
Transition Issues for Youth with Special Health Care Needs in Massachusetts: Background Brief



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National 2010 Goal #6: *All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.*

What is Transition?

A dictionary definition of the word **transition** is: “a passage from one form, state, style, or place to another.” However, the word takes on very specific meanings and usage when applied to children who have special needs. What’s more, this meaning will vary depending on the child’s age and nature of his/her special needs. For example:

- The parent of an **almost three year old** who receives Early Intervention (EI) services will associate “transition” specifically with the required change from an EI program to a pre-school program. This transition is often an emotional and worrisome time for families as they shift from the security of a smaller, specialized program to a more “mainstream” model but also brings with it the excitement of a new environment.
- Youth (age 14 and up) with special health care needs face a similarly mandatory shift with wide-reaching consequences. **Transition** is the term used to describe a dynamic process experienced by adolescents with special health care needs and other disabilities as they approach adulthood. In this case, the transition process has the goals of maximizing self-determination, self-advocacy skills, self-sufficiency and post-school outcomes. Use of the word conjures up many challenges, choices and concerns, as well as opportunities, in the world of students with special health care needs.

In this background brief, we will address the latter use and meaning of the word **transition** -- the process of growing into adulthood for youth with special health care needs. This entails all facets of adult life, including:

- Health care
- Education
- Employment
- Home Life/ Housing
- Recreation/Socialization/Community Participation

The topic of transition is receiving increasing attention from the medical, educational and employment worlds. In 2000, the Maternal and Child Health Bureau, Health Resources and Services Administration, identified six core outcomes for measuring progress in implementing community-based systems of service for children with special health care needs. These outcomes are used as performance measures for all state Title V programs (Title V is the federal block grant name for maternal and child health services). The sixth of these outcomes addresses transition:

All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.¹

¹ Health Resources and Services Administration. National Agenda for Children with Special Health Care Needs: Achieving the Goals 2000. Washington, DC. 2001.

However, even with this increased attention, the incidence of young adults with special health care needs reaching adulthood with satisfactory outcomes is unacceptably low:

- Adequate educational and/or vocational planning as federal law dictates does not take place in the schools starting at age 14;
- Primary care providers and internists are not identified or prepared to take over the young adult's health care from the pediatrician;
- Employment rates of individuals with disabilities continue to be unacceptably low (see box); and
- Young adults with special health care needs identify social isolation and loneliness as a major feature of their adult life.

National Statistics

- People with disabilities of employment age (18-64) are much less likely to be employed either full-time or part-time than people without disabilities (35% vs. 78%)
- People with disabilities are twice as likely to drop out of high school (21% vs. 10%)
- People with disabilities are less likely to socialize, eat out or attend religious services than their non-disabled counterparts
- Life satisfaction for people with disabilities also trails, with only 34% saying they are very satisfied compared to 61% of those without disabilities.

Massachusetts Employment Statistics: 2002

- The estimated employment rate of working age (25-61) civilian *men* without a disability is 91%. For those with a disability, it is 26%.
- The estimated employment rate of working age (25-61) civilian *women* without a disability is 84%. For those with a disability, it is 17%

Sources:

National Organization on Disability/Harris 2004/Harris Survey of Americans with Disabilities Ages 18 and Over; Houtenville, Andrew J. 2004. "Disability Statistics in the United States." Ithaca, NY: Cornell University; Rehabilitation Research and Training Center, www.disabilitystatistics.org. Posted May 15, 2003. Accessed August 03, 2004

Background and Context

The prognosis for children and youth with special health care needs (CSHCN) and disabilities has changed significantly in recent decades. More than 90% of children with disabilities now reach adulthood. In light of this, we face the challenge of providing appropriate services and resources to adolescents and young adults so that they can reach their potential in adulthood.

Chronic illness and disability has a significant impact on an adolescent's life. Studies show that adolescents and adults with disabilities are at increased risk of living in poverty as well as for substance abuse, sexual abuse, unemployment, depression and limited social experiences.

The aspirations of an adolescent with special health care needs are no different from that of any other adolescent -- for education, independent living, recreation, adult relationships and paid employment. However, the path to adulthood may be complicated by the need for some forms of ongoing care. Young people with special health care needs require services that simultaneously meet their special health needs and guard against undue medical, environmental, or social risk while promoting independence and autonomy.

For youth with special health care needs, it is often critical that plans be integrated, information be shared, and schedules be coordinated across various aspects of life. To achieve the crucial but potentially conflicting goals of assuring health and safety on the one hand and maximizing development on the other, people have to communicate. While awareness of the importance of transition has increased, the reality is that the experiences of families working toward these goals are often reported as negative and unproductive.

“Probably the most unmistakable challenge faced by parents trying to plan for their child’s transition from school to adult life is the difficulty of learning, accessing, and relying on service delivery systems designed to support them. Parents’ reports of their experiences with systemic challenges fell into three main categories. They perceived service delivery systems to be: (1) inconsistent, (2) complex and uncoordinated, and (3) unresponsive.”²

The parent of a **young** child with special health care needs, while dealing with many challenges, can still look to a “road map” and structure for how their child’s early years will unfold. For example, there are mandated services such as Early Intervention and federal laws that guarantee a public education up to 22 years of age. However, once that child becomes a young adult, the continuation, availability and coordination of resources, services and supports are not guaranteed. Entitlements are gone, agency communication and funding are lacking and “no one is in charge.” For families and youth, this loss of structure and supports makes planning very difficult. Even parents with considerable knowledge of the “systems” and with connections to existing resources report that the transition process is far from smooth. What’s more, as young adults reach the age of majority, they emerge into new roles and legal realities. Consideration must also be given to those youth with SHCN who, while they may not require special education in terms of specialized instruction, may benefit from special education in the form of related services such as OT or PT, or may only require accommodations that can be made outside the parameters of special education, such as extended time for testing, to fully participate in educational programs. As these youth transition to adulthood -- to post-secondary and employment arenas, they will continue to need accommodations and assistive technologies.

Providers familiar with the challenges of transitioning youth speak repeatedly of the heroic contributions of families in dealing with services and systems that are not “family-friendly” and where agencies that are involved do not talk to one another. Outcomes are too often associated with the parents’ ability to advocate on behalf of their young adult and are complicated by the reality that there is little consistency from one school system to another or one region to another. And, while the local education authority is the responsible party while the youth is in school, on leaving the public school system, there may well be no one agency outside the school responsible or familiar with the young person. “It’s like falling off a cliff” is the expression often used by families to describe the phenomenon of turning 22.

Throughout the United States, primary responsibility for helping youth with special health care needs in transitioning to adulthood belongs to the local education authority as mandated by federal law, the Individual with Disabilities Education Act Amendments of 1997 (IDEA ‘97). The law defines “transition services” and dictates not only the nature of the services to be

² “Who’s going to do this when I’m not around? Parents of young adults with special health care needs speak out on transition”, ICI 1997, Jaimie Ciulla Timmons, James P. McIntyre, Jr., Jean Whitney-Thomas, John Butterworth, Boston, MA

provided but also the type of planning and documentation required in a student's Individualized Education Plan (IEP). The IEP's statement of transition services must address the process promoting movement from school to post-school activities, including postsecondary education, vocational training, integrated employment, continuing and adult education, adult services, independent living (including medical services and care) and community participation.

For those students with special health care needs who do not require an IEP, the Rehabilitation Act Amendments of 1973 becomes the relevant law dictating transition provisions. Such a student is described as having a "504 Plan." Each public school should have a person (usually an assistant principal or a guidance counselor, but not a special educator) who serves as the school's "504 Coordinator." The 504 plan addresses reasonable accommodations, modifications, or auxiliary aids which will enable the student to participate in and benefit from the educational program. This does not include transition planning.

In Massachusetts, a law known as Chapter 688 - often referred to as the state's "Turning 22 Law" - provides an additional set of protections and serves a certain percent of more significantly disabled students who will continue to need assistance after the age of 22. Services needed, however, are not entitlements and are subject to appropriation. Many families report difficulties not only because there is no funding (or due to long waiting lists), but also because state agencies may not agree on which is the appropriate lead agency (e.g., Department of Mental Retardation vs. Massachusetts Rehabilitation Commission). Considerable time can be spent in making this determination before *any* services can be provided. What's more, there are many youth with special health care needs whose needs, while significant, do not meet the criteria for a state agency and they, in a word, "fall through the cracks."

Are Transition Services Working?

As noted above, the local education authority is the responsible party with respect to the provision of transition services and the development of transition plans. In 1995, the federal Office of Special Education Programs (OSEP) in its audit of the Massachusetts Department of Education (DOE) found the state to be in non-compliance in a number of areas related to transition. This 1995 audit was followed by a "validation study" by OSEP in 1999³ in which OSEP cited continuing areas of noncompliance. These areas were: failings related to inclusion of a statement of transition services in the IEPs of students with disabilities, indicating that students aged 16 or older are not receiving appropriate transition planning; failings with respect to including, or otherwise getting to the table, outside agencies in the planning of transition services for students with disabilities; failures related to inviting students with disabilities, 14 or older, in planning of transition services for themselves through the IEP meetings; and finally, failures of public agencies regarding statements of transition services and their relationship to the student's course of study.

The Massachusetts Department of Education (DOE), in a 2003 response to OSEP about its findings, described steps in place to increase student access to regular vocational education programs and to improve the state's performance on the requirement for IEP teams to consider the student's course of study in relation to the student's future goals. DOE reports that there are

³ OSEP'S Report on the Monitoring of Massachusetts, VIII. Part B: Secondary Transition, www.doe.mass.edu/sped/osep/2000/8b.html.

now high levels of compliance in ensuring that outside agencies likely to be providing or paying for post-school activities are invited to the IEP meeting.

In Massachusetts, all public high school students are required to pass the Massachusetts Comprehensive Assessment System (MCAS) in English and mathematics in order to receive a high school diploma, no matter their high school grades and performance. The DOE allows students a variety of accommodations (e.g., scribe, calculator use -- if these are accommodations the student routinely uses in school) and has developed a portfolio approach (known as the MCAS Alternate Assessment) for students who, because of their disability, are unable to demonstrate their competency by way of a standardized test. However, as with the mandates of the federal "No Child Left Behind Act" of 2001, the MCAS requirements leave many students with disabilities and special health care needs at a real disadvantage. Accordingly, there is a dramatic effect on these students' futures if they are unable to obtain a high school diploma.

Another recent report, "Higher Education Opportunities for Students with Disabilities: A Primer for Policymakers"⁴ produced in 2004 by the Institute for Higher Education Policy, finds that only 57% of youth with disabilities achieve standard high school diplomas that prepare them for college admission. "Students with disabilities face very fundamental challenges, including inadequate academic preparation in K-12 when compared to their peers without disabilities; lower academic expectations; inferior pedagogy and services; and the lack of full access to the general curriculum." The study finds that while statistics for students with disabilities completing high school are improving, they are not provided the counseling required for the transition to a dramatically different culture and system of higher education.

The National Longitudinal Transition Study (NLTS) was undertaken by OSEP in 1985 through 1993 to examine what has been the impact of IDEA, the No Child Left Behind Act and other state and local initiatives on improving outcomes for students who receive special education services in middle and high schools. This initial study has been followed up with the National Longitudinal Transition Study-2 (NLTS2), initiated in 2000 with data collection continuing for 10 years. While there are many findings and reports emanating from these two studies, a May 2004 report, "Services and Supports for Secondary School Students with Disabilities," documents that **schools overwhelmingly function as the primary source of information about related services**⁵. Parents of 81% of youth with disabilities report learning about services from their children's schools. Schools also provide service coordination for four to six times as many youth with disabilities as do other professionals or family members.

Another recent national survey has, for the first time, documented the extent to which transition services are in place and are helping teenagers with special health care needs to become adults. From October 2000 to April 2002, the national Centers for Disease Control and Prevention (CDC) conducted the National Survey of Children with Special Health Care Needs (CSHCN).

⁴ "Higher Education Opportunities for Students with Disabilities: A Primer for Policymakers", Institute for Higher Education Policy, Washington, D.C. , 2004, funded by the Ford Foundation.

⁵ Related services, as defined by this study are: assistive technology, audiology services, career counseling, help in finding a job, training in job skills or vocational education, medical services for diagnosis or evaluation related to a disability, nursing care, occupational therapy, orientation and mobility services, physical therapy, psychological or mental health services or counseling, a reader or interpreter, respite care, social work services, speech-language pathology or communication services, transportation because of a disability and tutoring.

Using the Maternal and Child Health Bureau definition for CSHCN⁶, this survey established uniform state, regional and national prevalence estimates for CSHCN less than 18 years of age with existing special health care needs. The parent or guardian who knew the most about the child’s health and health care provided the information, and 750 CSHCN interviews were completed per state. The survey found that nationally 12.8% of children have special health care needs and that 20% of child-caring households have a child with SHCN. In Massachusetts, the percentage of children with SHCN was slightly higher, at 14.6%.

The survey measured progress in achieving five of the six core outcomes. (Outcome #4, “Children will be screened early and continuously for special health care needs,” was not included.) Achievement of each of these outcomes is detailed below, nationally and in Massachusetts.

Outcome	National % (Families reporting that outcome has been achieved)	Massachusetts % (Families reporting that outcome has been achieved)
1. Families of CSHCN will partner in decision-making and will be satisfied with the services they receive.	57.5	64.4
2. CSHCN will receive coordinated, ongoing comprehensive care within a medical home.	52.6	61.0
3. Families of CSHCN will have adequate private and/or public insurance to pay for the services they need.	59.6	65.1
5. Community-based service systems will be organized so families can use them easily.	74.3	79.0
6. Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work and independence.	5.8	See discussion below

The survey results for this sixth outcome in Massachusetts have not been included above for two important reasons:

- The number of respondents in each state who answered this question was not large enough to meet the standards for reliability or precision set by the National Center for Health Statistics. The relative standard error is greater than or equal to 30%. Questions

⁶ Children with special health care needs (CSHCN) are defined by the Department of Health and Human Services as “... those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”

on transition were added late in the survey and the questions applied to only a subpopulation of CSHCN. As a result, state numbers are small and not statistically reliable.

- The survey framework does not allow for interviews with families of youth older than 17 or of youth themselves even though transition services apply to youth up through the age of 22.

Even without reliable data on transition in Massachusetts, analysis of the data indicates that the number who responded affirmatively to the question about receiving necessary transition services is as low in Massachusetts as it is in the other states.

A striking feature of the data is that while there is clear progress towards achieving the other four outcomes, transition services stand out as an area of deficiency. (It is important to emphasize that, as noted above, the survey framework did not allow for interviews relating to youth over the age of 17. Transition services provided through public schools for students with Individualized Education Plans should start at age 14 and may continue through the age of 21. Accordingly, these services probably become more prevalent for students 18 and over. Even so, anecdotal reports substantiate the measured poor performance on this outcome.)

The Special Population Surveys Branch of the Department of Health and Human Services also looked at the data results in terms of the role played by doctors in preparing a young adult (age 13-17) for transition to adulthood. Respondents answered questions about whether doctors talked about changing needs as a child becomes adult, and about whether doctors discussed the shift to an adult provider. The affirmative responses to these two questions were 50% and 42% respectively on a national level, suggesting considerable room for physicians to play a more active role in the transition process.

Current State of Transition Services in Massachusetts: 2003

“Transition-Related Activities and Resources in Massachusetts: A 2003 Sampling,” (Appendix A) describes a range of activities across the state that address key aspects of transition, including: health care, education, employment, recreation and independent living. The appendix covers activities that provide general information and supports as well as those which are more specific in scope. Some of the programs are designed for parents and others are for young adults. This appendix was compiled by the Transition Task Force in Fall-Winter 2003-2004 in an effort to document programs in place across the state that address transition needs of families. However, limited information was available on activities outside the greater Boston area.

It is important to note that the sustainability of transition programs is a real concern. Depending on state and federal funding initiatives, Massachusetts has been able to support particular transition programs which have now been “retired.” For example, the Maternal and Child Health Bureau, Health Resources and Services Administration supported the Massachusetts Initiative for Youth with Disabilities (MIYD), a Healthy and Ready to Work project of the Massachusetts Department of Public Health from 1997-2001. The objective of MIYD’s Medical Transition Project was to design, pilot and evaluate strategies to promote the transition of patients with disabilities and chronic illness from pediatric to adult medical care. Barriers and facilitators to transition were identified and a set of materials was developed. This project supported the development of a booklet for providers, “Transition Planning for Adolescents with Special

Health Care Needs and Disabilities: A Guide for Health Care Providers.” A companion piece for families was also developed. A recent check with Children’s Hospital, Boston about the current status of transition projects at the hospital indicated that many of the pilots that were undertaken under the MIYD project were not fully integrated into clinical practice, although some significant steps have been taken by individual providers. For example, one clinic serving adults has hired a nurse practitioner to help with older youth and has established relationships with providers serving adults at another medical center. In another case, a pediatrician serving children with SHCN has prepared materials for distribution to families addressing transition topics. Efforts to disseminate the excellent booklets developed for providers and families have not continued.

Summary of Findings

The findings and recommendations presented below have been developed over the course of more than a year and derive from a number of sources and findings, beyond those cited in this brief. These include:

- An exhaustive review of web-based resources, project reports and published resources (local, state and national).
- Conversations with family members and other specialists from a variety of fields (health care, disability and special education among others).
- Discussion among the members of the Transition Task Force (see Appendix B for a list of Task Force members). This Task Force was formed for the express purpose of evaluating the state of transition services in Massachusetts, preparing this brief and making recommendations to the Massachusetts Consortium for Children with Special Health Care Needs related to transition activities.

The Transition Task Force’s conclusions are as follows:

- “Transition Services” is itself a **confusing** term. The term implies a large, complex set of activities and planning. It also means different things to different people at different times. Because “Transition Services” for a young adult with special health care needs is *not* a concrete set of activities and because there is no single system (e.g., health, education, social services) responsible for addressing transition needs, approaches for optimizing transition to adulthood remain elusive and confusing.
- The existing **state service systems** which support adults with special health care needs tend to serve those who have **more involved** conditions and more constant support needs. Young adults who require fewer or periodic supports to maximize their autonomy are much less likely to receive state agency supports.
- Where there are transition-related initiatives, they are sporadic, fragmented and, for the most part, driven by temporary funding. The changing priorities of state and federal funding **challenge the sustainability** of programs whatever their findings and outcomes.
- Families find planning and preparing for their child’s adulthood **overwhelming and often unsupported**. Families’ limited knowledge of “next steps” is compounded by the reality of the limited availability of services for their adult children.
- Transition planning should be as **varied and unique** as the individuals themselves. There is no one “recipe” for preparing for adulthood.

- Transition is very **different for each child** depending on his/her level of physical, cognitive and/or medical and mental health issues. Achieving successful transition is more challenging for young adults with more complex conditions.
- Federal education laws require public schools to work with young adults and families around transition planning. **Even with the impetus of federal law** and with transition training programs for families, too many youth with special health care needs who are entitled do not receive the help needed to prepare for successful transition.
- Although they are not well versed about inclusive education or transition, **primary care providers are a constant, respected and important influence** in the life of children with special health care needs and their families. The medical universe offers opportunities for making positive interventions in transition planning.
- Care coordinators are one set of providers who interface frequently with CSHCN and their families. Since **good care coordination should include attention to transition issues**, there is a need to enhance the knowledge and skills about transition planning and resources of those who work as care coordinators.

What can the Massachusetts Consortium for Children with Special Health Care Needs do to Support Transition for Youth with Special Health Care Needs?

The Transition Task Force recommends that the Consortium focus its efforts to improve transition services by strengthening the capacity of existing care coordination services in this area. The Consortium should seek funding to develop and deliver a curriculum and training for care coordinators and case managers who are in contact with families across multiple systems of care. Training materials should include: timelines, mandates and entitlements of the transition planning process and a comprehensive review of the resources available. Training would seek to involve care coordinators from a variety of settings: hospitals, doctors' offices, state agencies, health plans, Medicaid, and MASSTART (Massachusetts Technology Assistance Resource Team). The specific features of the training initiative would include:

- A "Transition 101" workshop, which will help care coordinators find what they need and focus on the uniqueness of each individual's planning process. The curriculum should emphasize personalized planning for individual youth and highlight the importance of partnering with schools, family organizations, state agencies and others to ensure prompt follow-up on action items in a transition plan.
- A conference for parents, care coordinators and others to network and learn about approaches and resources for transition planning and post-school opportunities
- Piloting, demonstration and evaluation of the effectiveness of such a training program.

APPENDIX A

Transition-Related Activities & Resources in Massachusetts: A 2003 “Sampling”

NOTE: *The purpose of this attachment is to provide a sampling of the types of transition activities that took place in Massachusetts in the past year. These activities were identified through web searches, newsletters from family organizations, newspaper articles, “word of mouth,” telephone conversations and a listserv query. There are a host of other resources available to transitioning youth: national associations (such as the National Center for Secondary Education and Transition, the Association on Higher Education and Disability) and published materials, which are not detailed in this brief because of its Massachusetts-specific focus.*

The activities below have been divided into categories, although the programs are not always clear-cut. Some are specifically oriented to young adults, while others are more informational for youth and their families. Some are open to anyone interested, while others are geographically determined or have other criteria for participation.

General Information/Education about Transition

- **“Financial Planning for Special Education Families”** a seminar for parents. Speakers presented information on making college a reality, taking care of adult disabled children after the parents are gone, avoiding asset disqualification, long-term issues and avoiding delays in probate. Workshops like this take place on an intermittent basis, driven by the interests and needs of support and other groups. *Arlington Special Education Parents Advisory Council (PAC).*
- **“Planning a Life: Make the Most Out of High School,”** October 3-4, 2003, Andover. Sponsored by *Mass Families Organizing for Change, Federation for Children with Special Needs, Autism Support Center, East Middlesex ARC.* This conference was for parents with plans for follow-up workshops on topics identified by participants as priorities and a workshop for students on self-determination.
- **“Tools for Transition: Building a healthy tomorrow for young adults with disabilities and special health care needs,”** a one-day workshop held November 1, 2003, South Dennis, Massachusetts for parents and young adults. Sponsored by *PEP (People Empowering People; Cape and Islands coalition), DMR, DPH, Mass Family Voices, Kennedy Donovan Center, PYD, Cape Cod Medical Reserve Corps.*⁷

⁷ A survey was given to parents at this conference asking on which transition-related topics they would like more information. 13 parents completed the survey. Topics of greatest interest (in decreasing order) included: housing options, support services, post high school educational options. Parents reported that their young adults most needed: recreation opportunities, social activities and friendship opportunities.

General Support for Transitioning Youth

- **Mentor Match Program** arranges one-to-one relationships between young people and adults with similar disabilities. Matches are not limited to adolescents. *Partners for Youth with Disabilities (PYD)*.
- **Partners Online** was created to enable youth and adults with disabilities to share resources, advice and encouragement through a mentoring relationship. *Partners for Youth with Disabilities (PYD)*.

EDUCATION (High School and Post Secondary) related

- **“Alternative Strategies for Transition from School to Adult Life.”** The intent of the Alternative Strategies course, funded by the *Massachusetts Department of Education for general and special education teachers*, is to provide participants with a framework for the multiple issues that high school students, their families and their teachers must address in order to prepare students for successful postsecondary employment, education and community membership. (Institute for Community Inclusion at UMass Boston and Hampshire County Educational Collaborative in Western MA offer similar workshops.)
- The **Transition Workshop**, with a primary focus on education, lasts about two hours and provides basic information on the state and federal laws that require the IEP to address goals such as competitive employment and independent living. This is intended to assist students 14 and older with planning transition to adult living. This workshop is offered by the *Federation for Children with Special Needs* across the state, about 25-35 per year. The Federation has also developed a Transition Workshop curriculum and offered a “train the trainer” opportunity in Boston and Worcester in an effort to maintain a statewide network of transition trainers. To date, 30 have participated..

HEALTH related

- **“Every Child Deserves a Medical Home,”** a Medical Home training program for physicians and other medical providers; addressing all aspects of transition among other topics. Held November 2003 in Springfield and hosted by the *Massachusetts Department of Public Health (DPH)*, the *Massachusetts Chapter of the American Academy of Pediatrics* and others.
- **“Making Healthy Connections,”** a series of interactive discussions and recreational activities designed to help adolescents and young adults prepare for adult life, with a particular emphasis on health, self-management of health care, and transitioning to adult health services. Sessions are being conducted in the Boston and Springfield areas. Hosted by *Partners for Youth with Disabilities (PYD)*.
- **Outpatient clinic for adult patients with disabilities** who are also mentally retarded. They are eligible to receive routine check-ups and use the dental and eye clinics at the hospital. *Franciscan Children’s Hospital, Brighton, MA*.
- Workshop, **“Sexuality and Disability through the Life Span.”** Offered by the *Jewish Community Centers of Greater Boston (JCC)*.
- **Transition to adult health care:** The same hematologist cares for young adults with sickle cell, hemophilia and thalassemia when they become adults. *Children’s Hospital, Boston* and *Brigham and Women’s Hospital*.

- **“Youth and Family Perspectives on Transitioning to Adult Health Care.”** A webcast on November 17, 2003, from the *National Center for Cultural Competence (NCCC)*.

EMPLOYMENT related

- **Employment-related services for individuals who want to secure and/or maintain employment.** For young adults in particular, school-to-work services are offered which are self-paced and emphasize social and work-related skills critical to getting and keeping a job. Summer computer classes are also available to help reinforce educational and social skills. *Easter Seals of Massachusetts*.
- **“Living, Learning and Leading - Mentoring for Youth with Disabilities.”** For youth with disabilities ages 14-22, this grant funded program pairs a career support mentor with a young adult volunteer. The overall goal of the program is to give young adults a real world experience as they start to explore their career interests. Through this experience they will start to build their own personal networks that will serve as a stepping-stone to employment. *Jewish Vocational Services of Boston (JVS)*.
- **Peer Leadership Program** provides ongoing opportunities for young adults with disabilities to develop leadership and job readiness skills through involvement in group mentoring and after school community service. *Partners for Youth with Disabilities (PYD)*.
- **“Transitions from School to Work: Exploring Paths from Dependency to Self-Reliance for Young Adults with Disabilities.”** -A Panel Discussion and Opportunity for Networking, October 8, 2003. The panel and discussion highlighted the tasks and obstacles young adults with disabilities encounter on their journey from school to the world of work and identified resources and programs available to help them move from dependency to self-reliance. *Cambridge Commission for Persons with Disabilities*.
- **“Transition Planning and Introduction to Adult Issues: Employment 101,”** May 18, 2003, presented by the Director of Job Readiness and Job Placement Services for people with disabilities from Jewish Vocational Services. This one-time program, open to members and non-members alike, provided important information for parents to plan for the employment needs of students with disabilities transitioning from school to adult life. *Yesodot*.
- **“When Existing Jobs Don't Fit”** - a two-day seminar on what to do when "pre-existing" job openings often do not meet the needs of individuals with significant barriers to employment. Attendees learn how to work with employers to restructure jobs and maximize creativity in the job development process; **“Job Accommodations for People with Disabilities”** is a one-day workshop that provides an overview of accommodations from the no-cost simple solutions to the "high tech." Legal and practical realities of requesting accommodations from employers are also addressed. Workshops such as this are offered for a fee on a rotating basis by the Institute. *Institute for Community Inclusion (ICI) of Boston*.
- **Young Entrepreneurs Project** is an ongoing business program for high school students where they are encouraged to further their exploration of career, educational and business pursuits with the help of adult mentors. *Partners for Youth with Disabilities (PYD)*.

RECREATION related

- **Access to Theatre** for teens 14-19 provides an opportunity for youth to explore all phases of theatre including theatre games, acting, directing, improvisation, storytelling, choreography, movement, music, costume, props, set design and more. Youth meet in both large and small groups with the artistic director and with other artists throughout the year. Participants develop everything from original stories, dialogue, and music sound cues to figuring out how to build accessible sets. *Partners for Youth with Disabilities (PYD)*.
- **Backpacking Trip in the White Mountains, NH** for youth age 13-18. Learn skills necessary to plan your own adventure including map reading, campsite selection and proper use of gear. **Ropes and Rocks** teaches climbing skills to individuals age 18 and older. Outdoor Explorations (OE) works to challenge perceptions and change lives of people with and without disabilities through shared activities in the outdoors. In 2003, OE served over 1,000 with one-day clinics and multi-day overnight trips with activities such as kayaking, backpacking, sailing, rock climbing, whitewater rafting, snowshoeing, and community service. OE is the only outdoor education provider in New England that specifically designs its programs for people of all ages, with and without cognitive, sensory, physical, mental, and multiple disabilities. *Outdoor Explorations*, a Boston area program.
- **High-Challenge sports** for children and adults with disabilities. Daily, weekly or summer long programs to the community-at-large and through affiliations with camps, schools and hospitals. Depending on location, students may be involved in an intense weeklong program, a day-long program or weekly training sessions throughout the summer. *AccessSportAmerica*, a non-profit organization.
- **Junior Springboard**, a social club consisting of adults and adolescents with learning disabilities or Asperger's Syndrome. Its main purpose is to foster social relationships between its members by providing fun, interesting, recreational, cultural and educational activities. In the process of participating in activities and socializing with peers, members learn skills to help them better handle a variety of social relationships and situations. Springboard currently has over 100 members from eastern Massachusetts. *TILL (Toward Independent Living and Learning)*, a non-profit human services agency, Dedham, MA.
- **“Leadership Development in Sport and Inclusive Recreation for People with Disabilities.”** The program included inclusive outdoor recreation and education programs, adapting current programs, community recreation and sport programs and designing youth activities. There were also demonstrations of adaptive programs. *United States Sport and Wellness Center (USSWC) for Persons with Disabilities of Springfield College* in conjunction with the *Massachusetts Governor's Committee on Physical Fitness and Sports*:
- **Pre-Teen and Teen Friendship Group** - Opportunity to meet new friends for social activities at the JCC in the community. *Jewish Community Centers (JCC) of Greater Boston*.
- **Teen Support Group** - for teens with diabetes ages 13 to 17. Participants meet monthly, and have fun going to see movies, eating out and meeting new friends with diabetes. *Diabetes Association*.

- **Universal Access Programs** at state parks across the state: Accessibility to State Parks is achieved through site improvements, specialized adaptive recreation equipment, and accessible recreation programs. *Department of Conservation and Recreation (DCR)*.
- **Various recreation programs:** The Mass Hospital School, located in Canton, offers a variety of recreation programs, all of which are available to those who attend the school and some of which are open to others in the community and in Plymouth County. The department is called on by many communities to consult on adapted physical education for children with disabilities. 135 students from fourteen different communities use the school's Olympic size and fully accessible pool as part of a program called "Swim with a Special Child." Other community programs include: after-school recreation program, a Saturday Special Swim Program, and an eight-week summer program. *Massachusetts Hospital School (MHS) Recreation Department*.

Independent Living

- **Community Attainment and Transition Program (CAT)** offers specific courses as well as community-based education and employment opportunities to students who have a range of disabilities and are preparing to transition to adult services or independent living as adults. CAT focuses on getting students competitive jobs, community volunteer experiences, relationships and sex education, independent living classes and overnight stays in a Real Life Learning Laboratory Apartment, community-based recreation and leisure experiences as well as connections to health care, service providers and other community services. *United ARC, Greenfield, MA*.
- **The Real Life Laboratory** is an apartment that is furnished and fully equipped in Greenfield. Students can sign up for overnight stays to "try out" living on their own. Upon arrival, each student completes a budget and schedule form to plan what he or she will do with their time and money during their stay. Students come and go from the apartment, having to plan their free time, budget their funds, and take care of their own needs while staying at the apartment. A transition coordinator stays in the apartment to facilitate student problem solving and, if the students request it, teach them new skills related to living on their own.
- **Housing Workshops:** available at no cost and scheduled on an intermittent, irregular basis by the *Jewish Community Centers of Greater Boston (JCC), Special Needs Services*.
- **Project Access World:** Serving physically challenged individuals up to age 22 who attend the school and other from the Plymouth County Region, this program provides comprehensive assistive technology to enhance the youth's self-reliance and functional independence. *Massachusetts Hospital School*.
- **Student Independent Living Experience (SILE):** SILE is an experiential education program designated to prepare physically disabled adolescents at MHS and at home to live as independently as possible. Students receive instruction and training in all skill areas that include health and self-care, personal care attendant management, advocacy, homemaking, safety, financial management, management of time including leisure time, and community resources. Students, sixteen to twenty-two years of age participate in SILE sessions ranging from one to three weeks and repeat sessions during the course of the year. The program serves patients/students of MHS. *Massachusetts Hospital School*.

- **Transition to Adulthood Program (TAPS), Ancillary Supports and the Supported Living Program**, serve young adults with more significant physical disabilities. *Massachusetts Rehabilitation Commission (MRC)*. MRC has three different programs serving transition-aged youth. Each is described in brief detail below. (In addition, MRC serves those with traumatic brain injury, some of whom are transition-aged.)
 - **TAPS:** This program contracts with Independent Living Centers (ILCs) to provide early intervention with students with physical disabilities who have mobility impairments. Most of the students receiving TAP services attend the Mass Hospital School in Canton but the TAP also works with students from public and private schools throughout MA. Experienced skills trainers, who themselves have a disability, provide advocacy, skills training and peer counseling to young people with disabilities in their school setting. The ILC staff coordinates with supported living staff at the time of transition to the community and on an ongoing basis, as needed. Four ILCs in the state (all in the eastern part of the state) receive funding to provide this program and serve about 100 students. The hope is to offer this program in all 11 ILCs in the state but funding has not permitted expansion of the program.
 - **Supported Living Program** is for individuals who are not yet age 22, are exiting from a Chapter 766 educational program, are their own legal guardian, have a severe physical disability with a mobility impairment and other challenges (cognitive; mental health) but do not meet the criteria for services from other state agencies such as DMH or DMR. MRC works with the individual to find subsidized housing and to provide case coordination services addressing the areas of daily life with which the consumer needs help.
 - **Ancillary Supports** are directed to youth leaving the *Mass Hospital School* or *Cotting School* who want to return home to live. This program provides **funds to purchase adaptive equipment** for items designed to increase a consumer's independence.
 - **Youth in Preparation for Independence (YIPI):** Boston area peer support program for adolescents, with a focus on developing self-advocacy and independent living skills. Each year's program has a theme with topical speakers. Parents of youth involved in YIPI have concurrent meetings, often with guest speakers on transition topics. *Partners for Youth with Disabilities (PYD)*.

POLICY AND PLANNING related

- **Regional Transition Training and Technical Assistance Teams:** a collaboration of representatives from state agencies, community organizations, educators and parents who have expertise and/or involvement with transition of students with disabilities from high school to adult life. Five such groups were established statewide by the Mass Rehab Commission in 1994 and continue to meet every two or three months. The mission of these teams is to promote, enhance and expand positive outcomes in transitioning to employment, post-secondary education and/or community living. This is accomplished through sharing of information, networking and providing training and technical assistance to professionals, families and young adults.

Other

- **“Each Child According to His or Her Ability: Preparing for the Bar or Bat Mitzvah of a Child with Disabilities.”** *Etgar L'Noar* and *Yesodot* (Special programs for Jewish youth with special needs.)
- **Facilitators who can lead families and individuals with a disability in planning for the future.** After developing a vision statement, a facilitator helps start a Personal Network of support for the person with a disability. The members of the network are supervised volunteers who work to help the individual realize his/her goals. ***PALS (Personal Advocacy and Lifetime Support, Inc.), Waltham, MA.***
- **“Religious Inclusion & Life Cycle Events,”** Part 2 of series "In Our Voices: Jews with Disabilities Share Life Experiences." ***Special Needs Professional Group of the Jewish Community, Newton, MA.***
- **Workshops on guardianship, financial/estate planning, transition** for people served by DMR. ***Charles River ARC, Needham, MA.***

APPENDIX B

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