

Possible Illinois Resources and Contacts to Consider

Children with Special Health Care Needs
In Illinois the Division of Specialized
Care for Children
1-800-322-3722 (Toll Free)
(217) 785-4728 (TTY)
<http://www.uic.edu/hsc/dscc/>

Family Matters Parent Training and Info Center
1-866-436-7842 (Toll Free)
(217) 347-5428 (Voice/TTY)
<http://www.fmptc.org/index.html>

Supplemental Security Income (SSI)
for children
1-800-772-1213 (Voice)
1-800-325-0778 (TTY)
<http://www.ssa.gov/pubs/10026.html>

Illinois Assistive Technology Project
(TechConnect)
1-800-852-5110 (Voice/TTY)
<http://www.iltech.org/>

Healthy and Ready to Work National Center
<http://www.hrtw.org/>

The National Dissemination Center for Children
and Youth with Disabilities (NICHCY)
1-800-695-0285 (Voice/TTY)
<http://www.nichcy.org/>

Military Family Resource Center
1-703-602-4964
<http://www.militaryoneresource.com/>

Health Benefits for Workers with Disabilities
1-800-226-0768 (Voice)
1-866-675-8440 (TTY)
www.hbwdillinois.com/

Division of Rehabilitation Services (DRS)
1-800-843-6154 (Voice)
1-800-447-6404 (TTY)
<http://www.dhs.state.il.us/ors/>

Illinois Network of Centers For
Independent Living
1-800-587-1227
<http://www.incil.org/>

Disability Links
<http://www.irsc.org/disability.htm>

Adolescent Health Transition Project at the
University of Washington
1-206-685-1358
<http://depts.washington.edu/healthtr/>

SSDI for Disabled Adult “child”
1-800-772-1213
<http://www.ssa.gov/pubs/10026.html#older-children>

SSI The Work Site
1-800-772-1213
<http://www.socialsecurity.gov/work/index.html>

Illinois State Board of Education
Springfield - 1-866-262-6663
Chicago - 1-312-814-2220
<http://www.isbe.state.il.us/>

Illinois Employment & Training Center
1-888-367-4382
<http://www.ides.state.il.us/>

The Arc 1-301-565-3842
<http://www.thearc.org>

Illinois Department of Healthcare (HFS)
217-782-1200 (Voice)
1-800-526-5812 (TTY)

Job Accommodation Network (JAN)
www.jan.wvu.edu
1-800-526-7234 (Voice/TTY)

US Department of Housing & Urban Development
Resources for Housing for People with Disabilities
<http://www.hud.gov/groups/disabilities.cfm>

Modified from the State of Washington, developed by the Adolescent Health and Transition Project sponsored by the Office of Children with Special Health Care Needs Washington State Department of Health and the Division of Adolescent Medicine, University of Washington, 1995. Based on a model developed by Dr. Stephen L. Kinsman, Kennedy Krieger Institute.

Transition Timeline for Children and Adolescents with Special Health Care Needs



Children and families experience many transitions, large and small, over the years. Three predictable transitions occur: when children reach school age, when they approach adolescence, and when children move from adolescence into adulthood. Other transitions children make include moving into new programs, working with new agencies and care providers, and making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go of others.

As a parent of a child with special health care needs you may be caught up in day to day survival. You may ask, “How can I think about tomorrow when I’m just trying to make it through today?” But, when those moments come to you, and you are able to catch your breath, it may be helpful to be aware of those transitions and allow yourself to think about the future.

The Transition Timeline for Children and Adolescents with Special Health Care Needs may help you think about the future. We hope this timeline will give you ideas to help your child achieve independence in their own health care and other areas of life as he/she grows.

Transition Timeline for Children and Adolescents with Special Health Care Needs: Chronic Illnesses/Physical Disabilities

Parent and Child Interactions that Encourage Independence

Birth to 3-5, or according to your child's developmental ability

- Assure your infant the world is a good place in which to live. The development of a sense of trust is vital to the development of a healthy personality.
- Allow your child to develop at his/her own individual rate.
- As a parent it is important to take short breaks from your child to renew energy with which to enjoy him/her.
- Begin keeping a record of your child's educational and medical history, including immunizations.

By ages 3-5, or according to your child's developmental ability

- Assign your child chores appropriate for his/her ability level.
- Encourage decision-making skills by offering choices.
- Teach consequences of your child's behaviors and choices.
- Continue involvement in community and recreational activities that include children with and without special needs.
- Begin asking "What do you want to do when you grow up?"
- Begin teaching your child about his/her special health care need.
- Begin teaching your child self-care skills: normal skills and those related to his/her special health care need.

By ages 6-11, or according to your child's developmental ability

- Begin helping your child interact directly with doctors, nurses, therapists and teachers.
- Assess your child's perception and basic knowledge of his/her special health care need. Build on their understanding.
- Continue teaching your child normal self-care skills as well as skills related to his/her special health care need.
- Determine whether reasonable accommodations are needed to ensure equal access to school programs; if so, ask if your child qualifies for a 504 plan.
- Encourage hobbies and leisure activities; include exploring community and recreational activities, clubs, 4-H, Scouts, Campfire, YMCA, sports, etc.
- Continue to encourage decision-making skills by offering choices.
- Continue assigning your child chores appropriate for his/her ability level.
- Take your child shopping whenever possible so he/she can help in choices.
- Let your child choose how to spend some or all of allowance.
- Teach your child the consequences of his/her behaviors and choices.
- Allow your child to experience the consequences of a poor choice as well as a good choice.
- Begin teaching your child self-advocacy skills.
- Begin asking your child "What will you do when you grow up?"

By ages 12-18, or according to your child's developmental ability

- Assess your teen's perception and basic knowledge of his/her special health care need. Fill in gaps in understanding.
- Continue teaching your teen normal self-help skills as well as skills related to special health care need.
- Begin helping your teen keep a record of his/her medical history, including conditions, operations, treatments (dates, doctors, recommendations) and 504 plan if he/she has one.
- If has a 504 plan, encourage teen to participate in any 504 meetings.
- Begin helping your teen take responsibility for making and keeping his/her own medical appointments, ordering their own supplies, etc.
- Begin exploring health care financing for young adults at age 17.
- Discuss sexuality with your teen.
- Help your teen identify and build on his/her strengths.
- Explore support groups, if teen is interested.
- Begin to explore and talk about possible career interests with your teen.
- Help your teen find work and volunteer activities.
- Continue to allow your teen to help with family chores.
- Continue to encourage hobbies and leisure activities.
- Help your teen identify and be involved with adult or older teen role models.
- Begin, with your teen, looking for an adult health care provider.
- Encourage teen to contact campus disabled student services to request accommodations if he/she will be attending college.
- With teen, check eligibility for SSI the month he/she turns 18. At age 18, the teen's financial resources are evaluated, not the parents/guardians'.

By ages 18-21, or according to your child's developmental ability

- Act as a resource and support to your young adult.
- Encourage your young adult to participate in support groups and/or organizations relevant to his/her special health care need.
- Finalize health care financing with your young adult.
- With your young adult, finalize transfer of medical care to adult provider.
- For young adult attending college, encourage continued contact with disabled student services as needed for accommodations.
- Encourage young adult to investigate services provided by Division of Rehabilitation Services (DRS) if he/she has not already done so.

Programs

Years

