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**The HSC Foundation**

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**Health Roundtable Briefing**  
January 2007

**THE HSC FOUNDATION**

# Health Issues Impacting Youth Transitions Roundtable

November 28, 2006  
Washington, DC

**OVERVIEW** — Most of the available data on transition services suggest that the nation is doing a poor job in helping youth with disabilities and chronic illness transition into adulthood, and that any success achieved is in spite of the system, not because of it. So the key question is—*why is the nation failing at providing adequate transition support?* To address that question, The HSC Foundation, as part of its **Youth Transitions Initiative**, convened clinician experts from around the country to examine health issues related to youth transitions. In discussing the challenges to successful transitions, roundtable participants identified strategies in four key areas: (1) integrated service models of transition; (2) current and next generation of medical and nursing experts in transition; (3) potential partners in the public and private sectors; and (4) research agenda gaps.

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THE HSC FOUNDATION

# Health Issues Impacting Youth Transitions Roundtable

November 28, 2006  
Washington, DC

*The HSC Foundation 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. A briefing on the Summit is available on the Foundation's website ([www.hscfoundation.org](http://www.hscfoundation.org)). On November 28, 2006, HSCF convened clinician experts to obtain their insights on health programs related to youth transitions, including identifying those areas where there is the greatest need for improvement. This briefing summarizes the key insights from the November 28<sup>th</sup> Roundtable.*

## **Background: The Magnitude of the Problem**

Judith Palfrey, MD, and Jay Berry, MD (Division of General Pediatrics at Children's Hospital Boston and faculty of Harvard Medical School) shared the initial results of their study that seeks to estimate the epidemiology, resource use, and economic impact of children and adolescents with chronic illnesses and disabilities. They began with an historical overview to provide a context for the issue.

## **History of Chronic Illness and Disability in Children and Adolescents**

Society's methods for dealing with children and adolescents with chronic illnesses and disabilities have evolved significantly over time. Beginning in the 1800s, people with disabilities tended to be institutionalized in facilities or confined to their families'

homes. These practices continued well into the 1900s. The period from 1900 until the 1960s was also characterized by:

- High rates of infant mortality, especially for premature infants
- Huge epidemics, including outbreaks of polio
- Few cures for chronic illnesses
- Few surgeries for congenital anomalies

Beginning in the 1960s, conditions improved for children and adolescents with chronic illnesses and disabilities. An explosion of knowledge occurred, with the development of vaccines (e.g., for polio), antibiotics, neonatal care, surgeries for congenital anomalies, and medicines for chronic illnesses. Societal beliefs began to change as well, with an emphasis on moving those with disabilities and chronic illnesses out of institutions and into community settings.

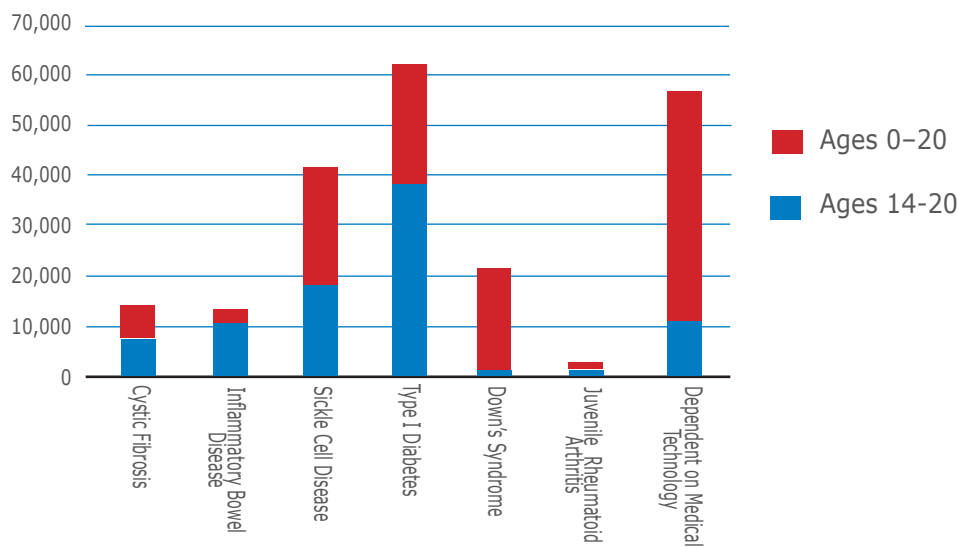
Between 1980 and 2000, the rapid progress continued. New technologies emerged that helped those with disabilities to live independently in the community, and “de-institutionalization” was no longer seen as adequate. The goal changed to “community inclusion”—in other words, the new thinking was that those with disabilities should become part of mainstream society by living, attending schools, and working in the community. By the turn of the century, the tremendous progress of the previous 40 years meant that very few children and adolescents with disabilities and chronic illnesses died. The longer life expectancy created large cohorts of individuals dealing with new but similar problems.

### **Health Care Utilization Rates for Children with Special Health Care Needs**

Given that the Children with Special Health Care Needs (CSHCN) population is increasing and living longer, one would expect that they are using a significant amount of health care services. Dr. Palfrey and her colleagues tested this hypothesis by conducting a study designed to quantify the use of inpatient health services by children and adolescents with special health care needs. The study paid special attention to adolescents (aged 14-20), as this is the population most in need of services that will help facilitate the transition to adulthood. The study looked at the number of hospitalizations, length of stay, and total hospital charges.

Asthma is by far the biggest reason for hospitalization in this population, with 375,000 youth under the age of 20 being hospitalized for asthma each year. Just over 85,000 (roughly 23%) of these hospitalizations involve adolescents between the age of 14 and 20. The chart below shows other major reasons for hospitalization among those under the age of 20, with the proportion of hospitalizations among adolescents broken out in a stacked bar. This chart shows that—in addition to asthma—diabetes, sickle cell disease, technology dependent, and inflammatory bowel disease are all responsible for more than 10,000 annual hospitalizations among adolescents each year.

### Number of Annual Hospitalizations



As shown in the chart below, the economic impact of these adolescent hospitalizations is quite substantial, with hospitalizations for adolescents with asthma being responsible for over \$1.1 billion in total hospital charges each year, followed by diabetes (\$480 million), technology dependence (\$385 million), sickle cell disease (\$270 million), Cystic Fibrosis (\$240 million), and inflammatory bowel disease (\$230 million). Some of these costs are being driven by long lengths of stay.

## Economic Impact

Disease	No. of Hospitalizations	Total Charges (millions)
Asthma	85,400	\$1,130
Diabetes Mellitus	37,300	\$480
Sickle Cell Disease	17,300	\$270
Technology	11,200	\$385
Inf. Bowel Disease	10,900	\$230
Cystic Fibrosis	6,800	\$240
Down's Syndrome	1,700	\$46
Arthritis	1,600	\$33

Not surprisingly, state Medicaid programs are the single largest payer for these adolescent hospitalizations. Medicaid covers 42 percent of all hospitalizations for adolescents with these diseases. Total charges for all these Medicaid-covered hospitalizations are just under \$1 billion.

### Employment and Education Impact

Children and adolescents who are hospitalized with chronic illnesses miss many days of school, both during and in some cases after their hospitalization. Adolescents who are hospitalized with chronic illnesses also miss time from work or are unable to work at all. In fact, between 45%-52% of adolescents with Cystic Fibrosis are unemployed, as are 32%-38% of adolescents with inflammatory bowel disease. Roughly one in five (19%) of those with diabetes report missing work or school, while those with asthma are five times more likely than the general population to report an inability to work.

## Next Steps, Future Directions for the Study

### Mental Health

Many Roundtable participants emphasized the need to add depression and other mental health conditions to the epidemiological analysis. This can be difficult to do because frequently mental health codes are not included for youth who are admitted to the hospital for major medical events. However, medical and environmental issues are often associated with and/or contribute to mental conditions. Asthma attacks, for example, are frequently triggered by anxiety disorders. Many youth with chronic illness have psychosocial issues as well. In fact, even mild depression can often be a major stumbling block for youth who are trying to work or go to school. A recent *Institute for the Future* report, for example, projects that the incidence of depression will increase rapidly between now and 2010, and that it will frequently develop right at the point when youth are transitioning to adulthood and taking on more responsibility for their lives. It is critical, therefore, to consider both physical and mental health issues facing youth as they transition into the community.

### Racial/Ethnic Disparities

Several Roundtable participants stressed the need to include racial and ethnic breakdowns in the analysis. Unfortunately, the data are woefully inadequate. While there is a race/ethnicity component to hospital admission coding, the information is often missing or unreliable. As a result, it can be difficult to speculate on disparities. It is clear, however, in some areas—such as Down Syndrome, where survival rates are much lower for African Americans (25% survival rate versus 50% for whites).

### Non-hospitalized Population

Several Roundtable participants noted that hospitalized children and adolescents represent only a small portion of the total CSHCN population. Most CSHCN are never sick enough to require hospitalized care. Dr. Palfrey noted, for example, that an evaluation of 130 youth with AIDS found that only a few of them had required hospitalization. Thus, any attempt to get a true handle on the magnitude of the problem must include this much larger population as well.

## Challenges for Transition Services

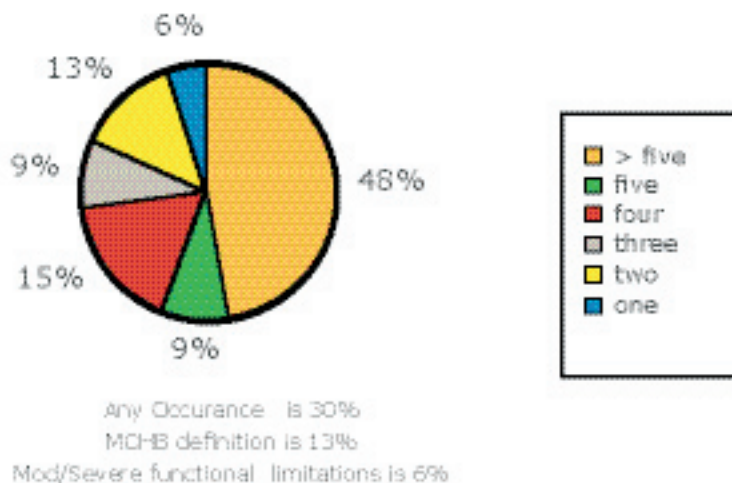
Most of the available data on transition services suggest that the nation is doing a poor job in helping youth with disabilities and chronic illness transition into adulthood, and that any success achieved is in spite of the system, not because of it. Most public sector institutions, including the Supplemental Security Income (SSI) program, are generally dysfunctional with respect to transition. So the key question is—*why is the nation failing at providing adequate transition support?*

### Case Complexity

One of the biggest challenges relates to the complexity of the issues that these children and adolescents face. As shown in the chart below, over 70% of CSHCN have four or more chronic conditions. These children and adolescents also come from diverse cultural and ethnic backgrounds (immigration rates today are at a peak not seen since 1900), which also needs to be considered in successful transition planning.

**Too often all that we say and do sends a signal to the youth that he or she is worthless and has no future. We have to stop doing that.**

### Characterization of CSHCN Have Multiple Conditions (n=151)



### Inadequate Capacity of the Adult Health Care System

Another challenge relates to the readiness of the adult health care system to take care of these individuals once they age out of the pediatric system by turning 21. Adult health care providers generally do not have adequate knowledge about the needs of this population, nor are they willing to spend the extra

time that is necessary to care for CSHCN. The unwillingness to spend time is driven by the failure of the reimbursement system to provide adequate additional payments to compensate providers for the additional effort that is required. A recent survey of 28 physicians (primarily pediatricians) by the Healthy & Ready to Work (HRTW) National Resource Center found that more than half reported that reimbursement issues (e.g., a lack of understanding eligibility requirements, limited coverage by private insurers and Medicaid, and low reimbursement rates) were a barrier to the provision of transition services.

### **“Silo” Approach to Transition Services**

Another challenge facing youth who are in the transition process is the fragmented nature of the system serving CSHCN. It is not uncommon for one individual to have interactions with many different agencies and organizations (e.g., hospitals, physician offices, mental health providers, schools, vocational training and rehabilitation, social services, the juvenile justice system, etc.), each of which is concerned with only one aspect of that individual’s life. No single agency, moreover, has the authority to require another agency to coordinate with it. As a result, coordination is often lacking. A study of special education agencies, for example, found that only a minority include vocational rehabilitation. And while improvement is being made in this area, it is quite slow. Furthermore, even when agencies do coordinate with each other, funding issues often limit the effectiveness of this coordination.

**Every discipline has its own dictionary,  
and they don’t share it with each other.**

### **Addressing the Challenges**

Much of the discussion during the Roundtable focused on strategies for addressing the challenges to successful transition. Participants discussed strategies in four areas, with the key insights summarized below.

### **Integrated Service Models of Transition**

Several integrated service models exist for transitioning CSHCN to adulthood. One of the most common is the medical home model, which focuses on providing comprehensive, coordinated, continuous, culturally appropriate, and family-centered care. Unfortunately, many internists and family medicine physicians are not familiar with this model or how to provide this type of



care. Furthermore, there is not adequate funding to compensate and incentivize providers to organize their practices around this model.

To assist caregivers and others in helping adolescents to transition to adulthood, a 1999 survey identified three transition models:

- A diagnosis or condition-based subspecialty program (e.g., for those with Cystic Fibrosis, congenital heart disease)
- A subspecialty, provider-focused program (e.g., where all patients see a specialist, such as a pulmonologist, neurologist, or gastroenterologist)
- A multidisciplinary team approach for adolescents with various chronic conditions

More recently three models have been proposed that build off of those found in the 1999 survey:

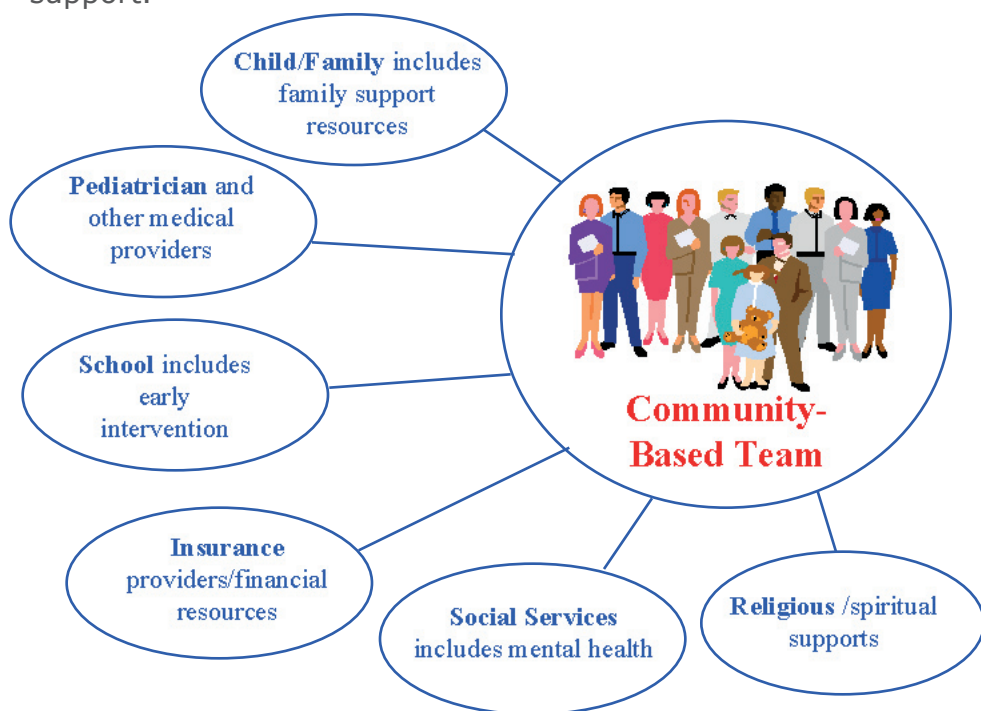
- Diagnosis or condition-based services based on the common needs of patients with a particular diagnosis or patients utilizing a particular subspecialist
- Age-based services for various chronic conditions, including use of a multidisciplinary team for adolescents transitioning in multiple areas of life, including school, work, home, and health care
- Primary care services that integrate transition planning and coordination into the medical home at the level of the primary care physician

Each of these models may be appropriate, depending on the individual needs of the youth in question. But they all are based on the following common principles:

- Use of toolkits and other resources of local, state, and national transition-related activities
- Inclusion of social work, financial counseling, and vocational rehabilitation services
- Use of needs assessment
- Care coordination
- Self-determination/empowerment for adolescents and families
- Involvement of community agencies

Regardless of the model chosen, the key to success appears to be the use of a community-based team (see chart below) that includes the following: the youth and his/her family (with family support from community-based resources), a pediatrician and other appropriate medical providers, school representatives, insurers and other sources of financial support, social service staff (including mental health), and individuals who can provide religious and spiritual support.

**All disciplines believe that team work is essential, and that their discipline should lead the team.**



While these models exist in theory, implementing them can be difficult. The nation's success in building high-quality, integrated systems of care at the community level has been fairly limited. Some communities have been able to get a few agencies to work together, but not all of those that are needed. In addition, community-based teams exist to some extent for pediatric patients, but only sporadically for adolescents, and not at all for adults. Under Title V of the Social Security Act, care coordinators are provided for children and youth, but these coordinators are generally not available once an individual turns 21. While government can assist with funding, only a local community can establish the authority, power, and legitimacy of an integrated service model.

## Supporting the Current and the Next Generation of Medical and Nursing Experts in Transition

There is a tremendous need to develop training and care coordination programs and other tools to help both the current and the next generation of physicians, nurses, and other health providers more effectively serve youth transitioning into adulthood. Roundtable participants identified a number of specific programs and tools that could help, including:

- Enhance Medicaid's EPSDT program to include a more structured protocol to help practitioners better assess both care coordination and disease management needs.
- Develop and staff a community-based hotline that provides information about available services in the community.
- Develop an assessment form that a nurse practitioner or other qualified health professional could use to evaluate the patient and his/her family, including education levels, financial situation, availability of support in the home, etc.
- Develop a tool to assist in the development of a long-term transition plan that begins at an early age and identifies different milestones, such as when to begin discussing drug and alcohol use with the child, when to start talking about post-secondary education or vocational training, etc.
- Include practitioners, youth, and parents in any training and provide tools to help parents envision what their children will need over time and to help both parents and practitioners understand the youth's perspective on his/her illness or disability.
- Develop a list of "go-to" people in the local community in each critical area (e.g., Medicaid approvals, independent living, vocational training, etc.) to help youth and their families take on greater responsibility for their future by making it easier for them to navigate complex, fragmented systems.
- Consider investing in "third-party" coaches who can help youth and family members throughout the transition process by providing guidance on next steps and by helping to make the necessary arrangements for accessing needed services.

- Approach existing training institutions (e.g., medical schools, residency programs) about adding specific education and training about transition issues, including diversity training.
- Build an independent consortium at the local level to tackle transition issues and mobilize the local institutions around them.
- Consider the funding of multi-year (3-4 years), interdisciplinary, research-intensive fellowships in transition services with the objective of training future leaders in the “science” or “discipline” of transitions.
- Conduct research studies to document the benefits of successful transition in terms of better outcomes (i.e., higher quality of life, lower long-term costs) that will convince potential funders of the wisdom of investing in this area.

### **Potential Partners in the Public and Private Sectors**

Roundtable participants identified a number of potential partners in both the public and private sectors that might be a source of funding and/or otherwise might be interested in collaborating with organizations like HSCF and others as they work to improve transition services in local communities. At the federal government level, the following agencies might be potential partners:

- Centers for Medicare & Medicaid Services (CMS), which administers the Medicaid and Medicare programs, including EPSDT and SCHIP, has the power to authorize and fund demonstration projects and waivers that can test innovative approaches in real-life settings. CMS can also approve reimbursement for certain services. For example, if “successful transition” were defined as an outcome, it is possible that some services that lead to this outcome could qualify for reimbursement.
- The Office of Disability within the U.S. Department of Health and Human Services has line authority to coordinate disability issues across their department’s agencies and programs.
- Also within the U.S. Department of Health and Human Services (HHS), the Maternal and Child Health Bureau’s Division of Services for Children with Special Health Care Needs has funded the development and demonstration of model Healthy & Ready to Work (HRTW) state programs focused on children and youth with special health care needs.

- Also within HHS is the Substance Abuse Mental Health Services Administration (SAMHSA), which funds the Children's System of Care program and may be a potential source of funding on transition-related programs and services.
- The U.S. Department of Labor (DOL) houses the Employment and Training Administration (ETA), which administers the Workforce Investment Act (WIA) programs and funding, including WIA-youth services and national demonstration projects. DOL also houses the Office of Disability Employment Policy (ODEP), which funds demonstration projects, including youth programs, and coordinates disability employment policy for the Department and across government agencies.
- The U.S. Department of Education has primary responsibility for transition-aged youth. Within the Department, the Office of Special Education and Rehabilitative Services (OSERS) administers the nation's special education programs through the Office of Special Education Programs (OSEP), vocational rehabilitation programs through the Rehabilitation Services Administration (RSA), and a disability and training program through the National Institute on Disability Rehabilitation and Research (NIDRR). OSERS has funded transition research and demonstration projects for the past 30 years.
- National Center for Medical Rehabilitation Research, a part of the National Institute of Child Health and Human Development (an institute within the National Institutes of Health—NIH), aims to foster the development of scientific knowledge needed to enhance the health, productivity, independence, and quality-of-life of people with disabilities.
- National Institute of Mental Health within NIH is sponsoring five-year grants on supportive employment. While transition is not a specific focus of the program, the evaluation phase is looking at why programs are and are not succeeding, and transition services may be found to be a key ingredient of success.
- The Social Security Administration, which administers the SSI and SSDI programs, funds demonstration projects such as the Youth Transition Demonstration Projects (YTDP).

- Office of Personnel Management, which administers the Federal Employee Health Benefits Program, is in a unique position to influence what insurers are doing with respect to transition services.

Within the private sector, employer foundations, chambers of commerce, trade associations, the AFL-CIO, and others may be willing to fund apprenticeships and other programs to support youth in transition. Walgreen's, for example, has committed to hiring 200 individuals with developmental disabilities (out of 600 total hires) at its two new warehouses in North Carolina and Connecticut. While Walgreen's interest is fueled by the CEO (who has an autistic child), other companies looking for increasingly scarce labor might also be interested in hiring from the large potential pool of individuals with disabilities.

Local, regional, and national foundations represent another potential partner and funding source. At the national level, the Robert Wood Johnson Foundation is active in the health care arena, although their agenda tends to be set from within the organization. Other local and regional foundations that might represent potential partners include the following:

- The MacArthur Foundation has an initiative known as transition to adulthood that focuses on child and adolescent development, community participation, education, and other areas (although neither health care nor disability are a primary focus).
- The William T. Grant Foundation focuses on disadvantaged populations (including adolescents), particularly with respect to promoting civic participation and citizenship. This research-focused foundation is also involved in health issues, and has funded a study on special education, disability, and transition.
- The Annie E. Casey Foundation focuses on foster care, including programs aimed at enhancing the capacity of young people as they leave foster care. Foundation programs help these youths to negotiate the adult world, including the transition to employment.

Finally, the provider community may also represent a potential collaborator, particularly hospital associations such as the American Hospital Association and the National Association of Children's Hospitals and Related Institutions (NACHRI).

## Addressing Research Agenda Gaps

Roundtable participants identified the following high-priority research topics related to transition services:

- Evaluation of how best to identify youth who need health-related transition services: This is a critical first step that needs to be better understood.
- Longitudinal studies that track youth over time: Some data sets exist today that need to be mined for research insights, including the National Transition Longitudinal Study-2, which includes in-depth, case-study evaluation of a representative sample of 12,000 students who were served under the Individuals with Disabilities Education Act (IDEA) and will identify factors that contribute to positive outcomes for youth, with the goal of determining if there are common themes and lessons that help to explain success or failure.
- Evaluation of the diversity of youth's experiences in transition: The goals of this research would be to understand whether and how health transition needs vary (e.g., by disease/disability, socio-cultural phenomenon, etc.), and whether there are disparities in the quality of transition services across age, ethnic, racial, and disease/disability groups.
- Evaluation of what defines a successful health transition: In most medical areas, it is relatively easy to define success (e.g., survival, no complications.) But additional measures are needed to gauge the extent to which transition services allow youth to realize their goals. The first step may be to define the attributes of a good transition process, and then to define the outcomes that would logically come out of each stage of that ideal process.
- Examine the relative merits of face-to-face interventions versus other types of interactions (e.g., telephone calls, reminder notices): The key issue is how much face-to-face interaction is needed (e.g., is more truly better?), with the ultimate goal of determining what kinds of interactions make a difference in terms of encouraging and supporting youth.
- Analysis of the best ideas from outside of health care: The field should not hesitate to "borrow" proven ideas from outside of health care that may have relevance.



## Promising Practices to Consider Implementing

Roundtable participants identified a number of promising practices to consider for implementation. Ideally, those implementing these programs will include an evaluation component so that true “best practices” can be identified and disseminated over time.

- Start early: Rather than beginning at age 16, transition services should likely start earlier, perhaps as early as age 10.
- Develop a long-term plan: The key to a successful health transition is to develop a long-term plan with the youth and his/family, and make sure that everyone understands the plan and his or her responsibilities in executing it. An HMO in Illinois has an innovative approach to plan development, with a nurse practitioner or family physician acting as a “health care consultant” to the family. The consultant spends three hours with the family and youth, conducting an independent medical review and jointly developing a long-term transition plan. The plan serves as a practical roadmap to link families, providers, care coordinators, and other stakeholders. The state of Illinois is now mandating this approach for individuals with certain diseases. The key to success, however, lies in following up to make sure that the plan is in fact being executed.
- Simplify and prioritize the message: Handing an adolescent and his/her family a lengthy, multidisciplinary assessment with dozens of action steps and priorities can quickly become overwhelming. The best approach is to collaboratively identify the handful of priorities (no more than 2 or 3) that are most important in the short term, and then work on these items. Additional priorities can be added over time as appropriate.
- Designate a “lifelong” care coordinator or case manager for each youth/family: Families consistently express a desire for access to one individual who serves as the “go-to” person. This individual needs to be aware of all available resources and stakeholder organizations in the community, and know how to access their services and bring them together in a coordinated fashion as necessary. Frequent contact between this person and

**We teach people incredibly well how to be dependent. Can we change that to teach them to be independent?**



the family appears to be critical. Part of this person's responsibility would be to teach the youth and his/her family how to navigate the system and take responsibility for activities that are critical to their well-being (e.g., setting up medical appointments, filling out insurance and other forms, or calling in prescriptions).

- Use aged-out youth as peer mentors: Peer-to-peer interaction often helps to change behaviors. Young adults who have successfully moved into the adult world can serve as informants and mentors for others still in the transition process.
- Create a "social contract," and hold youth and their families accountable: Valuable lessons can be learned when individuals are held accountable for failing to live up to their agreed upon responsibilities. To make sure the youth and their families understand their responsibilities, it is wise to develop (and clearly explain) a "social contract" between the institution and the youth/family that lays out in writing what behaviors are expected from each party.

Based on the insights and recommendations of Roundtable participants, combined with the findings from the September 21<sup>st</sup> Youth Transitions Summit, The HSC Foundation will build its program and funding agenda for 2007 and beyond.

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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.