Navigating Your Way

Ages Birth to Three

Congratulations on the newest addition to your family. Raising any child is hard work. However, if you add in special health care needs or developmental disabilities, there is even more to learn—whole systems of supports, services, transitions, and terminology. Understanding those systems and learning new terminology will be important, but equally important is getting connected to other families and broader community supports.

Other parents and family members can provide support, ideas and strategies to help you navigate your life with your child and help you not feel so alone.

The focus is not to “fix” your child, but to think in terms of supports and opportunities to enhance their growth and development. Some will come from paid services and supports, but many will come from building connections to your own community.

After your pediatrician, an early intervention program is the second point of contact for families who have a concern about their child’s development. Through the state’s early intervention program known as Early Support for Infants and Toddlers, or ESIT, local programs will assist you in determining your child’s eligibility at no charge.

To be eligible for ESIT, a child must have onedevelopmental delay, or a medical or physical condition known to cause developmental delay such as Down syndrome. Families are encouraged to call their local early intervention program directly. You do not need a referral to request an evaluation.

If you have not connected with an early intervention program, call ParentHelp123’s Family Health Hotline at 1-800-322-2588 or visit parenthelp123.org.

Once you have connected with a program, you will be assigned a Family Resources Coordinator, or FRC, who will work with your family, child, and other providers to develop an Individualized Family Service Plan (IFSP). This planning process looks at the physical, cognitive, communication, social, emotional and adaptive needs of your child. The plan should also address your family’s needs as well.

The FRC works with you throughout your child’s participation in ESIT and helps with the transition into preschool special education or other community services at age 3, if those services are needed.

No matter how many professionals enter your child’s life, you are a key member of the team. Be involved. Give your input and play an active role in your child’s early intervention services.

Services your child may need include: screening, diagnosis and treatment; specialized instruction, family training, counseling and home visits; physical, speech and occupational therapy, and, other early intervention services. The FRC can also assist families with connections to other services, such as health care, therapies, food stamps, cash assistance, and in-home support.

There are many options for paying for services—including federal, state, and local funding; public and private insurance; and a sliding fee scale based on income and family size.

If your family is low income and in need of financial assistance, contact the Social Security Administration to find out if your child qualifies for Supplemental Security Income. Call toll-free 1-800-772-1213 or visit online at www.ssa.gov. SSI is the gateway to Medicaid services, such as Apple Health, so it’s an important first step for families with low income.

WithinReach provides local and state resource information on health care coverage and other services for families of children with special health care needs in Washington State. For answers to your health care questions, call the Family Health Hotline toll-free at 1-800-322-2588 or visit [www.withinreachwa.org](http://www.withinreachwa.org).

If your child is eligible for Apple Health, an important benefit is called EPSDT, which stands for Early Periodic Screening, Diagnosis, and Treatment. With EPSDT, children can get a regular check up and treatment for medical issues found during an exam up to age 21. Call 1-800-562-3022 and ask about EPSDT services for your child.

The Washington State Developmental Disabilities Administration, known as DDA, is the state agency that provides case management and supportive services for children and adults with Intellectual and Developmental Disabilities in Washington State. Children enrolled in ESIT are also eligible for DDA up to age 4, when eligibility must be renewed. You will need to re-apply for DDA services *before* that happens, to avoid gaps in services for your child. DDA will send a notice 6 months prior to your child turning 4. Request a determination of eligibility from your local DDA office or online at dshs.wa.gov/dda.

In addition to paid services, it’s important to build your network of support and connection to your community.

Parent to Parent provides free support and information to families of children with special health care needs or other disabilities. If you are feeling alone and scared support from another parent can be helpful. Local offices are located in every area of the state. Visit [arcwa.org/getsupport](http://www.arcwa.org/getsupport) to find a Parent to Parent near you.

Many areas of the state have local Arc chapters, which provide information, referral and advocacy. Visit [arcwa.org](http://www.arcwa.org) to learn more.

Partnerships for Action, Voices for Empowerment, known as PAVE, is a parent-directed organization that provides information, training and support to families. Visit wapave.org to learn more.

If you have other children, there’s support for them, too. Sibshops provide peer support from other siblings in a lively, recreational setting. Visit siblingsupport.org to find a Sibshop near you.

The Family Community Connections Guidebook, a free publication of The Arc of Washington State, offers valuable tips and worksheets for identifying people, places and ideas to help broaden your family member’s social circle and community connections. Visit informingfamilies.org to download a free copy in English or Spanish.

As you navigate these early years, pay attention to your child’s interests, abilities and strengths. These will form the building blocks for the many types of planning that will take place throughout your child’s life—from educational and service supports to larger life goals.

My Life Plan, a free online planning tool, is a great way to document your child’s interests, strengths, abilities and needs. My Life Plan helps you create goals based on your child’s unique qualities at every stage of life. Visit mylifeplan.guide to get started.

Find links to all of these resources and more at informingfamilies.org, a program of the Washington State Developmental Disabilities Council.