

# **STARTING LIFE WITH YOUR CHILD WITH A DISABILITY**

**First Steps for Families  
in Alexandria, Arlington,  
Fairfax & Falls Church**



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

**May 2020**

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

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

Please send any comments or additions to Diane Monnig, Transition Manager, The Arc of Northern Virginia, Transition POINTS, 2755 Hartland Road, Suite 200, Falls Church, VA 22043 (703)208-1119 ext 118 [dmonnig@thearcofnova.org](mailto:dmonnig@thearcofnova.org).

Copyright © 2020 by The Arc of Northern Virginia

## TABLE OF CONTENTS

<b>Introduction to Transition POINTS</b> .....	1
<b>Starting Life with Your Child with a Disability</b>	
First Steps for Families .....	3
A Checklist for Parents .....	5
<b>If Your Child has been Diagnosed with a Developmental or Intellectual Disability</b> .....	6
<b>If You Have Concerns about your Child’s Development (No Diagnosis)</b> .....	9
Typical Developmental Milestones .....	10
<b>Starting Off: Local Early Intervention Programs</b> .....	11
<b>Transitioning from Early Intervention to Preschool</b> .....	15
Child Find .....	16
IFSP vs. IEP .....	18
<b>Strategies for Parents: Advocating for your Child with a Disability</b> .....	19
<b>Strategies for Parents: Keeping Good Records</b> .....	21
<b>Applying for Benefits:</b>	
Supplemental Security Income .....	24
Medicaid Waivers .....	27
<b>Ensuring Health Insurance</b> .....	29
<b>Securing the Future: Wills, Guardian for Minor Children, Trusts</b> .....	31
<b>Having Fun: Recreational Opportunities</b> .....	34
<b>Finding Care: Day Care &amp; Respite</b> .....	35
<b>Finding Support: Resources for Parents</b>	
Information and Support Groups .....	36
Web-Based Resources .....	36
For Military Families .....	38
The Arc of Northern Virginia Provider Directory .....	39
<b>Acknowledgements</b> .....	40

## INTRODUCTION

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

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

- 44% reported that support services are decreasing in their communities.
- 54% of families do not have a plan for the future
- 75% have difficulty finding after school care, community services, or summer activities for their loved one
- 91% of families indicated difficulty in finding direct support

### About Transition POINTS

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

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

1. Receiving a diagnosis and having a child enter an early intervention program
2. Starting school and entering the special education
3. Transitioning out of the school system and into adult services;
4. Entering the world of work and/or meaningful day supports

<sup>1</sup>Anderson, L Hewitt, A., S., Taylor, M., & Reagn, J. (2018) Family and Individual Needs for Disability Supports (v.2) Community Report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community integration, University of Minnesota. .,

5. Finding a place to live outside the caregiver's home; and
6. Aging with a disability.

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

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 <http://www.dbhds.virginia.gov/individuals-and-families/community-services-boards>. The CSB is the point of entry into the publically funded system of services for people with mental health, intellectual and developmental disabilities. Also, visit The Arc of Virginia at [www.thearcova.org](http://www.thearcova.org) to find the local Arc chapter in your community.

### Help for You, the Parent

As the first step in Transition POINTS, we have written six guides to address important issues that parents should consider at each of these important life stages. The guides are designed to help you recognize opportunities, weigh options, and work through decisions; checklists, timelines, worksheets, and links to other resources are included wherever possible. Each document has also been reviewed by a task force of parents and professionals with relevant experience and expertise. Please visit the Resource Library on our website at <https://thearcovnova.org/programs-services/library/>. [www.thearcovnova.org](http://www.thearcovnova.org) to explore helpful fact sheets and additional information on an array of topics. Our website includes a a Provider Directory that offers contact information for services in our area that can be found at <https://thearcovnova.org/directory/>. The Arc of Northern Virginia maintains a library of informative life planning and future planning videos and webinars on YouTube at <https://www.youtube.com/user/VideosatTheArcofNoVA>

Although each guide addresses issues related to a specific phase of life, you'll note that each also repeats

some information parents and caregivers need to know whether their loved one is two, 22 or 62 years old: which steps to take to protect your loved one's financial future, how to apply for benefits, and where to go for more help.

### **Your Rights and Responsibilities**

This is not a legal document and does not spell out your or your child's rights and responsibilities under the law. Every effort has been made to verify the information in the document, but please be aware that items such as program regulations, deadlines, and contact information can change.

Referrals to organizations and individuals are for informational purposes and do not constitute an endorsement of their services. Please send any comments to Diane Monnig, The Arc of Northern Virginia, Transition POINTS, 2755 Hartland Road, Suite 200, Falls Church, VA 22043  
dmonnig@thearcofnova.org.

## **STARTING LIFE WITH YOUR CHILD WITH A DISABILITY: First Steps for Families in Alexandria, Arlington, Fairfax and Falls Church**

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.

Parenting a young child with a disability or developmental delay can be challenging.

If you are reading this, you are already taking the first step: starting early to get help for your baby or toddler. *[NB: This guide is geared to parents of children who are infants up to age three. See box "First Steps."]*

Physical, emotional and financial demands can exhaust the whole family. Fortunately, you can get help through your local early intervention program, parent support groups, and nonprofit organizations such as The Arc of Northern Virginia.

**In fact, localities are required by federal law-- to find and screen infants and toddlers who have, or may have, a developmental disability or delay. In Virginia, this program is called Infant and Toddler Connection of Virginia. Local government entities, called Community Service Boards (CSBs) manage early intervention intakes and assessments.** Alexandria, Arlington, Falls Church and Fairfax all provide early intervention programs, and this guide takes you through the process of getting help for your child.

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.

To help you pursue early intervention for your child, as well as plan for the future, this document addresses the following issues:

**Who's in charge.** Parents are essential partners in early intervention. Your authority and responsibility in making decisions about your baby or toddler are recognized by law, and you will be deeply involved in every aspect of the process.

**Where to get information and support for you and your child.** Many organizations exist to help with

the medical, emotional, financial and legal issues that challenge families with special needs children.

**How to make your job easier.** Parenting a child with disabilities requires perseverance and preparation. Accepting your new role as advocate and adopting strategies like keeping good records will help you now and throughout the lifetime of your child.

**What kind of early intervention services are available.** Children under 36 months old with certain developmental delays or diagnosed disabilities may be eligible for services under local early intervention programs.

**Whether your child is eligible for government support.** Depending on your family income, your child may qualify for monthly income from the Social Security Administration and for Medicaid. Some children with a disability may also benefit from various waiver programs under Medicaid.

**Which steps to take now to protect your child's financial future.** All parents should have a will and name a guardian for *all* of their minor children (with or without disabilities). You also need to create a special needs trust to protect any public benefits that your son or daughter with disabilities may receive to avoid jeopardizing those benefits.

*Read through the "Checklist for Parents" for steps to take right away.*

#### **First Steps**

If your child has already been diagnosed with a developmental disability AND is **under 36 months of age**, go to page 5.

If you have concerns about your child's developmental progress AND he or she is **under 36 months old**, start on page 8.

If your child is **aged 2 (by September 30) to five**, find out about preschool options in your school district by contacting your local Child Find coordinator (page 16) and see our Transition POINTS Guide, *Getting the Most from Special Education*.

**Starting Life with Your Child with a Disability: A Checklist for Parents**

Step to Take by Age	Advocacy & Support	Early Intervention	Legal/ Financial	Benefits Planning	Transition to
---------------------	--------------------	--------------------	------------------	-------------------	---------------

			Planning		Preschool
<b>As soon as you have a diagnosis of a developmental disability</b>					
Have hospital or pediatrician provide info & training on child's medical needs, referrals to specialists	x				
Contact local Early Intervention Program		x			
Pursue specialists/private therapies to supplement early intervention	x				
<b>If you suspect developmental delays</b>					
Record behaviors and discuss with pediatrician; ask for developmental screener	x				
Contact local Early Intervention Program		x			
Pursue specialists/private therapies to supplement early intervention	x				
<b>For all parents ASAP</b>					
Find a support network	x				
Create a file for key documents	x		x		
Create a will; name guardians for minor children			x		
Draft a Letter of Intent			x		
Establish a Special Needs Trust			x		
Determine if <b>child</b> qualifies for Supplementary Security Income				x	
If qualified for SSI, set up a Rep Payee account				x	
Explore eligibility for Medicaid waivers: Get on wait list.	MAY	BE	LONG	x WAIT	LIST
<b>At age three</b>					
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.					x
If your child has not been in early intervention, contact your local Child Find program					x



## 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.

### Local Infant & Toddler Connection Programs

City of Alexandria

<https://www.alexandria.gov/dchs/childrenfamily/default.aspx?id=50246>

(703)746-3387 or (703)746-3350

Arlington County

<https://health.arlingtonva.us/public-health/health-clinics-services/parent-infant-education-program/pie/>

703) 228-1640

Fairfax County and Falls Church

<https://www.fairfaxcounty.gov/familyservices/office-for-children/infant-and-toddler-connection>

<http://www.fairfaxcounty.gov/csb/itc>

(703) 246-7121

Or contact Infant & Toddler Connection of Virginia at 1-800-234-1448 [www.infantva.org](http://www.infantva.org)

**Get connected with others.** No man 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 and Facebook, 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 support groups in this area for parents of young children with developmental disabilities (see appendix "Parent Resources"). Disability organizations such as The Arc of Northern Virginia, The Down Syndrome Association of Northern Virginia, and The Autism Society of Northern Virginia can refer you to resources.

**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 Center <http://childrensnational.org/choose-childrens/deciding-on-care/support-for-families/parent-navigator-program>

and Inova's Care Connection [www.inova.org/inova-in-the-community/care-connection-for-children/index.jsp](http://www.inova.org/inova-in-the-community/care-connection-for-children/index.jsp)

---

## 10 Things to Ask for After a Diagnosis

1. A file folder with information on your child's medical issues (in lieu of researching it yourself on the Internet)
  2. A recommendation for the local hospital that is best suited to address your child's diagnoses (especially true for kids with complex medical needs who will fare best with all doctors in one health system)
  3. A "technical assistance" session with a nurse or therapist to learn all the procedures you may need to perform at home.
  4. A list of all prescriptions needed.
  5. Lists of specialists who will need to see your child, as well as referrals for speech, physical and/or occupational therapies—with a three-month calendar of visits in **priority order**.
  6. Referral to and contact information for your local early intervention program (the doctor can do this for you, or you can self-refer).
  7. A consultation with a hospital social worker.
  8. Name of a parent support group and/or a parent that you could speak with and a list of local resources such as The Arc of Northern Virginia or Parent Educational Advocacy Training Center [www.peatc.org](http://www.peatc.org)
  9. Referral to a mental health professional who can assist you.
  10. If breastfeeding, get names of lactation consultants. If pumping breast milk, ask the hospital to rent you a commercial grade pump. If you are stressed and sleep deprived, a stronger pump may be useful.
-

## 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.

Please note that **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 5.

### Typical Developmental Milestones

Age	Physical	Cognitive	Language	Socio-Emotional
2 mo	hold head up when on tummy; brings hand to mouth	follows things with eyes; recognizes people at distance	cooing; turns head toward sound	smiles at people; tries to look at parent
4 mo	holds head steady unsupported; starts to roll; pushes on hard surface	responds to affection; reaches for toy; moves eyes together in all directions	babbles with expression; copies sounds; different cries for different needs	smiles spontaneously; copies basic facial expressions; enjoys play; laughs; recognizes familiar people
6 mo	rolls in both directions; begins to sit w/o support; supports weight when in standing position	pass things from one hand to another; reaches for objects	strings vowels together; responds to name; takes turns with parent in making sounds; begins to say "m" and "b"	shows affection for primary caregiver; responds to others' emotions; likes to look at self in mirror; likes to play w/ others
9 mo	pulls to stand; crawls; can get into sitting position on own.	pincer grasp; plays peek-a-boo; looks for things you hide; looks where you point	understands "no;" copies sounds & gestures of others; points to things they want	has favorite toys; shows fear at unfamiliar people; responds to name
12 mo	stands alone; walks with assistance; helps with dressing; points with index finger	knows objects exist even when hidden; uses simple gestures (nodding, waving "bye-bye")	speaks 1+ words with meaning; practices inflection; says "mama" and "dada;" imitates animal sounds	plays simple games (pat-a-cake, ball roll); develops attachment to particular toy; anxious when separated from parents
18 mo	walks without help; likes to pull, push, & dump things; scribbles; carries toy; builds 2-block tower	follows one-step instructions; recognizes self in mirror and pictures; laughs at silly actions	vocabulary of 5-20 words; repeats words/ phrases; puts emotion in speech; says "hi," "bye," and "please"	seeks attention; becomes anxious when separated from parent(s); looks at person talking; plays alone with toys
2 yrs	walks well; runs; walks up/down stairs w/railing; uses spoon & fork; drinks from straw; opens drawers & boxes; tosses large ball; turns pages of books	follows commands; understands own name; identifies pictures; labels body parts; likes to take things apart; sorts shapes and colors	can construct simple sentences; asks basic questions ("Ball?"); names familiar objects; begins to use pronouns (I, me, s/he); verbalizes feelings and wants	enjoys physical affection; comforts playmate; mostly plays by oneself; begins pretend play; imitates parents; prone to temper tantrums; shy around strangers
30 mo	copies circles and straight lines; throws ball overhand; kicks ball; begins potty training; stands on tiptoe	begins to understand self vs. other people; understands simple time concepts (before & after); develops strict rituals & likes to follow routine	50 word vocabulary; speaks in 3-4 word sentences w/ subject-verb-object; asks "wh" questions (except "why")	enjoys company of other children; displays less separation anxiety (knows parent will come back); resistance and uncooperativeness typical of age
3 yrs	runs well; marches; can stand on one foot; rides tricycle; feeds oneself & dresses w/ some help; works buttons & snaps; pours from pitcher	can answer "wh" questions; understands basic opposites and gender; recites nursery rhymes; better grasp on cause and effect	uses pronouns correctly (I, me, you); uses past tense and common prepositions (on, in, under); gives name, gender, & age; tells logical, sequential stories; 90% intelligible speech	enjoys playing alongside other children; engages in imaginative play; participates in group activities; takes turns; asks many questions; imitates adult activities and likes to "help"

**Source:** "Learn the Signs. Act Early." *Developmental Milestones*. From the website of the Centers for Disease Control. Adapted October 2017. . <https://www.cdc.gov/ncbddd/actearly/milestones/index.html>. You can download the checklists from the website and use as a guide to make notes and share with your pediatrician

## 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. For Early Intervention programs in your area, see page 4.

### 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.

A Focus on the Family

Early intervention focuses on the family and the power of parents to teach and support their child's development. A well-designed early intervention program:

- Regards the family as central to the child's learning and development
- Supports family members' efforts to teach their child and helps caregivers identify “natural learning opportunities” within the routines of daily life
- Listens to family's expressed priorities and needs
- Is flexible in tailoring services to respond to issues such as family structure, childrearing values, cultural beliefs, and economic circumstances.

Adapted from Seven Key Principles: Looks like /doesn't look like. Retrieved from [http://www.ectacenter.org/~pdfs/topics/families/Principles\\_LooksLike\\_DoesntLookLike3\\_11\\_08.pdf](http://www.ectacenter.org/~pdfs/topics/families/Principles_LooksLike_DoesntLookLike3_11_08.pdf)

### 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.

Second, your baby or toddler must have a **diagnosed developmental disability OR a developmental delay(s) OR differences in development.**

**Diagnosed developmental disabilities** that *automatically* qualify a child for local early intervention programs include, but are not limited to:

- genetic disorders, such as Down syndrome
- cerebral palsy
- cleft lip and/or palate
- vision or hearing loss
- autism spectrum disorder
- a stay of 28 days or more in a neonatal intensive care unit
- gestational age of 28 weeks or less

- effects of toxic exposure including fetal alcohol syndrome and drug withdrawal

NOTE: Other disabilities *may* qualify your child for early intervention services. Your referral coordinator will ask for more information to determine if your child is automatically eligible.

**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 [www.infantva.org](http://www.infantva.org)

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 have 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.

### 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.

## TRANSITIONING TO PRESCHOOL for Children Aged 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.
- 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 (ECID&S) 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 3<sup>rd</sup> 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 offers 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 (see below).

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)578-8217

1501 Cameron Street, Suite 235, Alexandria, VA

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

### **Arlington County**

(703)228-2709

2110 Washington Blvd. Arlington, VA

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

### **Fairfax County**

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

### **Dunn Loring Office**

(703)204-6760

2334 Gallows Road, Room 233 (entrance 3), Dunn Loring, VA

### **Bull Run Child Office**

(703)456-2200

15301 Lee Highway, Centreville, VA 20121

### **Virginia Hills Office**

(703)317-1400

6520 Diana Lane, Alexandria, VA

### Individual Family Service Plan vs. Individual Education Program

Issue	IFSP (Early Intervention Programs)	IEP (Preschool - Age 21)
Age	Infant to the day before 3 <sup>rd</sup> 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 <b>developmental</b> needs of the child & services that the <i>family</i> needs to enhance the child's development	Focuses on the <b>educational, functional, and behavioral</b> needs of child & services that can be provided in the school setting
What's in the document	<ul style="list-style-type: none"> <li>• in-depth assessment of child's present levels of development</li> <li>• medical necessity for EI services</li> <li>• outcomes desired for the child and family</li> <li>• services the child and family will receive to help them achieve the outcomes</li> <li>• 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</li> <li>• plan to transition to Part B services or other community programs</li> <li>• services needed in terms for amount, duration, and scope</li> </ul> <p>Family determines which outcomes will be in plan.</p>	<ul style="list-style-type: none"> <li>• present levels of educational, functional, and behavioral performance and participation in developmentally appropriate activities</li> <li>• measurable annual goals for academic, behavioral, and functional areas</li> <li>• how and frequency progress will be measured</li> <li>• how progress will be reported to family</li> <li>• parent(s) should include information about the family's concerns for meeting and enhancing the child's education, behavior, and functioning needs</li> <li>• accommodations/modifications, services and placement</li> </ul> <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>
Who is involved in developing plan	<p>Team may include:</p> <ul style="list-style-type: none"> <li>• a parent(s) or legal guardian of the child</li> <li>• other family members as requested by parent</li> <li>• advocate and persons outside the family, if requested by parent</li> <li>• service coordinator</li> <li>• individual(s) involved in conducting evaluations and assessments</li> </ul>	<p>Team must consist of:</p> <ul style="list-style-type: none"> <li>• parent or parents of child</li> <li>• special education teacher</li> <li>• principal or principal designee (representative from school district who can commit resources)</li> <li>• person who can interpret results of evaluations</li> <li>• others who have knowledge or special expertise about the child (invited by parent(s) and school.</li> <li>• Other possible participants: general education teacher (if considering or attending gen ed classes)</li> </ul>

Issue	IFSP (Early Intervention Programs)	IEP (Preschool - Age 21)
Which services may be provided	Includes the early intervention services and supports necessary to meet the unique needs of the child and family in order to achieve the identified outcomes	Includes the special education 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

## 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. You need to be able to "play the game," working with teachers and other professionals to support your child.

- 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 PEATC at [www.peatc.org](http://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.

## 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, the Department of aging and Rehabilitative Services 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 a filing system that works for you.** This can be a three-ring binder, a series of labeled folders, a large folder on your computer, or just a dedicated drawer. Online storage is also an option.
- **Consider separate files** or notebooks for school related records and another for legal, financial, and medical papers. Examples of documents to be kept in each type of file are described below.
- Then **copy or scan** important documents for easy access and keep originals in a safe place. Backup your computer regularly if storing digital versions.
- **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 only \$2000 in assets.
- **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 more on the rationale for a Letter of Intent, see <http://www.child-autism-parent-cafe.com/letter-of-intent.html>

## 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.

### Applying for Benefits

The steps for applying are:

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

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

At this time, only the Child Disability Report can be completed online. *You cannot complete the entire application online; you must call Social Security for an appointment.*

**Complete the online Child Disability Report.** At the end of the report, the agency asks you to sign a form that gives the child's doctor(s) permission to give Social Security information about his/her disability. They need this information 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. It is best to call the 800 number rather than the local office as field offices are understaffed and the hold times can be very long. You will be greeted by an automated answering attendant, who will prompt you to state why you are calling; say "Apply for SSI."

The auto attendant will 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**

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

#### **Fairfax Local Office**

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

**Go to the screening interview.** Bring any and all information to prove your child's age, citizenship, disability, and lack of assets/resources. SSA provides a list of needed information 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.*

#### **SSI Disability Reviews**

After your child starts receiving SSI, the law requires that the Social Security Administration review your

child's medical condition from time to time to verify that his or her disability still meets its criteria. The review is completed:

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

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

---

### **The Representative Payee**

A representative payee is appointed by SSA to receive Social Security and/or SSI benefits for someone who cannot manage his or her money. Rep Payees should be comfortable handling financial records and be trusted to keep in mind the best interests of the disabled beneficiary.

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

To be designated a Rep Payee, contact the local SSA office (see above). You must then submit an application, form SSA-11 and documents to prove your identity. SSA requires you to complete the 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](http://www.socialsecurity.gov/payee)

---

## APPLYING FOR BENEFITS: Medicaid Waiver Programs

This information is adapted from The Arc of Northern Virginia's website. For more information, visit the section on Waivers in our Resource Library <https://thearcofnova.org/programs-services/library/#waivers>. This link will take you to one page fact sheets and a host of webinars on the topic.

Family income and family assets are not a consideration under the Medicaid Waiver program if your child's personal income and assets qualify them, they have a disability diagnosis, and they meet functioning eligibility criteria. To watch our recorded webinar that walks you through Waivers from start to finish, visit [https://www.youtube.com/watch?v=WtM12h4s9NY&list=PLG3\\_4BW3RiS7y2ISlyBlruPys1MosQoGs&index=3&t=05](https://www.youtube.com/watch?v=WtM12h4s9NY&list=PLG3_4BW3RiS7y2ISlyBlruPys1MosQoGs&index=3&t=05)

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

### Services Covered Under the Waivers

#### **The Developmental Disability (DD) Waivers:**

There are 3 DD Waivers; they are the (1) Community Living, (2) Family and Individual Supports, and (3) Building Independence Waivers. These waivers cover supports in a variety of residential settings, including hourly staff at the home of a child's family and 24 hour staffed group home settings. These three waivers also cover a variety of employment and meaningful daytime supports for people no longer in school. Some additional services include respite care, in-home supports, companion care, assistive technology, environmental modifications, therapeutic consultation, non-emergency medical transportation, private duty nursing, skilled nursing, and Personal Emergency Response System (PERS). **The Community Living Waiver** is a comprehensive waiver that includes 24/7 residential services for those who require that level of support. It also includes services

and supports for adults and children, including those with intense medical and/or behavioral needs.

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

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

Individuals receiving waiver services are assessed every two years (as a child) and every three years (as an adult) with an assessment called the Supports Intensity Scale (SIS) to measure the intensity of their support needs. People can move between these three DD Waivers if their needs change over time. Moving to a waiver that serves people with higher needs may sometimes involve a significant waiting period and is a "first come, first serve system".

### Eligibility Criteria

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

- (1) **Functioning ability:** This is determined by the VIDES survey. The VIDES has one test for children aged 0-3, one for children ages 3-18, and one for adults. The surveys assess the person's need for assistance with a variety of daily living and independence skill activities. \* You can find the VIDES assessment in the Resource Library on our website.
- (2) **Diagnosis:** Persons applying for a Waiver must meet the diagnostic eligibility requirements for the DD Waivers. This means that a person must have a developmental disability as defined in 37.2-100 of the Code of Virginia.

a. "Developmental disability" means a severe, chronic disability of an individual that (1) is attributable to a mental or physical impairment, or a combination of mental and physical impairments, other than a sole diagnosis of mental illness; (ii) is manifested before the individual reaches 22 years of age; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independence living, or economic self-sufficiency; and (v) reflects the individual's needs for a combination and sequence of special interdisciplinary or generic services, individualized support, or other forms of assistance later are lifelong or extended duration and are individually planned and coordinated. An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (i) through (v) if the individual without services and supports, has a high probability of meeting those criteria later in life.

- (3) **Financial:** If the functioning and diagnostic criteria are met, then the child's income and assets are considered. Special Needs Trusts and ABLE Accounts are not considered when testing financial eligibility. People over 18 have an asset cap of \$2,000. Everyone receiving a Waiver has a monthly income cap of 300% of the current Social Security Supplemental Security Income amount (SSI is \$735 in 2017, so max monthly income is \$2,205).

**The Commonwealth Coordinated Care (CCC) Plus Waiver** covers personal care, respite care, medication monitoring, private duty nursing, assistive technology, environmental modifications, and the Personal Emergency Response (PERS) system. Personal care support hours may be

approved up to a maximum of 56 hours per week and cannot exceed 480 hours per state fiscal year.

To be eligible for this waiver, the person must have a disability and medical nursing needs, as assessed by the Virginia Uniform Instrument (UAI) [www.vda.virginia.gov/pdfdocs/uai/pdf](http://www.vda.virginia.gov/pdfdocs/uai/pdf)

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

### How Long is the Wait?

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

### To Apply for the Developmental Disabilities Waivers

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

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

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

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

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

## ISFP Funding

### For Those on the Waiver Waitlists

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

## ENSURING HEALTH INSURANCE

Having adequate health insurance is an important element in securing your child's financial as well as physical health. Children with a lifelong disability may stay on their parents' health insurance indefinitely (children without disabilities are not covered after age 26).

### Private Employer Health Plans

The Affordable Care Act of 2010 extended healthcare coverage for families and individuals and provided important protections for individuals with disabilities.

Dependents with a lifelong disability can remain under their parents' employer-sponsored policy beyond age 26. Also, job-based and new individual plans are not allowed to deny or exclude coverage to any child under age 19 based on a pre-existing condition, including a disability. These same plans cannot charge a higher premium for a pre-existing condition, including a disability.

### Medicaid

Medicaid is a government sponsored health coverage program available for low income Virginians who meet specific income and eligibility criteria that includes children, pregnant women, parents, older adults, and individuals with disabilities.

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.

### Health Insurance Premium Payment Program (HIPP)

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 [http://www.dmas.virginia.gov/content\\_pgs/rcp-hipp.aspx](http://www.dmas.virginia.gov/content_pgs/rcp-hipp.aspx)

or call the HIPP Program at 800-432-5924. Visit our YouTube channel for a Three Minute Webinar on HIPP <https://www.youtube.com/watch?v=KQweJ1A77wk>

### 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](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](http://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](http://dmasva.dmas.virginia.gov/Content_atchs/atchs/medbook-eng.pdf)

**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](http://www.insurekidsnow.gov) on the Internet or by calling 1-877-543-7669.

## State Children's Health Insurance Program (SCHIP)

Children may be able to get health insurance from SCHIP even if they do not get SSI. SCHIP provides health insurance to children from working families with incomes too high to get Medicaid, but who cannot afford private health insurance. SCHIP provides insurance for prescription drugs and for vision, hearing and mental health services in all 50 states and the District of Columbia. Your state Medicaid agency can provide more information about SCHIP. You can also go to [www.insurekidsnow.gov/](http://www.insurekidsnow.gov/) or call toll free **1-877-KIDS-NOW** (1-877-543-7669) for more information on your state's program.

## Applying Online for Benefits in Virginia

CommonHelp allows Virginia residents to apply online for 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/>

## SECURING YOUR CHILD'S FUTURE: Estate Planning

Key aspects of estate planning for *all* parents of young children are having a will and naming a guardian for your child or children. Parents of children with a disability also need to create a special needs trust to protect any means-tested benefits that child may receive.

### Creating a Will

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

### Reviewing Beneficiaries

In addition to naming a special needs trust as the beneficiary for monies inherited through a will, you should also **review the beneficiary designations for resources considered outside your will**, including:

- Employer provided life insurance (if both parents work and have insurance through their jobs, be sure to check beneficiaries for both)
- Private life insurance policies (again, check beneficiaries for all policies)
- Individual retirement accounts, including Roth IRAs\*
- 401K and 403(b) accounts\*
- SEP Plans\*
- Thrift Savings Plans\*
- Individual checking and savings accounts
- Brokerage accounts
- Savings Bonds

Special cautions apply when designating a special needs trust as a beneficiary of one or more of your

retirement accounts (those marked with an \*). The document creating the special needs trust (whether it is a will or a stand alone trust) needs to state that the trust is "an accumulation trust" for the purpose of receiving distributions from retirement accounts.

(This comes into play once your child with a disability turns 18 and may be eligible for SSI as an adult. After age 18, an adult receiving SSI can only have \$2,000 in assets. Typically, when someone inherits a retirement account, they have to start receiving periodic payments from the account which would most likely disqualify them for federal benefits such as SSI and Medicaid).

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

### Naming a Guardian for Minor Children

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

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

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

Explain your choice of guardian in writing if you feel there may be disagreement in the family over your choice.

### Special Needs Trust

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

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

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

### Two Kinds of Trusts

As part of a family's future planning, ***third-party trusts*** (family funded trusts) established by parents with an attorney or directly or with an authorized non-profit, such as The Arc of Northern Virginia, for their child with disabilities. The person establishing the trust, usually called the settlor or grantor, chooses to make some of his or her own assets available for the benefit of the beneficiary (person with disabilities).

These trusts may be funded during the parents' lifetime. You can contribute to them while you are still alive or you can fund them upon the death of the parents(s), grandparents(s), friend, etc. with an inheritance, life insurance policy or transfer from another trust.

***First-party trusts*** (self-funded or self-settled) are established by the beneficiary, parent, grandparent, guardian, or court ordered and are funded with resources that belong to the person with disabilities. Common sources of funding for first-party trusts are structured settlements, lump-sum paybacks from Social Security, irrevocably assigned child support for an adult child with disabilities and Survivor Benefits, and inheritances that mistakenly were given directly to the individual with the disability.

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

### Setting Up a Trust

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

For either option, you will have to pay fees to set up the trust and, possibly, to manage the funds. The Arc of Northern Virginia's Trust program does not require a minimum deposit.

### Uses of Special Needs Trust Funds

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

- Education and tutoring
- Out of pocket medical & dental costs
- Transportation (including purchase of a vehicle)
- Maintenance of vehicles, car insurance
- Materials for a hobby or recreational activity
- Trips, vacations, hotels, airline tickets
- Entertainment such as movies or ballgames
- Computers, videos, furniture, or electronics
- Athletic training or competitions
- Special dietary needs
- Clothing

- Housing costs (although this may reduce SSI benefits)
- The list is extensive!

### Acting as Trustee

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

For trusts set up with The Arc of Northern Virginia, the family and beneficiary do not have this burden of trust administration. Trust staff perform all administrative tasks and client relations and Key Bank handles all fiduciary and investment duties.

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

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

### ABLE Accounts

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

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

ABLE Accounts do not replace the need for a Family Funded Special Needs Trust, but may be used in conjunction. Funds in an ABLE account may only be used for Qualified Disability Related expenditures.

ABLE Accounts are similar to First Party or Self-Funded Trusts in that they require a Medicaid payback upon the death of the beneficiary. To learn more about ABLE Accounts, visit [www.ablenlc.org](http://www.ablenlc.org). To learn more about ABLEnow in Virginia, visit <https://www.able-now.com/>. 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/content/uploads/sites/6/2019/10/Comparison-of-Special-Needs-Trusts-with-an-ABLE-Account-VA.pdf](https://thearcofnova.org/content/uploads/sites/6/2019/10/Comparison-of-Special-Needs-Trusts-with-an-ABLE-Account-VA.pdf)

## HAVING FUN: Recreational Resources

All three localities have Therapeutic Recreation Offices providing recreation and leisure opportunities for individuals with disabilities both during the school year and in the summer. For an excellent guide to recreation programs in Northern Virginia, see

<https://poac-nova.org/wp-content/uploads/2019/02/Adapted-sports-and-rec-list-2019.pdf>

### Therapeutic Recreation Departments City of Alexandria

The Therapeutic Recreation Office can be reached at (703)746-5422 or visit <https://www.alexandriava.gov/recreation/info/default.aspx?id=45758>

### Arlington County

The Therapeutic Recreation Office has classes for tots with disabilities aged 3 and up. Call (703)228-4740, visit

<https://parks.arlingtonva.us/therapeutic-recreation/>

### Fairfax County

The Therapeutic Recreation Office offers the Early S.M.I.L.E.s program, an integrated play program for toddlers 15-36 months and the S.M.I.L.E. program, an integrated play program for children 3-5.

<http://www.fairfaxcounty.gov/ncs/trs/ctya.htm>

(703)324-5532

### Private Vendors

**Adaptive Learn-to-Skate.** MedStar Capitals IcePlex offers skating lessons. Call (571)224-0555 or visit <https://www.medstarcapitalsiceplex.com/>

**Adaptive Martial Arts** (4-18) Jhoon Rhee Tae Kwon Do has beginner through advanced classes to improve motor skills, coordination, focus and self-control. Call (703)532-7433, or visit <http://arlingtonkicks.com/adaptive-martial-arts> for more information.

**ArtStream.** Drama and movement classes for children and adults with disabilities. Classes in Silver Spring, MD, and Arlington and Fairfax VA. <http://www.art-stream.org> or call (301)565-4567

**Lifechanging Fitness.** An adaptive children's fitness center focusing on children ages 2 and older. Also offers bike riding lessons. Visit [www.lcfkids.com](http://www.lcfkids.com)

### Little League Baseball/Challenger League.

Ages 5-22. This volunteer-run program provides an opportunity to play ball, with players teamed up with a Majors 1 player, who acts as a buddy. Spring and fall. For Arlington: [www.arlingtonlittleleague.org](http://www.arlingtonlittleleague.org) (703)351-5111. For Springfield, (571)331-1167, <http://springfieldchallenger.org> For Fairfax Challenger: [www.fairfaxll.com](http://www.fairfaxll.com).

**TOPSoccer.** Ages 4-19. This is a volunteer-run skill development program. Fall, winter and spring. For current TOPSoccer programs in Northern Virginia, visit <https://www.vysa.com/Default.aspx?tabid=2519886>

**Young Athletes Program.** Focuses on fun activities important to mental and physical growth for children ages 2-7 with intellectual disabilities [www.specialolympicsva.org/programs/young-athletes](http://www.specialolympicsva.org/programs/young-athletes).

### Therapeutic Riding

Golden Dreams Riding (Middleburg) <https://www.goldendreamsridingcenter.org/> 540)687-5800

Lift Me Up! (Great Falls) <http://www.liftmeup.org> (703)759-3833

Northern Virginia Therapeutic Riding (Clifton), [www.NVTRP.org](http://www.NVTRP.org) (703)764-0269

Rainbow Therapeutic Equestrian Center (Haymarket) <http://www.rainbowriding.org> (703)754-6159

Spirit Open Equestrian Program (Herndon) <http://www.spiritequestrian.org> (703)600-9667

Sprout Therapeutic Riding <http://sproutcenter.org/>

## 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**

<http://www.easterseals.com/DCMDVA/our-programs/childrens-services/child-development-center-of.html> Offers an inclusive early education center from ages 6 weeks – 6years.  
300 Hunton Ave., Falls Church, VA  
703-534-5353

**Care.com.** Childcare and other resources for individuals with special needs.  
[www.care.com](http://www.care.com)

### Respite Care

#### **McLean Bible Access Ministries**

<https://archive.mcleanbible.org/connect/respite> Offers respite for children ages 2-15 on Fridays and Saturdays through their Breakout and Breakaway program. They also offer a Siblings Only Program for children who have brothers and sisters with special needs.

#### **Jill's House**

[www.jillshouse.org](http://www.jillshouse.org)  
Offers overnight respite services for children ages 6-17.  
9011 Leesburg Pike, Vienna  
703-639-5660

## FINDING SUPPORT: Information & Support Groups for Parents

### Parent Resource Centers (PRC)

#### **Arlington Public Schools PRC**

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

#### **City of Alexandria PRC**

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

#### **Fairfax County Public Schools PRC**

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

### Local Advocacy Groups

#### **The Arc of Northern Virginia**

(703)208-1119

#### **The Arc of Virginia**

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

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

#### **Autism Society of America, Northern Virginia**

Chapter (ASANV) <http://www.asnv.org> (703)495-8444

#### **Blind and Vision Impaired**

Department for the Blind and Vision Impaired  
397 Azalea Avenue  
Richmond, VA 23227-3623  
(800)622-2155 or (804)371-3140  
[www.vdbvi.org](http://www.vdbvi.org)

Fairfax Regional Office:

Department for the Blind and Vision Impaired  
11150 Fairfax Blvd, Suite 502

Fairfax, VA 22030-5066  
(703)359-1100 Regional Office Number

#### **Brain Injury Services, Inc.**

[www.braininjurysvcs.org](http://www.braininjurysvcs.org)

#### **CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder) of Northern Virginia**

[www.novachadd.org](http://www.novachadd.org)

#### **Down Syndrome Assn. of Northern Virginia (DSANV)**

[www.dsanv.org](http://www.dsanv.org), (703)621-7129

#### **Feeding Tube Awareness Foundation**

<http://www.feedingtubeawareness.com>

\*Also available on Facebook

#### **NVRC (Northern Virginia Association for Deaf and Hard of Hearing Persons)**

[www.nvrc.org](http://www.nvrc.org) OR [info@nvrc.org](mailto:info@nvrc.org)

Membership fee.

#### **Preemies Today**

[www.preemiestoday.org](http://www.preemiestoday.org).

#### **Spina Bifida Assn. of the National Capital Area**

[www.sbanca.com](http://www.sbanca.com)

(703) 455-4900

#### **Little Hearts (congenital heart defects)**

[www.littlehearts.org](http://www.littlehearts.org) or [www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)

#### **Virginia Association for Parents of Children with Visual Impairments**

[www.vaapvi.org](http://www.vaapvi.org)

#### **Virginia Smiles (cleft lip/palate)**

[www.virginia-smiles.org](http://www.virginia-smiles.org)

### **Local Parent Support Groups/List Serves**

*For a list of parent support groups (organized by disability/medical issue) meeting in Virginia, look at:*  
[http://www.peatc.org/peatc.cgim?template=parent\\_re\\_sources.support](http://www.peatc.org/peatc.cgim?template=parent_re_sources.support)

### **Arlington ADHD**

Listserve open only to parents of students who have ADHD.

<http://health.dir.groups.yahoo.com/group/ArlingtonADHD>

### **Arlington Autism Group**

Parent support group and autism information list serve. Contact Donna Budway at [donnabudway@aol.com](mailto:donnabudway@aol.com)

### **ASIS Yahoo Group of Arlington**

Support group for families with children ages 3-23 who have Asperger syndrome, high functioning autism, non-verbal learning disabilities. This is a closed group (you must have permission to join). You can join online or send a message to [arlingtonasis-subscribe@yahogroups.com](mailto:arlingtonasis-subscribe@yahogroups.com). You may also contact Michelle Best at [mczero@yahoo.com](mailto:mczero@yahoo.com) with other questions

### **Arlington Special Education Parent Teacher Association (SEPTA)**

[www.arlingtonsepta.org](http://www.arlingtonsepta.org)

### **Dulles Moms**

[www.dullesmoms.com](http://www.dullesmoms.com)

Opportunities for social and support activities for families with special needs

### **Hearing Loss**

[kidswithhearingloss-subscribe@yahogroups.com](mailto:kidswithhearingloss-subscribe@yahogroups.com)

### **Jewish Community Center of Northern Virginia**

[www.jccnv.org](http://www.jccnv.org) or (703)537-3040

### **Jewish Social Service Agency (JSSA)**

(703)896-7918

[www.jssa.org](http://www.jssa.org)

Parent training, advocacy & support groups

### **National Capital Area Asperger's & High-Functioning Autism Parent Support Groups**

Pam Escobar (703)430-3519  
[aspergers\\_nca@hotmail.com](mailto:aspergers_nca@hotmail.com)  
[www.autismva.org](http://www.autismva.org)

### **Northern Virginia Parents of Multiples (NVPOM)**

[membership@nvpom.com](mailto:membership@nvpom.com)  
[www.nvpom.com](http://www.nvpom.com)

### **Parent2Parent Meetings**

[julieandjoanne@gmail.com](mailto:julieandjoanne@gmail.com)  
[www.ptpofva.wordpress.com](http://www.ptpofva.wordpress.com)

### **Parents of Autistic Children of Northern Virginia**

[www.poac-nova.org](http://www.poac-nova.org)

### **Parent Education Advocacy Training Center (PEATC)**

[www.peatc.org](http://www.peatc.org).

### **Social Graces, LLC**

<https://socialgracellc.com/> Offers parent support groups.



## FINDING SUPPORT: Web-Based Resources

### Apps

OnePlaceforSpecialNeeds.com

[http://www.oneplaceforspecialneeds.com/main/library\\_special\\_needs\\_apps.html](http://www.oneplaceforspecialneeds.com/main/library_special_needs_apps.html)

Speech Therapy Games for Kids:

<http://www.speechbuddy.com/blog/games-and-activities/6-free-online-speech-therapy-resources/>

### Blogs

The Speech Mama: <http://www.thespeechmama.com/>

Our Adventures with Down Syndrome:

<https://www.facebook.com/groups/ouradventures/>

Down's Ed USA: <http://www.dseusa.org/en-us/>

### Online Magazines

#### Complex Child E-Magazine

<http://www.complexchild.com>

\*Also available on Facebook

#### Parenting Special Needs Magazine

<http://parentingspecialneeds.org>

\*Also available on Facebook

#### Parenting Children with Special Needs Magazine

<http://pcwsn.com>

\*Also available on Facebook

### Adaptive Equipment

<http://www.adaptivemall.com/>

<http://www.especialneeds.com/>

<http://tadpoleadaptive.com/>

<http://funandfunction.com/>

<http://enablingdevices.com>

<http://www.childrite.com/>

Toys R' Us Differently-Abled Guide:

<http://www.toysrus.com/shop/index.jsp?categoryId=3261680>

<http://www.rep-inc.com/> (local durable medical equipment provider)

<http://www.orthoticsolutions.com/>

<http://www.hiphelpers.com/index.htm>

## FINDING SUPPORT: For Military Families

Specifically for early intervention:

[http://apps.militaryonesource.mil/MOS/f?p=EFMP\\_DIRECTORY:HOME:0::::EKMT:37.30.20.0.0.0.0.0](http://apps.militaryonesource.mil/MOS/f?p=EFMP_DIRECTORY:HOME:0::::EKMT:37.30.20.0.0.0.0.0)

**Fort Belvoir Exceptional Family Member Program**

[www.fbch.capmed.mil/patients/efmp.aspx](http://www.fbch.capmed.mil/patients/efmp.aspx)

EFMP Coordinator

(571)231-1054

**U.S. Marine Corps Exceptional Family Member Program (EFMP)**

The EFMP provides assistance to military families with exceptional needs. [www.mccscp.com/efmp](http://www.mccscp.com/efmp)

(760)725-5363

## FINDING ADDITIONAL SUPPORT SERVICES INCLUDING:

Attorneys with Expertise in Special Needs Planning, Care Providers, Home Modifications, and Much More!

See The Arc of Northern Virginia's Provider Directory at <https://thearcofnova.org/directory/>

## ACKNOWLEDGEMENTS

The first printing of "Starting Life with Your Child with a Disability" in 2014 was made possible by contributions from parents and professionals dedicated to helping young children with disabilities get the best possible start in life.

### **Early Intervention Working Group/Transition**

#### **POINTS**

Kasey Card, Parent

Bianca Collins, Special education teacher

Erin Croyle, Former Staff, The Arc of Virginia

Robin Crawley, ITC of Alexandria

Leah Davidson, (PIE) of Arlington

Margaret Jones, Former Staff, ITC of Arlington

Brandy Nannini, Parent

Alan Phillips, Former Director, ITC of Fairfax-Falls Church

Susan Sigler, Director, ITC of Fairfax-Falls Church

### **Production**

Stephanie Sampson

Writer and Editor

Former Chair, Transition POINTS Committee

The Arc of Northern Virginia

Diane Monnig

Contributing Editor/Staff The Arc of Northern Virginia

[dmonnig@thearcofnova.org](mailto:dmonnig@thearcofnova.org)

Each year the guide is reviewed by professionals representing various public, non-profit, and private organizations, as well as, parent and then updated with current information.

Revised 2017, Revised 2020