

Please call the hospital with any questions at (801) 536-3500. If you are unable to reach the hospital and you feel it is an emergency, call 911 or go to the nearest Emergency Room.

Questions about Transition? Contact your
Care Coordinator:

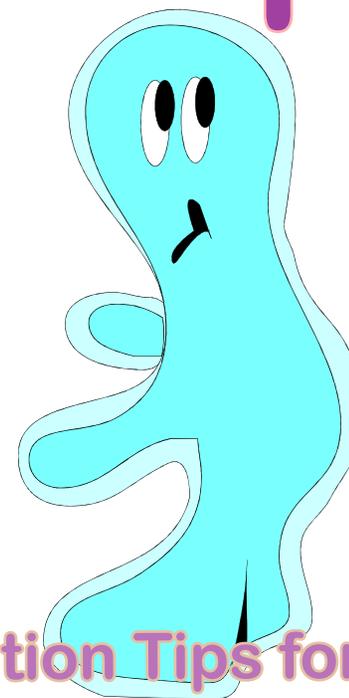
First Steps 02/07



Shriners Hospitals for Children
Intermountain
Fairfax Road at Virginia Street
Salt Lake City, Utah 84103
801 – 536 – 3500
http://www.shrinershq.org/Hospitals/Salt_Lake_City/



First Steps



Transition Tips for Parents of Young Children with Disabilities

How do I keep my young child physically healthy?

- If you have not already, find a medical home for your child. A medical home consists of a pediatrician or family doctor and his team who will work in partnership with your family to assure that your child's medical and non-medical needs are met.
- Stay up to date on your child's immunizations, screenings and well child check ups.
- Encourage your child to be physically active as much as possible. Be active as a family. Limit screen time (television, video games and computer).
- Teach your child good eating habits. Do not use food as a reward. Offer your child healthy snacks and meals. Keep in mind that children with disabilities are at a higher risk of obesity than their non-disabled peers.
- Keep your home and car smoke free.
- Work with your medical home provider to prevent "secondary disabilities." These are additional, preventable medical problems related to the primary condition. These can include skin breakdown, bowel and bladder problems, obesity and depression.



How do I keep my young child emotionally healthy?

- Encourage your young child to look at himself in the mirror. Help him to understand how he is the same and how he is unique from other people. Promote a "disability cool" attitude.

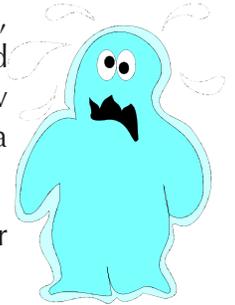
- **Health Finder:** Key resource for finding the best government and nonprofit health and human services information on the Internet. www.healthfinder.gov
- **National Center of Medical Home Initiatives for Children with Special Needs:** Provides information to families on the importance of a medical home and how to obtain an appropriate medical home for children with special health care needs. www.medicalhomeinfo.org/states/index.html
- **National Dissemination Center for Children with Disabilities (NICHCY):** Central source of information on disabilities in children and youth, programs and services for youth with disabilities and special education laws and rights. www.nichcy.org.html. NICHCY also creates state resource sheets which will help you locate organizations and agencies within your state that address disability-related issues. www.nichcy.org/states.htm
- **Parent Advocacy Coalition for Educational Rights (PACER):** This site offers educational materials, information about resources and services, online training and individual assistance for parents of children with disabilities. www.pacer.org
- **University of Michigan Health Systems:** Links to tools to help parents and child to prepare for procedures, surgeries and hospital stays. <http://www.med.umich.edu/1libr/yourchild/medproc.htm>
- **University of Wisconsin Family Village:** Information, resources, and communication opportunities for people with disabilities, their families and those who provide them with services and support. www.familyvillage.wisc.edu
- **Zero to Three:** Website supporting the healthy development and well-being of infants, toddlers and their families by informing, educating and supporting the adults who influence their lives. www.zerotothree.org

- The Maternal and Child Health Bureau contracts with each state to provide specialized medical services and care coordination to children under age 18 with special health care needs. Services vary by state and may include cleft lip and palate, neurology, genetics, physical and occupational therapy evaluations and orthopedics. https://perfdata.hrsa.gov/mchb/mchreports/link/statelink_result.asp
- State Children’s Health Insurance Programs are low cost health insurance programs for children of working families who are uninsured and meet income guidelines. www.insurekidsnow.gov
- Supplemental Security Income (SSI) pays monthly benefits to parents of children with disabilities who qualify based on income and severity of disability. www.ssa.gov
- Medicaid is government funded medical insurance available to children of families with limited income. Most children receiving SSI are automatically eligible for the program. Children with severe disabilities who do not meet income guidelines may still be eligible via Medicaid waiver programs. www.cms.hhs.gov/apps/contacts
- Parent Training and Information Centers are federally funded programs offering information and referral, peer support, training and advocacy to parents of children with disabilities. www.taalliance.org/centers/index.htm

What websites are available for parents of young children with disabilities?

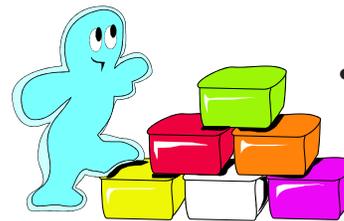
- **Bright Futures for Families:** Developmentally focused information on infancy, childhood, adolescence and transition. <http://brightfuturesforfamilies.org/home.htm>
- **DisabilityInfo.gov:** Federal government website that serves as a starting point for all government services and information sites www.disabilityinfo.gov

- Involve your child in pre-school, play groups, church activities and other neighborhood and community functions. This will teach him how to play with other children and will serve as a foundation for future friendships.
- Don’t over schedule your child. Allow time for free play.
- Look for books and movies that portray children with disabilities in a positive light. Consider joining a support group for families of children with disabilities. All children benefit from seeing others that “look” like them succeeding in life.
- Treat your child just as you would any other member of your family. Include him in work and play.



How do I begin to involve my young child in her health care?

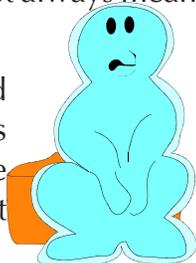
- Teach your child about her health care condition using words she will understand. Teach her the correct medical terms to describe her disability.
- Recognize that as your child grows and develops, she will have a new understanding of her disability and will ask new questions.
- Prepare your child for medical procedures in advance. Look into resources on developmentally appropriate play and preparation. You may want to connect with your hospital’s Child Life department for assistance.
- Include your child in making decisions about her medical care by allowing her to make choices such as what hand she wants to use for her IV, the color of her cast or whose lap she wants to sit in during the procedure.



- Recognize that some medical procedures and care may be stressful to your child. Comfort her by having soft, soothing music in the background or by allowing her to bring a favorite comfort item (blanket or stuffed animal) from home.
- Teach your child how to talk with her health care providers. Start by allowing your child to speak for herself when asked questions. Avoid the urge to speak for her.
- Make therapy a fun and regular part of your family routine. Join your child in her therapy routines and invite her siblings to participate. Instead of treating therapy as a medical procedure, view it as a life task all people should do.

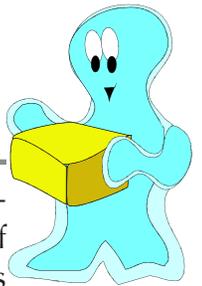
How do I encourage independence in my young child with a disability?

- Independence is learned by taking small steps. Find those small steps your child can do and build from there.
- Do not do for your child what he can do for himself or learn to do for himself. This can be a challenge for families of children with special needs. Although it may be difficult at times to stand by and watch your child struggle to learn new skills, the sense of accomplishment that your child will feel when he succeeds is worth it.
- Remember, responsibility helps develop independence. Your child will not grow towards independence by having a parent who does everything for him.
- Recognize that children learn by doing. It does not always mean they will do it right the first time.
- Find ways for your young child to help around the house such as folding clothes, picking up toys or helping with cooking. Children need to have responsibilities at home to show themselves what they can do.



- Involve your child in his self care. Start with simple things such as washing his hands, getting his toileting supplies ready or taking his own meds from a presorted pill box.
- Encourage decision making by offering simple choices to your young child. Let him make a choice between two options such as which of two shirts to wear, snacks to eat or books to read before bedtime.
- Allow your child to experience the consequences of his behavior and choices. Discipline him appropriately for poor behavior, just as you would your other children.

What resources should I be aware of for my child?



- Early intervention programs provide early identification and developmental services for families of infants and toddlers, birth to age three. Services may include assessment, service coordination and therapies (physical, occupational and speech). Check with your state's Department of Health via www.healthfinder.gov for contact information.
- Developmental preschools are offered by the state to children ages three to five with disabilities. Contact your state's Department of Education www.ed.gov or NICHCY's state resource sheets www.nichcy.org/states.htm for contact information.
- Developmental disabilities programs offer a variety of services to children with severe developmental and/or physical disabilities including respite care, family assistance and support and Medicaid waivers. Check with your state's Department of Human Services via www.healthfinder.gov, or NICHCY's state resource sheets www.nichcy.org/states.htm for contact information.