



Medical Home Newsletter

Transition to Adulthood for CSHCN

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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 ward@utah.gov.

Copies of newsletters may be found on the Utah Medical Home web portal: <http://www.medhomeportal.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.

According to the National Center for Youth with Disabilities:

"...Transition is a process, not an event. The actual process should be gradual, occurring in harmony with adolescent and family development. While there is not one current model, whenever it occurs, communication among pediatric and adult providers, parents and youth is critical."

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.

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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.
- Make transition planning an integral part of standard office procedures.

- 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.
- Prepare an up-to-date medical summary.
- Refer to a new adult care provider.
- Co-treat with the new provider until established.

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.

Before a transition action plan is developed, the Medical Home team should assess the youth’s capabilities, desires, strengths, and weaknesses. As appropriate, the youth must have a major voice in providing this information. The family or caretaker is 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 vital to develop a workable action plan unique to that individual.

The Action Plan

The Transition Action Plan (an example is available on the MedHome website) 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 the 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 written by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine go to this address:

<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/6/S1/1304>

In December 2002, a supplement to Pediatrics was published entitled "Improving Transition for Adolescents with Special Health Care Needs from Pediatric to Adult-Centered Health Care." The Department of Health and Human Services’ and the Health Resources and Services Administration sponsored the supplement. To order a copy:

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

Resources for the Medical Home, Families and Youth

Resources in Utah

Medical Home Website - Transition Module:

<http://www.medhomeportal.org>

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

Intermountain Collaborative Transition Center (ICTC)

Their mission is to help teens move into adult healthcare, access adult services, create opportunities for adult living, and provide resources and education important for independence. 801-536-3523

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. www.utahparentcenter.org

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. 801-538-7530
www.usor.utah.gov/vocrehab.htm

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

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. See the MedHome website for a list.

Youth Employability Services provides assistance in obtaining GED or high school diploma, occupational training and education to

become self-sufficient and free from public assistance. 801-468-310

Utah State Office of Education

Contact Susan Loving, transition specialist with the state office for information regarding the school transition plan. 801-538-7645.

Utah Work Incentive Network

The overall goal of the Utah Work Incentives Network (UWIN) is to create a comprehensive, consumer-responsive system of work supports that will increase employment outcomes for individuals with disabilities in Utah.
www.workabilityutah.org, 801-887-9500

The Ability Bank helps individuals with Severe Physical Disabilities, such as Paralysis, Traumatic Brain Injury, MS, Cerebral Palsy, and Spina Bifida transition from dependence to independence. 801-978-2452 <http://csc-ut.org/abilitybank.htm>

Work and Financial Programs from SSI : Ticket to Work

Individuals receiving SSI (Supplemental Security Income) or SSDI (Social Security Disability Insurance) can voluntarily participate in the “Ticket to Work” Program through the Social Security Administration. This program provides a ticket they may use to obtain vocational rehabilitation, employment or other support services from an approved provider of their choice to meet their employment goals. More info at: www.ssa.gov/work

Plan for PASS

PASS (Plan for Achieving Self Support) is an SSI work incentive program that allows individuals with disabilities to set aside additional income to achieve specific work goals such as an education, receiving vocational training, starting a business or purchasing additional work supports. The income set aside in a PASS account is not counted in determining SSI eligibility. By placing income in a PASS account an individual who does not qualify for SSI benefits may become eligible. 1-800-SSA-121
More info at www.passonline.org