



Medical Home Newsletter

Transition to Adulthood for CSHCN

Volume No. 14

<http://www.medicalhomeportal.org>

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Welcome

The purpose of this publication is to support health care providers in the establishment and maintenance of Medical Homes for their pediatric patients by providing tools and information for use in their practices.

To offer comments, suggest ideas for future newsletters, or to sign up for email delivery contact the Project Coordinator, Barbara Ward, RN BS barbaraward@utah.gov.

Copies of newsletters may be found on the Utah Medical Home web portal: <http://www.medicalhomeportal.org> (click on Newsletters/Conf. Calls)

Transitioning to Adulthood for CYSHCN

More than 85% of children born today with chronic health conditions will live to adulthood. This means, each year, more than 500,000 U.S. adolescents should transfer from pediatric care to the adult healthcare system. However, there is much more to transitioning to adulthood than just transferring health care services. Planning for the future should include addressing issues of employment, housing, health insurance, education, and recreation. The Medical Home, as a source of ongoing comprehensive care, is the ideal place to address these issues by incorporating transition planning throughout the child's life. A survey conducted by the Maternal Child Health Bureau, found only 6% of teens with special health care needs felt like they received the assistance they needed with transitioning to adult health care or vocational training to prepare for employment.

“The primary care provider plays an important role to . . . ensure that all young people with special health care needs have an identified health care professional who attends to the unique challenges of transition and assumes

responsibility for current health care, care coordination and future health care planning.”

A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs – AAP, AAFP & ACP (2002)

When addressing transition issues, it is imperative to keep in mind that individuals with disabilities want the same opportunities and control in their every-day lives that their non-disabled brothers and sisters, neighbors, and friends take for granted.

The Primary Care Provider's Role in Transitioning to Adulthood

The primary care provider is vital to the transition process and can help by providing information about the individual's special health needs as they relate to independent living, educational, and vocational issues to members of the Medical Home team. When thinking of patients transitioning to adult health care, the provider should recognize that many CYSHCN have little or no experience in managing their own health care, making appointments, or even discussing their medical condition. The primary care provider can assist the child and family by focusing his/her efforts on the following:

- Teach and encourage the child/young adult to take responsibility for his or her own care.
- Discuss the future, both short and long term, at every office visit.
- Help families anticipate the need for legal decisions, prior to age 18, regarding guardianship
- Provide youth and families with information about sexuality to build skills in setting safe boundaries, developing good decision making skills
- Make transition planning an integral part of standard office procedures.

- Prepare an up-to-date medical summary.
- Refer to a new adult care provider.
- Co-treat with the new provider until established.
- Link families of younger children with families of older children to share information.
- Start a “**transition action plan**” by age 14.
- Provide resources to the family regarding health insurance/funding, employment information and independent living.
- Collaborate with all involved.

Why Develop an Action Plan

Many students with disabilities do not receive the post-high school supports they need in order to successfully transition to college or employment. CYSHCN may spend 12-18 years struggling to graduate and then end up at home with nothing to do. Facilitating independence through higher education and/or employment will improve their self-esteem and satisfaction with life. Starting early with a transition action plan will allow families and youth to identify concerns, overcome challenges, and create opportunities. **All young people become legal adults at age 18 and those with disabilities are no exception.** The time to plan for the future is now.

As a transition action plan is developed, the Medical Home team should assess the youth’s capabilities, desires, strengths, and weaknesses. The youth should have as much input into this process as possible. The family or caretaker are also vital, as their expertise in dealing with the challenges of life with a special health care need provides unique insights that no one professional can offer. Communication and collaboration among all those involved is key to developing a workable action plan unique to that individual.

The Action Plan

The Transition Action Plan (an example is available at www.medicalhomeportal.org > For Parents and Families > Transition to Adulthood > Overview) should address the following areas:

1. Managing Healthcare
2. Sexuality and Reproductive Issues
3. Genetic Counseling
4. Health Care Funding
5. Adult Providers
6. Educational Needs
7. Independent Living
8. Financial Assistance
9. Employment
10. Legal Issues (guardianship)
11. Recreation
12. Spiritual
13. Community Resources
14. Advocacy Assistance

It is important to note that key differences between school programs and adult programs lie in the terms “**entitlement**” and “**eligibility.**” Special Education is an entitlement program, while adult service agencies are eligibility programs.

Physician Resources

For the **AAP Policy Statement** on transition <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/6/S1/1304>

A supplement to **Pediatrics** "Improving Transition for Adolescents with Special Health Care Needs from Pediatric to Adult-Centered Health Care."

<http://www.aap.org/sections/disabilities/transitions.htm>

Resources for the Utah Medical Home and Families

Medical Home Website - Transition Module:

<http://www.medicalhomeportal.org>

The module contains a toolkit with action plans, timelines, medical summaries, resources and general information on transition issues.

CSHCN Website

<http://health.utah.gov/cshcn/>

Bureau of Children with Special Health Care Needs

<http://health.utah.gov/cshcn/>

Transition specialists

Lynn Pease 801-584-8518

lynnpease@utah.gov

Walt Torres 801-584-8516 (Spanish)
wtorres@utah.gov
Sue Dickinson 801-584-8550
Care Coordinator school age
sdickins@utah.gov

Utah Young Adult Advisory Committee
Young adults video with advice to medical homes
<http://www.youtube.com/watch?v=RJVgU7aGUZw>

Becoming Leaders of Tomorrow (Utah)
The BLT Project provides resources and supports that promote independent living, transition skills, and healthy lifestyles and relationships of youth and young adults with developmental disabilities.
Al Romeo 801-584-8535
<http://blt.cpd.usu.edu/>

The Parent Transition Handbook: From “No” Where to “Know” Where is available free from the **Utah Parent Center** at 801-272-1051 or 800-468-1160. The handbook acquaints parents and youth with the issues and range of options they should explore to make informed choices. Found in the resource section, transition to adulthood.
www.utahparentcenter.org

Utah State Office of Rehabilitation (USOR)
Includes Services for the disabled, blind and visually impaired, and hearing impaired for job training and placement. 801-538-7530 Toll-Free 1-800-473-7530
<http://www.usor.utah.gov/>

USOR Includes:

1. Vocational Rehabilitation (VR). *The Rehabilitation Act of 1973* requires that VR and education work together to fund and train young adults with disabilities to prepare them for meaningful employment and reduce the gaps in services. 801-538-????
<http://www.usor.utah.gov/>
and the

2. Independent Living Centers are located in six Utah communities and their mission is to

assist people with disabilities to achieve greater independence. 801-466-5565
www.optionsind.org/Centers/centers.html

Guardianship

Explore levels and cost of guardianship that are available for your family
Guardianship Associates of Utah 801-533-0203
Office of Public Guardian 801-538-8255
www.disabilitylawcenter.org

Driver’s License

A guide for obtaining a license when your teen has a disability
http://www.medhomeportal.org/file.cfm?file_id=836&

Youth Resource List from Utah 211

<http://www.informationandreferral.org/youth.pdf>

Utah Work Incentive Network

Work Ability helps prepare people with disabilities to work. The program was designed for people who receive public benefits like Medicaid and Social Security due to a disability. 801-887-9529
www.workabilityutah.org,

Services for Students with Disabilities Offices in Higher Education Institutions

Most colleges have a Disability Resource Center to offer support services and arrange for classroom accommodations. For a list of Utah Centers see the services section of the
<http://www.medicalhomeportal.org>.

Utah State Office of Education

Contact Susan Loving, transition specialist with the state office for information regarding the school transition plan. 801-538-7645.
<http://www.schools.utah.gov/sars/servicesinfo/transition.htm>

Healthy and Ready to Work

This site focuses on understanding systems, access to quality health care, and increasing the involvement of youth. It also includes provider preparation plus tools and resources needed to make more informed choices!
<http://www.hrtw.org/index.html>