



Starting Life With Your Child With a Disability

First Steps For Families In Northern Virginia



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

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

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

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

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INTRODUCTION

Welcoming a child into your life is a profound and life-changing experience. When you learn that your child has a disability, it can come with a mix of emotions—love, worry, uncertainty, and hope. You may be facing questions you never expected and challenges you didn't plan for. But you are not alone, and there is a path forward.

This guide is here to support you as you take your first steps in this new chapter. While the journey may not look exactly as you imagined, it is still filled with joy, growth, and connection. With the right tools, information, and support, your family can thrive. Over time, you will build confidence, find community, and celebrate the many achievements—large and small—that lie ahead.

The Arc of Northern Virginia's Transition POINTS Guides were created to be a practical, compassionate companion during these early stages. It gathers essential information, resources, and strategies to help you understand your child's needs, access services, and plan ahead for the future. You'll find explanations of programs and benefits, tips for advocating for your child, guidance on navigating school and community systems, and suggestions for building a strong support network.

We know that every family's journey is unique, and there is no single "right" way to move forward. That's why this guide offers flexible, step-by-step ideas you can adapt to your own situation—whether you need immediate help or are simply looking to understand what lies ahead.

You don't need to have all the answers right now. What matters most is knowing that there is a network of people and resources ready to walk beside you. This guide will help you navigate the early days, begin building a strong and informed foundation for your child's future, and nurture your family's well-being along the way.

ABOUT TRANSITION POINTS

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

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

1. Receiving a diagnosis and having a child enter an early intervention program
2. Starting school and entering the special education system
3. Transitioning out of the school system to adulthood
4. Entering the world of work
5. Finding a home
6. Aging with a disability



Providing Opportunities, Information, Networking
and Transition Support

For each transition point, we provide materials in both print and digital formats, online resources, workshops, and webinars. All of these materials can be found on our website at www.thearcofnova.org. The Arc of Northern Virginia maintains a library of informative life-planning videos and webinars on our YouTube Channel at <https://www.youtube.com/user/VideosatTheArcofNoVA>.

The information 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 <https://dbhds.virginia.gov/community-%20services-boards-csbs>. The CSB is the point of entry into the public funded system of services for people with mental health needs, intellectual and developmental disabilities. Also, visit The Arc of Virginia at www.thearcofva.org to find the local Arc chapter in your community.



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FIRST STEPS FOR FAMILIES

FIRST STEPS FOR FAMILIES

If your child has recently been diagnosed with a disability, or if you have concerns about your child's development, you may be wondering what to do next. You're taking a great first step by reaching out for information and you'll find lots of supports with The Arc of Northern Virginia, as well as other nonprofit organizations and public programs.

LOCAL SERVICES AND ASSESSMENTS

Localities are required by federal law to screen infants and toddlers who have or may have a developmental delay. In Virginia, this program is called Infant and Toddler Connection of Virginia. Local government entities, called Community Services Boards (CSBs) manage early intervention intakes and assessments.

Early intervention can have a huge impact on the lifelong ability of your child to speak, develop motor and social skills, and become more independent. Reach out to your local Infant and Toddler Connection office as soon as possible to plan for an assessment and begin services like occupational therapy, physical therapy, and speech therapy. These supports will be offered on a sliding scale and may be covered by insurance. Some services, including service coordination, assessments, and transition planning for preschool are free.

Below is contact information for the Northern Virginia area. If you are outside of Northern Virginia, find your local office by visiting <https://www.itcva.online>.

NORTHERN VIRGINIA INFANT AND TODDLER CONNECTION OFFICES

ALEXANDRIA CITY | 703-746-3387 or 703-746-3350

<https://www.alexandriava.gov/child-and-family-services/program/parent-infant-education-program-pie>

ARLINGTON COUNTY | 703-228-1640

<https://www.arlingtonva.us/Government/Programs/Health/Public-Health/Health-Clinics-and-Services/Parent-Infant-Education-Program-PIE>

FAIRFAX COUNTY AND FALLS CHURCH | 703-246-7121

<https://www.fairfaxcounty.gov/neighborhood-community-services/itc>

LOUDOUN COUNTY | 571-258-3095

<https://www.loudoun.gov/2778/Infant-Toddler-Early-Intervention>

PRINCE WILLIAM COUNTY | 703-792-7879

<https://www.pwcva.gov/department/community-services/infant-toddler-services>

FIRST STEPS

if the child is under 36 months of age go to page 20. If you have concerns and under 36 months, go to page 26, If your child is 2-5, contact Child Find, page 39.



GENERAL NOTES

A CHECKLIST FOR PARENTS

STEP TO TAKE BY AGE	CHECK IF DONE	NOTES
IF YOU SUSPECT DEVELOPMENTAL DELAYS		
Record observations and discuss with pediatrician; ask for developmental screener pg. 28		
Contact local Early Intervention Program pg. 10		
Pursue specialists/private therapies to supplement early intervention		
AS SOON AS YOU HAVE A DIAGNOSIS OF A DEVELOPMENTAL DISABILITY		
Have hospital or pediatrician provide info & training on child's medical needs, referrals to specialists		
Contact local Early Intervention Program pg. 10		
Pursue specialists/private therapies to supplement early intervention pg. 10		
Sign Up for The Arc of Northern Virginia's newsletter and begin to attend webinars of interest www.thearcofnova.org		

STEP TO TAKE BY AGE	CHECK IF DONE	NOTES
FOR ALL PARENTS ASAP		
Find a support network pg. 84		
Create a system to organize documents pg. 52		
Create a will; name guardians for minor children pg. 72		
Draft a Letter of Intent pg. 54		
Establish a Special Needs Trust pg. 73		
Determine if child qualifies for Supplementary Security Income pg. 58		
If qualified for SSI, set up a Rep Payee account pg. 61		
Explore eligibility for Medicaid waivers: Get on wait list. pg. 62		
AT AGE THREE		
If your child has been in Early Intervention (EI), contact local school system or ask your EI coordinator about preschool before your child turns three years old. pg. 39		
If your child has not been in early intervention, contact your local Child Find program pg. 43		



NOTES

DATE FIRST CONTACTED PEDIATRICIAN	NAME AND CONTACT INFO FOR ATTORNEY WHO HELPED WITH WILL
DATE/NAME/INFO OF DIAGNOSTICIAN	INFO ON SPECIAL NEEDS TRUST
DIAGNOSES	CONTACT INFO OF EI CASE MANAGER
RECOMMENDED NEXT STEPS	EI ASSESSMENT DATES, MEETING DATES, MOST RECENT PLAN
LOCATION OF WILL/LETTER OF INTENT	PEOPLE WHO HAVE BEEN HELPFUL AT DOCTOR'S, HOSPITAL, PARENT GROUPS, ETC.



GENERAL NOTES

FAMILY INFORMATION AND SUPPORT TRACKER

CATEGORY	INFORMATION / NOTES	CONTACT NAME	PHONE / EMAIL	NEXT STEPS / FOLLOW-UP
Diagnosis Information	Date of diagnosis, diagnosis details, notes from doctor			
Primary Care Provider	Pediatrician or family doctor			
SPECIALISTS	Neurologist, developmental pediatrician, geneticist, etc.			
Therapies	Speech, occupational, physical, behavioral, or other therapies			
School / Early Intervention Contacts	Teacher, special education case manager, IEP team, or early intervention coordinator			
Service Coordinators / Case Managers	From local disability services, Medicaid waiver, or support organizations			

CATEGORY	INFORMATION / NOTES	CONTACT NAME	PHONE / EMAIL	NEXT STEPS / FOLLOW-UP
Community Resources	Local family support groups, respite programs, advocacy organizations			
Insurance Information	Policy numbers, coverage notes, claims contact			
Medications / Equipment	Name, purpose, dosage, provider contact			
Important Dates	Upcoming appointments, school meetings, service deadlines			
Questions / Notes for Next Appointment	Things to ask providers or follow up on			



GENERAL NOTES



**IF YOUR CHILD HAS BEEN
DIAGNOSED WITH A
DEVELOPMENTAL OR
INTELLECTUAL DISABILITY**

IF YOUR CHILD HAS BEEN DIAGNOSED WITH A DEVELOPMENTAL OR INTELLECTUAL DISABILITY

When a child is diagnosed with a developmental disability, many parents are in shock and feel completely overwhelmed. If you feel this way, you are not alone. Having a child with special needs may be opening up new parenting territory that you were not expecting and are not prepared for.

In spite of this, you are prepared with the most important thing: love and a desire to do your best for your child. Give yourself time to absorb the information and to talk about your fears and hopes for your child with your family and good friends. Other parents who have been in your situation have suggested the following:

EMBRACE WHERE YOU ARE RIGHT NOW.

Don't rush through whatever initial feelings you may be having. Give yourself time to process those feelings. It is understandable that you may want to "get over it" or "be strong," but this initial time is a valuable part of the whole journey. The way you feel right now is not the way you will feel forever.

TAKE CARE OF YOURSELF.

Eating right, getting enough sleep and exercising help reduce stress and will increase your physical and emotional energy. It's not selfish to put yourself first for a few minutes a day; taking care of yourself and taking time with your spouse or partner is the best thing you can do to take care of your family.

SEEK OUT A SOUNDING BOARD.

Find a good listener (spouse, friend, parent, or support group) who will allow you to express your frustrations and anger but not judge. Share your thoughts with them and have them help you problem-solve. Another's perspective may help you stay focused on your family's goals and hopes for your child with disabilities.

RECOGNIZE THE NEED TO MAKE SOME VERY TOUGH DECISIONS FOR YOUR CHILD.

While your friends are fretting about playdates, preschools, and ear infections, you may be dealing with far different things like heart surgery, tests to determine if your child can see or hear, learning how to manage seizures, or helping your child communicate. Trust that you will be able to do everything for your child that he or she needs.

LET YOUR CHILD LEAD THE WAY.

Doctors may offer their assessment of your child's potential or they may refuse to discuss it. Don't believe everything you hear, especially when it is negative. Often your child will be the one who shows you what he or she can do. As difficult as it is, many parents have recommended "living in the moment" rather than trying to guess the future.

ACT AS EARLY AS POSSIBLE TO GET HELP.

If you are reading this, you are already taking a key step: getting help. Research confirms that addressing developmental delays at an early age results in better outcomes for a child's health, language, motor, cognitive, social, and emotional development.

If your child has not yet reached his or her 3rd birthday, **call your local early intervention program.** Certain developmental disabilities, such as cerebral palsy, autism and Down syndrome automatically qualify your child for early intervention services.

GET CONNECTED WITH OTHERS.

No one is an island, they say, and this is especially true for parents of children with disabilities. Be open to all modes of support, including social media like blogs, Facebook, and Instagram groups, while not leaning exclusively on one mode to the exclusion of another.

Your friends and family will want to support and help you. Let them. People will love your child deeply and will do what they can to help.

There are also many local parent and advocacy groups.

- The Autism Society of Northern Virginia <https://asnva.org>
- Parents of Autistic Children of Northern Virginia <https://poac-nova.org>
- Down Syndrome Society of Northern Virginia <https://www.dsnva.org>
- The Arc of Loudoun County <https://thearcofloudoun.org>
- The Arc of Northern Virginia <https://thearcofnova.org>

START KEEPING TRACK OF PAPERWORK.

It's also a good idea to set up file folders or a binder for your child's specialists, medical, early intervention, and therapy records. Good records will save you time and effort for years to come (see the section on "Keeping Good Records" for ideas on what documents you should have on hand).

GETTING HELP FROM THE HOSPITAL

Most hospitals have in-house staff who are available to assist parents of newly diagnosed children.

Child Life specialists provide support to families and children on issues related to treatments and in-hospital procedures. Child Life Specialists are trained and certified to help children, adolescents and families understand and cope with illness, treatment, hospitalization, and therapeutic play experiences.

Case managers are registered nurses who help plan your child's discharge. Case managers make referrals for home care services, arrange home equipment and supplies, work with pharmacies to obtain special medications, and coordinate insurance coverage.

Social workers are licensed to counsel families coping with illness or injury, assess patient and family psychosocial needs, and provide crisis and therapeutic counseling; they may also help connect you to community resources. Some hospitals run special programs geared to helping families connect with resources outside the hospital. See, for example, the Parent Navigator Program at Children's National Medical <https://www.childrensnational.org/plan-your-visit/inpatient-and-hospital-stays/patient-services-and-hospital-amenities/family-support-services/parent-navigator-program> and Inova's Care Connection www.inova.org/inova-in-the-community/care-connection-for-children/index.jsp

10 THINGS TO ASK AFTER A DIAGNOSIS

Receiving a new diagnosis for your child can feel overwhelming. You don't have to have all the answers right away – and you're not alone. These questions can help you start the conversation with your child's doctors, teachers, and support team.

1. **What does this diagnosis mean for my child?**

Ask your doctor or specialist to explain how the diagnosis may affect your child's learning, behavior, or daily life in clear, simple terms.

2. **What support or therapies can we start right now?**

Early action can make a big difference. Find out if your child could benefit from speech, occupational, physical, or behavioral therapy.

3. **What can we expect in the weeks and months ahead?**

Knowing what's likely to happen soon—both challenges and possibilities—helps you plan, prepare, and celebrate progress along the way.

4. **Is there anything that needs to happen right away?**

Understanding what's urgent helps you prioritize without rushing into things that can wait. It also brings peace of mind when you know what's truly time-sensitive.

5. **Who else should be part of my child's care team?**

Specialists, therapists, and educators can work together to give your child the best support. This question opens the door to building a strong, connected team.

6. **How might this affect my child's daily life?**

Knowing how the diagnosis could shape learning, play, friendships, and routines helps you create an environment where your child can shine.

7. **Where can I find reliable information and resources?**

Not all online information is trustworthy. Having a list of dependable sources means you'll spend less time sorting fact from fiction.

8. **What financial or community supports are available to us?**

From early intervention funding to nonprofit programs, support is out there. This question helps you discover resources you might not know about.

9. **What changes should I watch for as my child grows?**

Your child's needs may change over time. Knowing what signs to look for can help you adapt supports and celebrate new milestones.

10. **How can I take care of myself and my family, too?**

Caring for your child starts with caring for yourself. Support groups, counseling, and respite care help you stay strong for the journey ahead.



GENERAL NOTES



GENERAL NOTES



**IF YOU HAVE CONCERNS
ABOUT YOUR CHILD'S
DEVELOPMENT
(NO DIAGNOSIS)**

IF YOU HAVE CONCERNS ABOUT YOUR CHILD'S DEVELOPMENT (NO DIAGNOSIS)

While babies grow at slightly different rates, most reach key developmental milestones at more or less the same time. For example, babies are usually lifting their heads and smiling by 3 months and sitting by themselves by 9 months of age.

For various reasons, some babies and toddlers lag behind their peers. Look at the chart “Typical Developmental Milestones” to get an idea of how your baby or toddler should be progressing. If you are concerned about your child’s development, it’s best to take action early. Here are some ways you can begin:

Become a specialist on your child. If you are concerned about certain behaviors (or lack thereof), start keeping notes or record them: what is the setting for the behavior, what happened before the behavior occurred, what is the behavior, when and where does it occur, and how long does it last. 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-baby 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. You may also get a referral to the local early intervention program.

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 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 be referred to and participate in an early intervention program in the meantime. Trust your gut!

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 an 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. Remember, too, that a diagnosis may change as your child ages or as more tests and evaluations are done. Work with the knowledge you have and continue to seek more; the better informed you are, the better advocate you are for your young child. Don’t let the diagnosis define your child.

If you have concerns about your child’s development, even if the pediatrician does not, you may refer your child yourself to your local early intervention program. While you are on the phone, the person doing the intake will listen to your concerns and review the screening, assessment, and eligibility process. For contact information for Local Early Intervention Programs, see page 31.



GENERAL NOTES

TYPICAL DEVELOPMENTAL MILESTONES

AGE	MOVEMENT/ PHYSICAL	COGNITIVE	LANGUAGE/ COMMUNICATION	SOCIAL/ EMOTIONAL	NOTES
2 mo	Holds head up when on tummy; opens hands briefly; moves arms and legs	Watches you as you move; looks at a toy for several seconds	Reacts to loud sounds; makes sounds other than crying	Calms down when spoken to; looks at your face; seems happy to see you; smiles when you talk to her	
4 mo	Holds head steady unsupported; holds a toy; uses arm to swing at toys; brings hands to mouth	Opens mouth when sees breast or bottle; looks at hands with interest	Makes cooing sounds, makes sounds back when talked to; turns head towards sound of your voice	Smiles spontaneously; chuckles; looks at you, makes sounds to get your attention	
6 mo	Rolls from tummy to back; pushed up with straight arms when on tummy; leans on hands to support when sitting	Puts things in mouth to explore them; reaches to grab a toy; closes lips to show she doesn't want more food	Takes turns making sounds with you; blows "raspberries", makes squealing noises	Knows familiar people, likes to look at himself in a mirror, laughs	
9 mo	Gets to a sitting position, moves things from one hand to another, sits without support	Looks for objects when dropped out of sight; bangs two things together	Makes different sounds like "mama mama" and "baba baba"; lifts arms to be picked up	Is shy, clingy around strangers; shows several facial expressions; looks when you call her; reacts when you leave; smiles or laughs when you play peek-a-boo	
12 mo	Pulls up to stand; walks holding on to furniture; drinks from a cup as you hold it; pick things up between thumb and forefinger	Puts something in a container; looks for things he sees you hide	Waves bye-bye; calls a parent "mama" or "dada"; understands "no"	Plays simple games (pat-a-cake, ball roll)	
15 mo	Takes few steps on his own; Uses fingers to feed herself food	Tries to use things the right way like a phone; stacks at least two small objects	Tries to say one or two words besides "mama" or "dada"; looks at a familiar object when you name it; points to ask for something	Copies other children while playing; shows you an object she likes; claps when excited; hugs a toy; shows you affection	

AGE	MOVEMENT/ PHYSICAL	COGNITIVE	LANGUAGE/ COMMUNICATION	SOCIAL/ EMOTIONAL	NOTES
18 mo	Walks without help; likes to pull; scribbles; drinks from a cup; feeds herself with fingers; tries to use a spoon; climbs off chair without help	Copies you doing chores like sweeping; plays with toys in a simple way like pushing a car	Tries to say three or more words besides “mama” or “dada”; follows one-step directions	Moves away from you, but looks to make sure you are close by; points to show you something; puts hands out for you to wash them; looks at pages in a book with you; helps you dress him	
2 yrs	Kicks a ball, runs, walks up a few stairs without help; eats with a spoon	Holds something in one hand while using the other hand	Points to things in a book when you ask; says at least two words together; points to at least two body parts when you ask; uses more gestures than waving and pointing	Notices when others are hurt or upset; looks at your face to see how to react in a new situation	
30 mo	Uses hands to twist things; takes some clothes off by himself; jumps off the ground with both feet; turns book pages one at a time when you read to her	Uses things to pretend; shows simple problem-solving skills; follows two-step instructions; shows he knows at least one color	50 word vocabulary; says two or more words together with one action word; names things in a book when you point and ask; says words like “I”, “me”, or “we”	Plays next other children and sometimes with them; shows you what she can do by saying “look at me”; follow simple routines when told	
3 yrs	Strings items together; puts on some clothes by himself; uses a fork	Draws a circle, when you show him how; avoids touching hot objects when you warn her	Talks in conversation using at least two back and forth exchanges; asks “wh” questions; says what actions is happening in a picture; says first name; talks well enough for others to understand	Calms down within 10 minutes after you leave her; notices other children and joins them to play	

Source: CDC Learn the Signs: Act Early 2025 https://www.cdc.gov/act-early/resources/milestone-brochure.html#cdc_cover_page_files_additional_versions-print-versions. You can download the checklists from the website and use as a guide to make notes and share with your pediatrician



GENERAL NOTES



STARTING OFF: LOCAL EARLY INTERVENTION PROGRAMS (BIRTH TO 3 YEARS)

STARTING OFF: LOCAL EARLY INTERVENTION PROGRAMS (BIRTH TO 3 YEARS)

Getting help for a child with potential developmental delays is vital. Early intervention not only helps your son or daughter; it is designed to give you and the rest of your family important information and skills to support him or her while at home or out in the community. Early intervention can also identify any issues that may affect your child's ability to learn later on in school.

Again, *finding and helping babies and toddlers with developmental issues is a legal responsibility of your local government.* If your baby or toddler has a diagnosed disability, a possible developmental delay, or if you have concerns about any area of your child's development, contact your local early intervention program as soon as possible. **Screenings are free!** For Early Intervention programs in your area, see page 10.

PRINCIPLES OF EARLY INTERVENTION

Early intervention programs put family first. Therefore, you are considered both the expert on your child and the expert on how you want and need your child to fit into the daily life of the family. Early intervention services take place in your home or in the community (such as at a playground)—what the law calls “natural environments” or places where young children with or without disabilities would be playing, learning, and interacting with family and peers.

The job of early intervention staff is to address your concerns about your child's development and behavior and to support your own efforts to teach your son or daughter. While staff rely on their expertise in fields such as child development, occupational, physical, or speech and language therapy or counseling, they are not there to teach specific skills or train you to be a therapist. The focus is on expanding your confidence and competence to help your child learn.

Eligibility Determination and assessment of your infant or toddler are free through your local early intervention program.

ELIGIBILITY FOR EARLY INTERVENTION

To qualify for public early intervention services, your child must meet two conditions. **First, he or she must be less than 36 months old.** If your child is between 3 and 5 years old, you need to contact your local school system about preschool. Children old enough for kindergarten (age 5 by September 30) would enter the school system and be evaluated under the Child Find program.

Children from birth to age three are eligible for Part C early intervention services if they:

- Are functioning 25% or more below their chronological age or adjusted age in one or more areas of development (i.e., having a 25% or greater delay in cognitive, physical, communication, social, emotional or adaptive development); and/or
- Show atypical development (e.g., behavioral disorders, affective disorders, abnormal sensory-motor responses); and/or
- Have a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay. Conditions include those such as significant central nervous system anomaly, congenital or acquired hearing loss, myelodysplasia (spina bifida), and visual disabilities.

Developmental delays or differences in development mean a child is not developing like other children his or her age. The delay or difference can be in one or more of the following areas:

- Thinking, learning, and playing
- Moving, seeing, and hearing
- Understanding and using sounds, gestures and words
- Developing relationships
- Taking care of one's self, including eating and dressing

More specifics on eligible diagnoses or delays can be found at <https://itcva.online>

There are five steps in the early intervention process: getting a referral, eligibility determination, conducting an assessment for service planning, writing the Individual Family Service Plan (IFSP), and IFSP implementation and review.

THE REFERRAL PROCESS

Usually, a parent or physician refers a child to an early intervention (EI) program either because the child already has a diagnosis of a qualifying disability or because you or the doctor has concerns about the child's development.

Once a referral is received, the service coordinator will schedule an intake visit at your home to learn more about your child's development, medical history, and his or her ability to participate in daily family life. You will be asked to provide copies of pertinent existing medical records to help fully screen and evaluate your child for eligibility and on-going services. You will be asked for written consent to determine if your child is eligible for EI services. **The date of the referral begins the 45-calendar day timeline** for completion of major steps in the process: eligibility determination, assessment, and initial meeting to create the IFSP.

ELIGIBILITY DETERMINATION

Certain diagnoses automatically qualify your young child for early intervention services. If your child was referred *without* a previous screening, assessment or diagnosis that shows the child is eligible for early intervention, the early intervention staff will use an evaluation tool combined with information from your child's medical record, input from the family, and clinical observations from the early intervention practitioner to initially determine whether your child is eligible.

This process involves asking you questions about your child's behavior and activities; you may also be asked to talk to or play with your child so that the early intervention service coordinator can observe the child "in action."

Your service coordinator will discuss the eligibility determination results with you. At any point in the process, you may ask early intervention specialists for help in finding a specialist who can conduct further evaluations of your child. This may be helpful in diagnosing autism, for example, for which no medical test exists (diagnosis is based on observation of the individual child's behavior).

A QUESTION OF CONSENT

Rights written into the Individuals with Disabilities Education Act (IDEA) ensure that you as the parent must **understand** the process and, with that understanding, **give your permission** for your child to participate in early intervention services.

Under the law, you must be **notified in writing of every proposed action** (prior written notice) to be taken on behalf of your child **and then give your informed consent in writing**. Prior written notice must clearly state the action being proposed (or refused) and the reasons for that action. For example, prior written notice and consent are required to:

- conduct evaluation(s) of your child to determine eligibility
- carry out assessments
- provide services and make changes to services
- terminate services

You may decline individual services without jeopardizing your child's eligibility for other early intervention services.

Your consent is voluntary and you may revoke your consent at any time, although not to actions that have already been taken. If you disagree with a decision or choose not to give consent, you have the right to appeal through mediation, a state complaint, or a due process hearing. See our Resource Library at <https://thearcofnova.org/resource-library/#special-education> for more information and resources for special education advocates and attorneys.

ASSESSMENT FOR SERVICE PLANNING

If the early intervention staff determines that your child is eligible, you will meet with a multi-disciplinary team of certified and licensed specialists such as an occupational therapist, speech therapist, and/or infant educator to figure out what services and activities might be most beneficial. Ask that professionals in each area of need be present at this meeting.

Information is gathered about the child's strengths and needs in cognition (thinking and problem solving), communication (expressive and receptive), social/emotional, small and big motor movements, and self-help behaviors (eating, sleeping, dressing, etc.) You will also be asked about how your child interacts with others and his environment during daily routines.

If your child has been assessed by an outside/private professional, the team will request those medical records (with your consent) and review the results. Whenever possible, these results will be incorporated into the assessment for service planning to avoid having the child undergo multiple assessments.

Family members will also be interviewed (with their approval) to identify resources, concerns, and priorities of the family related to enhancing the development of your child.

INDIVIDUAL FAMILY SERVICE PLAN (IFSP)

With all the information gathered from the assessment, it is now possible to write up the “plan of action,” the Individualized Family Service Plan (IFSP). The IFSP is a legal document and acts as a guide to the family and early intervention practitioners so that all team members are working together for the benefit of the child and family. The IFSP includes the following information:

- medical and referral history
- the child’s and family’s daily routines and activities
- family resources, priorities, and concerns related to the child’s development (if the family chooses to share this information)
- outcomes and goals for the child’s development that reflect both long and short term progress
- the supports and services that will be provided
- number and frequency of sessions your child will receive services and how long each session will last
- where in the natural environment the services will be provided (e.g., at home, child care or at a local playground)
- a plan for transitioning out of early intervention (e.g. community or special education preschool)

The meeting to develop the child’s first IFSP (and each annual meeting thereafter to review the IFSP) must include the following participants:

- the parent(s) or legal guardian of the child
- the Service Coordinator designated by the system to be responsible for implementing the IFSP
- person or persons directly involved in conducting the evaluations and assessments of the child and family
- as appropriate, persons who will be providing early intervention services under this part to the child and family (applies to the annual IFSP review)

You may also invite other family members, if feasible to do so, and/or an advocate or person outside of the family.

Again, the IFSP must be developed within 45 calendar days of the date of the child’s referral to the early intervention system.

For more information on what an IFSP contains and your rights to review or appeal it, see <http://www.parentcenterhub.org/repository/ifsp>

Services provided free to families through the IFSP are:

- service coordination: staff time to coordinate the eligibility determination, assessment for service planning, and development/review/monitoring of the IFSP, assistance with accessing other community programs and resources as needed
- evaluation for eligibility determination
- assessments (to determine your child’s and family’s needs and which services might be appropriate) by qualified professionals such as developmental service providers, speech pathologists, audiologists, physical therapists, occupational therapists, and nutritionists
- transition planning for preschool and/or other programs and therapies after your child turns 3 years old

Other early intervention services may incur a cost to families. These include:

- occupational therapy
- physical therapy
- speech therapy
- developmental services/infant education
- nutrition services
- vision and hearing services
- family counseling and support

Families have several options for paying the fees for early intervention services. Private insurance may cover some of the costs. You may also be charged on a sliding fee scale based on your income and family size. Families must complete a family cost share agreement before early intervention services begin.

REVIEW OF IFSP AND ELIGIBILITY

The team, including parents, meet to review the IFSP at least every six months. Annual IFSP reviews also include a full re-assessment of your child's development to reflect progress and any changes in family routines, medical needs, priorities or concerns.

WHAT HAPPENS AT HOME

Therapists do not always work directly with your child. Instead you are coached on or taught the skills that you will use with your child every day to achieve the developmental goals set in the IFSP. The goal of the EI program is for the parent or caregiver to learn from interactive participation with the practitioner and the child in order to be confident and competent in implementing the intervention strategies in the child's and family's typical routines, in-between visits from the practitioner.

Your EI practitioners will ask questions about your routines and observe what you are already doing to support your child's development. Together you will come up with ways to modify what you are already doing and develop new strategies. Finally, your EI practitioners will help you reflect on how the new strategies are working between sessions. Again, the emphasis is on having outcomes commensurate with what the family needs and wants for their child. In this way, you begin to feel more comfortable with what you are doing with your youngster. If you feel a more medical-model approach to learning fits your family's needs, you may also consider private therapists and discuss what EI can offer.



NOTES

DATE OF SCREENING

FINDINGS

DATE OF 1ST IFSP

THINGS YOU WANT TO MONITOR OR ASK AT THE NEXT MEETING



GENERAL NOTES



TRANSITIONING TO PRESCHOOL FOR CHILDREN AGES 2 TO 3 YEARS

TRANSITIONING TO PRESCHOOL FOR CHILDREN AGES 2 TO 3 YEARS

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 of the year that you would like to begin preschool special education services.

EARLY INTERVENTION VS. PRESCHOOL SPECIAL EDUCATION SERVICES

Leaving early intervention means moving into another “system,” the special education process that is the responsibility of local schools (under IDEA).

In general, the biggest change from an early intervention to 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. For more information see, The Arc of Northern Virginia’s Transition POINTS Guide, Getting the Most from Special Education found at <https://thearcofnova.org/resource-library/#special-education>.
- The legal document guiding your child’s special education services changes from an Individual Family Service Plan (IFSP) to an Individual Education Program (IEP). In addition to you as the parent(s), 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.

All special education services, even related services like transportation, speech and language, physical, and occupational therapy, are free since they are provided by your local school system. See the table on the page 17 on the differences between the IFSP used in early intervention and the IEP used beginning in preschool.

GETTING STARTED: REFERRAL AND ELIGIBILITY

Be aware that some children make enough progress in early intervention that they may not qualify for special education services in preschool or elementary school. Celebrate that! If, however, you and the IFSP team believe your child may be eligible for special education and related services in a preschool setting, then a referral is made to the Early Childhood Identification & Services in your school district. Your Service Coordinator can make this referral with your consent. This starts the 65-calendar 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 licensed therapists in each particular discipline, conduct these evaluations. For a detailed explanation of the move to special education, see Transition POINTS guide “Getting the Most from Special Education.”

PRESCHOOL PROGRAM OPTIONS

Your early intervention team will help you decide on the best transition plan for your child and family before your child turns 3 years old. Families will discuss multiple options and resources in the community for placing their toddler in a preschool program, child care, recreation classes, private therapies, etc. Your transition plan is individualized to meet the needs of your family. If eligible for special education services, your child may receive services in your home, a preschool class in a local school, Head Start program if your family is income eligible, cooperative or private preschool or daycare.

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 to special education services. The referral must occur at least 90 days before your child moves to preschool special education services (age 3), but no more than nine months prior to when your child may transition into preschool special education services (age 2)—so as early as early as 15 months, but no later than 33 months of age. This time is spent doing 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. If you decide to start the referral process you can change your mind at any point in the process, or wait to start special education services when your child turns 3 years old. 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.

MAKING THE TRANSITION EASIER

The transitions between early intervention and preschool services, and later between preschool and kindergarten, can be emotional ones for parents of children with disabilities. 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.

If your child is transitioning to a preschool classroom setting, prepare him/her in whatever communication mode works best:

- 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 preschool
- 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

When visiting a preschool or program, bring your spouse or other family member, friend, or early intervention coordinator so that there is someone with whom you can discuss your visit.

FAMILIARIZING YOURSELF WITH THE PROCESS.

As with early intervention, getting your child into special education is a process, one with mandated meetings, mandated deadlines and mandated documentation. Initially, the Child Find coordinator can help you navigate this road.

THINKING OF PRESCHOOL AS A TRANSITION IN ITSELF.

Consider the move to preschool special education services as part of the longer transition to kindergarten and elementary school. This is an opportunity for you to learn how the system works and adjust to working as part of the IEP team, as well as to introduce your child over time to all the new learning and social experiences inherent to school.

See Transition POINTS guide "Getting the Most out of Special Education" for help in understanding the special education process, particularly your role in developing the Individualized Education Program for your child.

IF YOUR CHILD HASN'T BEEN IN EARLY INTERVENTION

Virginia public schools offer Child Find that provides free screenings and/or evaluations for children 2-5 years of age suspected of having developmental disabilities or delays. If your child has not been in an early intervention program, call the Child Find program in your locality.

Similar to early intervention, the steps involved include: (1) referral to preschool special education services; (2) assessment of developmental progress (which may require several assessments with different licensed therapists); (3) determination of eligibility; and (4) writing of an Individualized Education Program.

CHILD FIND CONTACTS

CITY OF ALEXANDRIA

703-619-8000

<https://www.acps.k12.va.us/departments/teaching-learning-leadership/office-of-specialized-instruction/child-find-and-early-childhood-special-education-services>

ARLINGTON COUNTY

703-228-2550

<https://www.apsva.us/child-find>

FAIRFAX COUNTY

<https://www.fcps.edu/academics/early-childhood-education/early-childhood-child-find>

Dunn Loring Office **703-204-6760**

Bull Run Child Office **703-456-2200**

Virginia Hills Office **703-317-1400**

PRINCE WILLIAM COUNTY

703-791-8857

https://www.pwcs.edu/academics___programs/special_education/child_find/index

LOUDOUN COUNTY

571-252-1200

<https://www.lcps.org/o/doss/page/early-childhood-identification-services>

INDIVIDUAL FAMILY SERVICE PLAN VS. INDIVIDUAL EDUCATION PROGRAM

ISSUE	IFSP (EARLY INTERVENTION PROGRAMS)	IEP (PRESCHOOL – AGE 21)
Age	Infant to the day before 3rd birthday	3 to 22 (may start at age 2 if child enters preschool at that age)
Legal status	Legal document	Legal document
Why you need this document	Focuses on the developmental needs of the child & services that the family needs to enhance the child’s development	Focuses on the educational, functional, and behavioral needs of child & services that can be provided in the school setting
What’s in the document	<ul style="list-style-type: none"> • in-depth assessment of child’s present levels of development • medical necessity for EI services • 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 consent, it also includes information regarding the family’s daily routines, resources, priorities, and concerns related to the development of their child • plan to transition to Part B services or other community programs • services needed in terms for amount, duration, and scope <p>Family determines which outcomes will be in plan.</p>	<ul style="list-style-type: none"> • present levels of educational, functional, and behavioral performance and participation in developmentally appropriate activities • measurable annual goals for academic, behavioral, and functional areas • how and frequency progress will be measured • how progress will be reported to family • parent(s) should include information about the family’s concerns for meeting and enhancing the child’s education, behavior, and functioning needs • accommodations/modifications, services and placement <p>IEP team, including the parents, determine the goals, short term objectives, placement, services, and assessments.</p> <p>Parent may provide partial or full consent to the implementation of the IEP.</p>

ISSUE	IFSP (EARLY INTERVENTION PROGRAMS)	IEP (PRESCHOOL - AGE 21)
Who is involved in developing plan	Team may include: <ul style="list-style-type: none"> • a parent(s) or legal guardian of the child • other family members as requested by parent • advocate and persons outside the family, if requested by parent • service coordinator • individual(s) involved in conducting evaluations and assessments 	Team must consist of: <ul style="list-style-type: none"> • parent or parents of child • special education teacher • principal or principal designee (representative from school district who can commit resources) • person who can interpret results of evaluations • others who have knowledge or special expertise about the child (invited by parent(s) and school. • Other possible participants: general education teacher (if considering or attending gen ed classes)
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 and related services, supplemental aides and services, modifications, accommodations, and supports to be provided to help the child make adequate progress and participate in developmentally appropriate activities
Where services are carried out	In the child's home, child care or at a local playground, etc.	Preschool (home, classroom, daycare). Elementary through high school
Mandated Support	A service coordinator is legally mandated to provide support.	The school must provide information and ensure participation, but families may need to seek additional support (advocate, PEATC) if they want more guidance.
Rights to Appeal	Families have the right to appeal decisions about eligibility or services by requesting mediation, filing a complaint, or requesting a due process hearing.	Families have the right to formally appeal decisions about identification, evaluation, services, or placement by requesting mediation, filing a state complaint, or requesting a due process hearing.



NOTES

DATE MOVING FROM PART C TO PART B

IEP COMPLETED DATE	PRESCHOOLS OFFERED, PRESCHOOLS TOURED
READ THE ARC OF NOVA'S SPED GUIDE	SPECIALIST EVALUATIONS BY WHOM, WHEN, FINDINGS



GENERAL NOTES

A large, empty rectangular box intended for general notes, spanning the width of the page below the 'GENERAL NOTES' header.



STRATEGIES FOR PARENTS: BECOMING AN ADVOCATE FOR YOUR CHILD WITH A DISABILITY

STRATEGIES FOR PARENTS: BECOMING AN ADVOCATE FOR YOUR CHILD WITH A DISABILITY

While parenting any child has its rough spots, advocating for a young 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, programs, and interventions 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, what you may request to meet your child's needs, and how to make the most of it.

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 the individual that is your son or daughter. 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 doctors, teachers, and specialists are saying, especially when you are under stress. Acknowledge 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 meetings; they may be less emotional and 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 many people, going to lots of meetings, and reading excessive documents.

- Come prepared to all meetings with questions
- Take control and facilitate the meeting as if it were a business meeting
- Bring a spouse, family member or friend with you to be sure what is said is what you understood was said
- Audio record the meetings
- Document what was requested, agreed upon or rejected during the meetings. Request that it is included in the IEP. Take notes, then call or email to get clarification of things you did not understand.

Learn your rights under the law. Federal and state anti-discrimination, health care, early intervention and special education law govern many of the programs in which your child will participate during his or her life. If you do not understand your rights, ask the case manager at the hospital, the early intervention specialist, or someone on the special education team to explain them to you. Contact the Parent Education Advocacy and Training Center (PEATC) at www.peatc.org and other resources not affiliated with the school system. Attend workshops and conferences. Empower yourself!

Develop a team mentality. For most of your child's life, you will be working in tandem with a team to develop goals for your child's future. You are an integral and equal member of the team. Some parents feel they must defer to teachers and therapists, but the best results come when parents take an active role in IFSP and 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. Be open-minded and hear proposed solutions.



GENERAL NOTES



GENERAL NOTES



STRATEGIES FOR PARENTS: KEEPING GOOD RECORDS

STRATEGIES FOR PARENTS: KEEPING GOOD RECORDS

Gathering information 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 special needs. For example, the early intervention process is full of paper: every step of the process is documented, and you need to keep a copy of notices, evaluations, and IFSPs.

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 on him or her: medical records, IFSPs, IEPs, psychological evaluations, therapy assessments, teachers' notes, correspondence from the Social Security Administration, Power of Attorney and copies of Wills and Trusts, just to name a few.

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

- **More effective advocacy.** A lot of advocacy is having the "proof" in hand to make your case, whether to an IFSP team, a health insurance company, or Medicaid agency. Be sure to document in writing all requests for meetings, changes to the IFSP, appeals, etc.; then follow up your requests also in writing to confirm what was said or agreed on. Create a "paper trail", which may now be done most efficiently through email and the scanning and filing of documents.
- **More efficiency in carrying out your responsibilities while in the early intervention program and in legal and financial matters.** For example, being able to quickly find some observation notes or an evaluation from a private therapist can help make you a more effective part of the IFSP team.

If you are deducting medical expenses on your income tax return, you will need to have accurate records of those expenditures.

- **More peace of mind.** Although difficult to contemplate, leaving a literal "paper trail" helps future caregivers make decisions more in line with your vision for your child's life should you become disabled or die.

GETTING STARTED

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

- The first step is to **establish an organization system that works for you.** Copy or scan important documents for easy access and keep originals in a safe place.
 - Check out **The DaniPlan** <https://daniplan.com> a subscription service created by parents of a child with a disability that provides a centralized hub to organize and consolidate all information needed to care for an individual with special needs. Visit The Arc of Northern Virginia's YouTube Channel to see our webinar on this service at <https://www.youtube.com/@VideosatTheArcofNoVA>. PEATC (Parent Education Advocacy and Training Center) offers a free digital portfolio at <https://peatc.org/wp-content/uploads/2022/05/FINAL-PEATC-Portfolio.pdf> to keep track of important documents. It can be downloaded to a thumb drive. A version for military families is also available at [https://peatc.org/wp-content/uploads/2022/05/FINAL-PEATC-Military-Portfolio.pdf?ct=\(EMAIL_CAMPAIGN_8_17_2023_13_45_COPY_01\)](https://peatc.org/wp-content/uploads/2022/05/FINAL-PEATC-Military-Portfolio.pdf?ct=(EMAIL_CAMPAIGN_8_17_2023_13_45_COPY_01))
- **Keep your file up to date**, including revised Wills, changes in medical or prescription records, updated

ISFPs, IEPs, evaluations from therapists, and so forth. Set a day every year for adding and purging information 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 EARLY INTERVENTION TEAM

The early intervention process involves a lot of paperwork. Consider keeping the following in your child's file:

- Records of conversations and notes from meetings with IFSP team members.
- Copies of the current IFSP & latest Parental Rights. It is a good idea to keep all the IFSPs created over the course of your child's participation in early intervention.
- Psychological, speech and language, academic, OT or PT evaluations done by the early intervention team. Later these evaluations will be helpful to those determining eligibility for special education and related services once your child starts preschool.
- Psychological, speech and language, OT or PT **evaluations done by private therapists.** Keep all of these; they are part of your child's lifetime medical records.

FINANCIAL AND PERSONAL IDENTIFICATION RECORDS

For both estate planning and financial/tax reasons, be sure to collect and keep on file:

- **Basic identification documents for your child:** Birth certificate (often need the original), Social Security card, Medicaid card, health insurance card.
- **Bank information,** including any accounts opened for the benefit of your child. Medicaid regulations restrict a beneficiary to a resource limit of \$2000.
- **Tax returns:** your own and any tax return filed for a trust for which your child is a beneficiary. See the section on "Securing a Future" for more information on eligible expenditures from a special needs trust.
- **Legal documents** such as wills and special needs trusts. Names of guardians for your minor children and trustees can be kept here as well as named in the Letter of Intent (see below).
- **Medical history,** including diagnosis, evaluations, past and current treatments and therapies (including providers' contact information, dates of treatment, and facility where treated), and prescription records.
- **Other financial records,** such as evidence relating to assets or resources of your child, payments for medical services and equipment, or professional services related to estate planning or special education.

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 past and 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 young child. What goes into the document will vary with the individual but may include:

- **Your vision of your child's future.** Describe what goals you have for your child's life, where they would live and with whom, what activities they should maintain (such as playdates with friends, going to Sunday school, or taking vacations). Describe your child's relationship with the person you've named as guardian.
- **Your child's vision of his or her future.** Whenever possible, include your child's ideas and desires in the document.
- **Description of personal qualities.** Future caregivers would benefit from knowing the unique aspects of your child: overall personality and mood, talents and strengths, degree of independence, medical or behavioral challenges, and sense of humor. What they enjoy and what they dislike; what should be avoided.
- **Family relationships.** Include names and ages of siblings and generally how they get along. Also 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.** This could include school and home schedules; extracurricular activities, including therapies or playdates; bedtime routines; food and clothing preference and sensitivities; preferred toys and games, and typical outings, for example.
- **Medical history.** This section can be brief (diagnosis, hospitalizations, surgeries, current treatment & medication regimes), but then should state where to find more detailed medical records (see below).
- **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.** List 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, advocacy organizations such as The Arc of Northern Virginia, etc.

For a free Letter of Intent template go to <https://www.specialneedstrustsonline.com/letter-of-intent/form>.



GENERAL NOTES



GENERAL NOTES



APPLYING FOR BENEFITS

APPLYING FOR SOCIAL SECURITY BENEFITS

APPLYING FOR BENEFITS: SUPPLEMENTAL SECURITY INCOME (SSI)

Children under 18 may qualify for Supplemental 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 for a minor child.

If your child is not eligible for SSI, he or she will not be eligible for Medicaid in Virginia either.

Once your child turns 18, only his or her income and assets are counted (although 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 Child Disability (SSI for a minor child) *again, family income and resources are considered*.

DISABILITY DEFINITION

Your child must meet the following requirements to be considered disabled and therefore eligible for SSI:

- Have a physical or mental condition that very seriously limits your child's activities.
- The child's condition(s) must have lasted, or be expected to last, for at least 1 year or result in death.

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) **Note that eligibility before 18 is based on the whole family income. You may also call 1-800-772-1213.**

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 so they may make a decision on the child's claim.

Contact Social Security to find out whether the income and resources of the parents and the child are within the allowed limits, before starting 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!). **NEVER submit originals.**

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 considerably 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**) between 7 a.m. to 7 p.m., Monday through Friday or contact your local Social Security office or schedule online at <https://www.ssa.gov/manage-benefits/make-an-appointment>. Hold times can be very long. You will be greeted by an automated answering attendant, who will prompt you to state why you are calling; say "Apply for SSI." The auto attendant will you to say or key in your child's Social Security number. You will then be directed to a representative. During the phone interview, the representative will take information and enter it into a computer, which will secure the date of the application.

- Paperwork will be mailed to you. Complete and return it within the allotted timeline.
- The document generated during the phone interview will also be mailed to you. You must sign it for purposes of accuracy.
- Before mailing anything back to the agency, be sure to make copies.

Set up a screening interview. During the phone interview, the representative will set up a screening, which continues the application process, at your local Social Security office.

ALEXANDRIA OFFICE

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

FAIRFAX OFFICE

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

MANASSAS OFFICE

9500 Center Street
Manassas, VA 20110
800-325-0778

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 in its documents Checklist including:

- 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 when over 18 and not irrevocably assigned to a first party special needs trust). SSA considers the parents' income and assets when applying for SSI for a child.
- Checkbook or other papers that show a bank account number to have benefits deposited directly to an 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. You may also resolve the reason for denial then reapply.

The state agency may take three to five months to decide if your child meets the criteria for financial, functional and diagnostic criteria for disability. For some medical conditions, however, the Social Security Administration may 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.

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 application in a face toface 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

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.

APPLYING FOR BENEFITS: DEVELOPMENTAL DISABILITY MEDICAID WAIVERS

DEVELOPMENTAL DISABILITY MEDICAID WAIVERS

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

WHAT IS A WAIVER?

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

Waivers are funded by Medicaid and are often called Medicaid Waivers. The person with a disability must qualify for long-term care Medicaid to use a Waiver. As of 2026, this means that the person with a disability cannot have more than \$2,000 in assets in their name (no cap if under 18 years old), unless those assets are in a Special Needs Trust or ABLE Account, and they cannot earn more than (in 2026) \$2,982 per month. The income limit generally increases each year due to Cost-of-Living Adjustments. The person with a disability will get Medicaid once they get an active Waiver (not when they are placed on a waiting list).

WHO NEEDS A WAIVER?

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

WHY SHOULD I APPLY?

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

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

You can apply for up to \$500-\$1,000 each year to purchase supports you need to be independent and safe. This is called the Individual and Family Supports Program (IFSP). Information, applications, and instructions can be found at <https://mylifemycommunityvirginia.org/resources>. You can go to <https://dbhds.virginia.gov/developmental-services/ifsp> to receive routine emails from DBHDS to stay updated on when the program opens each year.

HOW DO I GET A WAIVER?

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

SERVICES COVERED UNDER THE WAIVERS

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

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

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

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

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

ELIGIBILITY CRITERIA

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

1. **Functioning ability:** This is determined by the Virginia Intellectual Developmental Eligibility Survey (VIDES). The VIDES has one test for children aged 0–3, one for children ages 3–18, and one for adults. The surveys assess the person’s need for assistance with a variety of daily living and independence skill activities. Families are encouraged to review the VIDES assessment available on our website prior to the intake. You can review copies of the VIDES assessment in our Resource Library at <https://thearcofnova.org/resource-library/#waivers>
2. **Diagnosis:** Persons applying for a Waiver must meet the diagnostic eligibility requirements for the DD Waivers. This means that a person must have a developmental disability as defined in 37.2-100 of the Code of Virginia.
 - a. “Developmental disability” means a severe, chronic disability of an individual that (i) is attributable to a mental or physical impairment, or a combination of mental and physical impairments, other than a sole diagnosis of mental illness; (ii) is manifested before the individual reaches 22 years of age; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independence living, or economic self-sufficiency; and (v) reflects the individual’s needs for a combination and sequence of special interdisciplinary or generic services, individualized support, or other forms of assistance later are lifelong or extended duration and are individually planned and coordinated. An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (i) through (v) if the individual without services and supports, has a high probability of meeting those criteria later in life.
3. **Financial:** If the functioning and diagnostic criteria are met, then the child’s income and assets are considered. Special Needs Trusts and ABLE Accounts are not considered when testing financial eligibility. People over 18 have an asset cap of \$2,000. Everyone receiving a Waiver has a monthly income cap of 300% of the current Social Security Supplemental Security Income amount (SSI is \$994 in 2026), so max monthly income is \$ 2,982. The income limit for SSI generally increases each year due to Cost-of-Living Adjustments.

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

HOW LONG IS THE WAIT?

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

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

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

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

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

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

Alexandria City CSB: **703-746-5999**

Arlington DHS/IDD Services: **703-228-1700**

Fairfax/Falls Church CSB/IDS: **703-324-4400**

Loudoun CSB: **703-777-0597**

Prince William CSB: **703-792-7800**

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

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

Alexandria City **571-213-7963 / 703-746-5999** (if over 18)

Arlington **703-228-1297 / 703-228-1700** (if over 18)

Fairfax/Falls Church **703-324-7948**

Loudoun: **703-737-8949**

Prince William: **703-792-7500**

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



GENERAL NOTES



ENSURING HEALTH INSURANCE

ENSURING HEALTH INSURANCE

Having adequate health insurance is an important element in securing your child's financial as well as physical health. Adult children with a lifelong disability may stay on their parents' health insurance indefinitely (non-disabled children are often not covered after age 26). Steps you can take now include:

- Apply for Supplemental Security Income for your child with a disability. Once approved, apply for Medicaid.
- Exploring options and costs of health insurance for your child once you are no longer working.

PRIVATE EMPLOYER HEALTH PLANS

Dependents with a lifelong disability may remain under your employer-sponsored policy beyond age 26. Contact your health insurance provider to check about this option.

MEDICAID

Medicaid is a federal health insurance program available to low-income persons, the elderly and people with a disability. One way to obtain Medicaid is to qualify for Supplemental Security Income (SSI). If you meet the requirements for SSI, you will meet those for Medicaid.

You can have private health insurance and still be covered by Medicaid or FAMIS Plus (excluding Plan First). If you have other insurance, the other insurance plan pays for medical services first. Having other health insurance does not change the Medicaid co-payment amount, if one is required, that you will pay to providers as a Medicaid enrollee.

Note: If you or your loved one has a developmental disability, is not receiving Supplemental Security Income (SSI), and has a Medicaid Waiver prior to age 18, then there will be a need to have a "disability determination" done before the 18th birthday to ensure there is no lapse in Medicaid Waiver services as the move from childhood to adult Medicaid occurs. For more detailed information on this topic, visit our Resource Library at <https://thearcofnova.org/resource-library/#medicaid>.

HEALTH INSURANCE PREMIUM PAYMENT PROGRAM

HIPP is a Medicaid program that helps families pay for employer sponsored health insurance premiums. It is for families with at least one person who received Medicaid. If your child has Medicaid, the Health Insurance Premium Payment (HIPP) can help pay all or part of your health insurance premiums.

Your health insurance plan may cover services that are not covered by Medicaid. HIPP allows you to have health insurance you might not otherwise be able to afford. HIPP evaluates the services covered under your health insurance plan and compares the average Medicaid cost for your Medicaid eligible family member to the cost of your health insurance premium.

Information is available on the DMAS website at

<https://coverva.dmas.virginia.gov/learn/premium-assistance/health-insurance-premium-payment-hipp-programs> or call the HIPP Program at 800-432-5924.

For a handout on "Managing Multiple Insurances for People with Disabilities": visit our Resource Library at <https://thearcofnova.org/resource-library/#medicaid>

EPSDT (EARLY PERIODIC SCREENING, DIAGNOSIS AND TREATMENT)

EPSDT is a comprehensive and preventive healthcare program for children ages 3–21 who receive Medicaid and can cover services that are not routinely covered for adults. States are required to provide any healthcare services that are medical necessary to correct, improve, or maintain physical or mental conditions. The most frequently provided EPSDT specialized services include: hearing aids, assistive technology, personal care, private duty nursing, therapies such as physical, occupational, behavioral or speech, medical formula, and medical nutritional supplements. For more information, visit http://dmasva.dmas.virginia.gov/content_atchs/mch/mch-epsdt_fs.pdf

INFORMATION RESOURCES

For more information on changes to private healthcare under the Affordable Care Act, see www.healthcare.gov.

For help with understanding Medicaid and private insurance issues, contact the Virginia Insurance Counseling & Assistance Program at **703-324-5851**.

Download a copy of the booklet “Medicaid and FAMIS PLUS Handbook” at

http://dmasva.dmas.virginia.gov/Content_atchs/atchs/medbook-eng.pdf

THE CHILDREN’S HEALTH INSURANCE PROGRAM (CHIP)

The Children’s Health Insurance Program (CHIP) enables states to provide health insurance to children from working families with incomes too high to qualify for Medicaid, but too low to afford private health insurance. The program provides coverage for prescription drugs, vision, dental, hearing, and mental health services, and is available in all 50 states and the District of Columbia. Your state Medicaid agency can provide more information about this program, or you can get more information about coverage for your children at www.insurekidsnow.gov or by calling **1-877-543-7669**.

APPLYING ONLINE FOR BENEFITS IN VIRGINIA

CommonHelp allows Virginia residents to apply online for income-based public assistance benefits including:

- Medical assistance and health insurance
- Child care assistance
- Cash assistance (TANF)
- Food stamps (SNAP)
- Energy assistance

<https://commonhelp.virginia.gov/access>



GENERAL NOTES



SECURING YOUR CHILD'S FUTURE: ESTATE PLANNING

SECURING YOUR CHILD'S FUTURE: ESTATE PLANNING

All parents should have a will, and those who have children with a disability also need to create a **family-funded (third party)** special needs trust to protect any public benefits that child may receive. A special needs trust ensures that funds are used for the sole benefit of the child.

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.

CREATING A WILL

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

REVIEWING BENEFICIARIES

In addition to naming a family-funded/third party 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*, Thrift Savings Plans*; individual checking and savings accounts; Brokerage accounts; Savings Bonds. You will need to use specific language to designate these monies to the SNT. Please check with the trustee to determine proper wording. Verify that these accounts can be named to the special needs trust.

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

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

SPECIAL NEEDS TRUSTS (SNT)

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

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

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

TWO KINDS OF TRUSTS

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

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

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

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

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

SETTING UP A TRUST

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

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

USES OF TRUST FUNDS

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

Here are some examples:

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

ACTING AS TRUSTEE

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

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

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

THE ARC OF NORTHERN VIRGINIA'S POOLED SPECIAL NEEDS TRUST

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

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

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

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

ABLE ACCOUNTS

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

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

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

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

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

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



NOTES

EXPLORED SSI

TRUST

WAIVERS

EMPLOYER HEALTH PLAN

MEDICAID

EPSDT



GENERAL NOTES



FINDING CARE: DAY CARE AND RESPITE OPTIONS

FINDING CARE: DAY CARE AND RESPITE OPTIONS

The Resource Directory on The Arc of Northern Virginia Website provides resources on respite and childcare. Visit <https://thearcofnova.org/directory>.

CHILD CARE

Easter Seals Child Development Center of Northern Virginia

<https://dcmdva.easterseals.com/get-support/areas-of-support/childrens-services/child-development-centers>

Provide early childhood education, early detection of disabilities, and mental health support for children and their families.

Care.com

www.care.com

An online platform that helps parents find and connect with caregivers — including babysitters, nannies, special needs sitters, and respite care providers. It lets you search for sitters experienced with children who have disabilities, read reviews, check qualifications, and communicate directly with caregivers.

RESPITE CARE

Virginia Lifespan Respite Voucher Program

<https://www.vda.virginia.gov/vlr.htm>

The Virginia Lifespan Respite Voucher Program (VLRVP) provides reimbursement vouchers up to \$595 per family to Virginia caregivers for the cost of temporary, short-term respite care provided to individuals of any age, with a documented disability or medical condition. For more information and to apply, visit <https://www.vda.virginia.gov/vlr.htm>

McLean Bible Access Ministries

<https://mcleanbible.org/tysons/special-needs>

Offers respite once a month for children ages 2-15 with special needs and their typically developing siblings.

Jill's House

www.jillshouse.org

Offers overnight respite services for children ages 6-22.

Ask your school social worker for additional resources.



GENERAL NOTES

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GENERAL NOTES



FINDING SUPPORT: RESOURCES FOR PARENTS

FINDING SUPPORT: INFORMATION & SUPPORT GROUPS FOR PARENTS

Raising a child with a disability can bring both unique joys and challenges, and you don't have to navigate it alone. Connecting with other families, local organizations, and trusted professionals can make a tremendous difference in your journey. Support groups offer understanding, encouragement, and practical advice from people who truly "get it," while community resources can help you access services, information, and opportunities for your child's growth and your family's well-being. In addition to local and national organizations, many families find connection and advice through online communities on platforms like Facebook and Instagram. This section will help you find the networks and tools that can provide strength, guidance, and a sense of belonging as you begin this new chapter.

PUBLIC SCHOOL FAMILY RESOURCE CENTERS:

ALEXANDRIA CITY PRC

<https://www.acps.k12.va.us/departments/teaching-learning-leadership/office-of-specialized-instruction/special-education-parent-resource-center>

Anne R. Lipnick Special Education Parent Resource Center

Alexandria City High School Minnie Howard Campus

3801 West Braddock Road, Room 134

Alexandria, VA 22302

ARLINGTON PUBLIC SCHOOLS PRC

<https://www.apsva.us/parent-resource-center>

2110 Washington Boulevard

Arlington, VA 22204

703-228-7239

prc@apsva.us

FAIRFAX COUNTY PUBLIC SCHOOLS FAMILY RESOURCE CENTER

<https://www.fcps.edu/frc>

Dunn Loring Center for Parent Services

2334 Gallows Road, Rm 105

Dunn Loring, VA 22027

703-204-3941

frc@fcps.edu

LOUDOUN COUNTY PUBLIC SCHOOLS PARENT RESOURCE SERVICES

<https://www.lcps.org/o/lcps/page/parent-resource-services>

21000 Education Court, Ashburn, VA 20148

571-252-1000

PRINCE WILLIAM COUNTY PARENT RESOURCE CENTER

https://www.pwcs.edu/academics___programs/special_education/parent_resource_center/index

Kelly Leadership Center

Second Floor, Suite 2200, 14715 Bristow Road

Manassas, VA 20112

703-791-7935

LOCAL ADVOCACY GROUPS

THE ARC OF NORTHERN VIRGINIA

<https://thearcofnova.org>

703-208-1119

Supports individuals with IDD and their families across the lifespan. It helps parents navigate services, access reliable information and resources, and advocate for their child's inclusion, rights, and future planning.

THE ARC OF VIRGINIA'S NEW PATH PROGRAM

<https://www.thearcofva.org/new-path-early-intervention>

New Path Program provides resources and information regarding Early Intervention services.

A program of The Arc of Virginia, New Path is a support network for families in early intervention to connection with one another.

AUTISM SOCIETY OF AMERICA, NORTHERN VIRGINIA CHAPTER (ASNV)

<http://www.asnv.org>

703-495-8444

Provide education, advocacy, and community support, helping families access information, resources, social opportunities, and connections to services. ASNV also offers support groups, social programs, and family events.

BRAIN INJURY SERVICES, INC.

www.braininjurysvcs.org

703-451-8881

Provides one-on-one support and connects individuals and families.

DOWN SYNDROME ASSOCIATION OF NORTHERN VIRGINIA (DSANV)

www.dsanv.org.

703-621-7129

DSANV provides resources, support, and programs for new and expectant parents.

PEATC (PARENT EDUCATION ADVOCACY AND TRAINING CENTER)

<https://peatc.org/services/early-childhood>

Provides information and resources on early intervention and education to help parents and caregivers of young children navigate services and support their child's development.

FINDING SUPPORT: FOR MILITARY FAMILIES

EXCEPTIONAL FAMILY MEMBER PROGRAM (EFMP)

<https://www.militaryonesource.mil/special-needs/efmp>

EFMP provides military families who have children with special needs resources to make informed assignment decisions and experience easier transitions.

MILITARY ONE SOURCE: EDUCATION DIRECTORY FOR CHILDREN WITH SPECIAL NEEDS

<https://www.militaryonesource.mil/resources/tools/education-directory>

The web-based tool provides information about education and early intervention services available on or near installations within the 50 states and the District of Columbia.

ADDITIONAL RESOURCES

For additional resources you can find hanbdouts in The Arc of Northern Virginia's Resource Library at

<https://thearcofnova.org/resource-library/#early-intervention> and in our

Provider Directory at <https://thearcofnova.org/directory>



GENERAL NOTES

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OTHER GUIDES IN THIS SERIES:

Getting the Most from Special Education

Transition from School to Adult Life

Entering the World of Work

Finding a Home for Adults with Disabilities

Aging with a Disability



Providing Opportunities, Information, Networking
and Transition Support