

STARTING LIFE WITH YOUR CHILD WITH A DISABILITY

**First Steps for Families in
The City of Harrisonburg,
Rockingham County, and the Vicinity**



Harrisonburg and Rockingham

**Produced for the Lifespan Project
of The Arc of Harrisonburg and
Rockingham, Virginia**

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This guide is one of six developed for parents of children with intellectual disabilities under the auspices of The Arc of Harrisonburg and Rockingham. It 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.

All of the guides can be found at <http://www.hrarc.org>. The printed version of this guide is updated periodically. As information changes, updated information and resources may be found at our website <http://www.hrarc.org>

The Arc of Harrisonburg & Rockingham
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INTRODUCTION TO LIFESPAN

Developmental disabilities (DD) by definition last a lifetime, so caring for a loved one with 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 of the U.S. found many families struggling to help their loved one with an intellectual disability:

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

About Lifespan

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 The Arc of Harrisonburg and Rockingham Virginia's Lifespan Project.

Lifespan focuses on six key decision points in the lifetime of an individual with an intellectual or developmental disability:

- Receiving a diagnosis and having a child enter an early-intervention (EI) program
- Starting school and entering the special education system
- Transitioning out of the school system and into adult services
- Entering the world of work
- Finding a place to live outside the caregiver's home
- Aging with a disability.

Help for You, the Parent

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

The information found in this guide is applicable to all people with developmental disabilities and their families. In this particular publication, much of the contact information for resources are particular to the Harrisonburg-Rockingham 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.dbhs.virginia.gov/individuals-and-families/community-service-boards>.

The CSB is the point of entry into the publicly-funded system of services for people with mental health and/or developmental disabilities. Also, visit The Arc of Virginia at <http://www.thearcofva.org> to find the local Arc chapter in your community.

As a first step in Lifespan, we have written six guides to address 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.

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. It will include steps to take to protect your loved one's financial future, how to apply for benefits, and where to go for more help.

First Steps

If your child has already been diagnosed with a developmental disability **and is under 36 months of age**, go to "**Introduction to Lifespan.**"

If you have concerns about your child's developmental progress **and he or she is under 36 months old**, start with "**Starting Life With Your Child With a Disability.**"

If your child is aged **2 to five by September 30**, find out about preschool options in your school district by contacting your local Child Find coordinator (**Familiarizing Yourself with the Process** section in this manual), and see the guide on special education, "**Getting the Most From Special Education.**"

For each lifespan phase, we are also developing online resources, workshops, podcasts, and webinars.

All of the guides can be found on the website of The Arc of Harrisonburg & Rockingham at <http://www.hrarc.org>

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 only and do not constitute an endorsement of their services. Please send any comments to

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STARTING LIFE WITH YOUR CHILD WITH A DISABILITY

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. (This guide is geared to parents of children who are infants up to age three.)

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 Harrisonburg and Rockingham, 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. Virginia's Early Intervention System is governed by Part C of the Individuals with Disabilities Education Act (IDEA). The Early Intervention system is managed by the Department of Behavioral Health and Developmental Services (DBHS) and is called Infant and Toddler Connection of Virginia. This guide takes you through the process of getting help for your child.

To help you pursue early intervention for your child, as well as a 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 a disability 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 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, and to avoid jeopardizing those benefits.

Read through the “Checklist for Parents” for steps to take right away.

A Checklist for Parents

Step to Take by Age	Advocacy and Support	Early Intervention	Legal/ Financial Planning	Benefits Planning	Transition to Preschool
As soon as you have a diagnosis of a developmental disability					
Have hospital or pediatrician provide info and training on child’s medical needs and referrals to specialists	x				
Call local Early Intervention Program		x			
Pursue specialists/private therapies to supplement early intervention	x				
If you suspect developmental delays					
Keep track of behaviors and discuss with pediatrician; ask for a developmental screener	x				
Call your local Early Intervention Program		x			
Pursue specialists/private therapies to supplement early intervention	x				
For all parents as soon as possible					
Find a support network	x				
Create a file for key documents	x		x		
Have a will drawn up for parents; name guardians for minor children			x		
Draft a Letter of Intent			x		
Establish a Special Needs Trust			x		
Determine if your child qualifies for Supplementary Security Income				x	
If your child qualifies for SSI, set up a Representative Payee account				x	
Explore eligibility for Medicaid waivers, get on wait list(s)	May	be	long	x wait	list
At age 3					
If your child has been in Early Intervention, contact local school system or ask your Early Intervention coordinator about preschool					x

Step to Take by Age	Advocacy and Support	Early Intervention	Legal/ Financial Planning	Benefits Planning	Transition to Preschool
If your child has not been in early intervention, contact your local Child Find program					x

If Your Child Has Been Diagnosed With a Disability

When a child is diagnosed with a developmental disability (DD), 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 not prepared for.

However, you **are** prepared with the most important thing: 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. Other parents who have been in your situation have suggested the following:

- **Embrace Where You Are Right Now**
Don't rush through whatever initial negative feelings you may be having. Give yourself time to grieve. 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) 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 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. Often your child will be the one who shows you what he or she can do. As difficult as it is, many parents have recommended "living in the moment," rather than trying to guess the future.
- **Act as Early as Possible to Get Help**
If you are reading this, you are already taking a key step: getting help. Research confirms that addressing developmental delays at an early age results in better outcomes for a child's health, language, motor, cognitive, social, and emotional development. If your child has not yet reached his or her 3rd birthday, call your local early intervention program. Certain developmental disabilities (such as cerebral palsy, autism, and Down syndrome) automatically qualify your child for early intervention services.
- **Get Connected With Others**
No man is an island. This is especially true for parents of children with disabilities. Be open to all modes of support, including social media like blogs and Facebook, rather than relying exclusively on one mode to the exclusion of another. Allow your friends and family to support you. 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 issues. Disability organizations such as The Arc of Harrisonburg and Rockingham can refer you to resources.

- **Start Keeping Track of Paperwork**

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

- **Get Help from the Hospital**

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

Local Early Intervention Programs

Harrisonburg-Rockingham Community Services Board sponsors:

McNulty Center for Children and Families
463 E Washington St
Harrisonburg, VA 22802
(540) 433-3100
Open: Monday-Friday, 8:30 am to 3:00 pm

Or, contact Infant and Toddler Connection of Virginia at 1 (800) 234-1448
<http://www.infantva.org/Families.htm>

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 the 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

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.

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 on the local hospital that is best for your child's diagnosis (especially 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, 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 to and a list of local resources such as The Arc of Harrisonburg and Rockingham, Virginia, or Parent Education Advocacy Training Center <http://www.peatc.org>
9. Referral to a mental health professional who can provide assistance to you, if needed
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 (Before Diagnosis)

While babies grow at slightly different rates, most reach key developmental milestones at more or less the same age. 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 such as 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 the 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.

- Use any Diagnosis to Your Advantage**
 For many parents, a diagnosis of a developmental delay or disability is just the beginning of the story. It may be affirmation of your concerns or a surprise, but it will definitely lead you to therapies, programs, and services that will help your child. It will also help guide you in doing your own research and in seeking support for yourself and your family. 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 an advocate you are for your young 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.** While you are on the phone, the person doing the intake can set up a meeting in your home to screen for any possible developmental issues.

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 without 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 with others
9 mo	Pulls to stand; crawls; can get into a sitting position on own	Grasps; plays peek-a-boo; looks for things you hide; looks where you point	Understands “no;” copies sounds and 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 one or more words with meaning; practices inflection; says “mama” and “dada;” imitates animal sounds	plays simple games (patty cake, ball roll); develops attachment to particular toy; anxious when separated from parents
18 mo	walks without help; likes to pull, push, and 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

Age	Physical	Cognitive	Language	Socio-Emotional
2 yrs	Walks well; runs; walks up/down stairs w/railing; uses spoon and fork; drinks from straw; opens drawers and 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/ 2 ½ yrs	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 and after); develops strict rituals and likes to follow routine	50 word vocabulary; speaks in 3-4 word sentences with subject-verb-object; asks “when” and “where” questions	Enjoys company of other children; displays less separation anxiety (knows parent will come back); resistance and uncooperation 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 “what,” “when,” “why,” “where,” and “how” 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, and 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. Downloaded November 30, 2015.

<http://www.cdc.gov/ncbddd/actearly/milestones/index.html>

Starting Off: Local Early Intervention Programs For Children From Birth to 3 Years

Getting prompt 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 the 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.

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_Doesn'tLookLike3_11_08.pdf

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) in what the law calls "natural environments" or places where young children with- or without a disability 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 training in fields such as child development, occupational therapy, counseling, or speech therapy, 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. Screening and assessment of your infant or toddler are **free** through your local early intervention programs.

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 would 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:

- Genetic disorders, such as Down syndrome
- Cerebral palsy
- Cleft lip and/or palate
- Vision or hearing loss
- Autism spectrum disorder (ASD)
- A stay of 28 days or more in a neonatal intensive care unit

NOTE: Other disabilities **may** qualify your child for early intervention services. The above are just the ones for which eligibility is automatic.

Developmental delays or differences in development mean a child is not developing like other children of 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/ delays can be found at www.infantva.org

There are five steps in the early intervention (EI) process: getting a referral, screening and 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 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 program coordinator will schedule an intake visit with you 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 ongoing services. You will be asked for written consent to determine if your child is eligible for early intervention 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 showing 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."

The 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 ensure that you as the parent must **understand** the process and, with that understanding, **give permission** for the 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 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
- 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 your child is eligible, you will meet with a multidisciplinary 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 professional, the team will request those medical records (with your consent) and review the results. Whenever possible, these results will be incorporated into the evaluation 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 will be 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 information:

- Medical and referral history
- The child's and family's daily routine 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 (at home, childcare, a local playground, or elsewhere)
- A plan for transitioning out of early intervention (such as 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
- A 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 to the child and family (annual IFSP reviews)

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/>

Free Services Provided by the IFSP are:

- Service coordination: staff time to coordinate the eligibility screening, 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 Have 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 Eligibility

The team, including parents, meet to review the IFSP at least every six months. Annual IFSP reviews also include a full reassessment of your child’s development to evaluate 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, to be confident and competent in implementing the intervention

strategies in the child's and family's typical routines, in the time 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 to evaluate how new strategies are working between sessions. Again, the emphasis is on having outcomes commensurate with family needs and wants for their child. In this way, you begin to feel more comfortable with what you are doing with your child. If you feel a more medical-model approach to learning suits 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 30th 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. The regulations 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), other members of the team developing this document include special-education teachers (when general education services are to be provided, general educators), related service providers such as therapists, and a special education administrator. Your early intervention team members may also participate in the IEP process if it occurs before your child turns 3 years old. You may also invite them after your child turns 3. 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 therapy, physical therapy, and occupational therapy, are free since they are provided by your local school system.

See the relevant table comparing 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. That is a good thing—it is one of the desired outcomes of Early Intervention. If, however, you and the IFSP team believe your child might be eligible for special education services in a preschool setting, then a referral is made to the Early Childhood Identification and Education Services (ECID) 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 most to special education, see guide “**Getting the Most from Special Education**” at www.hrarc.org.

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, childcare, 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, and/or cooperative or private preschool daycare.

Timing for Transitioning at Age 2

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

Talk to the early intervention team and discuss the pros and cons of transitioning your child out of early intervention at the age of two or staying until his or her 3rd birthday. If you decide to start the referral process, you can change your mind at any point in the process, or wait to start special education services when your child turns 3 years old. (Keep in mind, if you choose to transition out at the age of two, your child can go back if you decide it was too early.)

Making the Transition Easier

The transition 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 out of the family home for more hours in the day 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 made easier in a number of ways as follows:

Preparing Your Child

Prepare your child for preschool 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 (multiple times if helpful)
- 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, a 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 as part of the longer transition to kindergarten and elementary school. This is an opportunity for you to learn how the system works and get used 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 in going to school.

See Lifespan guide “**Getting the Most out of Special Education**” for help in understanding the special education process, particularly your role in developing the Individualized Education Plan for your child at [http:// www.hrarc.org](http://www.hrarc.org).

Child-Find Contacts

Harrisonburg Community Services Board
 McNulty Center for Children and Families
 463 Washington St
 Harrisonburg, VA 22802
 (540) 433-3100
<http://www.hrcsb.org/category/childrens-services>

Rockingham County Public Schools
 100 Mt Clinton Pike
 Harrisonburg, VA 22802
 (540) 564-3220 or
 (540) 564-3241
info@rockingham.k12.vg.us

Harrisonburg City Public Schools
 1 Court Square
 Harrisonburg, VA 22802
 (540) 434-9916
<http://harrisonburg.k12.va.us/>

If Your Child Hasn’t Been in Early Intervention

Virginia public schools offer Child Find, a program 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 coordinator in your locality (see left).

Similar to early intervention, the steps involved include:

- Referral to a preschool special educational services;
- Assessment of developmental progress (which may require several assessments with different licensed therapists);
- Determination of eligibility
- Writing of an Individualized Education Programs

Individual Family Service Plan vs. Individual Education Program

Issue	IFSP (Early Intervention Programs)	IEP (Preschool - Age 21)
Age	Infant to day before 3rd birthday	3 to 22 (may start at age 2 if child enters preschool at that age)
Legal status	Legal document	Legal document
Why you need this document	Focuses on the developmental needs of the child and services that the family needs enhance the child’s development	Focuses on the educational, functional, and behavioral needs of child and services that can be carried out in school setting

Issue	IFSP (Early Intervention Programs)	IEP (Preschool - Age 21)
What's in the document	<ul style="list-style-type: none"> ● In-depth assessment of child's present levels of development ● Medical necessity for EI services ● Outcomes desired for the child and family ● Services the child and family will receive to help them achieve the outcomes ● Methods, timelines, and plan to measure progress with the family's consent, it also includes information regarding the family's daily routines, resources, priorities, and concerns related to the development of their child ● Plan to transition to Part B services or related to the development of their child ● Plan to transition to Part B services or other community programs ● Services needed in terms for amount, duration, and scope <p>Family determines which outcomes will be in plan</p>	<ul style="list-style-type: none"> ● Present levels of educational, functional, and behavioral performance and participation in developmentally-appropriate activities ● Measurable annual goals for both academic and functional areas ● How and how often progress will be measured ● How progress will be reported to family ● Parent(s) should include information about the family's concerns for meeting and enhancing the child's education, behavior, and functioning needs ● Accommodations/modifications, services, and placement <p>IEP team, including the parents, determine the goals, short-term objectives, placement, services, and assessments. Parents 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"> ● Parent(s) or legal guardian of the child ● Other family members as requested by parent ● Advocate or person outside the family, if requested by parent ● Service coordinator ● Individual(s) involved in conducting evaluations and assessments 	<p>Team may consist of:</p> <ul style="list-style-type: none"> ● Parent(s) parents of the child ● Special education teacher ● Principal or principal designee (representative from school district who can commit resources) ● Person who can interpret results of evaluations ● Others who have knowledge or special expertise about the child (invited by parent[s]) and school ● Possibly general education teacher(s) (if considering or attending general education classes).

Issue	IFSP (Early Intervention Programs)	IEP (Preschool - Age 21)
Which services may be provided	Includes the early intervention services and supports necessary to meet the unique needs of the child and family in order to achieve the identified outcomes	Includes the special education, related services, supplemental aids and services, modifications, accommodations, and supports to be provided to help the child make progress and participate in developmentally-appropriate activities
Where services are carried out	In the child's home, at childcare, at a local playground, and/or other appropriate venue	Preschool (home, classroom, and/or daycare). Elementary through high school

Strategies for Parents: Advocating for Your Child with a Disability

While parenting any child has its difficulties, 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 entire solution for your child. Your job is to learn about what is available 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 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 process and apply what doctors, teachers, attorneys, and specialists are saying, especially when you are under stress. Be aware that you are under stress and may be defensive at times. Instead, try to be a good listener and solution-oriented.

Take someone like your spouse or a good friend with you to meetings; they may pick up on different things that are being said and provide some objectivity and perspective.

Be Prepared and Organized

Parenting a child with special needs requires working with lots of people, going to lots of meetings, and reading lots of documents. You need

to be able to cooperate 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 if possible
- 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 <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.

Keep 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 a disability.

Keeping thorough and accurate records is crucial.

One example is if you deduct medical expenses on your income tax return—you will need to have accurate records of those expenditures, both to file your taxes and for support should you later be audited by the Internal Revenue Service.

Some tips for keeping good records include:

- Establish a filing system **that works for you**. A file system is worth nothing if you can't find what you're looking for, and you need a system that makes sense to **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, another for legal records, and perhaps separate notebooks or files for financial and medical papers. Examples of what documents to be kept in each are described further below.
- **Copy or scan** important documents for easy access and keep originals in a safe place. Backup your computer regularly if storing digital versions. Keep in mind that digital media such as email can also be valuable, and it, too, should be kept organized.
- **Keep your files up to date**, including revised wills, changes in medical or prescription records, updated ISFPs, evaluations from

therapists, and so forth. Review your records regularly—some records are worthy of keeping longer than others. It's okay to discard records that can have no future use, just as it is important to add records that are new or become updated.

- **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 to the safe is, or the password to your computer.

Which records belong together?

Below are some useful categories for organizing documents, and the kinds of documents they might include

Records For and From the Early Intervention Team

The early intervention process involves lots 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** and 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, academic, OT or PT evaluations done by the early intervention team.** Later these evaluations will be helpful to those determining eligibility for special education 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 the original is required),

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 \$2,000 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 the 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 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 and with whom they would live, 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, mood, talents, strengths, degree of independence, medical information, behavioral challenges, and sense of humor. You might outline what they enjoy and what they dislike, and what should be avoided.
- **Family relationships** Include names and ages of siblings and generally how they get along. Also include names and relationships of other family members (grand-parents, 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 schedules, extracurricular activities (including therapies or playdates), bedtime routines, food and clothing preferences, sensitivities, preferred toys and games, and typical outings.
- **Medical history** This section can be brief (diagnosis, current treatment and medication regimens), 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, and the like, 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, therapists, preferred pharmacy; school information, lawyers, trustees, guardians for minor children, insurance agents, bankers, and financial planners

For more on the rationale for a Letter of Intent, see <https://specialneedslifeplanning.com/blog/what-is-a-letter-of-intent/>

You may purchase a fill-in-the-blank Letter of Intent at <http://www.specialneedsplanning.net> for \$10.00.
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 SSI for a minor child (**again, family income is considered**).

Disability Definition

Your child must meet all of 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.html> 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.**

Fill Out 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

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

The application asks for names, addresses and telephone numbers of doctors and therapists who have treated your child and information on any hospitalizations. More descriptive medical records such as a letter explaining a diagnosis or evaluations by therapists or schools can be brought to the intake meeting (make copies!). **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 7:00 am and 4:00 pm, 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 menu system, which will prompt you to state why you are calling; say “Apply for SSI.”

The automated system will ask for you to say or key in your child’s Social Security number. You will then be directed to a representative. During the phone interview, the representative will take information and enter it into a computer, which will secure the date of the application.

- Paperwork will be mailed to you. Fill it out and return within the allotted time
- The document generated during the phone interview will also be mailed to be signed for accuracy.
- Before mailing anything back to the agency be sure to make copies.
- Set Up a Screening Interview
- During the phone interview, the representative will set up a screening, which continues the application process, at your local Social Security office.

U.S. Social Security Office
351 N. Mason Street
Harrisonburg, VA 22802
(866) 964-1718 (local)

SSA Office Hours:

Monday, Tuesday, Thursday, Friday 9:00 am to 4:00 pm, Wednesday 9:00 am to 12:00 noon

Closed Saturday, Sunday, and Federal Holidays

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 Plan (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. **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 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 (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 may have already 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 own money. Representative Payees should be comfortable handling financial records and be trusted to keep in mind the best interests of the disabled beneficiary. A Representative 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. This must be filled out promptly and mailed back. You may also submit the report online.

To be designated a Representative 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-to-face interview.

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

Medicaid and Medicaid Waivers Programs

Family income and family assets are not a consideration under the Medicaid Waiver program if your child's personal income and assets qualify them, they have a disability diagnosis, and they meet functioning eligibility criteria. To watch our recorded webinar that walks you through Waivers from start to finish, visit

<https://www.youtube.com/watch?v=yJzF8FXmmfs&t=45>

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

Services Covered Under the Waivers

The Developmental Disability (DD) Waivers: There are 3 DD Waivers, they are the Community Living, Family and Individual Supports, and 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 support for people no longer in school. Some additional services include respite care, in-home support, 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.

People receiving waiver services are assessed every two- to three years 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 waiting period.

Eligibility Criteria

There are three criteria a child under 18 must meet in order to be eligible for a Medicaid DD Waiver:

Functioning ability: This is determined by the VIDES survey. 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.

Diagnosis: Persons applying for a Waiver must meet the diagnostic eligibility requirements for DD Waivers. This means that a person must have a development disability as defined in 37-2-100 of the Code of Virginia.

“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
2. Is manifested before the individual reaches 22 years of age
3. Is likely to continue indefinitely
4. 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 independent living, economic self-sufficiency
5. 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 numbers 1 through 5 (listed immediately above) if the individual without services and supports, has a high probability of meeting those criteria later in life.

Financial: If 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 \$783 in 2020, so max monthly income is \$2,349).

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/usi/pdf

Wait List Eligibility

You can be on the waiting list for a Developmental Disabilities Waiver and apply for the CCC PLUS Waiver, assuming you meet the eligibility for the CCC PLUS Waiver as well. Many people do this because the CCC PLUS Waiver has no wait 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 (unemployment or other major changes, for example), notify your support coordinator. These situations can increase your urgency of need for support services.

The Community Living Waiver is the one waiver that pays for 24/7 staffing, which is awarded based upon the needs of the person who will be receiving support.

The CCC PLUS Waiver covers personal care, respite care, medication monitoring, and the Personal Emergency Response System (PERS). Support hours are generally capped at 56 hours/week, though exceptions can be made.

Required Diagnostic Documentation

A psychological evaluation confirming a diagnosis of intellectual disability, based upon the definition by the American Association on Intellectual and Developmental Disabilities (AAIDD). "Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18."

Where to Apply

Early intervention teams usually do the intakes for waivers. If they cannot, see:

Harrisonburg Community Services Board
1241 N. Main Street
Harrisonburg, VA 22802
(540) 434-1941
www.hrscsb.org

The screening form should be completed and sent to your local health department:

Virginia Department of Health
110 N. Mason Street
Harrisonburg, VA 22802
(540) 574-5100

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 program available to 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 copayment 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 Resources

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

Information is available on the DMAS website at: http://www.dmas.virginia.gov/content_pgs/rcp-hipp.aspx or call HIPP Program at 1-800-432-5924

EPSDT (Early Periodic Screening, Diagnosis and Treatment)

EPSDT is a comprehensive and preventive healthcare program for individuals 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, medical formula, medical nutritional supplements, personal care, private duty nursing, and/or therapies such as physical, occupational, behavioral, or speech. For more information visit:

http://dmasva.dmas.virginia.gov/content_atchs/mch/mch-epsdt_fs.pdf

Information Resources

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

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

Download a copy of "Medicaid and FAMIS PLUS Handbook" at http://dmasva.dmas.virginia.gov/Content_atchs/atchs/mebook-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, 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 on the internet at

www.insurekidsnow.gov or by calling (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/ or call toll free 1-877-KIDS-NOW (1-877-543-7669) for more information on your state's programs.

Applying Online for Benefits in Virginia CommonHelp allows Virginia Residents to apply online for public assistance benefits including:

- Medical assistance and health insurance
- Childcare 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.

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 these retirement accounts

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.

The “accumulation trust” designation is necessary for when 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 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 child rearing philosophy
- Whether your children would have to move away from neighborhood, 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 issues, 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 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 beneficiary’s assets and resources, your son or daughter could be disqualified from benefits if he or she received (for example) an inheritance or proceeds from a lawsuit.

However, the law allows families to set up a special needs trust (SNT) that can act as a repository for an inheritance, stocks, property, insurance settlements, or other assets **without** a loss of public benefits.

If your family member with a disability receives Supplemental Security Income (SSI) and Medicaid (or you are contemplating having them apply for these benefits), creating a Special Needs Trust is a necessity. **Such benefit programs limit your loved one to just \$2,000 in assets 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) can be 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 (the 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 parent(s), grandparent(s), or other individuals, with an inheritance, life insurance policy, or transfer from another trust.

Special Needs Trusts (SNTs, also called first-party, self-funded, or self-settled trusts) 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, irrevocable assigned child support for an adult child with disabilities, 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 and 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. Third-party special needs trusts can be funded while the parents are still alive (with the caveat that any money put in the trust cannot be withdrawn except to pay for services for the beneficiary).

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 provides such services and 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, since that might jeopardize government benefits. Instead, they must be 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 and dental costs
- Transportation (including purchase of a vehicle)
- Maintenance of vehicles, car insurance
- Materials for a hobby or recreational activity
- Trips or vacations, hotels, airline tickets
- Entertainment such as movies or sporting events
- Computers, videos, furniture, or electronics
- Athletic training or competitions
- Special dietary needs
- Clothing
- Housing costs (although this may reduce SSI benefits)

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. **Professional legal and investment advice are crucial for trustees administering a special needs trust themselves.** For more information about being a trustee, download a free handbook at:

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

ABLE Accounts

ABLE Accounts are an additional tool that may be used by 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 benefit programs.

ABLE accounts do not replace the need for a Family-Funded Special Needs Trust, but may be used in conjunction with one. 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.

For a better Understanding of the differences between Special Needs Trusts and ABLE accounts, see **Securing A Future for Your Child Toolbox** at www.hrarc.org

Having Fun: Recreational Resources

The Parks and Recreation offices offer some recreation and leisure opportunities for individuals with disabilities, both during the school year and in the summer. For information, see: www.HarrisonburgVA.gov/Recreation-Facilities
Most of the parks in the City of Harrisonburg are handicapped accessible. For additional information, call Harrisonburg Parks and Recreation Department at (540) 433-9168.

A Dream Come True (inclusive) Playground
1050 Neff Avenue
Harrisonburg, VA 22801
<https://vimeo.com/103819471>

Harrisonburg Boys & Girls Club
620 Simms Avenue
Harrisonburg, VA 22802
(540) 434-6060
<http://www.bgchr.org>

Finding Support: Resources For Parents

Legal Resources

Attorneys with expertise in Special Needs Planning

Mr. Matthew Sunderlin
Clark & Bradshaw, PC
92 N Liberty Street
Harrisonburg, VA 22802
www.clark-bradshaw.com
(540) 433-2601

Mr. Clint Sellers
66 S Court Square
Harrisonburg, VA 22801
www.clintsellers.com
(540) 437-9400

Blue Ridge Legal Services
204 N High Street, P.O. Box 551
Harrisonburg, VA 22803
www.brls.org
(540) 433-1830

Virginia Legal Assistance Program
PO Box 11322
Richmond, VA 23230
(804) 358-5855

Disability Law Center of Virginia
1512 Willow Lawn
Richmond, VA 23230
www.dlcv.org or
(800) 552-3962 or
(804) 225-2042

Virginia Guardianship Association
www.vgavirginia.org
(804) 261-4046

“Virginia Handbook for Guardians and Conservators: A Practical Guide for Court-Appointed Guardians and Conservators of Adults” <http://www.vda.virginia.gov/pdfdocs/guardbook.pdf>

Virginia Association of Community Services
Boards. “Guide to Consent & Substitute
Decision Making.” Download from www.vacsb.org
(click on “Resources and Links,” then “VACSB
Special Projects”)

Estate Planning & Trusts

Karen Rowell, Esq
Layman and Nichols PC
268 Newman Avenue
Harrisonburg, VA 22801
www.laymannichols.com
(Estate Planning)

Chad Knicely
New York Life
31 S. Gate Court, #102
Harrisonburg, VA 22801
(540) 746-1761
(Estate Planning)

Matt Sunderlin
Clark & Bradshaw, PC
92 N. Liberty Street
Harrisonburg, VA 22801
www.clark-bradshaw.com
(540) 433-2601
(Special Needs Trusts)

Clint Sellers, PC
66 Court Square
Harrisonburg, VA 22801
www.clintsellers.com
(540) 437-9400
(Special Needs Trusts)

Info on Writing a Will
<http://tinyurl.com/spedtoolbox>

Info About Being a Trustee
<http://www.specialneedsalliance.org/free-trustee-handbook>

Information and Support Groups for Parents

Autism/PDD/Asperger’s Syndrome
<http://www.firstsigns.org/screening/DSM4.html>

Department for the Blind and Vision Impaired 397
Azalea Avenue
Richmond, VA 23227-3623
(800) 622-2155 or (804) 371-3140

Virginia Association for Parents of Children with
Visual Impairments
www.vaapvi.org

Brain Injury Services, Inc.
www.braininjurysvcs.org

Care.com.
Childcare for individuals with special needs
www.care.com

Feeding Tube Awareness Foundation
<http://www.feedingtubeawareness.com>
(Also available on Facebook)

Preemies Today
www.preemiestoday.org

Little Hearts (congenital heart defects)
www.littlehearts.org or www.mendedlittlehearts.org

Virginia Smiles (cleft lip/palate)
www.virginia-smiles.org

Mamie Grace, LLC
www.mamiegrace.com

Claude Moore Precious Time
<http://www.clausemoorefoundation.org>
Provides respite care

Local Parent Support Groups/Lists

For a list of parent support groups (organized by
disability/medical issue) meeting in Virginia, see:
[http://www.peatc.org/peatc.cgim?template=parent_](http://www.peatc.org/peatc.cgim?template=parent_resources.support)
[resources.support](http://www.peatc.org/peatc.cgim?template=parent_resources.support)

Hearing Loss
kidswithhearingloss-subscribe@yahoo.com

Jewish Social Service Agency (JSSA)
(703) 896-7918
www.jssa.org
(Parent training, advocacy, and support groups)

Federal Agencies

[Birth to 5: Watch Me Thrive!](#)

www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive

Special Education Law

Parent's Guide to Special Education

http://www.doe.virginia.gov/special_ed/parents_parents_guide.pdf

Two respected publications regarding legal opinion on special education and educational advocacy issues are

Wright, Peter WD and Darr Wright, Pamela.

Wrightslaw: Special Education Law, 2nd Edition

Wright, Peter WD and Darr Wright, Pamela.

Wrightslaw: From Emotions to Advocacy, 2nd Edition

In-depth information also available online at:

www.Wrightslaw.com

Parent2Parent Meetings

julieandjoanne@gmail.com

www.ptpofva.wordpress.com

Parent Education Advocacy Training Center

(PEATC)

www.peatc.org

Special Needs Kids Info

www.specialneedskidsinfo.com

Web-Based Resources

Apps

ABC Go

Alphabet Discovery by Letter Buddies

Articulation Station

Bubble Popper Fireworks Arcade

Fisher Price Giggle Gang

Fisher Price Laugh & Learn (variety of different apps) Fisher Price Laugh & Smile

Interactive Alphabet ABCs

Little Writer - The Tracing App for Kids

Monkey Word School Adventure Monkey Math

School Sunshine

Musical Hands Peekaboo Friends Pocket Pond

Pre-School Adventure Island See.Touch.Learn

Sentence Maker Special Words Teach Me:

Toddler

Teach Me: Kindergarten Word Wagon HD

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://](https://www.facebook.com/groups/ouradventures/)

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.rep-inc.com/> (local durable medical equipment provider)

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

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

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

Fort Belvoir Exceptional Family Member Program

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

(760) 725-5363

Safety & Crisis

The Department of Health & Social Services assesses and provides services to adults & children and families in an effort to protect children, preserve families, whenever possible, and prevent further maltreatment. Adult and Child protective services is non-punitive in its approach and is directed toward enabling families to provide adequate care for their family members. Local departments of social services are responsible for receiving reports of abuse and neglect, conducting investigations to determine the validity of the reports, and providing services that enhance safety and prevent further abuse and neglect to families and children. If you suspect your person with DD has been abused or neglected, report it. The contact information is as follows:

Department of Health and Social Services

110 N. Mason Street

Harrisonburg, VA 22802

(540) 574-5100

www.rockinghamcountyva.gov/206/social-services

For further CPS information:

www.dss.virginia.gov/family/cps/index.cgi

Valley Children's Advocacy Center

1234-E Middlebrook Avenue

Staunton, VA 24401

M-F, 8:30-4:30

(540) 213-0592

Out of State (804) 786-8536

CPS Hotline (800) 552-7096

www.valleychildrenscenter.org

If the person with DD has been injured or suffered mental trauma, taking them to the nearest hospital Emergency Room is recommended. Not only do hospitals treat injuries, Sentara RMH has a Psychiatric Emergency Team (PET) that is available 24/7, and will be of assistance and provide guidance to the caretaker. For Sentara RMH, the POC for Inpatient and Outpatient Behavioral Health is Ms. Tina Bibb (540) 689-5451. The POC for Integrated Case Management at Sentara RMH is Ms. Cindy Harlowe. Teach your person with DD about inappropriate touching, sexual, or physical abuse, etc. Department of Health & Social Services have manuals on this subject and can be obtained in person or via their website.

<http://www.dss.virginia.gov/family/cps/index.cgi>

Although most of the information in their manuals is geared to children, most is applicable to adults as well.

Compass Counseling Services of Virginia

298 S. Liberty Street

Harrisonburg, VA 22801

(540) 437-1605

REACH

672 Berkmar Circle

Charlottesville, VA 22901

Adult Crisis Center hotline: (855) 917-8278

Health; sexual violence, advocacy, & prevention

Reach is the area's regional crisis service that supports adults with intellectual, developmental, and mental health disabilities or who otherwise exhibit challenging behaviors that are negatively affecting their quality of life. Reach emphasizes the prevention of crises before they occur. This is done through early identification of individuals, development of crisis response plans, training, and technical assistance. Individuals aged 18 and over with developmental or intellectual disability, and a mental health or behavioral need, are eligible for this service. Referrals can be made by individuals and families, case managers, and other natural supports in the person's life.

Reach provides mobile support services to individuals in order to maintain stability in their current placement/residential situation. Services can be provided on a planned or emergency basis. The clinical team will provide 24/7 consultation as well as ongoing preventative, cross systems planning for eligible adults. Once the immediate crisis is resolved, the REACH clinician will continue to work with the individual and his/her system of supports and services in order to problem solve, reduce the frequency of emergency interventions, and assist with ongoing stability.

Selected List of Case Managers for Individuals and Family Developmental Disabilities (DD) Waiver

Ability Home Care Services

125 Hailey Lane, Suite E8,
Strasburg, VA 22657
(540) 247-3275 (cell)

Contact: Darlene Pine, tripleiofva@msn.com

Service area: Winchester, Shenandoah Valley, Clarke Co., Paige Co., Fauquier Co., Loudoun Co., Leesburg, and Fairfax

Moms In Motion

10 Beau Lane,
Front Royal, VA 22630
(800) 417-0908

Contact: Keri Ayres at
Keri@MomsinMotion.net

Service area: Winchester, Front Royal, Warrenton, Fauquier, Northern Virginia, Alexandria, Arlington, Fairfax, Prince William, Springfield, Manassas, Spotsylvania, Fredericksburg, Woodbridge, Virginia Beach, Norfolk, Chesapeake, Portsmouth, Hampton, Williamsburg, Newport News, Charlottesville, Waynesboro, Harrisonburg

Harrisonburg Community Services Board

57 N. Mason Street
Harrisonburg, VA 22802
(540) 434-1941

www.hrcsb.org

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