



THE HSC HEALTH CARE SYSTEM
The HSC Foundation

Youth Transitions Summit
January 2007

THE HSC FOUNDATION

Youth Transitions Summit

September 21, 2006
Washington, DC

OVERVIEW — Since the mid-1980s, an increasing amount of attention has focused on the “transition” period, during which young people move from adolescence to adulthood. During this period, youth with disabilities and their families face critical challenges as the young people transition from the health, educational, and other systems serving children and youth to adult settings and services. As part of its **Youth Transitions Initiative**, The HSC Foundation convened a national summit of professionals, youth with disabilities, and their families to examine the education, career preparation, independent living, and social and attitudinal barriers to successful transitions. The summit was organized around a research-based framework that identified five guideposts to successful transitions: (1) school-based preparatory experiences; (2) career preparation and work-based learning experiences; (3) youth development and leadership; (4) connecting activities; and (5) family involvement and supports.

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THE HSC FOUNDATION

Youth Transitions Summit

September 21, 2006
Washington, DC

The HSC Foundation (HSCF) has held several meetings focused on issues surrounding youth transitions. On September 21, 2006, HSCF convened a summit of professionals, youth with disabilities, and their families to examine the education, career preparation, independent living, and social and attitudinal barriers to successful transitions. On November 28, 2006, HSCF convened clinician experts to obtain their insights on health issues related to youth transitions, including identifying those areas where there is the greatest need for improvement. A briefing on the November Health Roundtable is available on the Foundation's website (www.hscfoundation.org). This briefing summarizes the key insights from the September 21st Youth Transitions Summit, including comments from the Advisory Committee before and after the Summit.

Background

A widely quoted study based on the National Health Interview Survey estimates that 18% of youth under the age of 18 have disabilities and require special health care services. In 2003-2004, over six million of these young people were enrolled in special education. Since the mid-1980s, an increasing amount of attention has focused on the "transition" period (age 14-25) during which young people move from adolescence to adulthood. During this period, youth with disabilities and their families face critical challenges as the young people transition from the health, educational, and other systems serving children and youth to adult settings and services.

While transition is difficult for all young people, students with disabilities face particular challenges. For example:

- 24% of school-age children with disabilities live in poverty, compared with 16% of students in the general population; as adults, people with disabilities are three times more likely than non-disabled people to live in poverty.
- Nearly a third of youth with disabilities do not finish school, as compared to roughly 17% of non-disabled students; and graduation rates decline based on the severity of the disability. Students with severe disabilities have nearly a 39% non-completion rate.
- Approximately 19% of youth with disabilities attend post-secondary school after leaving secondary school, compared to 40% of those in the general population. Only 6% of students with disabilities are enrolled in four-year colleges, making them four-and-a-half times less likely to go to these schools than non-disabled students.
- Just over 40% of youth with disabilities were employed following high school when surveyed by the National Longitudinal Transition Study 2. This employment rate is much lower than the 63% employment rate for non-disabled youth of the same age who have left school.

The fact that there are a number of systems and services involved in this process—those that deal with custody, Social Security income, independent living, health, transportation, housing, education, employment and other crucial issues—adds many complexities to the youth transition field. While there have been notable successes, untold thousands of young people with disabilities across the nation fall through the many cracks in these systems.

Unless broad cross-system changes are instituted, a lifetime of poverty and exclusion awaits many of those whose condition is present from birth or early-onset and who make the transition to adulthood with significant disabilities.

Summit Proceedings

The HSCF Summit was organized around a research-based framework for organizing what youth need to successfully transition to adult life that was developed by a national technical assistance center, the National Collaborative on Workforce and Disability for Youth (www.ncwd-youth.info). The Summit presented sessions on the first four guideposts, described below. Guidepost 5, Family Involvement and Supports—covering participation and involvement of parents, family members, and/or other caring adults to promote social, emotional, physical, academic and occupational growth of youth—was integrated throughout the program. Each guidepost lists what all young people need, concluding with specific needs for youth with disabilities.

The opening speaker, Judith Heumann—currently the lead consultant to The World Bank for the Global Partnership for Disability and Development and formerly Assistant Secretary for the Office of Special Education and Rehabilitative Services—set the tone for the Summit by pointing out that in spite of the “tremendous progress made in the transition field over the past decade, we have a long way to go to reach the desired level of success.” She emphasized that we not only need quality education and quality work experiences, but we also need employers who are willing to hire students with disabilities once they graduate. Students not only need services in school and in the workplace, but they also have to develop the strength of personality to see themselves as meaningful participants in the workforce and to ask for the accommodations they need, most of which are not expensive. For that to happen, the system must change to recognize that requiring services is not “negative,” but is rather a means to getting the job done. In addition, there must be collaboration across agencies and a general recognition that transition of youth with disabilities is “everybody’s responsibility” because they make up a substantial proportion of “youth at risk.”

Guidepost 1. School-Based Preparatory Experiences. In order to perform at optimal levels in all education settings, all youth need to participate in educational programs grounded in standards, clear performance expectations, and graduation exit options based upon meaningful, accurate, and relevant indicators of student learning and skills. Youth with disabilities also need to use their individual transition plans to drive their personal instruction and to access and use learning accommodations.

What's Right: What Works and What's Useful

- The National Longitudinal Transition Study 2 (www.nlts2.org) reports that transition planning is in place for 90% of school-age students with disabilities. However, the study still paints a "mixed picture" of transition planning (See "Gaps" below).
- A taxonomy for transition planning developed by Dr. Paula Kohler in 1996 (www.nsttac.org) is still relevant today and corresponds in many ways to the NCWD-Youth Guideposts.
- Several website resources offer valuable information on a wide range of transition-related issues:
 - > The National Center on Secondary Education and Transition coordinates national resources, offers technical assistance, and disseminates information on secondary education and transition for youth with disabilities in order to create opportunities for youth to "achieve successful futures." (www.ncset.org)
 - > The National Secondary Transition Technical Assistance Center is funded by the Office of Special Education Programs (OSEP) to help states build capacity to support and improve transition planning services and outcomes for youth with disabilities. (www.nsttac.org)
 - > The National Dissemination Center for Children with Disabilities is a national source of information on IDEIA (the law authorizing special education), No Child Left Behind as it related to children with disabilities, and research-based information on transition and other effective educational practices. (www.nichcy.org)

- > PACER Center, created and staffed primarily by parents to expand opportunities and enhance the quality of life of children with disabilities, operates a number of projects focused on or including transition. The website (www.pacer.org) contains information for parents on these projects, along with a series of "parent briefs" on a variety of transition issues.
- > The website of the National Collaborative on Workforce and Disability for Youth (www.ncwd-youth.info) contains the Guideposts for Success and the research underlying their creation, an online database of promising programs and practices in the workforce development system that effectively address the needs of youth with disabilities, and other resources to help state and local workforce development systems to better serve youth with disabilities.
- > www.nlts2.org is the Web home of the National Longitudinal Transition Study-2 (NLTS2). Funded by the U.S. Department of Education, NLTS2 is documenting the experiences of a national sample of students who were 13 to 16 years of age in 2000 as they move from secondary school into adult roles. The site has a wide range of important topics, such as high school coursework, extracurricular activities, academic performance, post-secondary education and training, employment, independent living, and community participation.

"Because in the past there's been so little thought and coordination between supports offered through the schools and the transition to meaningful adult lives, we speak about young adults as "falling off the age-21-cliff" into some kind of oblivion."

– educator and researcher

What's Wrong: Gaps and Disconnects

- Special education students are more than twice as likely as their peers in general education to drop out of high school, and youth with disabilities are half as likely as their peers without disabilities to participate in post-secondary education.
- The attention devoted to transition plans of individual students is insufficient. School staff report that just over half of students with visual impairments have programs

well suited to their transition goals, and only a third of students with emotional disturbances have appropriate programs. Parents report that one in four students with emotional disturbance or health impairments have transition plans that are not very or not at all useful.

- Many states require students to pass standardized tests in order to receive a high school diploma. Those who cannot pass such tests receive "certificates of completion," which indicate that the student has completed her/his IEP goals and/or credit requirements. Many students with learning disabilities are not able to pass the standardized test and receive the certificate, which is frequently seen as a "lesser" degree. This type of certificate is not recognized by post-secondary institutions, the military, or employers.

Guidepost 2. Career Preparation and Work-Based Learning Experiences.

These experiences are essential to enable youth to form and develop aspirations and to make informed choices about work and careers. Requiring collaboration between schools and other organizations, these experiences can be provided during the school day, through after-school programs, and through summer employment. In addition to the education, training, and work experience recommended for all youth, young people with disabilities should learn how to obtain disability-related work supports and understand the relationship between planning and work supports.

What's Right: What Works and What's Useful

- Research shows that the single most important factor predicting success for work *after* high school is work experience *in* high school, including paid and unpaid internships.
- People who have graduated from high school are five times more likely to be employed as adults than those who have not.
- *High School/High Tech* is a national network of state and locally operated programs designed to provide high school students with all types of disabilities the opportunity to explore jobs or post-secondary education leading to technology-related careers.

(<http://www.ncwd-youth.info/HSHT/index.html>)

- The Power of One (personal advocacy): one parent created an incentive for all of his firm's offices to start hiring people with disabilities, particularly focusing on those of transition age, as well as actively carrying the hiring message to other firms.

"The mentors and managers I had helped me develop my skills and find out what I wanted to do. Exposure is the key—the earlier, the better."

— young professional with a disability

What's Wrong: Gaps and Disconnects

- As few as 50% of youth with disabilities can expect to exit school and be employed as adults. One study found that, for students labeled "moderately, severely or profoundly handicapped," only an estimated 12% had worked in the five years following public school.
- There is a disconnect between having high expectations for youth with disabilities and a system that offers "low expectation" opportunities.
- Schools don't prepare youth for employment. This is a common complaint from employers.
- For college students with disabilities, there is often a gap between disability services, where students go for accommodations, and career services, where employers go to recruit—leaving students with disabilities invisible to recruiters and employers frustrated.

Guidepost 3. Youth Development and Leadership. Youth Development is a process that prepares young people to meet the challenges of adolescence and adulthood through a coordinated, progressive series of age and stage appropriate activities and experiences that help them gain skills and competencies. Youth leadership is part of that process. Apart from the mentoring, skills and self-advocacy training, and exposure to role models needed by all youth, young people with disabilities need to understand disability history, culture, and public policy issues and to have mentors and role models *with* and *without* disabilities.

What's Right: What Works and What's Useful

- There are a number of highly successful programs that work with young people with disabilities to build leadership and development skills. Examples of national programs include:
 - > *National Consortium on Leadership and Disability-Youth (NCLD-Youth)* — a youth-led resource, information and training center for youth and emerging leaders with developmental disabilities. NCLD-Youth designs disability-specific youth development and leadership curricula; supports other national, state and local networks through dissemination of materials, and trains youth to influence state and local public policy in the field. (www.nclid-youth.info).
 - > *National Council on Disability's Youth Advisory Committee (YAC)* is a 12-member committee of young people with disabilities who provide youth perspectives to NCD's study and project teams that work on key national issues, prepare "youth-friendly" issue summaries, share personal stories with Capitol Hill staffers, and conduct national forums on youth issues. (http://www.ncd.gov/newsroom/advisory/youth/yac_document_09-06.htm)
 - > Twenty-three states currently hold some form of a Youth Leadership Forum (YLF) for youth with disabilities. High school youth apply to participate in the YLF, in which they come to the state capitol for several days of exposure to leadership opportunities, including meeting people with disabilities in key leadership positions.
 - > Practices like peer-mentoring are valuable experiences that connect students to their communities and community leaders, and nurture a sense of belonging.

What's Wrong: Gaps and Disconnects

- Too little dissemination and adoption of best practices, such as peer-mentorship, adult mentors and role models with and without disabilities, self-advocacy training, youth leadership experience, instilling disability culture, and learning disability history.
- Leadership opportunities for youth with disabilities that currently exist are limited and serve only small numbers of participants.
- The notion must be countered that "high expectation" apply only to young leaders who work in the disability field, and success should be expected from all youth with disabilities.

"Youth empowerment and peer support and youth involvement on all levels counter all the negativity that youth with disabilities experience."

— youth participant

Guidepost 4. Connecting Activities. Young people need to be connected to programs, services, activities, and supports that help them gain access to chosen post-school options. For all young people, these include mental and physical health services, transportation, financial planning and management, and connection to other services and opportunities. In addition, youth with disabilities may need assistive technologies, mobility training, independent living center services, personal assistant services, benefits planning, counseling, and other supports.

What's Right: What Works and What's Useful

- *The Healthy & Ready To Work National Resource Center (HRTW)* (<http://www.hrtw.org/>) provides leadership, resources, and knowledge to improve community participation, productivity, and life for youth in transition — including transferring from pediatric to adult care providers and encouraging physicians to be part of the process.

- The Maternal & Child Health Bureau and Health Resources and Services Administration now require their health grant recipients to set performance measures on incorporation of the medical home concept, family involvement, and other disability-related needs. "Medical home," is a concept for providing continuous, comprehensive, coordinated, family-centered primary care in a setting that the family can easily access.
- A very significant experience for one youth participant with a disability was attending a private "boot camp" to learn and practice living skills in real life situations.
- There are independent living centers (ILCs) all over the country; some of them provide mentoring or some other service related to transitioning youth with disabilities into the world of work and productivity.
- High School/High Tech sites offer a range of experiences for students, including career focused e-mentoring and community and service learning opportunities.

"We don't have the adequate infrastructure and trained support people in the field to help someone like my daughter. We are her parents—we don't want to be her providers."

—parent participant

What's Wrong: Gaps and Disconnects

- Ineffective collaboration across agencies and among agencies, schools, health care providers, and other stakeholders and, in particular, between the mental health, juvenile justice, and foster care systems with the workforce development and education systems.
- Inadequate infrastructure: (1) No national system of professional development that identifies, builds, and certifies youth service practitioners; (2) Insufficient implementation of integrated service models of transition from childhood to adult health service providers.
- Lack of high expectations for youth with disabilities leads too many professionals in schools, businesses and other institutions to operate on a set of assumptions that people with disabilities cannot meet the knowledge and skill requirements of today's workplace.

Opportunities

Transition planning and services — social, educational, employment, and family — need to take into consideration a comprehensive view of youth and the issues they face. With that in mind, Summit participants were asked to recommend projects or activities that might be undertaken in the next five years that would increase the successful transition of youth with disabilities — taking into consideration: (1) proven approaches that could be replicated; (2) community readiness to move forward; and (3) activities that government can't or won't do. A summary of their recommendations follows:

- Conduct an ongoing series of roundtable discussions, conferences, and other convening events to bring together a diverse group of individuals, organizations, and agencies involved in youth transitions to promote systems improvement that will ultimately improve transition outcomes.
- Support program development on youth leadership and independent living skills for national piloting and dissemination.
- Support the long-term adoption of Youth Leadership Forums for local use and encourage the national expansion of statewide Youth Leadership Forums.
- Turn “the power of one” into “the strength of numbers” by supporting existing employer-based information on hiring and supporting young people with disabilities; disseminating promising practices; and promoting coalitions of employers.
- Launch an “Expect Success” public relations campaign designed to change attitudes about the goals and dreams of youth with disabilities, and target the youth, their families, teachers, and service providers to raise expectations relating to the futures of young people with disabilities.

- Identify pediatricians' interest and abilities to increase practice capacity for enhancing their role in providing comprehensive, interdisciplinary care of adolescents with disabilities, including effective transition services.
- Support and expand opportunities for young people to have early work experiences.
- Establish joint ventures with mainstream programs (4-H, Boys and Girls Clubs, Scouting, etc.) that are already successful in developing leadership to integrate youth with disabilities.
- Engage the foundation and corporate giving community in collaborative funding of: (1) mainstream projects that significantly include youth with disabilities; (2) disability-focused programs that focus on youth transitions; and (3) public relations campaigns targeted to families and students with disabilities, employers, and the general public.

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THE HSC HEALTH CARE SYSTEM

The HSC Foundation

The HSC Foundation is dedicated to improving access to services for individuals with special needs who face challenging health care and social barriers. The Foundation has distinguished itself by its concern for and specialization in children's medical services and urban issues, particularly in the Washington metropolitan area. An important asset is the Foundation's connection to a working subacute hospital (The HSC Pediatric Center) and a care coordination health plan (Health Services for Children with Special Needs, Inc.) that have reputations of outstanding service to children and youth with disabilities and chronic illnesses. The Foundation serves as the parent organization to both of these nonprofit organizations.