

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:

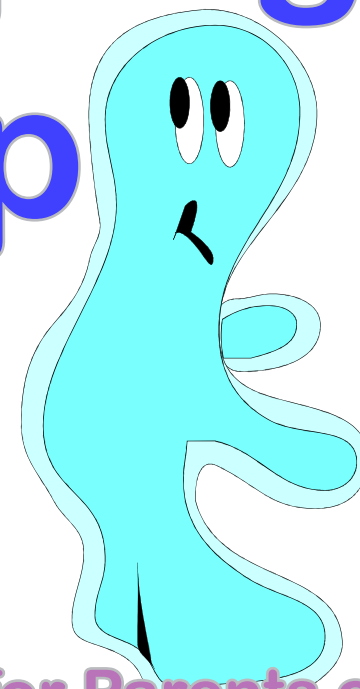
Stepping Up 02/07



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/



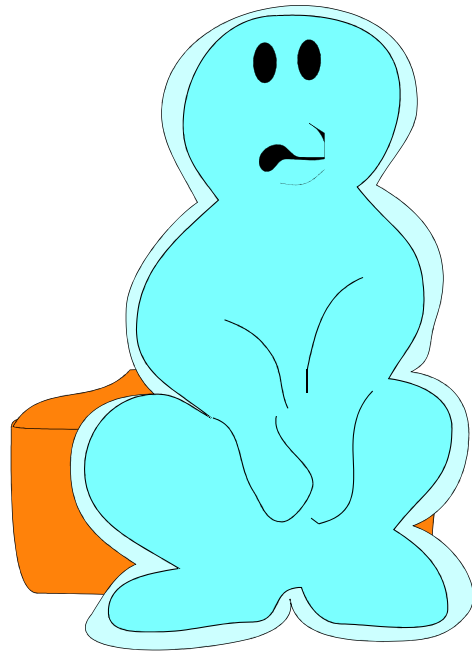
Stepping Up



Transition Tips for Parents of School Aged Children with Disabilities

How do I begin to teach my child to take care of his personal needs?

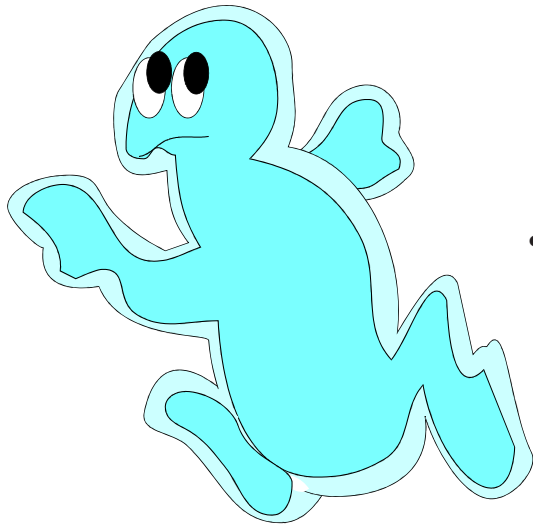
- Begin teaching your child self-care skills at a young age and give him more responsibility as he grows older and/or masters these skills.
- Recognize that as your child grows and understands more, he can learn new ways to care for himself.
- Using words he can understand, teach your child about his diagnoses or special health care needs and how they affect his daily life.
- Teach your child the warning signs that he is getting sick or needs to see a doctor.
- If your child requires assistance with self-care at school or in other settings, teach him how to direct those who provide this care. Teach your child that he is in charge of his own body and his self-care.



- **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/index.html
- **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 Wisconsin Family Village:** Information, resources and communication opportunities for people with disabilities, their families and those that provide them services and support. www.familyvillage.wisc.edu

What websites are available to families of children with disabilities?

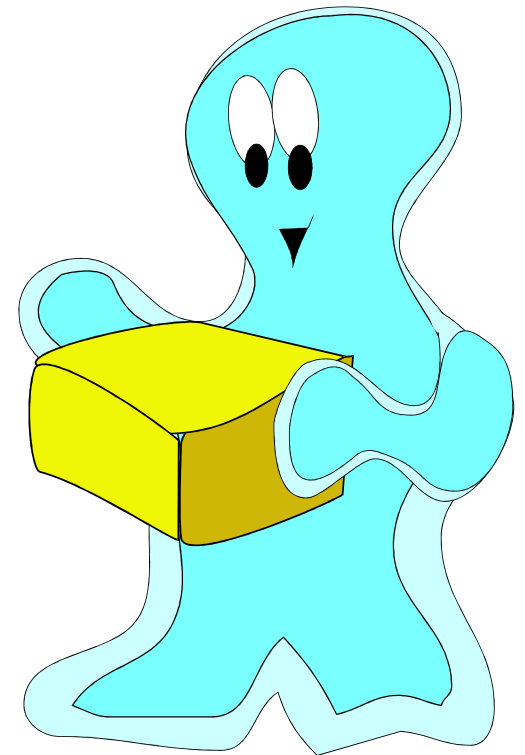
- **Ability Online:** A free and monitored online support community that links youth ages 11-24 with disabilities or illness to other kids and adults who care. www.ablelink.org/public/new/index.html
- **Band-Aids and Blackboards:** Site for youth growing up with any type of medical problem or disability. Includes poetry, stories, art, photos and essays by and for children and teens with special health care needs. www.lehman.cuny.edu/faculty/jfleitas/bandaides
- **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

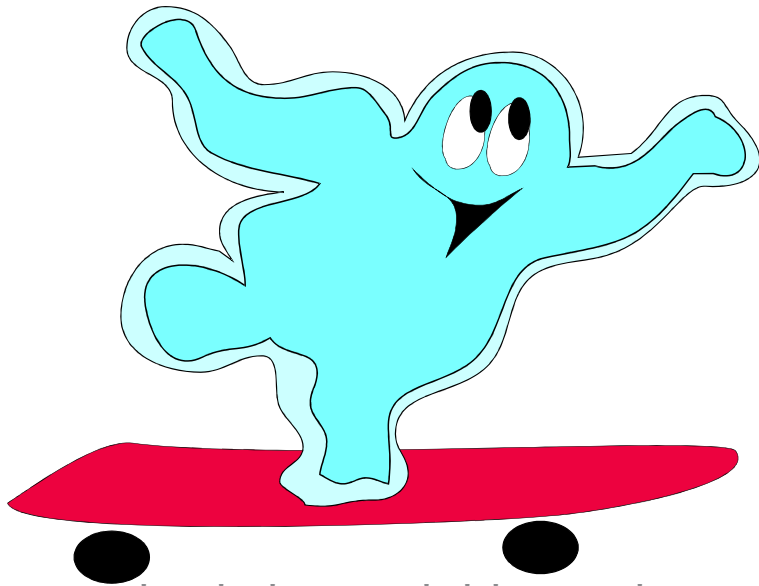


- **Health Finder:** Key resource for finding the best government and nonprofit health and human services information on the Internet. www.healthfinder.gov
- **Healthy and Ready to Work National Dissemination Center:** This site provides various tools and resources to assist youth with special health care needs in the transition to adulthood. www.hrtw.org

How do I help my child become more involved with her health care?

- Include your child in discussions with her doctors, nurses and other health care providers. Allow your child to speak for herself when asked questions by health care providers. Avoid the urge to speak for her.
- Teach your child how to talk with her health care providers. Help her make a list of questions to ask at each visit or to give a brief report on how she has been doing.
- Include your child in making decisions about her health care. Explain in words she can understand what needs to happen and why. Invite her to co-sign treatment consent forms. Including children in decision making and asking for their consent may help them to feel more in control of what they may see as scary or powerless situations.
- Begin teaching your child how to make doctor appointments, call in prescription refills, carry her insurance card, co-sign consent forms and what to do in case of a medical emergency.



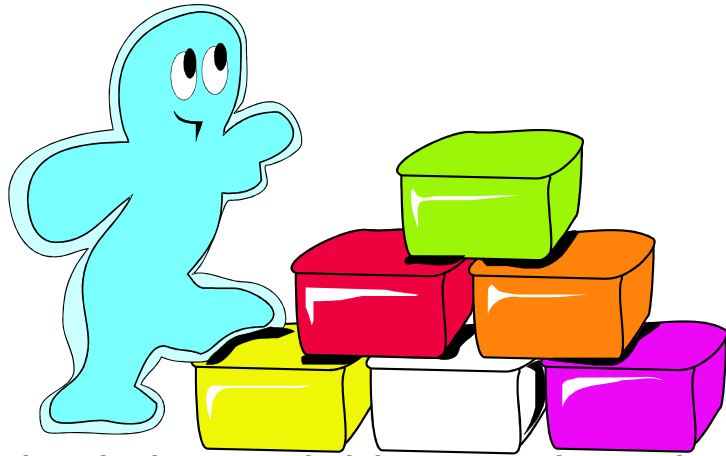


How do I help my child stay physically healthy?

- Model good health behaviors and choices for your child. He is learning from you.
- Limit screen time (television, video games and computer). Encourage your child to be physically active as much as possible. Be active as a family.
- Look into adapted recreation programs in your community. Almost any sport or physical activity can be adapted for people with disabilities.
- Teach your child good eating habits. Children with disabilities are at a higher risk of obesity than their non-disabled peers.
- Keep your home and car smoke free. Talk to your child about saying no to drinking, smoking and using drugs. Talk with him about how to resist peer pressure.
- Talk with your older child about puberty and the changes that will be happening to his body.

What resources should I be aware of for my child?

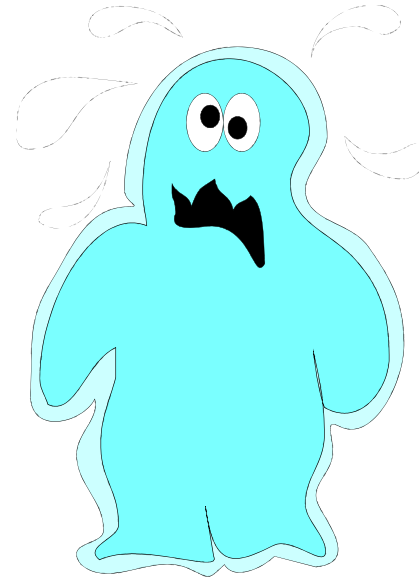
- Developmental disabilities programs offer a variety of services to children with severe developmental and/or physical disabilities including respite care, family assistance and support and Medicaid waivers. Check with your state's Department of Human Services via www.healthfinder.gov, or NICHCY's state resource sheets www.nichcy.org/states.htm for contact information.
- 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 from 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



How do I help my child succeed in school?

- Get to know your child's teachers and peers by volunteering at the school.
- Communicate clearly with your child's teacher regarding your child's needs.
- Learn about 504 Plans and Individualized Education Plans (IEP). These plans provide accommodations for students with disabilities. Your local Parent Information and Training Center (see page 8) can give you detailed information on these plans and help you to determine if your child would benefit from them.
- If your child already has a 504 or IEP, bring her to at least a portion of the 504 or IEP meetings. This not only reminds the team that they are making decisions about a real human being, but teaches your child that her input and involvement is important.
- If you are unhappy with the services that your child is receiving at school, find an advocate to assist you in getting your child's education needs met. Connect with your local Parent Information and Training Center (see page 8) or ask your Care Coordinator for referrals.

How do I help my child stay emotionally healthy?



- Realize that some children begin to grieve about their disability during the school age years, just as you may have grieved when your child was born with or diagnosed with a disability. They may need someone with special training to talk to such as a counselor or therapist.
- Join a group for children with your child's disability and their families. Children benefit from "seeing" others who look like them and are living fulfilled lives.
- Give your child various opportunities to make friends at school, in after school clubs or activities, in church groups and by taking part in sports, recreation and other community activities. This may mean that YOU are the designated school cookie baker or field trip parent. Finding ways to get your child to and included in these activities is important.
- Remember that keeping the "friend connection" may be more difficult in the summertime and other times when school is out, especially if your child goes to a school that is not in the neighborhood. Help your child stay connected with friends by arranging for play dates, outings and other activities during these times.
- Encourage your child to participate in team sports. Many life lessons can be learned by participating in team sports including team work, inclusion, responsibility and hard work. If your child cannot physically take part in team sports, be creative in finding other ways for her to participate. Options may include being the equipment manager, score keeper, announcer or time keeper.

- Get your child involved in adapted recreation. Skiing, horseback riding, hockey and bowling are among the many sports that can be adapted for people with disabilities. Participation in adapted recreation can improve self-esteem, body image, confidence and give your child a sense of accomplishment.
- Recognize that many children with and without disabilities experience bullying at school. However, children with disabilities are more at risk and need to know that the bullying is not about their disability. Role play what your child should do if she is bullied. Encourage her to tell you, her teachers and principal if she is being bullied. Work with the school to adopt a school wide “zero tolerance” for bullying.

How do I help my child to become more independent?

- Give your child with a disability chores at home, just as you do your children without disabilities. Children need to have responsibilities at home to show themselves what they can do.
- Remember, responsibility helps develop independence. Your child will not grow towards independence by having a parent who does everything for him.



- Independence is learned by taking small steps. Find those small steps your child can do and build from there.
- Expect your child to learn new skills and praise him when he does. Encourage him when he struggles and don't be afraid to discuss your expectations.
- Encourage decision making by offering choices to your child. Let him chose what shirt to wear to school, what healthy snack to have or what homework assignment to do first.
- Teach your child the consequences of his behaviors and choices. Allow him to experience the consequences of a poor choice as well as a good choice. This will help him learn to make better choices next time.
- Establish high but realistic expectations, clear limits and appropriate consequences.
- Ask your child what he wants to be when he grows up. This is a question all too often unasked of children with disabilities. This question will let your child know that you have great expectations and hope for his future