and individuals with disabilities can get the help needed to successfully cast a ballot. Examples of accommodations may be:

- Absentee voting, in person or by mail
- Accessible parking at the polling place
- Curbside voting
- Accessible voting booths and chairs
- Help to understand and complete the ballot from an election officer or someone you bring with you

If your adult child encounters any issues trying to vote because of his or her disability, it is a great idea to take a picture or video and share with the Virginia Department of Elections. You can also contact The Arc of Northern Virginia at www.thearcofnova.org/answers.

THE ARC OF NORTHERN VIRGINIA'S TECH FOR INDEPENDENT LIVING PROGRAM (TFIL)

Technology to Empower Young Adults for Transition

At the heart of the program is Arc2Independence, our app designed to support individuals with managing daily routines and overcoming challenges. The app offers a comprehensive library of lessons in key areas, including Transportation, Daily Living Skills, Employment, and Safety, accessible on phones, tablets, or computers. We also offer free, customized virtual lessons, the program provides essential tools to build independence and confidence in navigating everyday life. With a variety of options and personalized lessons, young adults can learn new skills, practice routines, and achieve goals. Arc2Independence is a reliable tool that provides virtual support, like a travel trainer or job coach, tailored to your personal goals. To learn more, visit our website at https://thearcofnova.org/program/tfil, contact techforindependence@thearcofnova.org, or sign up for our virtual information session, Building Independence with the TFIL Team at https://thearcofnova.org/tfil-events.

If you live outside of the Northern Virginia and are interested in accessing the **Arc2Indepedence** app, contact arc2independence@thearcofnova.org.

NOTES

Date applied to vote

Self-advocacy options explored

Other ways plans to develop adult skills

Precinct information

First time voting

Attended Tech for Independent Living Program event

Applied for Tech for Independent Living

Tech for Independent Living contact

GENERAL NOTES

The Positive Personal Profile is a simple document outlining an individual's interests and strengths, used to identify what is important and what the individual aspires to achieve. The focus is on skills and preferences, rather than labels and deficits. This positive approach helps to determine what the individual can do and loves to do. It also identifies the person's passions and values, which helps to determine what is meaningful for the individual. For a guide on how to use this form along with other great tools to prepare for employment, visit Transcen, Inc.

https://www.transcen.org/training-ta/resources

POSITIVE PERSONAL PROFILE

Name: _____ Date: _____

DREAMS AND GOALS:
INTERESTS:
TALENTS, SKILLS AND KNOWLEDGE:
LEARNING STYLES:
VALUES:
POSITIVE PERSONALITY TRAITS:
ENVIRONMENTAL PREFERENCES:

DISLIKES:

WORK EXPERIENCES:

SUPPORT SYSTEM:

SPECIFIC CHALLENGES:

SOLUTIONS AND ACCOMMODATIONS:

CAREER IDEAS, COMMUNITY CONNECTIONS AND POSSIBILITIES TO EXPLORE:

GENERAL NOTES

THE LEAP INTO LEGAL ADULTHOOD

SUPPORTED DECISION MAKING

We at The Arc of Northern Virginia are often asked about the need and value of guardianship and other forms of legal authority, especially as they relate to "protecting the person". The answer to what is appropriate depends upon the person. It is critical to remember that guardianship and similar measures are simply legal authority on a piece of paper. They cannot manage behavior, prevent someone from doing something, or undo many decisions they have been made.

DIGNITY OF RISK AND SUPPORTED DECISION MAKING

In recent decades, a movement has grown talk about the "dignity of risk" we all have to make decisions. The concept is simply that all people need help making some decisions and we all learn by making bad decisions. For example, many people without developmental disabilities rely on tax accountants or doctors to explain life decisions in simple terms they can understand. And, many of us have learned the most from our biggest mistakes. People with disabilities should have the same opportunities to make decisions and learn through natural consequences and a support team about how to proceed next time. We all express preferences in some ways. Using those preferences, along with support from a person-centered team, to make educated decisions is called "supported decision-making". A team of people (one person or more) who care about the person with a disability are asked by the person to work together to help them understand and make decisions. It does not involve taking away legal rights; instead, it builds a foundation for growing decision-making ability and independence over time, centered around working with the person on expressing their preferences. It has no cost and is probably what you are already doing. You can learn more about Supported Decision Making and view webinars on this topic on our website at https://thearcofnova.org/SDM. SDM can be used on its own and in conjunction with all forms of legal authority.

THE SPECTRUM OF LEGAL SUPPORTS

SPECIAL EDUCATIONAL POWER OF ATTORNEY

This document allows an appointed decision maker to participate in/consent to IEPs and other school documents. It is only valid in public primary and secondary schools, not universities/colleges. You can find a template at https://www.dlcv.org/wp-content/uploads/2020/03/Educational-Power-of-Attorney.pdf. Fairfax County Public Schools also has a fillable PDF that can be found at https://www.fcps.edu/sites/default/files/media/forms/se340.pdf. This document can be shared with the IEP Team.

MEDICAL POWER OF ATTORNEY

An agreement that grants an individual the authority to act on someone else's behalf for health-related matters. This allows the individuals to make decisions about things like medical treatment, prescriptions, and nursing home arrangements.

DURABLE POWER OF ATTORNEY

A durable power of attorney will remain in effect for the person designated as an individual with the authority to act on someone's behalf even if the individual later becomes mentally incapacitated. Powers of Attorney can be drafted by attorneys or you can use an online template. They can be notarized, which can be done by your local bank or any other notary. The cost is minimal or free. You can buy and customize low cost POAs at sites like www.legalzoom.com. Powers of Attorney can be created and signed on the day your child turns 18.

MEDICAL DIRECTIVE

An Advance Directive helps you and your child prepare for a time when he or she may not be able to make informed decisions or communicate his or her wishes. An "agent" (parent, relative, or other trusted adult) can make healthcare decisions when necessary, while still protecting the individual's right to make decisions he or she is able to make. There are several ways to make an Advance Directive: Sample forms can be found at http://www.virginiaadvancedirectives.org/picking-an-ad-form.html; You and your child can talk to your doctor about making an Advance Directive; You can hire an attorney to complete an Advance Directive. Once your child's Advance Directive is written, it needs to be signed in the presence of two witnesses. Virginia does not require it to be notarized, but it is a good idea to do so if possible. Once you have the necessary signatures, you should give copies to the Agent, doctors, and other trusted family members. You can also register the Advance Directive online at Connect Virginia https://www.vhi.org/ConnectVirginia/adr.asp.

GUARDIANSHIP AND CONSERVATORSHIP

Legal, court-ordered relationships in which one individual is appointed by the court to become the substitute decision maker for another. This is the most restrictive form of limiting civil rights. Guardians handle contract and medical decisions. Conservators manage financial affairs. You can have both or either restrictions in place, and the same person can serve in both roles. If you do explore guardianship or other legal authority, remember that no matter what you legally sign and agree to do, the person with a disability ultimately consents by participating or not.

Generally, the person seeking guardianship hires an attorney who meets with the individual who may be in need of decision making support. The attorney will ask for evaluations showing a diminished ability to make decisions and relevant diagnoses. Then, the attorney will work with the courts to have a Guardian ad Litem (GAL) appointed. The GAL is an independent attorney who should meet with the individual and proposed guardian to ensure the proposed guardian is appropriate and that the individual understands what is going on to the best of their ability. If all goes well, the parties appear briefly before a judge in civil court for a legal appointment to take place. It is very important to work with an attorney experienced in this field. The process usually takes 2-3 months and costs about $3000-$4000 in the Northern Virginia area. You can request payment plans or reduced fees, but there is no guarantee of either. You can begin the guardianship process as early as 17.5 years of age, and can be done at any time over the age of 18.

Parents can be appointed as co-guardians, which allows either to act independently. You may ask the court to appoint "standby" guardians, who would serve when the appointed guardians are no longer able to serve. Standby guardians can act as guardians for up to 30 days, but must got to Court to become the permanent legal guardian. Once the individual with a disability has a guardian appointed, someone must always be a guardian, unless the rights of the individual are restored by the Court, following a request or petition to do so . Guardians are required to submit a report every year to the local Department of Social Services; the court will provide a form. Guardians must all take a one-time training from the state to explain the roles and responsibilities of a guardian, and certify that they have done this training on their annual reports.

LIMITED GUARDIAN OF THE PERSON

The courts can limit or specify the authority and responsibilities of the guardian to specific areas of the individual's life; such as medical and health care decisions. The Courts can retain specific rights for an individual through a written order, like the rights involving voting, marriage, and driving.

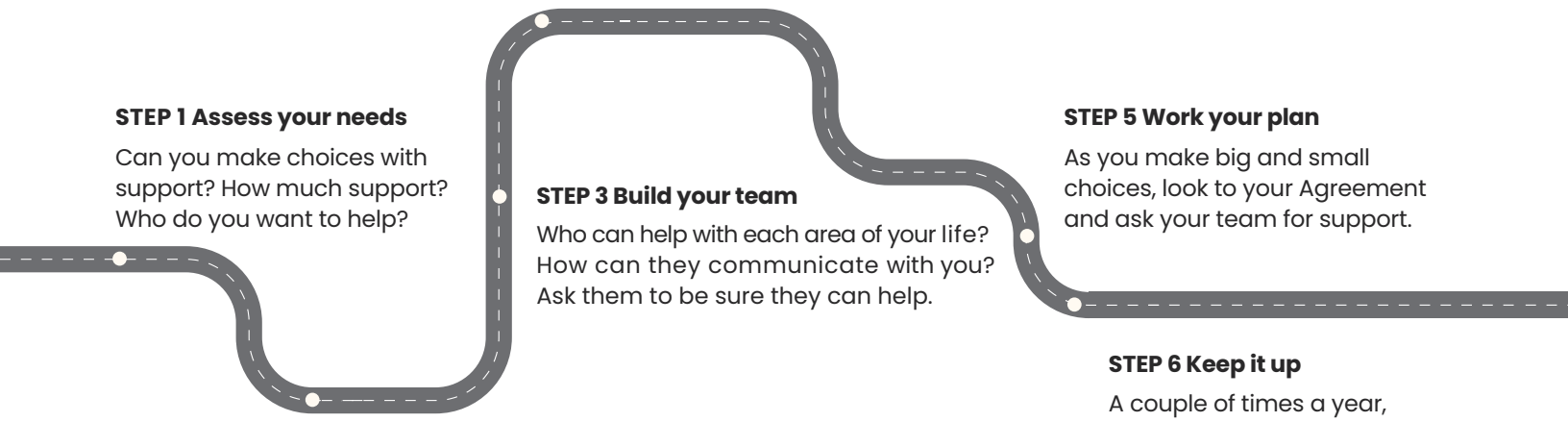
TEMPORARY GUARDIANSHIP

For specific reasons, a person can be appointed as temporary guardian on a time limited basis. For example: to assist in moving an individual to a residential placement; to make medical decisions, etc.

Supported Decision Making can be used with all forms of legal authority and various support options

SDM doesn't involve any cost or court relationship. It is a matter of working as a team to present information to the person with a disability in a way they understand it and using guiding principles important to the person to help them. You can use tools like Powers of Attorney, Special Needs Trust, or any other options that will be helpful in ensuring the person with a disability gets the right support. You can see a sample SDM agreement, along with tips on filling it out and educating selected supporters, at https://dbhds.virginia.gov/supported-decision-making-supported-decision-making-agreements.

ROADMAP TO SUPPORTED DECISION MAKING



STEP 1 Assess your needs

Can you make choices with support? How much support? Who do you want to help?

STEP 2 Explore options

Read about decision making options, watch videos, talk to others. What kind of ideas work for you?

STEP 3 Build your team

Who can help with each area of your life? How can they communicate with you? Ask them to be sure they can help.

STEP 4 Get it on paper

Write up a Supported Decision Making Agreement, Special needs Trust, or whatever tools you need.

STEP 5 Work your plan

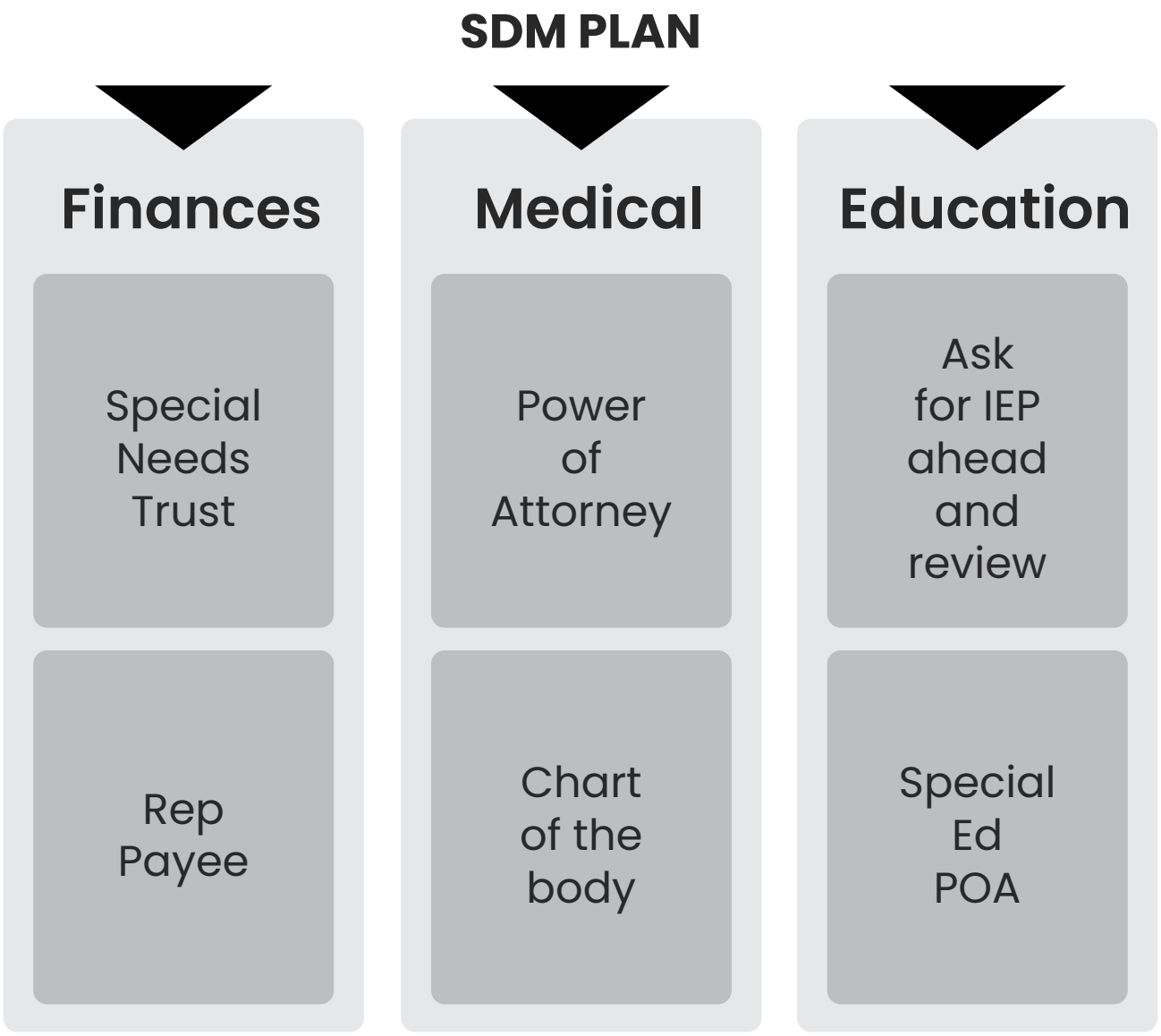
As you make big and small choices, look to your Agreement and ask your team for support.

STEP 6 Keep it up

A couple of times a year, review your agreement. See what is working. Change your plan as your needs change.

SUPPORTED DECISION MAKING RESOURCES	WHERE TO FIND IT
The Arc of Northern Virginia's SDM Toolkit with SDM in action videos, ideas on how to use and get started with SDM, 3 minute and extended recorded presentation on SDM, and SDM handouts and quick guides.	https://thearcofnova.org/sdm
Webinars on SDM implementation and team building	https://youtube.com/user/VideosatTheArcofNoVA
Asking any SDM questions	https://thearcofnova.org/answers
"Supported Decision Making" book by Jonathan Martinis and Peter Blanck with ideas on wording for Powers of Attorney, background on SDM in the courst, and data on self-determination and SDM increasing safety	https://tinyurl.com/SDM-book
"Setting the Wheels in Motion" article by Suzanne Francisco for a description of how a mom of three kids with DD implemented SDM for all of them, including her worksheets on getting started	https://tinyurl.com/SDM-Wheels
Jenny Hatch Justic Project info on start of SDM in VA and SDM data	http://www.jennyhatchjusticeproject.org
National Resource Center for SDM's stories, videos, agreements, and research	http://www.supporteddecisionmaking.org
"When Do I Want Support" SDM tool for a tool you can use to start creating your own SDM plan	https://tinyurl.com/SDM-ACLU
Center for Public Representation's SDM forms, stories, news, and laws	https://supporteddecisions.org
The Arc's national SDM toolkit with a SDM agreement building tool and more SDM in action stories	https://tinyurl.com/ArcSDMtools
disAbility Law Center for free Power of Attorney builder, help with advanced directives, and information on rights and choices	https://ww.dlcv.org/supported-decisionmaking

HOW MIGHT THIS WORK...



For more examples of how SDM can be used in all aspects of life, see 100 Ways to Use Supported Decision Making on our website at https://thearcofnova.org/sdm.

NOTES

Explored decision making options?	
Options to try first?	**SDM plan creation date and location where kept?**
Power of Attorney creation date and location where kept?	**Guardianship/Conservatorship explored?**
Attorney contacted?	**Court date?**
Date finalized and qualified?	**Copies kept?**

GENERAL NOTES

STRATEGIES FOR PARENTS:
Keeping Good Records

STRATEGIES FOR PARENTS: KEEPING GOOD RECORDS

Gathering information for and keeping key documents on hand will make it easier to carry out the advocacy and caregiving tasks you will face throughout the lifetime of your child with a disability.

The special education process in particular is full of paper: every step of the process is documented, and you need to keep a copy of each notice, evaluation, and report, along with any communication with the teacher or other school staff. Keeping some classwork, tests, projects and artwork is also valuable to show how your child is progressing. This section discusses ways to ensure you have the documents you may need whether you are advocating at tomorrow's IEP meeting or planning for the future. There are many videos on YouTube and other sites with ideas on record keeping if it helps to see it in action first.

THE RATIONALE FOR GOOD RECORDKEEPING

Keeping these documents updated and organized is important for several reasons:

- **More effective advocacy.** Advocacy is much more likely to succeed when you have the "proof" in hand to make your case to the IEP team. While your child is receiving special education services, be sure to document in writing all requests for meetings, changes to IEPs, appeals, etc.; then follow up your requests also in writing to confirm what was said or agreed on. This can help you demonstrate timelines. You can also keep your own progress notes and ideas, along with observations from home and community settings that seem to help your student succeed.
- **More efficiency in carrying out your responsibilities in the special education process.** For example, being able to find quickly your meeting notes, a progress report, or an evaluation can make the difference in keeping the special education process on track and on time. It will also help relieve some of the anxiety you would feel if you had lost something or couldn't quite remember what had been done before. Let your current self help your future self.
- **More peace of mind.** Although difficult to contemplate, leaving a literal "paper trail" helps future caregivers make decisions more in line with your vision and your child's own desires for his or her life should you become disabled or die. There is more on this idea, like using Letters of Intent, in our Aging with a Disability Guide, available at https://thearcofnova.org/program/transition-points

GETTING STARTED

Good record keeping is basically good organization repeated over time. Start here:

- The first step is to **establish a filing system that works for you**. This can be a three-ring binder, a series of labeled folders, a large folder on your computer, or just a dedicated drawer. Online storage is also an option. Keep a separate file or notebook for school-related records (and others for legal, financial, and medical papers). Separate things by type (e.g., IEPs, emails) or put them in chronologically. Examples of documents to be kept in each type of file are described below.
- **Consider audio recordings of meetings.** With AI, it is easier than ever to record meetings and get a summary afterward, though it should always be checked for accuracy. You must inform those at the meeting that you are recording the conversation, generally in advance of the meeting.
- **Copy or scan** important documents for easy access and keep originals in a safe place. **Back up your computer** regularly if storing digital versions. Audio or video recordings should also be backed up. Give files labels with the name of what is on there, along with a date for when they were created.

- **Keep all of your files up to date**, including revised wills, changes in medical or prescription records, IEP progress reports, annual Rep Payee reports, and so forth. Set a day every year for adding and purging materials from your child's file that are no longer relevant and making sure any needed updates are done.
- **Let family members and your attorney know where these documents are.** Be sure to communicate how to access your files: where the key to the filing cabinet is hidden, what the combination is to the safe, or the password to your computer.

RECORDS FOR AND FROM THE SCHOOL

Consider keeping the following in your child's school-related file:

- **Records of conversations and notes from meetings** with teachers, school administrators, or therapists about your child's progress in school. Write the date on these notes if they are not part of a dated email or letter.
- **Copies of the current IEP** and latest Parental Rights. It is a good idea to keep every IEP developed over the course of your child's education.
- **Notices or printed copies of emails related to the IEP process.** In many cases, sending the school a request for things such as an IEP meeting must be in writing in order to initiate certain procedural protections.
- Psychological, speech, academic, OT or PT **evaluations done by the school system**. In addition to any evaluations done initially to determine eligibility for special education, you and/or the school system may request that some or all of these evaluations be updated as part of your child's triennial review. After years in the school system, you will need a very large ring binder to store them, but do keep them all.
- Psychological, academic, speech, OT or PT **evaluations done by private therapists**.
- **Examples of school work**, especially homework or projects related to academic goals in areas like math, reading and spelling. These can provide background for monitoring your son or daughter's progress during that year, and from year to year.

GENERAL NOTES

LETTER OF INTENT

One of the most important documents to have in your child's file is a Letter of Intent. In it, you have an opportunity to describe your child's current life and to express your values, wishes and vision for his or her future. Although not legally binding, a Letter of Intent is invaluable to those who may need to take over the care of your child. It will tell them all the things anyone would want to know if they had to suddenly step into a new role, in this case, as your child's advocate. What goes into the document will vary with the individual, but it may include:

- **Your vision of your child's future:** what goals you have for your child's life, where they would live and with whom, what activities they should maintain (such as playdates with friends, going to Sunday School, or taking vacations). Describe your child's relationship with the person you've named as guardian.
- **Your child's vision of his or her future.** Whenever possible, include your child's ideas and desires in the document.
- **Description of personal qualities.** Future care-givers would benefit from knowing the unique aspects of your child: overall personality and mood, talents and strengths, degree of independence, medical or behavioral challenges, and sense of humor. What are the "tells" for when your child is happy, sad, or sick?
- **Family relationships.** Provide the names and ages of siblings and generally how they get along, as well as names and relationships of other family members (grandparents, aunts, uncles, cousins, etc.), especially those who have formed a particular bond with your child. This can also include family friends, professionals in their life with whom they have a special connection, or anyone else who knows and loves your child.
- **Specifics on the individual's daily life:** school schedules; extracurricular activities, including therapies or playdates; bedtime routines; food and clothing preferences and sensitivities; preferred toys and games, and typical outings, for example. If there are things that only happen monthly, quarterly, annually, etc., write them down, along with the last time they were done.
- **Medical history:** This section can be brief (diagnosis, current treatment & medication regimes, pharmacies they use, doctors that are helpful or not), but then should state where to find more detailed medical records.
- **Living expenses.** It may be helpful to include annual costs of items such as food, medical visits and equipment, health insurance, extracurricular activities, vacations, etc., to give future caregivers an idea of how the individual's trust and benefit monies might have to be spent.
- **Contact information:** grandparents, aunts, uncles or other relatives; friends; doctors and therapists; preferred pharmacy; school information; lawyers, trustees; guardians for minor children; insurance agents, banker, and financial planners, etc.

There is more on this idea, like using Letters of Intent, in our Aging with a Disability Guide, available at https://thearcofnova.org/program/transition-points

NOTES

Where is my filing system

Who can get in

How to access files

Location of Letter of Intent

Last time Letter of Intent was updated

GENERAL NOTES

APPLYING FOR BENEFITS BEYOND SCHOOL:

Social Security Disability Programs

APPLYING FOR BENEFITS BEYOND SCHOOL: SOCIAL SECURITY DISABILITY PROGRAMS

You may begin the application process for Social Security benefits the month after your child turns 18 (or at any age if the entire household meets the low income qualifications). The first step is to determine eligibility for any benefit program; the Social Security Administration (SSA) will decide which program is appropriate. For webinar presentations on SSI/SSDI visit The Arc of Northern Virginia's YouTube channel at https://www.youtube.com/@VideosatTheArcofNoVA.

SSI VS. SSDI

For both Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), a person must meet SSA's definition of disability. Disability is defined as the inability to engage in Substantial Gainful Activity (SGA) by reason of any medical (physical and/or mental or blind) impairment. Your disability must have lasted or be expected to last for a continuous period of not less than 12 months or result in death. For 2026, the wage limit for the SGA is $1,690 gross income/month.

SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a cash assistance program for those with limited income AND who are either 65 years old or older or blind or disabled. Adult SSI beneficiaries must have limited income and resources ($2,000 in assets); parents' income does not count for adult applicants. You do not have to have any work history. Monthly benefit payments are determined by the current benefit rate ($994 a month in 2026), minus any "countable income." If eligible for SSI, you will also be eligible for Medicaid. ** Note: It can take close to one year to begin receiving payment, but back payments will go back to the date of the approved application.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

While SSI is a needs-based program, SSDI is an insurance program with benefits dependent on previous payments into the system. In other words, SSDI beneficiaries must have worked enough (or their parents or spouses must have worked long enough) to have made contributions into FICA. Monthly benefit payments are based on the worker's lifetime average earnings covered by Social Security.

APPLYING FOR BENEFITS

The steps for applying are:

1. **Start with a disability report.** Go to the website at https://www.ssa.gov/ssi and click on How to Apply (You may also call **1-800-772-1213**) to get started. Complete as much information here as you can prior to your appointment at the local office. The application asks for names, addresses and telephone numbers of doctors and therapists who have treated your child and information on any hospitalizations. More descriptive medical records, such as a letter explaining a diagnosis or evaluations by therapists or schools can be brought to the intake meeting (make copies of anything you give Social Security, along with notes on when and how it was provided). If you do not have access to a computer, you can request an application be mailed to you when you call the 800 number. You cannot fully complete the application for benefits online; you must request an appointment online or by calling Social Security.

2. **Call Social Security.** To make an appointment, call 1-**800-772-1213** (TTY **1-800-325-0778**) Monday through Friday between 8am to 7pm, or contact your local Social Security office or schedule online at https://www.ssa.gov/manage-benefits/make-an-appointment. Hold times can be very long. You will be greeted by an automated answering attendant, who will prompt you to state why you are calling; say "Apply for SSI". The auto attendant will ask for you to say or key in your child's Social Security number. You will then be directed to a representative. During the phone interview, the representative will take information and enter it into a computer, which will secure the date of the application.
    - Paperwork will be mailed to you. Complete and return within the allotted timeframe.
    - The document generated during the phone interview will also be mailed, to be signed for accuracy.
    - Before mailing anything back to the agency, be sure to make copies.
3. Set up a screening interview. During the previous phone interview, the representative will set up a screening, which continues the application process, at your local Social Security office. If outside of the Northern Virginia area, visit https://www.ssa.gov/locator to find your local office.

ALEXANDRIA OFFICE
5510 Cherokee Ave., Suite 200
Alexandria, VA 22312
800-472-2402

FAIRFAX OFFICE
10800 Park Ridge Drive, Suite 100
Reston, VA 20190
800-829-3158

MANASSAS OFFICE
9500 Center St.
Manassas, VA 20110
800-325-0778

GENERAL NOTES

4. Go to the screening interview. Bring to the intake interview any and all information to prove your child's age, citizenship, disability, and lack of assets/resources:
    - Original birth certificate (or other proof of age and citizenship) and Social Security card
    - Documentation to verify your address
    - Copy of special needs trust, ABLE Account, guardianship and/or conservator order and letter of qualification
    - Individual Education Program (IEP)
    - Income slips if your child has income
    - Information on any assets your child owns like a savings account, investments, title to a car or life insurance. These cannot total more than $2,000 for SSI benefits (unless held in a special needs trust or an ABLE Account). Note that for programs with income limits, SSA considers parents' income and assets up until your child turns 18; individuals over 18 years of age are considered independent households.
    - If you have not completed the application online, bring the required medical records and contact information to the screening.
    - Checkbook or other papers that show a bank account number to have benefits deposited directly to a Representative Payee account or an ABLE Account.
    - A signed rent agreement between parent and child (to receive the full benefit). SSI is intended to cover expenses like rent and utilities. It is recommended that you charge your adult child rent if he or she lives in the family home. Note that as of 2024, SSI recipients may receive family assistance with covering most food costs without penalty. A recipient must be spending at least current Presumed Maximum Value (PMV) on rent and utilities to avoid a penalty or reduction in benefits. For much more detailed information on calculating rent in the family home, keeping receipts, and a sample lease agreement, visit our resource library at https://thearcofnova.org/resource-library/#social-security.
5. Wait for eligibility determination. The agency will send your Disability Report Form and medical history to the Disability Determination Service (DDS). DDS may or may not request more information, such as work history, when the disability began, and what treatment has been given. DDS may also request, on behalf of SSA, a medical or psychological exam (SSA pays for the exam by a physician chosen by SSA). A decision is made and in 2025, decisions are taking 9-10 months on average. If you are denied, you have 60 days to appeal.
6. Set up a Representative Payee account. While applying, you will need to set up a Representative Payee account at a bank; be sure to title the account correctly (SSA has suggested wording). Automatic deposit of benefits is required. Alternatively, you can also set up an ABLE Account for deposits from SSA. For more information on ABLE Accounts, visit https://www.ablenow.com and visit our YouTube Channel for a webinar on this topic at https://www.youtube.com/@VideosatTheArcofNoVA.

    Note that having power of attorney, being an authorized representative or having a joint bank account with the beneficiary does not give you the legal authority to negotiate and manage the beneficiary's Social Security and/or SSI payments. For more information on being a Representative Payee, visit our Resource Library at https://thearcofnova.org/resource-library/#social-security and https://www.ssa.gov/payee.

THE REPRESENTATIVE PAYEE

A Representative Payee (Rep Payee) is appointed by SSA to receive Social Security and/or SSI benefits for someone who requires support managing his or her money. Rep Payees should be comfortable handling financial records and be trusted to keep in mind the best interests of the disabled beneficiary. To be designated a Rep Payee, contact the local SSA office (see above). You must then submit an application, form SSA-11 and documents to prove your identity. SSA requires you to complete the payee application in a face-to-face interview. A payee must keep records of how the payments are spent or saved, and be able to make all records available for review if requested by SSA.

TIPS FOR REPRESENTATIVE PAYEES

A payee must report any earnings to Social Security. This includes work income, one-time payments, child support, trust payments, etc. SSI is a needs-based month-to-month benefit. Any delay in reporting to SSA could mean an overpayment of benefits. Keep a record that you sent documentation to Social Security.

- When you call SSA (**1-800-772-1213**), keep a record: date, name of the person you spoke to, what you asked, what they told you.
- Make copies of all documents you give to SSA.
- Promptly open and read ALL mail sent by SSA. When SSA gives a deadline response date, compliance within that date is required. Seek help immediately if needed. Keep ALL paperwork, letters, and mailing envelopes in your file.
- Report by mail, online, or using the SSA app. Keep wage records in your file.
- If a person receives SSI and/or Medicaid, remember to keep all resources/assets below $2000 in any month to maintain eligibility.
- Everyone should have their own my Social Security account – needed to report earnings, apply for benefits and track application status.
- When a major life change occurs (address, marriage, employment, loss of job) report to SSA immediately, both to the **1-800-772-1213** and to the local SSA field office.
- If you need help managing Social Security and benefits, work with a benefits counselor to help you manage this. Benefits counselors are available at the Endependence Center https://endependence.org/services/benefits-counseling and the Endependence Center of Northern Virginia (ECNV) https://www.ecnv.org.

For additional information on Reporting Tips for Beneficiaries of Social Security Disability Programs, visit the Resource Library on our website at https://thearcofnova.org/resource-library/#social-security

If you need additional guidance navigating the application process or other Social Security related questions, reach out to us through The Arc of Northern Virginia's I&R Portal at https://thearcofnova.org/answers for resources on fee based services that can provide one on one support such as Inclusion Consultants https://inclusionconsultants.com.

NOTES	CHECK IF DONE	NOTES
Checked to ensure you have all of the needed documents?		
Lease prepared? Comparable rents ready?		
Rep Payee account set up? Bank name and account info?		
Date applied for SSI?		
Notified all listed doctors they may get called?		
Date of scheduled calls?		
Documents submitted to Social Security and when? Where are copies of submitted info kept?		
Rep Payee confirmed?		

HOUSING AND SSI

In general, at least one-third of your SSI benefit is assumed to be paying for housing expenses (rent or mortgage, utilities, property insurance/renter's insurance, etc.) and the other two-thirds for other eligible expenses like food and clothing. If monies from a special needs trust are used to purchase a home with a mortgage, and the trust makes monthly mortgage payments, then the beneficiary's SSI payments will be reduced by about one-third each month (the portion of SSI associated with housing). ** Note: this is not the case if you use an ABLE Account. ABLE accounts can pay rent without penalty.

Whether the home is purchased outright or with a mortgage, SSI payments will be reduced by slightly more than one-third if the trust pays for household expenses such as taxes, heat, electricity, water, sewer and trash collection.

See
https://secure.ssa.gov/poms.nsf/lnx/0500835300 and https://secure.ssa.gov/poms.nsf/lnx/0500835901

NOTES	CHECK IF DONE	NOTES
Date work began		
Date work reported to SSI		
Calendar reminder for regularly submitting paystubs?		
Working with a benefits counselor?		

GENERAL NOTES

APPLYING FOR BENEFITS BEYOND SCHOOL:

Developmental Disability Medicaid Waivers

This section provides a basic overview of Medicaid Waivers. For more comprehensive information, watch recorded webinars on our YouTube Channel at https://www.youtube.com/@VideosatTheArcofNoVA and visit our Resource Library at https://thearcofnova.org/resource-library/#waivers. You can also call Virginia's Waiver assistance hotline at 1-844-603-9248 or visit the Department of Behavioral Health and Developmental Services' website at http://www.mylifemycommunityvirginia.org.

WHAT IS A WAIVER?

A Waiver is a long-term support system for someone who will have long-term care needs. Once you're awarded a Waiver, you will have access to a menu of services offered by your Waiver. Frequently used services include attendants who work one-on-one with the person with a disability, respite care so parents can have a break from care provision, group home supports where a person with a disability lives in a home shared by other people with disabilities, long term employment or meaningful day services, assistive technology, environmental modifications, nursing, and more. These services are offered at no or very low cost.

Waivers are funded by Medicaid and are often called Medicaid Waivers. The person with a disability must qualify for long-term care Medicaid to use a Waiver. As of 2025, this means that the person with a disability cannot have more than $2,000 in assets in their name (no cap if under 18 years old), unless those assets are in a Special Needs Trust

OR

ABLE Account, and they cannot earn more than (in 2025) $2,901 per month. The income limit generally increases each year due to Cost-of-Living Adjustments. The person with a disability will get Medicaid once they get an active Waiver (not when they are placed on a waiting list).

WHO NEEDS A WAIVER?

People who need assistance with taking care of themselves, managing their environment, working toward greater independence, or maintaining a job because of a disability should consider Waivers. It is the only public funding for long term developmental disability supports.

WHY SHOULD I APPLY?

Anyone with a developmental disability should apply. You will need a psychological evaluation with an IQ score to apply. Submit the evaluations that you have already on hand and if a new evaluation is requested and you need a practitioner, reach out to The Arc of Northern Virginia's Information and Referral Portal at https://thearcofnova.org/answers.

Even though some Waivers have waiting lists, if you qualify for a Waiver, you will eventually receive services. As you grow and change, you can use more or fewer Waiver services to meet your needs. The Waiver should grow with you over time and provides the supports you need to be as independent as possible in your community. You can apply for both Waivers if you think you may be eligible for both. Then, you'll move from one to another with more services as they're made available.

Also, as a result of a Department of Justice settlement agreement with Virginia, if you're on the waiting list for a DD Waiver, you can apply for up to $500-$1,000 each year to purchase supports you need to be independent and safe. This is called the Individual and Family Supports Program (IFSP). Information, applications, and instructions can be found at https://mylifemycommunityvirginia.org/resources. You can go to https://dbhds.virginia.gov/developmental-services/ifsp to receive routine emails from DBHDS to stay updated on when the program opens each year.

HOW DO I GET A WAIVER?

Virginia currently has two main types of Waivers. One type, the Developmental Disabilities (DD) Waivers, are most commonly used by people with developmental disabilities. They're called the Community Living Waiver, the Family and Individual Supports Waiver, and the Building Independence Waiver. People with disabilities and medical support needs often use the Commonwealth Coordinated Care (CCC) Plus Waiver. The DD Waivers are far more robust and offer many more services than the CCC Plus Waiver. Follow the general guidelines below to figure out which Waiver(s) may be right for you, how to apply, and what to expect.

SERVICES COVERED UNDER THE WAIVERS

The Developmental Disability (DD) Waivers: There are 3 DD Waivers: (1) Community Living, (2) Family and Individual Supports, and (3) Building Independence Waivers. These waivers cover supports in a variety of residential settings, including hourly staff at the home of a child's family. The Community Living Waiver is the only waiver that provides 24 hour staffed group home settings. These three waivers also cover a variety of employment and meaningful daytime supports for people no longer in school. Some additional services include respite care, in-home supports, companion care, assistive technology, environmental modifications, therapeutic consultation, non-emergency medical transportation, private duty nursing, skilled nursing, and Personal Emergency Response System (PERS).

The Community Living Waiver is a comprehensive waiver that includes 24/7 residential services for those who require that level of support. It also includes services and supports for adults and children, including those with intense medical and/or behavioral needs.

The Family and Individual Supports Waiver is designed to support individuals living with their families, friends, or in their own homes. It supports individuals with some medical or behavioral needs and is available to both adults and children.

The Building Independence Waiver supports adults 18 and older who are able to live in the community with minimal supports. This waiver does not include 24/7 residential services. Individuals will own, lease, or control their own living arrangements and supports may need to be complemented by non-waiver funded rent subsidies.

Individuals receiving waiver services are assessed every two years (as a child) and every three years (as an adult) with an assessment called the Supports Intensity Scale (SIS) to measure the intensity of their support needs. People can move between these three DD Waivers if their needs change over time.

ELIGIBILITY CRITERIA

There are criteria everyone must meet to be eligible for a Medicaid DD Waiver:

1. Functioning ability: This is determined by the Virginia Intellectual Developmental Eligibility Survey (VIDES). The VIDES has one test for children aged 0-3, one for children ages 3-18, and one for adults. The surveys assess the person's need for assistance with a variety of daily living and independence skill activities. Families are encouraged to review the VIDES assessment available on our website prior to the intake. You can review copies of the VIDES assessment in our Resource Library at https://thearcofnova.org/resource-library/#waivers.
2. Diagnosis: Persons applying for a Waiver must meet the diagnostic eligibility requirements for the DD Waivers. This means that a person must have a developmental disability as defined in 37.2-100 of the Code of Virginia.

a. "Developmental disability" means a severe, chronic disability of an individual that (i) is attributable to a mental or physical impairment, or a combination of mental and physical impairments, other than a sole diagnosis of mental illness; (ii) is manifested before the individual reaches 22 years of age; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independence living, or economic self-sufficiency; and (v) reflects the individual's needs for a combination and sequence of special interdisciplinary or generic services, individualized support, or other forms of assistance later are lifelong or extended duration and are individually planned and coordinated. An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (i) through (v) if the individual without services and supports, has a high probability of meeting those criteria later in life.

3. Financial: If the functioning and diagnostic criteria are met, then the child's income and assets are considered. Special Needs Trusts and ABLE Accounts are not considered when testing financial eligibility. People over 18 have an asset cap of $2,000. Everyone receiving a Waiver has a monthly income cap of 300% of the current Social Security Supplemental Security Income amount (SSI is $994 in 2026), so max monthly income is $2,982. The income limit for SSI generally increases each year due to Cost-of-Living Adjustments.

If you qualify, you will be put on a Waiting List. You will be given one of the of the three disability Waivers based upon the type of services you need.

HOW LONG IS THE WAIT?

The Developmental Disability Waivers have a waiting list based upon urgency of need. People in Priority One of urgency need services within the year, people in Priority Two need services in 1-5 years, and people in Priority Three need services several years out. Wait time is unpredictable and many people on the priority one list wait many years for a waiver. As your life circumstances change, for example, behavioral or medical needs change, you or your spouse become ill, become unemployed, etc., notify your support coordinator, as these situations will increase your urgency of need for support services.

You can be on the waiting list for a Developmental Disabilities Waiver and apply for the CCC Plus Waiver, assuming you are eligible for the CCC Plus Waiver as well. Many people do this because the CCC Plus Waiver has no waiting list and can provide some interim supports.

Visit our Resource Library https://thearcofnova.org/resource-library/#waivers for a handout on "Navigating the DD Waiver Waiting List"

The Commonwealth Coordinated Care (CCC) Plus Waiver covers personal care, respite care, medication monitoring, private duty nursing, assistive technology, environmental modifications, and the Personal Emergency Response (PERS) system. Personal care support hours may be approved up to a maximum of 56 hours per week and cannot exceed 480 hours per state fiscal year.

To see if you may be eligible for the CCC Plus Waiver, you can utilize a self-assessment online eligibility tool offered by Mom's in Motion at https://momsinmotion.net/commonwealth-coordinated-care-plus-eligibility-self-help-tool. To be eligible for this waiver, the person must have a disability and medical nursing needs, as assessed by the Virginia Uniform Instrument (UAI). You can view the UAI in our Resource Library at https://thearcofnova.org/resource-library/#waivers.

To Apply for the Developmental Disabilities Waivers, Contact your local Community Services Board

ALEXANDRIA CITY CSB
703-746-5999

ARLINGTON DHS/IDD SERVICES
703-228-1700

FAIRFAX/FALLS CHURCH CSB/IDS
703-324-4400

LOUDOUN CSB
703-777-0597

PRINCE WILLIAM CSB
703-792-7800

If not in Northern Virginia, visit http://www.dbhds.virginia.gov/community-services-boards-csbs to find your local CSB

To Apply for the CCC Plus Waiver contact your county's Department of Social Services

ALEXANDRIA CITY
571-213-7963
703-746-5999 (if over 18)

ARLINGTON
703-228-1297
703-228-1700 (if over 18)

FAIRFAX/FALLS CHURCH
703-324-7948

LOUDOUN
703-737-8949

PRINCE WILLIAM
703-792-7500

If not in Northern Virginia, visit http://www.dss.virginia.gov/localagency/index.cgi to find your local DSS.

NOTES	CHECK IF DONE	NOTES
Date applied for DD Waiver		
Date sent in Waiver paperwork		
Date VIDES completed		
Date applied for CCC Plus Waiver		
Waiver status (waiting list priority or have Waiver)		
Name of Waiver Support Coordinator		
Last time talked to CSB		
On IFSP email list if on the waiting list?		
Years applied for IFSP and what requested?		

CREATING AN ESTATE PLAN FOR THE FUTURE

CREATING AN ESTATE PLAN FOR THE FUTURE

All parents should have a will, and those who have children with a disability also need to create a family-funded special needs trust to protect any public benefits that child may receive.

CREATING A WILL

A will is critical to ensuring that your wishes are carried out regarding how and to whom your assets are divided after your death. If you have a child with a disability, this is doubly important. Find an attorney who specializes in special needs planning; he or she will be able to address the unique needs of each of your children and not jeopardize the benefits or services of your child with a disability and/or the relationship between the siblings and family members. A list of attorneys can be found in our Provider Directory on our website at https://thearcofnova.org/resources/business-directory. While many wills create family trusts, to avoid jeopardizing the benefits or services of your child with a disability you need to create a separate special needs trust.

REVIEWING BENEFICIARIES

In addition to naming a (third-party/family-funded) special needs trust as the beneficiary for monies inherited through a will, you should also **review the beneficiary designations for resources considered outside your will**, including:

Employer provided life insurance (if both parents work and have insurance through their jobs, be sure to check beneficiaries for both); Private life insurance policies (again, check beneficiaries for all policies), Individual retirement accounts, including Roth IRAs* 401K and 403(b) accounts*, SEP Plans*, Thrift Savings Plans*; individual checking and savings accounts; Brokerage accounts; Savings Bonds. You will need to use specific language to designate these monies to the SNT. Please check with the trustee to determine proper wording.

Special cautions apply when designating a special needs trust as a beneficiary of one or more of your retirement accounts (those marked with an *). The document creating the special needs trust (whether it is a will or a stand-alone trust) needs to state that the trust is "an accumulation trust" for the purpose of receiving distributions from retirement accounts. This comes into play once your child with a disability turns 18 and may be eligible for SSI as an adult. After age 18, an adult receiving SSI can only have $2,000 in assets. Typically, when someone inherits a retirement account, they have to start receiving periodic payments from the account which would most likely disqualify them for federal benefits such as SSI and Medicaid.

If siblings, other family members, or friends wish to leave your loved one money, be sure to inform them that they must designate the special needs trust as the beneficiary. Give them the exact name of the trust and the date it was created.

SPECIAL NEEDS TRUSTS (SNT)

Special needs trusts allow families to provide for the future financial stability of their loved one with a disability. Since some federal benefits programs impose limits on beneficiary's assets and resources, your son or daughter could be disqualified from benefits if he or she received, for example, an unexpected inheritance or proceeds from a lawsuit. However, the law allows families to set up a special needs trust (SNT) that can act as a repository for an inheritance, stocks, property, insurance settlements or other assets **without** a loss of public benefits.

If your family member with a disability receives Supplemental Security Income (SSI) and Medicaid (or you are contemplating having them apply for these benefits), creating a special needs trust is a necessity as these programs limit your loved one to just $2,000 in assets to remain eligible.

In the event that one receives an unexpected inheritance, or other forms of unexpected income, these would be directed to what we refer to as a self-funded trust (aka a first party special needs trust). While this is a feasible option for someone who is over-resourced or needed assistance managing their finances, this is often a last resort type of trust given the requirement of a Medicaid payback; in contrast, a family-funded trust is not subject to a Medicaid payback and therefore it's beneficial to elect this route if an option to plan for the future is available.

TWO KINDS OF TRUSTS

Family-Funded Trusts (third-party trusts) are established by parents or with an authorized non-profit, such as The Arc of Northern Virginia, for their child with disabilities. The person establishing the trust, usually called the grantor, chooses to make some of his or her own assets available for the benefit of the beneficiary (person with disabilities).

These trusts may be funded during the parents' lifetime or after the parents' lifetime for anyone electing to provide monies to the person with a disability without directly paying funds to their pocket and therefore jeopardizing means-tested benefits. You can contribute to them while you are still alive or you can fund them upon the death of the parent(s), friend, etc. with an inheritance, life insurance policy or transfer from another trust.

In a family-funded trust, the Grantors decide who will inherit any funds remaining after the Beneficiary passes away. Frequently grantors leave the funds to other family members, including siblings, as well as, to charitable organizations.

Self-funded trusts (first-party trusts) are established by the beneficiary, parent, grandparent, guardian, or court order and are funded with resources that belong to the person with disabilities. Common sources of funding for first-party trusts are structured settlements, lump-sum paybacks from Social Security, irrevocably assigned child support for an adult child with disabilities and Survivor Benefits, and inheritances that mistakenly were given directly to the individual with the disability. The first-party SNT involves a mandatory Medicaid-payback clause which means any funds remaining in the trust after the Beneficiary's death must first reimburse Medicaid for any Medicaid-funded care the individual received during his or her lifetime. In The Arc of Northern Virginia's Special Needs Trust program, there is one exception to the Medicaid payback requirement: Instead of electing to satisfy the Medicaid payback, grantors can elect to leave the remaining funds to The Foundation of The Arc of Northern Virginia's Personal Support Self-Funded Trust.

While many legal matters can be undertaken with a lawyer with a general background, SNTs require the services of an elder law or special needs attorney with expertise in disabilities and this particular kind of trust.

SETTING UP A TRUST

Special needs trusts can, and should be, set up as early as possible as part of the parents' overall estate planning.

For either option, you will have to pay fees to set up the trust and, possibly, to manage the funds. The Arc of Northern Virginia's Special Needs Trust program allows for a trust to be established while remaining unfunded, or funding can be elected with a minimum of $500 seed money.

USES OF TRUST FUNDS

Funds from a special needs trust are usually not distributed directly to the beneficiary, as that may jeopardize some government benefits. Instead, they are usually disbursed to third parties who provide goods and services for the use and enjoyment of the beneficiary. Funds from the trust can be used for a variety of life-enhancing expenditures without compromising your loved one's eligibility for government benefits:

Here are some examples:

- Education and tutoring
- Out-of-pocket medical & dental costs not covered by insurance
- Transportation (including purchase of a vehicle)
- Maintenance of vehicles, car insurance
- Materials for a hobby or recreational activity
- Trips, vacations, hotels, airline tickets
- Entertainment such as movies or ballgames
- Computers, videos, furniture, or electronics
- Athletic training or competitions
- Special dietary needs
- Clothing
- Housing costs (although this may reduce SSI benefits)
- The list is extensive!

ACTING AS TRUSTEE

A trustee is the person who oversees trust assets and administers the trust provisions, including investing, account reporting and tax reporting, check writing, and disbursements. The Arc of Northern Virginia's trustee is Key Bank while The Arc manages the trusts and provides day to day client relations. Professional legal and investment advice are crucial for trustees administering a special needs trust themselves.

For more information about being a trustee, download a free handbook at:
http://www.specialneedsalliance.org/free-trustee-handbook

THE ARC OF NORTHERN VIRGINIA'S SPECIAL NEEDS TRUST

For trusts established with The Arc of Northern Virginia, the family and beneficiary do not have this burden of trust administration. Trust staff perform all administrative tasks and client relations and Key Bank handles all fiduciary and investment duties. To learn more about The Arc of Northern Virginia's Special Needs Trust visit https://thearcofnovatrust.org.

Our program offers a handful of ways on how to pull funds from a trust, pending review and approval of submissions. These methods include:

One Time Disbursement: good for one-time expenses where we're reviewing and issuing payment to a vendor (ex: one-time payment for reimbursement to a person who paid for an item on the beneficiary's behalf). Supporting documentation includes disbursement form, receipt/invoice, and statement showing charge (if someone is requesting reimbursement).

Recurring Disbursement: good for recurring bills (ex: a monthly car insurance payment). Supporting documentation includes completion of a recurring disbursement form for us to retain on file, and submission of the bill each month it's received to enable us to initiate payment.

ABLE ACCOUNTS

ABLE Accounts are an additional financial tool that may be used by some people with disabilities and their families to save for the future while protecting eligibility for public benefits.

The Achieving a Better Life Experience (ABLE) Act of 2014 allows states to establish tax-advantaged savings accounts for certain individuals with disabilities for their disability related expenses. Contributions of up to $20,000 (in 2026) a year can be made to an ABLE Account and up to a total of $100,000 without endangering eligibility for certain means tested benefits such as Supplemental Security Income (SSI) and Medicaid. An eligible individual is someone who developed the onset of their disability before age 46 and; is entitled to Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits based on blindness or disability; and self-certifies that they have a qualifying disability diagnosis from a physician.

An eligible individual over the age of 18 may open and manage an ABLE account independently or an Authorized Representative may open and manage an ABLE account on behalf of the eligible individual. Authorized Representatives include an eligible family member (spouse, parent, grandparent, or sibling), legal guardian, someone with Power of Attorney, or a care representative. An eligible individual may only have one ABLE account. Any person may contribute to an ABLE account for an eligible beneficiary.

ABLE Accounts do not replace the need for a Family Funded Special Needs Trust, but may be used in conjunction. Funds in an ABLE account may be used for Qualified Disability Related Expenses. Qualified Disability Expenses are expenses that maintain the health, independence, and quality of life of the individual with a disability. Key aspects of ABLE Accounts are similar to First Party or Self-Funded Trusts in that they require a Medicaid payback upon the death of the beneficiary.

The ABLE program in Virginia, ABLEnow is administered by Commonwealth Savers (formerly known as Virginia 529). To learn more about ABLEnow go to www.ablenow.com. The National ABLE Resource Center https://www.ablenrc.org offers lots of good information and allows you to compare programs in different states. No matter where you reside, you can open an ABLE account in any state that accepts outside residents into their program.

For a better understanding of the differences between Special Needs Trusts and ABLE Accounts visit the Resource Library on our website at https://thearcofnova.org/resource-library/#s-n-t.

NOTES	CHECK IF DONE	NOTES
Will created? Location? Update plans?		
Beneficiaries updated on all stocks, bank accounts, etc.?		
Special Needs Trust webinar attendance plan		
Special Needs Trust establishment date		
ABLE account information		

KEY PARTS OF A FULL LIFE

KEY PARTS OF A FULL LIFE

BUILDING SOCIAL CONNECTIONS

Recreation and social activities are vital parts of a full and meaningful life, especially for young adults with intellectual and developmental disabilities (IDD). Beyond just having fun, these experiences offer opportunities to build friendships, develop independence, and strengthen communication and social skills. Whether it's joining a local art class, participating in inclusive sports, attending social clubs, or exploring hobbies, recreational programs can help young adults discover their passions and feel connected to their community. Included here are only a handful of recreation opportunities that are available. To see a full list of social and recreation opportunities that are both in-person and virtual, visit our Resource Library https://thearcofnova.org/resource-library/#recreation.

THERAPEUTIC RECREATION AGENCIES

All Northern Virginia localities have Therapeutic Recreation Offices providing recreation and leisure opportunities for individuals with disabilities. Offerings for young adults include adapted classes, social clubs, and summer camps. If you are new to the area, you may request that an assessment be completed to help the staff understand the needs of your child.

City of Alexandria
Therapeutic Recreation
https://www.alexandriava.gov/recreation/info/default.aspx?id=45758
703-746-4311

Arlington County
Department of Parks and Recreation
Therapeutic Recreation Office
https://parks.arlingtonva.us/therapeutic-recreation
703-228-4740

Fairfax County
Fairfax Therapeutic Recreation Services
https://www.fairfaxcounty.gov/neighborhood-community-services/therapeutic-recreation
703-324-5532

Loudoun County
https://www.loudoun.gov/1185/Adaptive-Recreation
703-777-0343

Prince William County
https://www.pwcva.gov/department/parks-recreation/inclusion-based-programs
703-792-8066

Special Olympics
Provides year round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities. Some online programs are also available.

Special Olympics
Arlington, Alexandria, Fairfax, and Falls Church
https://www.novasova.org

Special Olympics
Manassas, Manassas Park, Prince William
https://www.specialolympicsva.org/rappahannock-region/area-23

Special Olympics
Loudoun County
https://sovaloudoun.org

Our Stomping Ground
https://ourstompingground.org

Our Stomping Ground builds inclusive residential communities that also offer a variety of programs including book clubs, games nights, art and fitness classes and more. Some events are only open to residents of a specific community, but others are open to anyone in the Northern VA area. Explore their event calendar to see what opportunities are available.

NOTES	CHECK IF DONE	NOTES
Hobbies and interests		
Clubs		
Classes		
Social groups		
Sports/rec groups		

NAVIGATING RELATIONSHIPS

Navigating relationships and sexual health is an important aspect of adulthood, and individuals with intellectual and developmental disabilities (IDD) deserve access to information and support that empowers them to build healthy, safe, and fulfilling relationships. As parents, guiding your child through this transition can feel overwhelming, but there are some resources available to help.

EASE (Empowerment Advocacy and Sexuality Education) https://www.easeeducates.org offers online and in-person classes for teens and adults with Intellectual & Developmental Disabilities. EASE also offers Parent Workshops on how to talk with your child of any age about relationships and sex ed.

Elevatus Training https://www.elevatustraining.com offers self-study and online classes for parents.

Hello, It's Me https://hello-itsme.com is an inclusive fee based online platform designed to support individuals with IDD in building meaningful connections and enhancing social skills. The app offers interactive features such as story-based learning modules that teach real-life scenarios, relationship coaching, and opportunities for friendship and dating. Users can also participate in live virtual events like dance parties and karaoke sessions to foster community engagement.

GETTING AROUND IN THE COMMUNITY

People with disabilities may benefit from travel training and from reduced fares for Washington-area bus and subway. Taxi companies also provide reduced rates and special services for persons with disabilities.

NON-DRIVER IDENTIFICATION CARD

Since many reduced fare programs—whether for students, persons with a disability or senior citizens require proof of age and/or photo identification; a worthwhile first step is to obtain a non-driver identification card from the Virginia Department of Motor Vehicles (DMV). These cards have no age restriction and are available for an adult or child who does not hold a learner's permit or driver's license.

You can request a medical indicator on their driver's license or identification card to signify conditions such as autism spectrum disorder (ASD) or intellectual disability (IntD). To obtain this indicator, applicants must provide a signed statement from a licensed physician confirming the diagnosis. This request is made during the application process at a Virginia DMV customer service center. Once approved, a "9" will appear in the restriction field on the front of the ID, with "ASD" or "IntD" decoded on the back, aiding law enforcement in recognizing communication needs during interactions.

All of the information a customer needs to prepare for a DMV visit is available on the DMV web site at https://www.dmv.virginia.gov/licenses-ids/id-cards

FREE STUDENT BUS PASSES

FAIRFAX COUNTY

Free bus passes are available to Fairfax County and City of Fairfax County/FCPS middle school and high school students (registered 7-12 grade ONLY). Students can sign up for the Free Student School Bus Program at all Fairfax County public high schools and middle schools, and ride the Fairfax Connector and City of Fairfax Cue bus for free. Find more information at your school's administration office. You need to have a parent's or guardians' approval to sign up.

FREE STUDENT BUS PASS + METROBUS

https://www.fairfaxcounty.gov/connector/student-pass

Students attending Annandale, Davis Center, Falls Church, Justice, and Marshall can sign up for the Free Student Bus Pass + Metrobus Program. Students who attend these schools can ride Metrobus for FREE in Northern Virginia, along with Fairfax Connector and City of Fairfax CUE. When you sign up for the pass, you'll receive a specially designed and programmed SmarTrip card. This expanded program includes Fairfax Connector, Cue, and Metrobus access between 5:00 a.m. and 10:00 p.m., seven days a week. Visit the Fairfax Connector website.

ARLINGTON COUNTY

https://www.apsva.us/transportation-services/public-transportation

Students in Arlington can ride the Arlington Transit (ART) for free and can also register for a Student iRide SmarTrip card to ride approved WMATA Metrobus routes for free, and if the trip begins or ends in Arlington.

If a student does not have a Student iRide SmarTrip card, contact the Transportation Coordinator (TC) located onsite at your school or visit a Commuter Store.

ALEXANDRIA CITY AND LOUDOUN COUNTY

https://www.dashbus.com
https://www.loudoun.gov/bus

DASH buses in the City of Alexandria and buses in the Loudoun County Transit System are free for residents of those localities.

PRINCE WILLIAM COUNTY

https://omniride.com

OmniRide offers local buses in eastern and western Prince William County, Manassas and Manassas Park that operate along fixed routes that are free for residents. OmniRide also offers paratransit door to door service. For more information, visit https://omniride.com/omniride-access-paratransit-service.

TRAVEL TRAINING

A key element of independence is being able to get around on public transportation for one's work and social life.

ECNV (The ENDependence Center of Northern Virginia) offers free travel training on Washington-area bus and subway routes for people with disabilities. www.ecnv.org

WMATA www.wmata.com/ride/accessibility/metroready-travel-training-and-system-orientation.html offers MetroReady Travel Training at no cost to seniors and people with disabilities. MetroReady is short-term, comprehensive, intensive instruction designed to teach customers how to travel safely and independently on the accessible Metrobus and Metrorail public transportation systems.

The Arc of Northern Virginia's Tech for Independent Living (TFIL) Program offers travel training experiences to gain independence and confidence. With hands-on guidance, participants will receive an orientation to the various transit systems throughout the DMV. These trips aim to boost safety awareness, introduce problem-solving skills, and promote independence. To learn more or register for an event, visit our website at https://thearcofnova.org/tfil-events or contact techforindependence@gmail.com.

METRO DISABILITY ID CARD

All jurisdictions in the Washington area offer reduced transportation fares, but you will first need to obtain a free Metro Disability ID card. You will need to complete an application and have a health care professional certify the individual's disability. Call 202-962-2700 or download an application from

http://www.wmata.com/accessibility/doc/Reduced_Fare_Application.pdf

The Metro Disability ID card is good on Metro buses in the District as well as ART in Arlington, CUE, Fairfax Connector, RideOn, TheBus, VRE and MARC also accept it.

REDUCED FARECARDS/BUS PASSES AND/OR SMARTRIP CARD

One option for reduced fares is a reduced fare bus pass or fare card (metro). Use your Metro Disability ID to purchase a SmarTrip card that is encoded for discount fares. This provides 50% off Metrorail and Metrobus fares for all reduced fare programs. Customers also receive a discounted fare on regional bus service providers that accept the SmarTrip card such as Alexandria Transit Company (DASH), Arlington Transition (ART), CUE Bus System (Fairfax), Fairfax Connector, and OmniRide/PRTC (Prince William County).

It is highly recommended that you register your SmarTrip card. If you lose it, you will get a replacement card for $5 that includes the fare value of the lost card at the time you reported the loss. Add value to your SmarTrip card in any Metro station at the fare card machines or on Metrobus.

USING PUBLIC TRANSPORTATION

A good place to start to learn about available routes is www.CommuterPage.com with links to Virginia and Maryland bus and rail services.

Alexandria www.dashbus.com
Arlington www.arlingtontransit.com
Fairfax www.fairfaxcounty.gov/connector
Fairfax City www.cuebus.org

DISABLED PLACARD/PLATES

In Virginia you need to get a MED-10 form for a disabled parking placard or license plate. You can pick one up at the Department of Motor Vehicles (DMV), or you can get one from their website at https://www.dmv.virginia.gov. A physician must fill out the form. Bring the completed form to the DMV. You can get a placard or a plate, or both. Placards offer flexibility since you can move it into any car in which you are the driver or a passenger. You will need to pay a fee and you will receive your placard or plate on the spot. You can do it by mail, but the process does take longer.

PARATRANSIT OPTIONS

MetroAccess is the area's ADA paratransit service that provides shared-ride, door-to-door service that operates during the same hours of operation as corresponding Metrorail and bus service. Unlike non-emergency medical transportation, MetroAccess is a shared ride public transportation service for people who are unable to use the accessible fixed-route Metrobus and Metrorail public transit due to disability. MetroAccess can be used for any trip purpose within 3/4 of a mile of areas serviced by Metrobus and Metrorail, during the same hours of operation as regular Metrobus and Metrorail service. "Shared ride" means that multiple passengers may ride together in the same vehicle.

To be eligible for MetroAccess service, a person must meet one of the following conditions:

1. Have a disability as defined by the ADA AND be unable as a result of disability to utilize fixed-route transportation (Metrobus and Metrorail);

OR

2. Need to use a ramp or wheelchair lift to use a public transit vehicle, but an accessible public transit vehicle is not being used at the time, date, and on the route you would travel. (Please note: All Metrobuses are wheelchair accessible);

OR

3. Be unable to travel to or from a bus stop or rail station due to a disability.

An application must be completed and certified by a health care professional detailing your disability and the need for paratransit services. To apply, you can download an application at https://www.wmata.com/service/accessibility/metro-access/eligibility.cfm. You will then need to set up an in-person appointment with the Transit Accessibility Center of by calling **202-962-2700**. You may register to travel with a personal care assistant at the time of application. The personal care assistant rides free of charge when travelling with you on MetroAccess.

Once you have been approved, you can schedule your ride 1-7 days in advance by calling **301-562-5360**, TTY **301-588-7535** or book online. Fare is calculated by doubling the fastest comparable route fare on bus and/or Metrorail up to $4.50 each way.

TOPS (TRANSPORTATION, OPTIONS, PROGRAMS & SERVICES)

https://www.fairfaxcounty.gov/neighborhood-community-services/transportation/tops

TOPS provides subsidized transportation funds on an easy-to-use debit card for eligible older adults, persons with disabilities, and those with limited income who are residents of Fairfax County, the City of Fairfax, or the City of Falls Church. TOPS connects riders with a variety of transportation modes and options including taxicabs, rideshare services (Uber and Lyft), public transportation, and Capital BikeShare rentals, enabling them to travel affordably, safely, and independently.

STAR (ARLINGTON COUNTY)

STAR https://www.arlingtontransit.com/star is the paratransit component of Arlington Transit – ART. ART provides public fixed route bus services in Arlington County. STAR serves Arlington residents who have difficulty using public fixed route transit due to the effects of age or disability. STAR is a shared ride paratransit service intended to provide a comparable level of transportation as provided by ART, Metrobus and Metrorail. STAR riders share trips if they are generally traveling in the same direction at the same time. Trips are scheduled, with a few exceptions, without regard to the purpose of the trip. All rides are arranged in advance through the STAR Call Center, or online through their website. STAR riders must preplan activities and schedule STAR trips in advance as same day service is generally not available.

Arlington County residents currently certified eligible for MetroAccess are automatically certified for STAR. Rides are provided on a curb-to-curb basis. Drivers park in front of the address and assist riders into and out of the vehicle.

FASTRAN (FAIRFAX COUNTY)

https://www.fairfaxcounty.gov/transportation/fastran

Fastran offers specialized transportation services for residents of Fairfax County and the Cities of Fairfax and Falls Church participating in human services agency programs. To apply, request an application by calling **703-222-9764**.

MODIVCARE

https://www.modivcare.com

Transportation for Medicaid recipients to a non-emergency Medicaid-covered service.

DOT

https://www.alexandriava.gov/Paratransit

DOT is the City of Alexandria's specialized transportation service for residents of Alexandria and visitors who cannot use regular transit buses or rail due to their disability. Trips are provided by taxicabs and wheelchair accessible vans.

EXPLORE THE POTENTIAL FOR DRIVING

The **Woodrow Wilson Workforce Center (WWRC)** offers comprehensive driving services. Driving services are managed and provided through the Occupational Therapy (OT) Department. This state-certified program is comprised of Certified Driving Instructors (CDI's) and Driver Rehabilitation Specialists (CDRS's). Services include:

Occupational Therapy Driving Evaluation (1/2 day): this is a prerequisite for any other driving service at WWRC. Occupational Therapists assess vision, perception, cognition and motor skills in order to determine an individual's feasibility for obtaining a driver's license. For more information, visit http://www.wwrc.virginia.gov/DrivingServices.htm

Learner's Permit Class (4 weeks)

Driver's Training (4-6 weeks): Behind-the-Wheel training provided by an Occupational Therapist or a Certified Driving Instructor. A valid learner's permit is required.

Other Driving Services: Evaluation and training in use of adapted driving controls; evaluation and training in management of mobility devices for vehicles, evaluation of van needs for drivers.

ServiceSource https://www.servicesource.org/drivers-permit-prep offers Driver's Permit Prep, a study group to help students prepare for the written portion of the permit test. The study group is conducted virtually and consists of 8 sessions, each lasting 1.5 hours. These classes are eligible to students with disabilities ages 16-22 and who are receiving Pre-ETS services through DARS. Attendees will learn:

- The testing process and requirements (including practice questions for Part I and Part II of the permit test)
- Traffic signs, signals, and pavement markings
- Safe driving techniques and other important information
- Accommodation Request Process

To learn more contact your DARS counselor or reach out to ServiceSource at **703-223-9331**.

DRIVER REHABILITATION CENTER FOR EXCELLENCE (DRCE)

https://www.driverrehabcenter.com

The DRCE provides comprehensive, individualized driver evaluation and training services. The center offers adaptive driving instruction tailored to meet an individual's unique physical, cognitive, or sensory needs. Services include clinical assessments, behind-the-wheel training with specialized vehicles, and the use of adaptive equipment.

NOTES	CHECK IF DONE	NOTES
Bus pass received		
Travel training plan		
Travel training destinations		
Metro Access card received, number of card, where kept Adapted Driver's Ed contact		

ADDITIONAL STATE AND NATIONAL RESOURCES:

ADDITIONAL STATE AND NATIONAL RESOURCES:

Parent Educational Advocacy Training Center (PEATC)
https://peatc.org/offers trainings, workshops, webinars, and one-page handouts on transition planning.

PACERS (National Parent Center on Transition and Employment)
http://www.pacer.org/transition/learning-center/independent-community-living/self-determination.asp offers resources for families, educators, and professionals to support effective transition planning. The center emphasizes self-advocacy, family engagement, and inclusive practices to improve outcomes for young people with disabilities.

Parent Center Hub
https://www.parentcenterhub.org
is a central resource for the network of Parent Centers across the U.S. It provides information, tools, and training materials to support families of children with disabilities. The Hub offers resources on special education, transition to adulthood, and family engagement, helping parents navigate services and advocate effectively for their children's needs.

GENERAL NOTES

GENERAL NOTES

GLOSSARY OF COMMON ACRONYMS

A

ABA: Applied Behavior Analysis
ADA: Americans with Disabilities Act
ADLs: Activities of Daily Living
ASD: Autism Spectrum Disorder
AT: Assistive Technology
Ability One
ABLE Accounts: Achieving a Better Life Experience

B

BI Waiver: Building Independence Waiver

C

CCC+: Commonwealth Coordinated Care
CMS: Centers for Medicare & Medicaid Services
CIL: Center for Independent Living
CDS: Consumer Directed Services
CL Waiver: Community Living Waiver
CSB: Community Services Board
CTS: Career and Transition Services

D

DD – Developmental Disability
DABS: Diagnostic Adaptive Behavior Scale
DAC: Disabled Adult Child
DBHDS: Department of Behavioral Health and Developmental Services
DDS: Disability Determination Service
DMAS: Department of Medical Assistance Services
DARS: Department of Aging and Rehabilitative Services
DSP: Direct Support Professional
DSS: Department of Social Services

E

ESY: Extended School Year
EPSDT: Early and Periodic Screening, Diagnostic, and Treatment

F

FAPE: Free Appropriate Public Education
FIS Waiver: Family and Individual Supports Waiver

G

GAL: Guardian Ad Litem
GSE: Group Supported Employment

H

HCBS: Home and Community-Based Services
HCV: Housing Choice Voucher
HIPP: Health Insurance Premium Payment program
HIPAA: Health Insurance Portability and Accountability Act

I

IDD: Intellectual and Developmental Disabilities
IEP: Individualized Education Program
IFSP: Individualized Family Support Program
IPE: Individual Plan for Employment
ISE: Individual Supported Employment
IRWE: Impairment Related Work Expenses
ISP: Individual Service Plan

L

LRE: Least Restrictive Environment
LTSS: Long-Term Services and Supports

P

PCA: Personal Care Attendant
PERS: Personal Emergency Response System
PERT: Post-Secondary Education Rehabilitation and Transition Program
POA: Power of Attorney
Pre-ETS: Pre-Employment and Transition Services

S

SSI: Supplemental Security Income
SIS: Support Intensity Scale
SDS: Self-Directed Services
SGA: Substantial Gainful Activity
SSA: Social Security Administration
SRAP: State Rental Assistance Program
SNT: Special Needs Trust
SSDI: Social Security Disability Insurance
SPED: Special Education

T

TANF: Temporary Assistance for Needy Families

U

UAI: Uniform Assessment Instrument

V

VR: Vocational Rehabilitation
VIDES: Virginia Individual Developmental Eligibility Survey

W

WIOA: Workforce Innovation and Opportunity Act
WIC: Work Incentives Coordinator
WIPA: Work Incentives Planning and Assistance
WWRC: Wilson Workforce Rehabilitation Center

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OTHER GUIDES IN THIS SERIES:

— Starting Life with Your Child with a Disability

— Transition from School to Adult Life

— Entering the World of Work

— Finding a Home for Adults with Disabilities

— Aging with a Disability

Transition POINTS

Providing Opportunities, Information, Networking and Transition Support