

GETTING THE MOST FROM SPECIAL EDUCATION Preschool through High School

A Guide for Parents of Students with Disabilities
in Arlington, Alexandria, Fairfax & Falls Church



Produced for the Transition POINTS Program
of The Arc of Northern Virginia

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This guide is one of six developed for parents of children with intellectual 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; starting school; transitioning out of the school system; securing employment; finding a place to live outside the caregiver's home; and aging with a disability.

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The printed version of this guide is prepared periodically. As information changes, updated information may be found in the Employment Guide Toolkit on our website. This version, as well as, translations of the series of Transition POINTS guides in Spanish, Vietnamese, Chinese, Arabic, and Korean are available to download at <http://www.thearcofnova.org/programs/transition/transition-points>. Translations are made possible by a grant from the Virginia Board for People with Disabilities. Additional support was provided by the Rotary Club of Alexandria.

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TABLE OF CONTENTS

Introduction to Transition POINTS	2
Getting the Most from Special Education	
Introduction	4
Table: A Checklist for Parents	6
Starting with the Basics	
The ABCs of Special Education & Your Rights under IDEA.....	10
Table: Your Rights in Plain English	12
Learning about Special Education	
Identification and Referral	14
Evaluation	14
Graphic: The Special Education Process	15
Determination of Eligibility	16
Writing the Individualized Education Program	17
Reevaluation	17
What is a Section 504 Plan	18
Getting a Handle on the Individualized Education Program (IEP)	
The Big Picture: What IEPs are Supposed to Accomplish.....	18
Advocating in IEP Meetings.....	19
The Nitty Gritty: 9 Key Components of an IEP	20
Entering Special Education: Differences by Grade	
Transitioning to Preschool (Ages 2-5).....	28
Child Find	29
Table: IFSP vs. IEPs.....	31
Kindergarten and Elementary School.....	33
Middle and High School: The Transition Years	35
Strategies for Parents: Advocating for your Child with a Disability	40
Strategies for Parents: Keeping Good Records	41
Applying for Benefits:	
Supplemental Security Income.....	43
Medicaid Waivers	46
Securing Your Child’s Future: Wills, Guardian for Minor Children, Special Needs Trusts	48
Considering Legal Authority Options	51
Table: Determining a Decision-Making Role	54
Finding Support: Resources for Parents	55

Glossary: Acronyms in Special Education56
Acknowledgements 57

INTRODUCTION

Intellectual and developmental disabilities (ID/DD) by definition last a lifetime, so caring for a loved one with ID/DD is a lifelong responsibility. Because of the nature of these disabilities, caregivers must make crucial (and often very difficult) decisions throughout the lifespan of their loved ones – where they go to school, what they will do for recreation, where they will live, and how to ensure their financial security once the caregivers are no longer there.

While caregivers want to make the best choices for their loved one, research shows that many do not have the resources to do so. A national survey by The Arc found many families struggling to help their loved one with an intellectual disability:

- 80% of families surveyed don't have enough money for needed care and almost half report having more care giving responsibilities than they can handle
- 85% report that their adult family member with ID/DD was not employed either full- or part-time
- 62% of families don't have a long-term care plan
- 75% can't find after school care, community services or summer activities for their loved one
- 59% report they don't have enough information to make good choices about housing options
- 65% report that they don't have enough help in planning for the future.¹

About Transition POINTS

Families need realistic, actionable information with which they can make a wide range of decisions as their child grows up. Providing this information is the mission of a program of The Arc of Northern Virginia—Transition POINTS (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

¹ Anderson, L.L., Larson, S.A., & Wuorio, A. (2011). 2010 FINDS National Survey Technical Report Family Caregiver Survey. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

3. Transitioning out of the school system and into adult services;
4. Entering the world of work;
5. Finding a place to live outside the caregiver's home; and
6. Aging with a disability.

For each transition point, we provide materials in both print and digital formats, online resources, workshops, and webinars.

For additional information particular to Special Education in Virginia, visit the Virginia Department of Education at

http://www.doe.virginia.gov/special_ed/index.shtml

The information found in this guide is applicable to all people with intellectual and developmental disabilities and their families, although much of the contact information for resources are particular to the Northern Virginia area. 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

<http://www.dbhds.virginia.gov/community-services-boards-csbsor>. The CSB is the point of entry into the

publically funded system of services for people with mental health, intellectual and developmental disabilities. Also, visit The Arc of Virginia at

www.thearcofva.org to find the local Arc chapter in community.

Help for You, the Parent

As a first step in Transition POINTS, we have written six guides to address important issues that parents should consider at each of these important life stages. The guides are designed to help you recognize opportunities, weigh options, and work through decisions; checklists, timelines, worksheets, and links to other resources are included wherever possible. Each document has also been reviewed by a task force of parents and professionals with relevant experience and expertise. Please visit the Transition POINTS page on our website at www.thearcofnova.org to explore toolkits corresponding with each guide that include additional resources.

The Arc of Northern Virginia maintains a library of informative life planning and future planning videos and webinars on YouTube at <https://www.youtube.com/user/VideosatTheArcofNoVA>

Although each guide addresses issues related to a specific phase of life, you'll note that each also repeats some information parents and caregivers need to know whether their loved one is two, 22 or 62 years old: which steps to take to protect your loved one's financial future, how to apply for benefits, and where to go for more help.

Your Rights and Responsibilities

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. Please send any comments to Diane Monnig, The Arc of Northern Virginia, Transition POINTS, 2755 Hartland Road, Suite 200, Falls Church, VA 22043
dmonnig@thearcofnova.org.

GETTING THE MOST FROM SPECIAL EDUCATION: A Guide for Parents of Children with Disabilities

While all parents are understandably interested in their children's education, parents of students with disabilities are particularly concerned that their child is taught in a manner that addresses his or her individual needs. Indeed, tailoring instruction for your child with a disability is the whole point of the special education provided by your child's school.

Federal law, the Individuals with Disabilities Education Act (IDEA), governs the overall structure of the special education process and grants rights to you and your child. However, the details of how your child's education is carried out are decided by you and staff at the school. For more explanation of key principles in IDEA, see the section "Starting with the Basics."

Defining Special Education

Under IDEA, the term special education means "specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including ... instruction conducted in the classroom...[and] instruction in physical education..."

This guide discusses the special education process in Virginia for children aged 3-22. If your child is coming into the special education system from an early intervention program, you may be familiar with the process and some of the paperwork involved. If you are new to special education or have concerns about your child's development or performance in school, this guide will help you act on any decision to seek help from the school system. Read first about the special education process and the IEP (Individual Education Program) in the first two sections of the guide, then turn to the section on "Entering Special Education: Differences by Grade" for grade-level specifics.

For information on what happens **after your child "ages out" of the school system entirely at age 22**, see *Securing a Future for Your Child with a Disability*. Both documents are available online at www.thearcofnova.org under Transition POINTS. Be sure to check out the online toolkit for sample documents, checklists, and links to more resources

<https://thearcofnova.org/programs/transition/getting-special-education/>

Starting in Special Education

If your child is **aged 2 (by September 30) to five**, find out about preschool options in your school district by contacting your local Child Find coordinator.

At age 5, register your kindergartner with your local school and contact your local Child Find coordinator (See p.29)

For students entering grade school, middle school, or high school, contact the Special Education Director or principal at your base school.

What's in this Guide

This guide will help you with the following issues:

Which children may be eligible for special education services. Federal law lays out a process for determining if your child is eligible for special education services. Your child needs to have a qualifying disability, and that disability needs to have an adverse effect on his or her education.

Who's in charge. As a parent, you know your child better than anyone, and you are his or her best advocate. As a consequence, you are a key member of the team that sets educational goals for your son or daughter. Being a full participant in meetings about your child's education program keeps you in the loop and provides valuable input for teachers and therapists.

What your rights are. Once found eligible for services under IDEA, your child is part of the special education system; as parents you have both rights and responsibilities in that system.

How to develop an effective Individualized Education Program (IEP). The IEP is the document that outlines the rationale for and the specific ways your child will participate in general and special education. Understanding both the potential and the limits of the IEP is key to providing the most appropriate education for your son or daughter.

When to speak up for your child. Learning to be an effective advocate in the school system takes some time; this guide makes some common sense suggestions on how, for example, to prepare for meetings and keep lines of communication open with the school.

Which steps to take now to protect your child's financial future. *All* parents should have a will and name a guardian for their minor child or children. Parents of children with a disability may also need to create a special needs trust to protect any public benefits that their child may receive.

Look at tasks marked ASAP in the "Checklist for Parents" for decisions to be made right now.

Join Us for Small Group Trust Discussions

Come learn about the importance of special needs trusts at The Arc of Northern Virginia's Small Group Trust Discussions. Tia Marsili, Director of Trusts, will walk you through the importance of planning for the future of your loved one with a disability, why special needs trusts are important, who may establish these trusts, and how they are funded. Sessions are held once a month from 10am-11:30 a.m. at The Arc of Northern Virginia, 2755 Hartland Road, Suite 200, Falls Church, VA 22043. Registration required. Visit <https://thearcofnova.org/trust-presentations/> or contact Tia Marsili at tmarsili@thearcofnova.org or call (703)208-1119 ext.115.

Getting the Most from Special Education: A Checklist for Parents of Children with Disabilities

Step to Take by Age	Estate/ Legal	Financial/ Benefits	School	Recreation/ Therapies
ASAP				
Create file for key documents	x			
Have a will drawn up for parents; name guardians for minor children	x			
Create a Special Needs Trust	x	x		
Determine if child with disability qualifies for Supplementary Security Income (SSI)		x		
Explore child's eligibility for Medicaid waivers: Get on wait list(s).	MAY BE	X LONG	WAIT	LIST
Write your Letter of Intent	x			
Every year				
Update IEP			x	
Update list of teacher contact information			x	
Update Letter of Intent	x			
Every 3 years				
Triennial review of <i>eligibility</i> for special education			x	
At age 3 years				
If your child has been in Early Intervention, begin eligibility process for preschool with EI coordinator.			x	
If your child has not been in early intervention, contact your local Child Find program. Begin eligibility process for preschool special education.			x	
Pursue specialists/private therapies, if appropriate				x
Discuss child's needs with local therapeutic recreation dept; explore private recreational options				x
Spring before entering kindergarten				
For eligible preschoolers in special education, IEPs written for move to kindergarten. If you think your child might attend postsecondary education or training, begin financial planning.			x	

Step to Take by Age	Estate/ Legal	Financial/ Benefits	School	Recreation/ Therapies
At age 5				
Register child for kindergarten (optional). Must register by age 6 for first grade (required by law).			x	
Make attendance a priority. Missing 2 days per month impacts instruction and your child's opportunity to learn and stay up with classmates.			x	
When your child enters elementary school, become knowledgeable about state assessment options and their implications. See http://www.doe.virginia.gov/special_ed/ for more information.			x	
Begin to help your child develop self-determinations skills. Think about how you will discuss disability with your child.			x	

Step to Take By Age	Estate/ Legal	Post HS Education	Job/Day Support	Leisure	Transport
Beginning at age 14					
Begin transition planning with the first IEP in which the student turns 14. This includes age appropriate transition assessments & information, post- secondary goals, transition services & activities, agency referrals & course of study.		x	x	x	x
Your child will be invited to IEP meetings. Talk to them about their participation in the development of their IEP.		x	x	x	x
If using public transit, obtain Metro reduced-fare or MetroAccess ID cards					x
Age 16-18					
Continue transition planning. Explore eligibility for DARS (Department of Aging and Rehabilitative Services). Invite support coordinator (if a Waiver is in place), service providers to IEP meetings. Parents must provide consent for the school division to have an outside agency to an IEP meeting. Parents may invite any agency or person.		x	x	x	x
If college-bound, research colleges & visit campuses; meet w/ disability support services. Research scholarships, financial aid & grant opportunities.		x			
Decide on diploma options		x			
Gather information on employment service organizations & meaningful day support programs; open case with DARS.	Eligibility	is not a	x guarantee	of	services
Determine eligibility for adult services through appropriate local agency; fill out application and release of information forms			x		
At age 17, discuss transfer of rights with your child and the school. Understand what your options are.	x				

Step to Take by Age	Estate/ Legal	Post HS/ Education	Job/Day Support	Leisure	Transport
Age 17 (or 12-18 mo. before leaving school)					
For college-bound, take required tests; apply		x			
Explore employment service and day support organizations			x		
If staying in school until age 22, include move to post-grad programs as IEP transition goal		x	x		
1 month before 18th birthday					
If you choose to pursue legal authority, have attorney prepare final documents	x				
After 18th birthday					
Apply for Supplementary Security Income (SSI)	x				

STARTING WITH THE BASICS: THE ABCs of Special Education & Your Rights

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.”

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 the table on the next page.

YOUR RIGHTS IN PLAIN ENGLISH

Your Right Under the Law	This Means You...	This Means the School...
Right to Participate	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • May refuse to consent fully or partially to services proposed by the LEA (Local Education Agency) 	<ul style="list-style-type: none"> • 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 RIGHTS IN PLAIN ENGLISH

Your Right Under the Law	This Means You...	This Means the School...
Right to Review Records	<ul style="list-style-type: none"> • Must make a request for records in writing • May review any record and request copies if needed 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • May provide information for your child's evaluation from professionals such as psychologists, occupational or physical therapists, speech-language pathologists, etc. 	<ul style="list-style-type: none"> • Must review and consider evaluations and information provided by the parent
Right to Request Independent Educational Evaluation (IEE)	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Must provide <i>informed</i> consent and therefore must be able to understand and take part in IEP decisions 	<ul style="list-style-type: none"> • Must provide an interpreter (including sign language interpreter)
Right to Have Required Members in IEP Team	<ul style="list-style-type: none"> • May invite other individuals who have knowledge of the child to IEP meetings 	<ul style="list-style-type: none"> • Must ensure that at a minimum, the following are part of the IEP team: <ul style="list-style-type: none"> --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)

* Many thanks to Cheri Belkowitz, Esq., for her help in developing and reviewing this table.

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

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. (See the chart on the following page.)

For more detail on the special education process, see the Virginia Department of Education's handbook at http://www.doe.virginia.gov/special_ed/parents/parents_guide.pdf and VDOE's Guidance on Evaluation and Eligibility www.doe.virginia.gov/special_ed/disabilities/guidanceevaluation_eligibility.docx

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.**

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.

Step 2: Evaluation

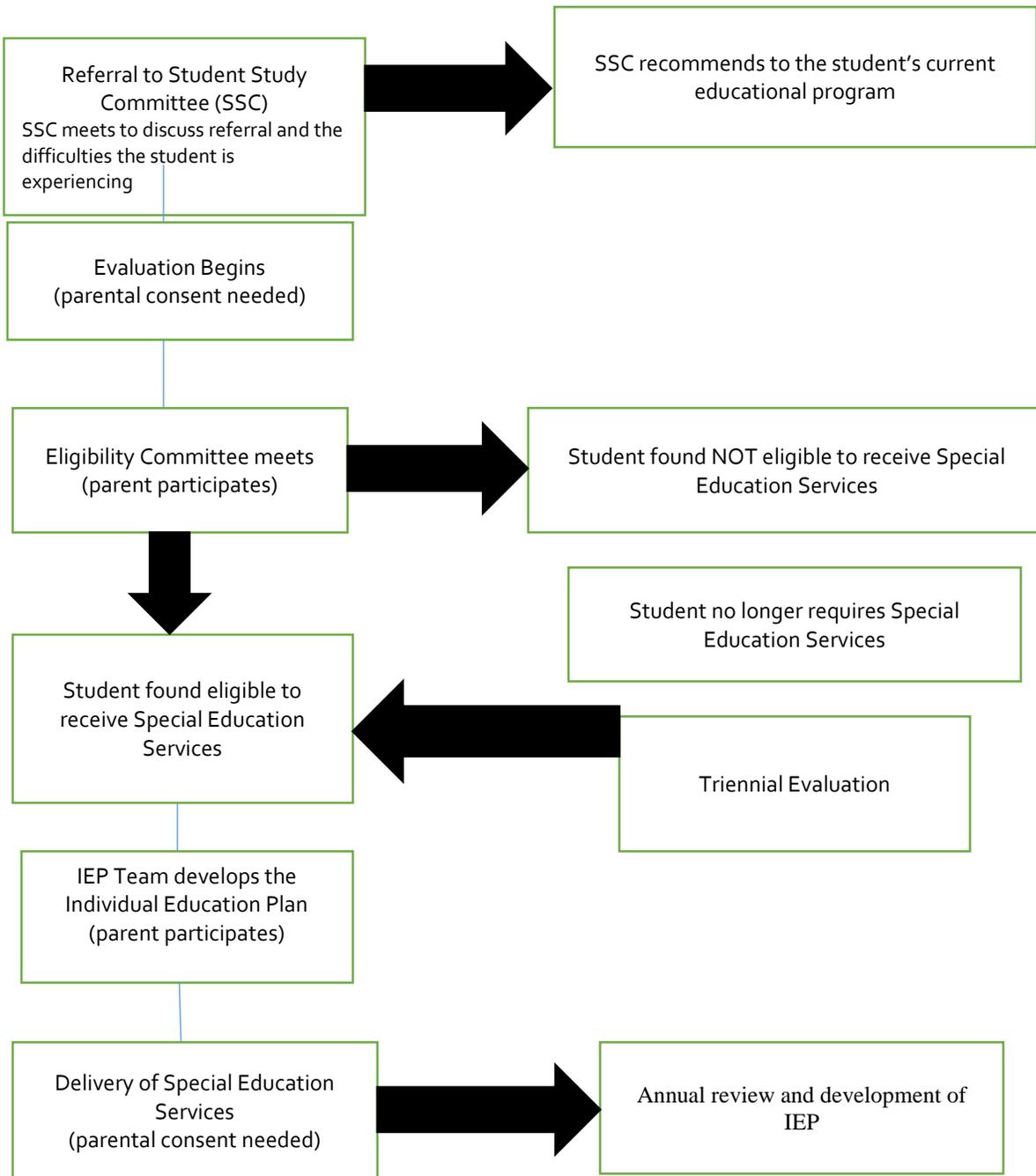
Once your child is identified as possibly needing special education services, **he or she must be evaluated. This is the law** and is the only way the school system can:

- 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. 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)



* Adapted from Arlington County Public Schools "Special Education Cycle". <https://www.apsva.us/student-services-special-education/special-education-office-of/special-education-cycle/>

- 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

For a list of assessment tools that the school system may use during the evaluation process (not all tests are available in all school districts), see:

http://dredf.org/special_education/Assesments_chart.pdf

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. Again an **evaluation does not result in a diagnosis or even in recommendations for services** (this is done in the eligibility meeting).

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.

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>

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 outlining your concerns and highlight the information in the report with which you disagree.

Making the Most of Evaluations

- If you think your child would benefit from a related service like speech or occupational therapy, *request an assessment* that would support the need for that service. You would *request the service itself later*, when writing the IEP.
- 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.
- Assessment reports should have recommendations for potential goals and objectives.

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.

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.

To qualify for special education services, (1) your son or daughter must have one of 13 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
- 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 13 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.

Step 4: Writing the Individualized Education Program

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."

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.

What is a Section 504 Plan?

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
-

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).

The Big Picture: What IEPs are Supposed to Accomplish

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 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: http://www.doe.virginia.gov/special_ed/parents/parents_guide.pdf

Advocating in IEP Meetings

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.

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.

See "Ten Common Mistakes Parents Make During an IEP Meeting" for more detail.

<http://www.kidstogether.org/IEP/iepd-10-mistakes.htm>

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>

The Nitty Gritty: 9 Key Components of an IEP

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

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)

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.

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

NOTE. The 2004 Amendments to IDEA no longer require goals to be broken down into smaller objectives, (by semester, for example). The IEP team may decide to do this, however. Benchmarks or short-term objectives **are** required only for children with disabilities who take alternate assessments.

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.

Keeping Up with Your Child's Progress

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.

Speaking practically, supplementary aids and services can be accommodations and modifications to the curriculum under study or the manner in which that content is presented or a child's progress is measured.

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

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/>

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.

Accommodations are changes that help your child *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.

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.

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.

City of Alexandria

<https://www.acps.k12.va.us/specialeducation>

Arlington County

<https://www.apsva.us/student-services-special-education/special-education-office-of/>

FairfaxCounty

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

City of Falls Church

<http://www.fccps.org/cms/one.aspx?pagelD=1187741>

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

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:

<http://doe.virginia.gov/testing/participation/index.shtml>

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 http://www.doe.virginia.gov/testing/alternative_assessments/vaap_va_alt_assessment_prog/index.shtml

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 court rulings on extended school year and FAPE, see this guide

http://www.doe.virginia.gov/special_ed/regulations/federal/extended_schoolyear_services.pdf

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.

For more examples of transition goals, visit the Special Ed Toolkit on our website

<https://thearcofnova.org/programs/transition/getting-special-education/>

1. Examples taken from “Development of Postsecondary Goals,” Virginia Dept. of Education Guidance Document, 2011. For more on what is required by IDEA and how to develop these goals, see http://www.doe.virginia.gov/special_ed/transition_svcs/guidance_postsecondary_goals.doc

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.

For more information see

http://www.doe.virginia.gov/special_ed/regulations/state/transfer_rights_students_disabilities.pdf

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 than during the transition planning years. Self-determination must begin as early as elementary school.

For the Student

Turning 18 confers specific rights on students with disabilities, including the right to:

- Have all information regarding their disability and the IEP presented in a format they understand
- Accept or refuse IEP services
- Disagree with the IEP and receive help in writing a complaint or requesting mediation or a due process hearing

Obviously, with these rights come responsibilities. Students participating in their IEPs should understand the best way to exercise their rights is to:

- Think about future goals and communicate those to the IEP team
- Discuss how school staff can help you achieve your goals
- Ask questions about what resources are available in the community to help you meet those goals
- Discuss what accommodations you might need in post-secondary education or on a job
- Attend all meetings and actively participate in decisions regarding your IEP
- Understand that if you refuse IEP services, you may not get them back
- Be cooperative

For information on transition and independent living, see <http://www.parentcenterhub.org/iep-transition/>

For the Parent

Once your son or daughter turns 18, you as the parent can continue to be involved in his or her education, but you will no longer have the legal authority to do so.

By law, schools respect the educational decisions of every adult student, *unless* that person has been determined to be incapable of making those decisions. However, parents (or other competent adult) may retain authority over education-related decisions through:

- **Power of attorney** granted by a *competent adult student*. The power of attorney must be signed by the adult student before a Notary Public.
- **Certification as an “educational representative.”** Two professionals in the medical or legal field (see list in the toolkit under Transition POINTS Special Education at www.thearcofnova.org) certify that the adult student with a disability is *unable or incapable of providing informed consent* in making educational decisions. The process of having an educational representative appointed is much less restrictive than guardianship.
- **Guardianship.** The parent obtains guardianship through the local court; guardians may make decisions about a wide range of social, financial and medical issues in addition to those related to education. See the section in this guide “Legal Authority Options”

For more information about transfer of rights at age 18, see the Virginia Department of Education’s website at: http://www.doe.virginia.gov/special_ed/regulations/sate/transfer_rights_students_disabilities.pdf

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.

However a child comes into the special education system, families can discuss multiple options for placing their toddler in a preschool program. If 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. Federal law requires the transition from Part C of the IDEA to Part B). 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 you as the

parents, special education teachers, when general education services are to be provided then general educators, related service providers such as therapists, and a special education administrator are part of the team developing this document. Your early intervention team members may also participate in the IEP process, if it occurs before your child turns 3 years old. You may also invite them after your child turns three. You may also invite people who are familiar with your child- friends, family members, advocates, private therapists, etc.

See the chart at the end of this section for a comparison of the IFSP and the IEP.

Making the Transition Easier

The transition between early intervention and preschool services, and later between preschool and kindergarten, can be an emotional one for parents. Your child will be away from home for more hours in the day than previously and it's easy to feel one is "losing control". It is therefore important to understand your role in shaping your child's school experience. The transition process may be easier by preparing your child by:

- talking to him or her about what to expect; showing pictures of the school, their teacher, the school bus, etc. posting a visual schedule at home
- visiting the school, daycare center or program (maybe more than once!)
- asking the preschool teacher to make a home visit
- inviting a potential classmate over for a series of play dates, so that your child will know at least one other person on the first day of school
- taking photos of your child at the new venue and creating a book with simple text and photos
- schedule play dates at the new site's playground after "regular" hours

Timing for Transitioning at Age 2. The timing is a bit complicated, but your service coordinator 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 offers Child Find that provides free screenings and/or evaluations for children 2-5 years of age suspected of having developmental disabilities or delays. (See list in box.) **You may call the Child Find office yourself; 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.
- **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.
- **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.** For many parents, a diagnosis of a developmental delay or disability is just the beginning of the story. It may be affirmation of your concerns or a surprise—but it will definitely lead you to therapies, programs, and services that will help your child. It will also help guide you in doing your own research and in seeking support for yourself and your family.

Follow your gut: if you believe something is "not right," take action.

Child Find Contacts

City of Alexandria
(703)578-8217
1501 Cameron Street, Suite 235, Alexandria, VA
<https://www.acps.k12.va.us/childfind>

Arlington County
(703)228-2709
1644 McKinley Road, Arlington, VA
<https://www.apsva.us/student-services-special-education/special-education-office-of/child-find/>

Fairfax County
<https://www.fcps.edu/registration/early-childhood-prek/child-find>

Dunn Loring Child Find
(703)204-6760
2334 Gallows Road, Room 233 (entrance 3), Dunn Loring, VA

Bull Run Child Find
(703)456-2200
15301 Lee Highway, Centreville, VA

Virginia Hills Child Find
(703)317-1400
6520 Diana Lane, Alexandria, VA

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 (IEE for which the school system pays).

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 <i>family</i> 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	<ul style="list-style-type: none"> • 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 <p>Family determines which outcomes will be in the plan.</p>	<ul style="list-style-type: none"> • 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 <p>IEP team, including the parents and student, determine the goals.</p>
Who is involved in developing the plan	<p>Team may include:</p> <ul style="list-style-type: none"> • 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 	<p>Team must consist of:</p> <ul style="list-style-type: none"> • 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 <p>The team may include others who have knowledge or special expertise about the student</p>

Issue	IFSP (Early Intervention Programs)	IEP (Preschool - Age 21)
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

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.

To enroll your child in kindergarten, contact your child’s base school; most schools host an orientation or open house for incoming students. Each locality has a website with boundary maps to help you determine which school your child should attend and information on registration procedures.

City of Alexandria

See the following website for a map showing school boundaries for the City of Alexandria:

<https://www.acps.k12.va.us/boundaries>

Registration requirements and forms may be found at <http://www.acps.k12.va.us/enroll/>

Arlington County

For students in Arlington County, the searchable boundary locator can be used to determine your child’s base school. <https://www.apsva.us/boundary-locator/>

Registration forms and required vaccinations and other information for Arlington County schools can be found at <https://www.apsva.us/registering-your-child/>

Fairfax County

The FCPS [boundary locator service](http://boundary.fcps.edu/boundary/) provides the names of the elementary school assigned to each home in the county at <http://boundary.fcps.edu/boundary/>. To access the service by telephone, call (703) 329-9831 and follow the instructions.

You will need to register your child at the school he or she will attend. See your local school website:

Alexandria City www.acps.k12.va.us

Arlington County www.apsva.us

Fairfax County www.fcps.edu

City of Falls Church www.fccps.org

If You Have Concerns about Your Kindergartener

For some children, the expectations of kindergarten—sitting still, learning letters and numbers or interacting with peers—may uncover cognitive, behavioral or social issues that had not previously been apparent. ***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.

Starting School at First Grade

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.

Child Find

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 <http://www.spanadvocacy.org/content/keys-success-family-school-partnership-pacer-center-action-information-sheet>

Communicating with the School

"Back to School" night at your child's school helps introduce you to your child's teachers and curriculum. To help stay in touch with what's going on in school:

- 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.

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.

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.

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>

Transition: The Big Picture

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.

Be realistic. 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), a work-based learning or career pathway may be a more realistic option. It is OK to revisit post-secondary goals based on past grades, test scores, and experience.

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 Services) at <https://www.vadars.org/services.htm#disabilities> and DBHDS (Department of Behavioral Health and Developmental Services) for more information on customized employment.

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.

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.

Disability Support Services at Northern Virginia Community College
<https://www.nvcc.edu/disability-services/index.html>

Sample placement tests at Northern Virginia Community College
<http://www.nvcc.edu/testing/placement.html>

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 "Securing a Future for Your Child with a Disability" and "Entering

the World of Work” at www.thearcofnova.org under 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.

Fairfax County offers career and technical academies (housed in high schools) for students interested in pursuing careers in International Studies and Business; Engineering and Scientific Technology; Health and Human Services; or Communications and the Arts. <http://www.fcps.edu/is/cte/academies.shtml>

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/academic-overview/special-education-instruction/career-and-transition-services/programming-for-students-18-22>

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 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. The program includes building of life skills such as travel training, money management, and workplace behavior and expectations. In high school, students begin to

have internships outside of school.

ACPS is in partnership with Project Search at Alexandria Hospital. This is a limited opportunity for a small number of students ages 18-22 year that are selected to participate in a school year long program at the hospital where they do job rotations. <http://www.projectsearch.us/>

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) <http://www.vadars.org/learnmore.htm> Virginia Apprenticeship Programs http://www.doli.virginia.gov/apprenticeship/registered_apprenticeship.html Fairfax County Adult & Community Education <http://www.fcps.edu/is/ace/>

Employment and Day Support Services

For more information on these options, see The Arc of Northern Virginia parent guides “Securing a Future for Your Child with a Disability” and “Entering the World of Work” at <https://thearcofnova.org/programs/transition/>

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://vadars.org/>.

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 son or daughter. 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. These are additional pathways to 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 <http://www.doe.virginia.gov/instruction/graduation/resources/diploma-options/Diplomaproject.html>

VDOE Applied Studies Diploma

http://www.pen.k12.va.us/instruction/graduation/applied_studies/index.shtml

VDOE Standard Diploma with credit accommodations
http://www.doe.virginia.gov/instruction/graduation/credit_accommodations.shtml

VDOE Standard Diploma

<http://www.doe.virginia.gov/instruction/graduation/standard.shtml>

VDOE Advanced Diploma

http://www.doe.virginia.gov/instruction/graduation/advanced_studies.shtml

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 special needs.

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.

Accept the stress and emotion that comes with being a parent and advocate.

It can be difficult to "hear" what teachers and specialists are saying, especially when you are under stress. Be aware that you are under stress and may be defensive at times. Instead, try to be a good listener and solution-oriented.

Take someone like your spouse or a good friend 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.

Be prepared and organized. Parenting a child with special needs requires working with lots of people, going to lots of meetings, and reading lots of documents. Work with teachers and other professionals to support your child.

- come prepared to meetings with your own agenda (things you want to discuss or have questions about)
- 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

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 in writing and write polite follow-up letters. Make and keep copies of emails, letters, meeting notices, evaluation reports...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.

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.

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!

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. Keeping 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.

The Rationale for Good Recordkeeping

You'll soon discover that having a child with a disability increases your household paperwork quotient! Through their school years you will accumulate all kinds of paper: medical records, IEPs, psychological or other therapy evaluations, teachers' notes, emails to and from the school, and progress reports from school, to name a few.

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

- **More effective advocacy.** Advocacy is having 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.
- **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.
- **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.

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). Examples of documents to be kept in each type of file are described below.

- **Consider audio recordings of meetings.** You should inform those at the meeting that you are recording the conversation.
- **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.
- **Keep 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.
- **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 School

The special education process involves lots of paperwork. 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. Pencil in 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.
- **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.
- **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.
- **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.
- **Medical history:** This section can be brief (diagnosis, current treatment & medication regimes), 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.

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. 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.

For more on the rationale for a Letter of Intent, <http://www.child-autism-parent-cafe.com/letter-of-intent.html>

APPLYING FOR BENEFITS: Supplemental Security Income (SSI)

Children under 18 may qualify for Supplementary Security Income (SSI) under the Social Security Administration if they meet Social Security's definition of disability **and** have limited income. Parents' and family members' income and resources **are** counted when determining eligibility.

Once your child turns 18, only his or her income and assets are counted (the child must still have a qualifying disability), and it is definitely worth applying for SSI at that time.

Here is the basic process for applying for SSI for a minor child (*again, family income is considered*).

Disability Definition

Under the law, a child is considered disabled for SSI purposes if:

- he or she has a medically determinable physical or mental impairment (or combination of impairments); and
- the impairment(s) results in marked and severe functional limitations; and
- the impairment(s) has lasted (or is expected to last) for at least one year or to result in death.

Applying for Benefits

The steps for applying are:

Start with a disability report. Go to the website at <http://www.socialsecurity.gov/pgm/ssi.htm> and click on Apply for Disability Benefits - Child (Under Age 18). (You may also call 1-800-772-1213 or go to a Social Security Field Office.)

You will need to complete an Application for Supplemental Security Income (SSI) **AND** a Child Disability Report. The report collects information about the child's disabling condition and how it affects his/her ability to function.

At this time, only the Child Disability Report can be completed online. *You cannot complete the entire*

application online; you must call Social Security for an appointment.

Complete the online Child Disability Report. At the end of the report, the agency asks you to sign a form that gives the child's doctor(s) permission to give Social Security information about his/her disability. They need this information to make a decision on the child's claim.

Contact Social Security right away to find out whether the income and resources of the parents and the child are within the allowed limits, and to start the SSI application process.

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!).

You may also complete the application at the appointment at the local SSA office, although this means taking all your medical records with you and consider-ably more time with the interviewer. If you do not have access to a computer, you can request an application be mailed to you when you call the 800 number.

Call Social Security. To make an appointment, call **1-800-772-1213** (TTY **1-800-325-0778**). It is best to call the 800 number rather than the local office as field offices are frequently under staffed and the 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. Fill it out and return within the allotted timeline.
- 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.

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.

Alexandria Office

PLAZA 500, Suite 190
6295 Edsall Road
Alexandria, VA 22312
1-(800) 772-1213

Arlington Local Office

401 Wilson Blvd. Suite 200
Arlington, VA 22209
(703) 235-1188

Fairfax Local Office

11212 Waples Mill Rd
Fairfax, VA 22030-7401
1-800-772-1213

Go to the screening interview. Bring any and all information to prove your child's age, citizenship, disability, and lack of assets/resources. SSA provides a list of needed information on their website at https://www.ssa.gov/disability/disability_starter_kits.htm#&sb=0 :

- Original birth certificate (or other proof of age and citizenship)
- Social Security card
- Documentation to verify your address
- Copy of special needs trust, guardianship or conservator order
- Individualized Education Program (IEP)
- Proof of current income for the child and family members living in the household (for example, pay stubs, self-employment tax returns, unemployment or other program benefits, child support). **SSA considers the parents' income and assets when applying for SSI for a child (under 18)**
- Checkbook or other papers that show a bank account number to have benefits deposited directly

to a Representative Payee account

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 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 in approximately 60 days about eligibility for benefits. If denied, you have 60 days to appeal.

The state agency may take three to five months to decide if your child meets the criteria for disability. For some medical conditions, however, the Social Security Administration make make SSI payments right away (and for up to six months), while the state agency decides if your child has a qualifying disability. Following are *some* of the conditions that may qualify:

- HIV infection
- Total blindness
- Total deafness
- Cerebral palsy
- Down syndrome
- Muscular dystrophy
- Severe intellectual disability (child age 7 or older)
- Birth weight below 2 pounds, 10 ounces

If the state agency ultimately decides that your child's disability is not severe enough for SSI, you won't have to pay back the SSI payments that your child received.

Set up a Representative Payee account. Once your child receives benefits, you will need to set up a Representative Payee account; be sure to title the account correctly (SSA has suggested wording). *Automatic deposit of benefits is required.*

SSI Disability Reviews

After your child starts receiving SSI, the law requires that the Social Security Administration review your child's medical condition from time to time to verify that his or her disability still meets its criteria. The review is completed:

- At least every three years for children younger than age 18 whose conditions are expected to improve; and
- By age 1 for babies who are getting SSI payments because of their low birth weight. If SSA determines that your child's medical condition isn't expected to improve by his or her first birthday, it may schedule the review for a later date.

For these reviews, you present evidence that your child's disability still severely limits his or her daily activities and that your child has been receiving treatment that's considered medically necessary for his or her medical condition.

The Representative Payee

A representative payee is appointed by SSA to receive Social Security and/or SSI benefits for someone who cannot manage 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.

A Rep Payee must keep records of expenses and be able to account each year for all spending of SSI funds. SSA sends out a "Representative Payee Report" annually; fill out the report promptly and mail it back, or you may submit the report online.

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 Rep Payee application in a face-to-face interview.

Note that having power of attorney, being an authorized representative or having a joint bank account with the beneficiary *do not* give you the legal authority to negotiate and manage the beneficiary's Social Security and/or SSI payments. See www.socialsecurity.gov/payee

APPLYING FOR BENEFITS: Medicaid Waiver Programs

This information is adapted from The Arc of Northern Virginia's website. For more information, www.thearcofnova.org/programs/waivers

Family income and family assets are not a consideration under the Medicaid Waiver program if your child's personal income and assets qualify them, they have a disability diagnosis, and they meet functioning eligibility criteria. To watch our recorded webinar that walks you through Waivers from start to finish, visit <https://www.youtube.com/watch?v=yJzF8FXmmfs&t=45>

You can read the latest information on the new Waivers from the state at <http://www.mylifemycommunityvirginia.org/> or call their hotline at **1-844-603-9248**.

Services Covered Under the Waivers

The Developmental Disability (DD) Waivers: There are 3 DD Waivers; they are the (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 and 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 is a supports waiver that 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. Moving to a waiver that serves people with higher needs may involve a significant waiting period and is a "first come, first serve system."

Eligibility Criteria

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

- (1) **Functioning ability:** This is determined by the VIDES survey. 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. This test is administered annually once a waiver is received.
- (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 (1) 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 \$735 in 2017, so max monthly income is \$2,205).

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.

Waiting List Eligibility 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.

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, 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.

To Apply for the Developmental Disabilities Waivers

Alexandria City CSB: (703) 746-3400
 Arlington DHS/IDD Services: (703) 228-1700
 Fairfax/Falls Church CSB/IDS: (703) 324-4400

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

Alexandria City: (703)746-5700
 Arlington: (703)228-1350
 Fairfax/Falls Church: (703)324-7948

ISFP Funding

For Those on the Waiver Waitlists

If you are on the waiting list for a waiver, you are eligible to apply for The Individual and Family Support Program (IFSP). This program is designed to assist individuals on the waiting list for the Disability Medicaid waivers to access short-term resources, supports, and services that will help them remain in their own homes in the community. Information, applications and instructions can be found at <https://ifsonline.dbhds.virginia.gov/>

SECURING YOUR CHILD'S FUTURE: Estate Planning

Key aspects of estate planning for *all* parents of young children are having a will and naming a guardian for your child or children. Parents of children with a disability also need to create a special needs trust to protect any means-tested 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 an heir 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 heir with a disability and/or the relationship between the siblings and family members. * A list of attorneys can be found in the provider directory on our website at <https://thearcofnova.org/directory/>. While many wills create family trusts, to avoid jeopardizing the benefits or services of your heir with a disability you need to create a separate *special needs trust* (see next page).

Reviewing Beneficiaries

In addition to naming a 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

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 some 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.

Naming a Guardian for Minor Children

In general, the law recognizes biological parents as a child's natural guardians. On the death of one parent, the surviving parent becomes the sole guardian.

In the event of both parents' deaths, however, you need to name *in your will* who you would like to be the guardian of your minor children. Unless there is a significant reason not to, the court will honor your request. Once appointed, the guardian becomes legally responsible for the upbringing of your child or children.

You may name a relative or friend to be the guardian of your children (you may also have a couple, such as sister and brother-in-law but should name each person individually). In deciding on this individual, focus on big issues such as: whether the person you are considering would truly love your children; how well your children would fit into their household; the guardian's values and childrearing philosophy; whether your children would have to move away from your neighborhood and friends (and special needs programs); the age and stamina of the guardian, particularly if your children are very young. You would also want to ensure that any potential guardian understands and accepts your child's disability, including his or her medical and therapeutic regime, behavioral and educational needs.

Explain your choice of guardian in writing if you feel

there may be disagreement in the family over your choice.

Special Needs Trust

Special needs trusts (sometimes called supplemental benefits/needs trusts) allow families to provide for the future financial stability of their loved one with a disability. Since some federal benefits programs impose severe limits on a 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 special needs trusts (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 since these programs limit your loved one to just \$2,000 in assets and resources to remain eligible.

Although no income or asset limits currently exist for the Social Security Disability Income (SSDI) program, individuals receiving SSDI benefits may also set up a first-party special needs trust (see below) for money management purposes.

Two Kinds of Trusts

As part of a family's future planning, ***third-party trusts*** (family funded trusts) established by parents with an attorney or directly 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 settlor or 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. You can contribute to them while you are still alive or you can fund them upon the death of the parents(s), grandparents(s), friend, etc. with an inheritance, life insurance policy or transfer from another trust.

First-party trusts (self-funded or self-settled) are

established by the beneficiary, parent, grandparent, guardian, or court ordered 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.

While many legal matters can be undertaken with a lawyer with a general background, SNTs are complicated enough to 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 Trust program does not require a minimum deposit.

Uses of Special Needs 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 by the beneficiary. Trust funds 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
- 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 and tax reporting, check writing, and disbursements. The Arc of Northern Virginia's trustee is Key Private 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 trusts set up 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.

For more information about being a trustee, download a free handbook at:

<http://www.specialneedsalliance.org/free-trustee-handbook>

To learn more about The Arc of Northern Virginia's Special Needs Trust, contact Tia Marsili, Director of Special Needs Trusts for a free consultation at tmarsili@thearcofnova.org or via the website at <http://thearcofnovatrust.org/make-an-appointment/>

ABLE Accounts

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

The Achieving a Better Life Experience (ABLE) Act enacted by Congress in late 2014 allows states to establish tax-advantaged savings accounts for certain individuals with disabilities for their disability related expenses. In addition, these funds would generally not be considered for supplemental security income (SSI) program (up to \$100,000), Medicaid, and certain other federal means-tested benefits.

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 only be used for Qualified Disability Related expenditures.

ABLE Accounts are similar to First Party or Self-Funded Trusts in that they require a Medicaid payback upon the death of the beneficiary. To learn more about ABLE Accounts, visit <http://www.ablenrc.org/>. For a better understanding of the differences between Special Needs Trusts and ABLE Accounts visit, the Securing a Future for Your Child Toolbox on our website <https://thearcofnovatrust.org/content/uploads/sites/16/2016/04/2017-Comparison-of-Special-Needs-Trusts-with-an-ABLE-Account-1.pdf>

CONSIDERING LEGAL AUTHORITY OPTIONS

Families often struggle to determine the need for 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 prevent someone from doing something or undo something that has been done.*

Dignity of Risk and Supported Decision Making

In recent years, a movement has grown to 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. This idea is called “[supported decision making](http://supporteddecisionmaking.org/)” and there is a growing international movement towards this policy. A team of people 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 but does build a support team and a way to grow decision making ability and independence over time. It has no cost and is probably what you are already doing. You can learn more about Supported Decision Making and view webinars on the topic at <http://supporteddecisionmaking.org/>

“Dignity of Risk” also means understanding that it is okay to make some bad decisions. We are all allowed and it is often how we learn best. Many people learn from spending too much that it is hard to pay bills and learn from weight gain and health issues that they ate too much. This is a right all people have and exercise every day. People with disabilities should have the same opportunities to make decisions and learn through natural consequences and a support team about how to proceed the next time.

Guardianship and Conservatorship

Guardians and conservators are appointed by a local court to protect an incapacitated person-- that is, someone who cannot receive or evaluate information

effectively to meet his or her health, care and safety needs, or to manage property or financial affairs.

A guardian and/or conservator is often appointed for a person with a disability. However, **only a Circuit Court judge can decide that a person is incapacitated** and appoint a guardian and/or a conservator to act for the person. The appointment of a guardian or conservator is not a routine matter, and it is appropriate to take it very seriously, as the legal system does.

In essence, **guardianship** makes someone (like parents) responsible for *making financial, medical, social, and legal decisions* on behalf of a person who cannot make those decisions completely by themselves. In Virginia, a guardianship can be structured to fit the individual, with some rights taken away and others retained. An experienced attorney can assist you in crafting a guardianship that fits the individual and allows you to remain as a strong advocate for the individual with a disability.

A **conservator’s** decision-making responsibility is focused on managing a person’s financial and property affairs. A conservator’s authority, like that of a guardian, may also be limited depending on the situation of the incapacitated person.

The court may appoint only a guardian, only a conservator, or both. For most young adults with a disability, only a guardian is necessary. The extent of the guardian’s or conservator’s authority will be set forth in the judge’s order and in the Virginia Code.

Typically, the young adult has less than \$2,000 in assets; the only income is from SSI or earnings that typically can be managed by a Representative Payee or by the individual with some assistance.

Considering Guardianship

In a guardianship, the law strikes a balance between preserving the rights and personal autonomy of an adult and the duty of the Commonwealth of Virginia to protect individuals who lack sufficient capacity to make decisions regarding themselves or their property.

Families should consider less restrictive alternatives before petitioning for guardianship if they believe the individual may not fit the criterion of “incapacitated.”

Parents considering guardianship should keep in mind that:

- **Your child will not be labeled “incompetent.”** Virginia has eliminated that term from the law. Now a person is found to be “incapacitated” to the extent that they cannot make certain decisions.
- Overall, it is important to realize that guardianship is a **very flexible system in Virginia.**
- Guardianships can be **tailored to the needs of your child**, allowing parents to remain in a strong advocacy position.
- As part of that flexibility, **guardianship need not take away all or even most of the individual’s rights.** It is very common, for example, to preserve the right to vote, the right to hold a driver’s license, and other rights.
- Even under guardianship, your adult child **can still participate in decision-making** about his or her life to the extent of their capabilities. The guardianship order will typically say that the individual with a disability will be consulted and his/her wishes taken into account.
- **Your child remains eligible for government benefits.** There is no loss of government benefits because someone has a guardian. The guardian’s income and assets are not counted when computing benefits for an adult individual with a disability.
- --Guardianship **does not make you financially responsible for the person under guardianship.** For example, parents who are guardians do not have to provide food and shelter for their child but would be responsible for making the *decisions* about where their child would live and the kind of care he or she would receive.
- As a guardian, **you are not responsible for the financial, civil or criminal liabilities of your child.** If an individual under guardianship hurts someone or something, the guardian is not

liable. If they were, few people would be willing to serve as a guardian.

Parents are frequently appointed as guardians, but other family members, an attorney, a friend, or a public guardian may also serve in this capacity.

To help determine if guardianship is the appropriate choice for your young adult, fill out the screener at <https://thearcofnova.org/content/uploads/sites/6/2016/07/Thinking-about-Guardianship-checklist.pdf>

Obtaining Guardianship

To obtain guardianship, parents need to file a petition with the Circuit Court of the jurisdiction in which the individual lives. Typically, parents are appointed as co-guardians, which allows either to act independently. You must provide a medical or psychological evaluation of your loved one that supports the need for guardianship. You may ask the court to appoint “standby” guardians who would serve when you no longer can.

When the petition is filed, the court appoints a guardian ad litem (GAL). The GAL is an attorney in private practice appointed from an approved list. The GAL’s primary job is to ensure that the rights of the individual with the disability are protected. The GAL will therefore meet the individual, serve him or her with the court paper-work, and explain their rights. The GAL will also make a report to the Court giving an opinion as to whether the appointment of a guardian is necessary and who should be appointed.

After the GAL has filed a report, a hearing is held at the Court. Usually the persons being appointed as guardians must attend the hearing, and after the hearing will go to the Clerk of the Court’s office to complete all necessary paper-work. The individual for whom the guardian is being appointed may choose to attend the hearing or not.

As a guardian, you are required to submit a report every year to the local Department of Social Services; the court will provide a form.

Weighing Alternatives

The appointment of a guardian or a conservator should be considered only as a last resort. Petitioners for

guardianship must provide evidence, and a judge must determine, that an individual is “incapacitated” in terms of making certain decisions.

However, if the person is not considered “incapacitated” but still needs help, the individual and his or her family may choose among several other options. These alternatives range from having a caregiver (who has no legal authority to make decisions) to giving a trusted person a durable power-of-attorney (may make all medical, legal and financial decisions).

For example, an individual needing some assistance may be able to sign a Power of Attorney or Advance Medical Directive, appointing you or another family member as their agent for decision-making.

It’s important to remember that the individual must be capable of understanding what they are doing when they execute a Power of Attorney or Medical Directive. A Power of Attorney or Medical Directive *does not allow you as the agent to override the decision of the individual with the disability*. So if the individual enters into a contract he or she did not understand, the agent under a Power of Attorney cannot void that contract. If the individual is in the emergency room yelling that they do not want a shot or test, the agent under the Medical Directive cannot override that decision.

For a list of attorneys in the Northern Virginia area that specialize in guardianship, visit The Arc of Northern Virginia’s Provider Directory at <https://thearcofnova.org/directory/>.

¹Thanks to Kelly Thompson, Esq., for her work on this section and her insights on issues parents face in deciding on guardianship

Determining a Decision-Making Role

Type	Decision-making Responsibilities	Notes
Full guardianship	All financial, legal, personal care, and social decisions	Individual must be incapacitated Guardian must file an annual report with Dept. of Social Services
Limited guardianship	Decisions on specific issues (e.g., just health care), as determined by the judge	Individual must be incapacitated Guardian must file an annual report
Standby guardian	Person designated in guardianship order to become guardian when current guardian dies	Does not assume any duties until death of primary guardian
Full conservatorship	All financial decisions, including paying bills, investing money, and selling property. Conservator must post a surety bond.	Individual must be incapacitated Conservator must file annual report on all financial transactions
Limited conservatorship	Decisions on specific financial matters, such as paying bills or filling out tax returns, as specified by the judge. Conservator must post surety bond.	Individual must be incapacitated Conservator must file report on income and expenses
Representative payee	Receives another person's government benefits on behalf of that person; responsible for using benefit to pay beneficiary's living expenses	Rep Payee must report annually to the Social Security Administration
Advance medical directive	Person with disability provides instructions about his or her wishes for health care treatment and designates an agent to make health care decisions when he or she cannot	Agent's powers are defined in the document Agent cannot override decisions
Durable power of attorney	Written authority giving a parent or another person (agent) power to make decisions on behalf of the individual with a disability (the principal). Agent may act even if principal becomes incapacitated.	Agent cannot override decisions Power ends if principal revokes it or dies
Special education power of attorney	Written authority giving a parent or another person (agent) power to make decisions on behalf of the individual with a disability (the principal) regarding educational decisions ONLY.	Agent cannot override decisions Power ends if principal revokes it or dies
Emergency order for adult protective services	Short-term guardianship (15 days) to handle an emergency or correct conditions causing an emergency	Local Department of Social Services must apply to Circuit Court for temporary guardianship order

FINDING SUPPORT: Resources for Parents

Parent Resource Centers (PRC)

Parent Resource Centers in each school system promote parent awareness of the special education process. The centers encourage parent participation in the educational process and provide information to foster the parent-professional relationship.

Arlington Public Schools PRC

Syphax Academic Center at Sequoia Plaza
2110 Washington Blvd., Suite 158
Arlington, VA 22204
(703) 228-7239 www.apsva.us/prc

City of Alexandria PRC

Anne R. Lipnick Special Education Family
Resource Center
<http://www.acps.k12.va.us/curriculum/special-education/prc/>
T.C. Williams High School - Minnie Howard Campus
3801 West Braddock Road, Room 134
Alexandria, VA 22302
(703) 824-0129

Fairfax County Public Schools PRC

2334 Gallows Road, Room 105
Dunn Loring, VA 22315
(703) 204-3941 www.fcps.edu/dss/osp/prc

Parent Educational Advocacy Training Center

PEATC works collaboratively with families and schools to help parents negotiate the education and service system maze, effectively communicate their child's needs, develop self-advocacy skills, and organize information. www.peatc.org (703) 923-0010

Center for Parent Information & Resources

The CPIR serves as a central resource for Parent Resource Centers across the country. The website discusses a wide range of topics related to special education. www.parentcenterhub.org

The Arc of Northern Virginia Special Education Toolkit and Provider Directory

www.thearcofnova.org

These online resources on our website are designed to inform parents' decision-making around special education, estate planning, recreation, and benefit programs:

- Attorneys with specialties in education and special needs law
- Education consultants
- Local support groups for parents
- Apps and other web-based resources
- Local public and private recreational resources
- IEP Goals Bank

Additional Online Resources

Talking to Your Child About His/Her Disability

<http://www.pbs.org/parents/education/learning-disabilities/supporting-your-child/talk-to-your-child/>

Self Determination

<https://www.imdetermined.org/>

Glossary: Acronyms in Special Education

You will come across many acronyms while your child is in the special education system. Here are a few of the most common ones.

- 504** A section of the Rehabilitation Act of 1973
- ADA** Americans with Disabilities Act
- BIP** Behavioral Intervention Plan
- CSB** Community Services Board
- DD** Developmental Disability
- ESY** Extended School Year
- FAPE** Free Appropriate Public Education
- FAPT** Family Assessment Planning Team
- FBA** Functional Behavioral Assessment
- DARS** Department of Aging and Rehabilitative Services)
- ETR** Employment Transition Representative
- ID** Intellectual Disability
- IDEA** Individuals with Disabilities Education Act
- IFSP** Individual Family Service Plan
- IEE** Independent Educational Evaluation
- IEP** Individualized Education Program
- ISP** Individual Services Plan
- LAC** Local Advisory Committee (also SEAC)
- LEA** Local Education Agency (also school division or SOP)
- LRE** Least Restrictive Environment
- OT** Occupational Therapy
- PEP** Program for Employment Preparedness
- PLOP** Present Levels of Performance
- PRC** Parent Resource Center
- PSL** Procedural Support Liaison
- PWN** Prior Written Notice
- PT** Physical Therapy
- SEA** State Educational Agency (in Virginia, VDOE)
- SEAC** Special Education Advisory Committee
- SLP** Speech Language Pathologist
- SPED** Special Education
- STEP** Secondary Transition to Employment Program
- SOL** Standards of Learning Test
- T/TAC** Training/Technical Assistance Center
- VAAP** Virginia Alternative Assessment Program
- VR** Vocational Rehabilitation Services
- WAT** Work Awareness and Transition

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