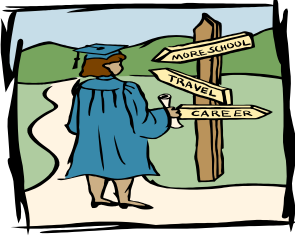


Asking the Experts

Adolescent Health Care Transition



“Do you know the names of your medications and how they help you?” It is a simple question—an important

question, particularly if you have a special health care need. For youth with special health care needs (YSHCN), knowing the answer to that question can be another important step on their journey toward maximum independence—a journey that can, with appropriate planning, result in high quality, developmentally appropriate health care as these youth become adults with special health care needs. A recent survey of youth served by the Division of Specialized Care for Children (DSCC), the state’s children with special health care needs agency, found three key ongoing needs to help youths and their families reach their goals for maximum independence. These needs are:

- Promoting self care, health care management and self advocacy skills.
- Enhancing community integration through community involvement to reduce social isolation.
- Educating youth and their families on the availability of transition resources.

Physicians and other health care providers can have a dynamic role in the process of a young person acquiring skills to manage their own health care.

Why Transition Planning?

For the first time, a generation of YSHCN has survived past prognoses and are now living into adulthood and developing adult medical conditions/concerns requiring adult medical expertise. Preparing these youth for their future, providing them with knowledge about available resources for whatever supports they may need, educating them about health care options, job training, independent living skills and transportation services is crucial to improving health outcomes as they become adults. Currently young adults with disabilities are more likely to: have poorer health status; lack needed medical services; live in households with income below \$15,000; and be more isolated without a network of friends and available transportation (Taylor, 1998). In 2002, DSCC conducted its first survey of youth in an effort to understand the challenges faced by youth served by the DSCC.

Building self-advocacy skills is an important part of the transition process . . .

You're the Pro; Let Us Know . . . Again

In April 2005, 385 youth ages 14 to 21 who receive services from DSCC were surveyed about this pivotal time in their lives.

Twenty-four percent of those surveyed responded, providing insight into their transition experience and the need for continued attention to transition issues. As in a previous survey conducted in July 2002, youth were again asked to respond to questions about the following:

- Health care transition
- The helpfulness of DSCC transition materials
- Agencies, programs and people helpful to the transition planning process
- Plans for independent living
- Involvement in recreation and social activities
- Knowledge of key disability laws

WHAT YOUTHS SAID IN 2005

About Health Care Management

Health care management, knowing how to manage their own health care, how to partner with health care providers, and ways to stay healthy is an important component of transition. The results of the survey indicated that:

- 47% received help on how to become more independent compared to 25% in 2002.
- 51% received a copy of their DSCC Transition plan as compared to 16% in 2002.
- 95% had a regular doctor and of those 66% said that doctor treated adults.
- 71% were able to recognize when their condition was worsening.

- 79% who took medication, knew their medication and how it helped them compared to 73% in 2002.
- 27% arranged to refill their own medication.
- 53% knew the name of their health coverage compared to 61% in 2002.

DSCC Transition Assistance

DSCC care coordination staff are working to improve transition for youth through the dissemination of transition focused materials and planning materials.

In addition to a health care checklist, some materials help the youth work with



the healthcare provider to set appropriate healthcare skill goals to move toward maximum independence. The results of the survey indicated that:

- 72% said DSCC materials/tools are helpful.
- 70% said that the transition plan was helpful.
- 67% said that the referrals to other agencies by DSCC care coordinators were helpful.
- 75% said that they found DSCC care coordinators assistance in maximizing health insurance benefits helpful.

Knowledge of the Laws

Building self-advocacy skills is an important part of the transition process and knowledge of the laws that protect the rights of individuals with disabilities can help build self-advocacy skills. Youth were asked about their knowledge of laws such as the American with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA) and Section 504,

Fair Housing Law, and HIPAA. The results of the survey found that:

- 34% of youth ages 14-17 were knowledgeable about key laws compared to 19.4% in 2002.
- 44% of young adults ages 18-21 were knowledgeable about key laws compared to 52% in 2002.

Community Involvement

Transition planning that promotes community involvement is important to the quality of life as an adult. Youth and young adults were asked if they participated in clubs and community organizations. The results of the survey found that:

- A higher participation (64%) was found for youth ages 14-17 compared to young adults 18-21 (44 %).
- The majority of youth participated in three or fewer activities or clubs.
- Even though an increase in planning efforts focused on encouraging and linking youth/young adults to community activities, these results are mostly unchanged from the 2002 survey.

Transition Planning Resources

For youth with special health care needs, assistance to maximize independence is provided by people, agencies and other groups. Community service agencies offering transition related services remain an untapped resource by many of the youth/young adults surveyed.

Survey results indicated that:

- Family and friends remained the most helpful group, among 14 service agencies and people, in planning for adult life.
- Youth rated DSCC as the second most helpful resource with doctors and social security following respectively.

- DSCC care coordination services that were found most helpful were obtaining third party payment of medical services, followed by DSCC's transition tools.

Improving Health Care Practices: Reaching for the Stars

For youth and young adults served by DSCC, transition planning is becoming more integrated into the care coordination process. More is needed. Key to strengthening transition services is the development of partnerships with the youth, family, community, and health care providers. By focusing on strengths, capacities, and opportunities, by creating and supporting the hopes and expectations of youth with special health care needs, and by starting comprehensive transition planning early, we reach toward the best possible future for youth with special health care needs—a future that includes personal life choices and maximum independence.

For More Information

To access the full report of the DSCC's Youth Survey click here [Adolescent Health Care Transition Youth Survey](#).