

Creating Pathways for Transition

The CHOICES Transition Project
1996 - 1999

The CHOICES Transition Project is jointly funded by the
USDHHS Maternal and Child Health Bureau
Grant Number MCJ21HRW4
and
Shriners Hospitals for Children



The CHOICES staff offers special thanks to:

- **The participants in the teen, family, young adult, and staff surveys for their insights**
- **The presenters and participants in the three annual CHOICES Conferences for their time and expertise**
- **From Shriners Hospitals for Children Headquarters: Joseph Melchiorre, Jr., Executive Administrator; Dr. Newton McCollough, III, Director of Medical Affairs; and Kathy Achorn, Corporate Director, Hospital Support Services**
- **From MCHB: Merle McPhersen, MD, MPH; Bonnie Strickland, PhD; Tom Gloss, Project Officer; and Karen Etchinson, Grants Manager**
- **The CHOICES Transition Project Steering Committee members for direction and encouragement**
- **The staff of Shriners Hospitals and state Children with Special Health Care Needs and Vocational Rehabilitation agencies throughout the United States**
- **The staff of the Pilot Projects for their creativity and enthusiasm**
- **The staff of the Kentucky Commission for Children with Special Health Care Needs for administrative and technical grant support**

Healthy and Ready to Work Adolescent Transitions

Promoting a comprehensive system of family-centered, culturally competent, community-based care for children with special health care needs who are approaching adulthood and may need assistance in making the transition from pediatric to adult health care and to post-secondary education and/or employment.

The CHOICES Transition Project is one of nine projects in MCHB's Healthy and Ready to Work Network. Healthy and Ready to Work (HRTW) is an initiative of the Division of Services for Children with Special Health Care Needs (DSCSHCN) in the Federal Maternal and Child Health Bureau (MCHB).

Copyright and Distribution. This paper is not copyright protected and is available via the world wide web at www.shrinershq.org/choices

The authors and sponsors encourage readers to photocopy and distribute this document. Acknowledgment of the source of the material is appreciated. This document was supported through a Healthy and Ready to Work Grant MCJ 21 HRW4 from HRSA/DHHS/MCHB, Integrated Services Branch (MCHB Project Officer Tom Gloss), but does not imply endorsement of the funding agency.

Recommended Citation: Creating Pathways for Transition: The CHOICES Transition Project, 1996-1999. Kentucky Commission for Children with Special Health Care Needs and Shriners Hospitals for Children, Lexington, KY.

Project staff members are Kathy Blomquist, Carolyn Keller, Anja Peersen, Betty Presler, and Amy Stone

Contact the CHOICES Transition Project at choices001@aol.com

For more information contact the CHOICES website at www.shrinershq.org/choices

Creating Pathways for Transition

The CHOICES Transition Project

1996-1999

Transition is a commonly heard and popular term. What does it mean? The term transition really defines the process of life. We all experience the process of transition as we move from one stage in life to the next. Transitions can be both predictable and unpredictable. Our information, support systems, coping mechanisms, and resiliency all help us to negotiate the transitions in our lives. Transition starts at birth. Predictable transition milestones children make are moving from home to preschool, preschool to elementary school, elementary to middle school, middle to high school and high school to higher education, work, community life, marriage and raising children. Adolescence is a dramatic time of transition. For all teens moving from childhood to adulthood is challenging. For teens with disabilities the challenges can be more daunting and unpredictable. The developmental tasks that all adolescents need to accomplish in order to become self-directed adults can be greatly affected by how all aspects of disability are managed.

The CHOICES Transition Project was designed to look at ways to help children with disabilities and their families negotiate the developmental tasks in the transition process. The goals of the three-year CHOICES Transition Project were to work on strategies and develop model programs in pilot projects which build knowledge and experience in how to best help young people transition to adult health care and be healthy and ready to work and self-sufficient as they transition to adulthood. National meetings provided forums to disseminate transition-related information and promote exchange among professionals, young adults, and families.

CHOICES Transition Project Efforts

- ❖ The infrastructure of the CHOICES Transition Project is the CHOICES project. CHOICES, funded jointly by Shriners Hospitals for Children and the federal Maternal and Child Health Bureau from 1990-1997, developed collaborative relationships among Shriners Hospitals, state agencies for Children with Special Health Care Needs, and state Vocational Rehabilitation and Early Intervention programs. The program helps remove barriers and improves interagency service coordination and use of resources. Families receive expert inpatient services free of charge at Shriners Hospitals and community-based health services from the state agencies.
- ❖ In 1996, CHOICES expanded to include a transition focus when the CHOICES Transition Project grant (1996-1999) was initiated.
- ❖ The CHOICES Transition Project was also funded by Shriners Hospitals for Children (SHC) and the federal Maternal and Child Health Bureau in collaboration with state Children with Special Health Care Needs (CSHCN) and Vocational Rehabilitation (VR) agencies. The project had a national staff based at Shriners Hospital in Lexington, KY, which planned and conducted project activities on a national level and

coordinated with the four regional pilot projects. The CHOICES Transition Project is one of nine MCHB Healthy and Ready to Work projects.

- ❖ Initially during 1997, the CHOICES Transition Project staff conducted a massive national survey of teens, families, young adults, and staff (Shriners, Title V, and VR) to identify perceived needs and barriers to successful transitions. Respondents were 420 families, 484 teens, 197 young adults, and 1188 staff from SHC, CSHCN, and VR. These surveys of former patients and teens and families currently receiving care from Shriners Hospitals and state CSHCN agencies, and a separate survey of teens and families receiving care at the KY Commission for CSHCN support the need for programs to prepare young people for adult life. The survey data provide evidence that the young people served by Shriners Hospitals and CSHCN agencies want to increase their independence. Their families are supportive of this goal and want help. Staff express willingness to support transition but need training.
- ❖ Following this survey, in the late fall of 1997, four regional pilot projects were selected from proposals submitted from Shriners Hospital-state agency teams. Each pilot project focused on direct service or systems change to impact how young people with disabilities transition to adulthood.
- ❖ The CHOICES Transition project national staff conducted three annual national meetings to stimulate and promote transition efforts in Shriners Hospitals, state CSHCN and VR agencies across the country.

CHOICES Transition Project National Needs Assessment - 1997

***About the Teens Surveyed:** Respondents were 318 teens from 45 states and 166 teens from Kentucky with a broad range of disabilities. Median age was 16 (range 12-22). More than half lived in a rural area. 41% of the teens said they received help with the survey.*

What Did Teens Tell Us? Teens expressed high hopes for the future including going to college and getting jobs and their own places to live.

- ❖ Adult healthcare is an issue for teens. 42% expressed concern about where to go for quality care, how to find a new doctor, and knowing the options.
- ❖ When given a list of options, 89% of teens want to have a job in the next 5 years; 24% now have paying jobs and 63% have had volunteer or paid jobs.
- ❖ 65% of teens with disabilities do inside household chores and 29% do outside chores.
- ❖ Teens perceive their families (61%) and counselors/teachers/school/VR (35%) as most helpful in planning for the future.
- ❖ Teens and families differ in some expectations for the next 5 years. Families more than teens want teens to attend school-to-work programs or vocational technical school, work with VR for job training, make their own decisions, and live with family.
- ❖ Families and teens agree on attending college, managing money, driving, and being willing to have the young person move to take a job.
- ❖ Teens (more than families) want to get married and have children.

- ❖ Teens need opportunities to develop independence just like their siblings and friends without disabilities. Parents tend to compare their children with their siblings and friends.

About the Families Surveyed: Respondents were 297 family members from 45 states and 132 family members from KY. The median age of the children with disabilities in the national families was 17. The majority of families lived in a rural area (53%) and were Caucasian (69%); annual income was below \$25,000 for 43% of the national respondents. For the KY respondents the median age of children with disabilities in the families was 15, 77% were Caucasian, 69% were from a rural area, and 69% had an annual income below \$25,000.

What Did Families Tell Us? Families stated that they were willing to take on the responsibility for all transition issues, but they felt that they needed help from schools, health care professionals, and community agencies in managing new systems. Needs identified include financial, transportation, resources, guidance, and opportunities for their children to practice work and independence skills. Families do not know about community resources.

- ❖ 66% of families felt that health care systems should help with transitioning to adult health care. Less than 20% of families said they were getting help in the transition to adult health care.
- ❖ Families felt that it was appropriate for the health care team to help with: educational planning (78%), recreational and social activities (77%), and job planning (75%).
- ❖ Parents perceived the following barriers to health care: lack of money (61%); restrictions on healthcare programs/insurance (54%); and lack of doctors familiar with needs and care of CSHCN (37%).
- ❖ 47% of parents are concerned about finding similar quality and compassionate care after leaving pediatric providers and do not know how to find adult providers and help with care coordination.

About Young Adults Surveyed – Respondents were 136 young adults from 38 states with a median age of 24 (range 19-32) and 38% rural. The 61 respondents from the KY survey had a median age of 21 (range 17-43) and 48% were from rural areas.

What Did Young Adults Tell Us? Consistently the advice and personal experience for successful transition from the respondents were themes of strong family support, determination, self-advocacy, self-knowledge, and perseverance.

- ❖ Learning specific life skills and adaptations are important for independence; driving and/or transportation are particularly important for independence.
- ❖ Barriers to independence include parental protectiveness, fears, lack of motivation and lack of resources and school transition programs.
- ❖ Less than a third of respondents say they know their legal rights.

- ❖ About half of respondents say they are usually able to let people know their needs and thoughts.
- ❖ The long term health condition affects functioning in school (38%) less than in the workplace (54%), in daily living activities (59%) and social/recreation activities (64%).
- ❖ The survey respondents with disabilities were as successful in achieving a college education as the general population (20%).
- ❖ Compared to the general population the survey respondents are less likely to live independently and less likely to be working.
- ❖ About 60% of respondents earn less than \$10,000 per year.
- ❖ Respondents who were on SSI were much less likely to be working, especially full time, for all educational levels.
- ❖ Respondents who were on SSI were much less likely to be working even if they reported little need for assistance in functioning.
- ❖ While growing up, 75% of survey respondents did chores at home; however only about 44% had paid jobs as compared with 64% of general population of 15 year olds in the National Longitudinal Study of Youth (1997).
- ❖ Young adults lack knowledge about community resources so do not use them.
- ❖ Young adults with disabilities worry that their health will get worse (50%) and about their safety (40%).
- ❖ Barriers to health care include lack of doctors familiar with the condition (45%) and lack of payment source or restrictions of the health care program (40%).
- ❖ Approximately 2/3 of the respondents have a doctor for general care; less than half are receiving care from a multidisciplinary clinic offering access to the newest medical knowledge and referral to community resources.
- ❖ Only about 20% of respondents say that anyone in the Shriners Hospitals or state CSHCN agency health systems referred them to adult health care.

Advice from Graduates of Shriners Hospitals and the Kentucky Commission for CSHCN

- *Establish a relationship with a health care provider and learn everything possible about the condition, future needs and potential problems, and doing self care.*
- *When looking for work be positive, believe in yourself, have goals, work hard, and get an education*
- *Start early planning for your education, stay in school, do research on schools, careers, and financial and other types of aid.*
- *Do what you like to do rather than what others tell you to do.*

About the Staff Surveyed: The 183 respondents from Shriners Hospitals for Children (SHC) in 17 hospitals and 212 respondents from state Children with Special Health Needs agencies (CSHCN) in 30 states were predominately nurses (48%) and social workers (36 %). 27% of SHC respondents were therapists. The 793 VR respondents were counselors and administrators from 40 states.

What Did the Staff Tell Us? Staff repeatedly commented that transition programming should begin early through an interdisciplinary approach.

- ❖ Shriners, CSHCN, and VR staff think that it is appropriate for health care providers to be involved with families and teens in planning post high school education (85% state CSHCN, 78% Shriners, and 79% VR) and work (92% state CSHCN, 87% Shriners, and 86% VR).
- ❖ PACER findings indicate that adolescents want advice from health care professionals but are not getting much help. PACER teens ranked job training as their number one concern and wanted someone to talk with about this issue. Our survey shows that staff members are willing to offer more help to teens and their families if given some training.
- ❖ 76% of CSHCN, 73% of Shriners Hospital staff, and 64% of VR staff report that young people they work with have difficulty transitioning to adult health care and taking responsibility for their own health.
- ❖ 38% of state CSHCN staff and 29% of Shriners Hospital staff say they very often refer patients being discharged from their system to an adult health care provider (compared with the 12-23% of families and young adults who say they received a referral).
- ❖ Staff perceives the following as barriers to transition to independence: lack of transition programs in the school, parental protectiveness, fear by young person, lack of community resources, lack of motivation by young person, and lack of access to VR.
- ❖ Staff perceives the following barriers to adult health care: restrictions in health care programs, lack of funding, lack of collaboration among agencies, lack of follow-through by young people to seek care, lack of adult Primary Care Physicians familiar with special needs and failure of pediatricians to recognize and address transition.
- ❖ Other barriers to independence identified included: SSI and other financial disincentives, transportation, lack of coordinated services, and lack of preparation for young people.

We asked: “In what ways do you think YOUR AGENCY could help decrease barriers to independence for young people transitioning to adulthood?”

Respondents from Vocational Rehabilitation told us that counselors have been and see themselves as significant team members in the transition process. “We continually try to learn about new resources and coordinate service with others. In addition we are trying to increase our marketing to get the word out about services we offer.” A major theme is the need for interdisciplinary team communication and collaboration among agencies and

young people and their families. Categories of responses (in order of frequency mentioned) with representative comments from VR respondents include:

- ◆ **Closer relationships with the schools:** educate teachers so they refer students; help teachers understand disabilities and the accommodations possible so they develop expectations of students; transition programs for all students; teamwork with teachers and counselors; more extensive and better funded school-to-work programs; prevocational training; more on-job-training experiences in schools; more focus on vocational education and less on “college for everyone”; teach more independent living skills and advocacy; more contact with students by VR counselors and more direct VR services in schools; work focus early in curriculum; more creative job training experiences; contact with parents through PTA; get guidance counselors more active with children with special needs with aid from rehab counselors and special education teachers; encourage and assist schools and communities to work together during the transition into post-secondary education and/or the workforce; better identification of students not in special education in need of VR services; attendance is low at meetings of human service groups presenting information to students and their parents so need creative ideas for presentation of information; develop ability and desire in young persons to organize themselves and follow up on activities--only about a fourth of my clients follow up with VR after high school; some expect to have rent paid for them. Schools differ greatly in work focus and see transition responsibilities differently; school administrators should mandate VR involvement; schools have the power in transition programming.
- ◆ **Marketing VR services:** VR is a well-kept secret; market to target population in public and private schools, lectures, workshops for parents and young people on ADA, work; job fairs; market to department of education and medical society; VR videos in public libraries; educate businesses; posters, booths, promotional items, web sites; advertise at hospitals, clinics, schools; more in media about abilities of people with disabilities.
- ◆ **Community involvement and comprehensive services from a variety of sources:** develop alliances with supplies of goods and services for transitioning students; participate in interagency transition councils and interagency groups, mayor’s office task forces, transportation committees; create a seamless system of services for people with disabilities through liaisons with other agencies; develop resource manuals; facilitate interagency meetings; attend IEP meetings; participate in local Chamber of Commerce, centers for independent living and school-to-work for job shadowing; establish cooperative agreements between agencies, i.e. medical, dental, mental health, and other health care providers, Medicare, Medicaid, welfare, county hospitals, school district, state foster care, juvenile justice system, JTPA, mental health; train persons developing IEPs in what is available in community and how to implement change programs so they benefit students and don’t just fill spaces in file cabinets. Transportation is important especially after HS; clients need ability to drive and a vehicle. Real need for services for young people with severe disabilities when it comes to supported employment opportunities, job coaching, mentoring. More

socialization and recreation activities for young people who have graduated from HS—depression often sets in; need more services available for an unlimited amount of time which would provide long term supports; some think VR is the fairy godmother rather than a case manager. Too many agencies “take care of” rather than help clients to take care of themselves; clients actions often fail to match their verbal commitment. Costs of housing to live independently are prohibitive in some areas. Coordinated effort needed—people assume everyone else will provide necessary services and students fall through the cracks—people don’t ask because they don’t want to appear ignorant.

- ◆ **Start early in home and school:** all through life, children should be brought up with the expectation that they will work and everything will not be given to them; kids see themselves as more limited than they are; parents may not understand child’s real limitations. Offer orientation to VR in elementary school; help young children develop confidence in their abilities; help students with accommodations; talk about the benefits of working and develop work ethic; develop high expectations for young people; start placing more responsibility on the young people; monitor the progress and intervene if necessary to help with transition; let them make mistakes; educate young adults to advocate for themselves regarding hiring and being an active participant regarding accommodations; problem of parents with low abilities and low motivation; many families need time to understand and think about information. There are so many agencies giving information and services that it is confusing to families.
- ◆ **Education of families:** help families overcome overprotectiveness and create expectations for work; help families and young people learn to make needs known and learn to be self advocates; develop motivation for work; focus on abilities; look at preventive health care taught from young age. Some parents do not believe that the client is able to do any type of employment; many times it is harder for the family caretakers to adjust their roles than for the children/adults with disabilities; parents can be great motivators and advocates for children; some parents expect students with no training to walk into career jobs with great pay and benefits right after high school graduation; kids need to learn household responsibilities at a young age to prepare for work; some parents are most concerned with obtaining special education “rights” until client is 26 years old; they are often not willing to become involved in work situations until after the school is no longer involved to detriment of client; parents or others can coach the adolescent through the process until they are able to handle it on their own; this should be an ongoing process with the young persons having increased responsibility as they age. Parents are hesitant/afraid to relinquish responsibility or control; networking with other parents is helpful. Families should get idea that kids with disabilities can be valuable contributors to society.
- ◆ **More staff and more funding for VR services:** if VR caseloads are decreased, more time would be available to concentrate on transition; more VR staff in schools; counselors need special training for transition.

- ◆ **Systems problems:** get more physicians in the rehab field; reduce fees for services; lower insurance premiums, greater access to insurance coverage; make filing insurance claims less complicated; require insurance companies to provide better care—national problem; dental care not often available without insurance due to cost; families and young people need education regarding loss of health insurance benefits, when, why; brochures/education explaining options of health insurance and differences in coverage between traditional plans. Age restrictions for work doesn't allow for early exposure to world of work. Too much paperwork. Usually federal grant programs do training which is not integrated into school or service providers at expiration of the grant. Lobby congress to change laws; develop cash incentives for work; end SSI at age 18; focus on disability prevention services to decrease need for VR for people with disabilities.

- ◆ **Education of health care providers who could do more:** help providers address fears of young people and their parents about adult independence and work; work with managed care systems to see value of readiness to work; work with medical society so physicians understand what VR can offer; include the health care plan and prognosis in the rehab plan; health care providers usually have limited skills in determining the vocational implications of disabilities and are resistant to letting VR counselors be involved in vocational planning; too much medical model; health care providers are an excellent resource for VR counselors in determining limitations, stamina, family supports. Health care providers can help clients to see their aptitudes and accept their limitations; health care professionals could be contacted for their opinion of the client's physical/mental capabilities to meet the demands of a specific job after a complete job analysis has been done; health care team should concentrate on health care and recreational/social activities, as well as paying attention to obtain maximum health so client can work; health care providers need to help young people plan for appropriate career goals compatible with their limitations; there isn't enough communication between pediatricians, pediatric specialists, and the adult health care providers; need pediatricians to refer to adult MD and give information for a smooth transition. Involve VR counselors before discharge from hospitals; VR counselors can work in hospital settings.

- ◆ **VR counselors can help find adult health care.** Negative attitude of some MDs about caring for people with disabilities—have to because they have Medicaid/Medicare. Some MDs dominate planning meetings even though they do not have expertise; our doctors are good consultants on medical aspects of vocational planning. Social workers can look at complete picture and do services coordination. Policies for release of information (requiring notarizing) can be burdensome and delay services.

- ◆ **Make VR more “user-friendly”:** decrease agency lingo and paperwork; decrease bureaucracy; lift financial barriers; more individual counseling; ensure confidentiality.

- ◆ **Involve employers:** help young people meet expectations of employers! Involve employers in the teaching process and employer mentoring would be most helpful.

- ◆ ***People in need of VR services are a diverse group:*** transition planning must consider a range of skills, problems, and expectations of a variety of family, social, and professional groups and the cultural meanings of disability and work. Expectations and services from a variety of professions are important in transition and all must change in harmony. Forums can bring together families, young people, VR personnel, and advocacy groups. Families and professionals need to see the clients as adults, not perpetual children but give time to mature.

Comments from VR respondents reflect a commitment to working with young people.

“Transition is a process, not an event in time.”

“Jobs are an important aspect of who we are and how we feel about ourselves.”

“Be realistic, but emphasize need for meaningful work.”

“Young persons have an extremely difficult time transitioning to the adult system on their own; fortunately there are a wealth of resources to help them with the transition.”

Ways the CHOICES Needs Assessment Directed Project Activities

Finding	Activities
Families stated that they were willing to take on the responsibility for transition issues, but they needed help from schools, health care professionals, and community agencies. Over 50% said they did not know about VR, legal, employment, housing, independent living or adult health care providers.	Educational activities: posters, handouts Transition guidelines/screening tools/Life Maps/ teaching sheets: topics for staff to discuss with families when their children are young so they can begin thinking about independence and overcome overprotectiveness
Teens expressed high hopes for the future that included learning to drive, going to college, getting jobs, and their own places to live. Many express fear about becoming independent, concern about parental protectiveness	Teen areas with resources to learn about planning for the future. Teen camps to learn independence skills, talk with working people with disabilities. Involvement of parents in workshops to help them support independence and competence in teens.
Adult health care is a concern for teens and their families; who will be knowledgeable about them and how will they pay for it?	Staff training to talk with families and young people starting about age 16 about a PCP, insurance, options for care after SHC or CSHCN. Involvement of health care educational programs to expose students to young people with disabilities Conferences at SHC to train pediatricians, family practice docs, and internists about cerebral palsy, spina bifida etc.
Staff of SHC, CSHCN, and VR don't know about each other and many don't know about other resources in the community for transition assistance	Handouts, inservices, posters for staff CHOICES Annual meetings focusing on work, independence, resources for people from across the country in SHC, CSHCN, VR, parents, young people, and others. State interagency meetings.
Young adults gave themes of strong family support, determination, self-advocacy, and perseverance as reasons for success.	Transition guidelines to help staff work with parents early in their children's lives to increase parents' abilities to support independence in their children. Programs with young adults with disabilities to talk with and role model work and independence.
Young adults with disabilities are successful in post-secondary school but are not working to levels of non-disabled young adults	Find out why; offer vocational abilities testing and referral to VR; study disincentives of SSI and Medicaid system and support work incentives
Advice in moving to adult health care: keep up with health problems—your responsibility is everyday, doctor's is temporary; only you know what you are experiencing.	Camps and workshops to help teens learn about self care and disability management Handouts and posters Working with parents to help young people learn to take responsibility and learn cues about their own body and mind.
Staff have concerns about motivation, mental health, entrenched family patterns of not working	Develop programs for young people to learn social skills to be appropriate and successful at work. (i.e. mentorship program)

Collaborations for Successful Transition - Pilot Projects

Hawaii Transition Project

Shriners Honolulu Hospital and the Hawaii Department of Health Children with Special Health Care Needs Branch, Honolulu, Hawaii

- ❖ A major component of the Hawaii Transition Project is the E O’o me ka Pono (To mature with goodness and truth) Project, a patient transition program in collaboration with the Hawaii Center for Independent Living which provides mentoring opportunities to teens. The purpose of the program is to help patients adjust to their disabilities and to provide them with tools that will enable them to work toward adopting independent, productive lifestyles.
- ❖ Opening doors is the key focus for the mentor program. Activities are geared toward developing self-esteem, self-advocacy, and self-confidence. The first step of the program is to identify and match youth with mentors who are adults with disabilities who either work or attend school. The next step is to identify employment and educational opportunities for the youth. Besides the one-to-one long-term relationship with the mentors, the youth have multiple opportunities for group activities and social/recreational activities.
- ❖ A successful activity has been the nationally sponsored “Make a Difference Day” community service project in which the youth have participated during the last two summers. Proceeds from the group’s effort will fund supplies for children and families in shelters. This project gives the youth an opportunity to “give back” to others in need.
- ❖ Examples of other growth experiences by the youth include: job placements, obtaining a GED, enrollment in community college, volunteering, obtaining a drivers license, interpersonal skill improvement with peers and communications with adults.
- ❖ In a period of two years the project has developed a broad base of community agency support, involved local Shriners in a work mentorship component, promoted educational support for families and professionals, and provided adult health care through Queen Emma Clinic at Queens Medical Center for a “gap” group of young adults who have no source of medical coverage.

Intermountain Collaborative Transition Center Project (ICTC)

Shriners Intermountain Hospital and the Utah Department of Health CSHCN Department, Salt Lake City, Utah

- ❖ The goal of the ICTC pilot project is the planning and development of workshops for young adults and their families which focus on transition-related health care, future plans and connections to available resources. With the support of a broad community-based Advisory Board, the ICTC has become an active partner in community programming for young adults and families facing transition issues. Several program models and schedules were piloted to best meet the needs of teens and families. Input from participants was the guide for developing and fine-tuning the format and topics presented. One of the most successful workshops was the Information Fair which brought representatives from multiple community agencies together for a half-day fair

which gave participants the opportunity for individualized help. Teens and families have been surveyed to determine which disability topics are of most interest for ongoing workshops. To date popular topics for teens included self-esteem skills, dating and relationships, and independent living services. Preferred topics were different for parents and included how to find and work with doctors and health care providers, dealing with agencies, independent living services, and job skills. 21 young adults and 11 parents have been surveyed. Incentive tokens such as t-shirts and key chains were given to respondents. The ICTC will continue to analyze future surveys to determine what trends emerge.

- ❖ A major accomplishment for the Intermountain Collaborative Transition Center project was the May 1999 conference, *Transitions: Expeditions to the Top*, which was planned by the ICTC and co-sponsored by the Utah State Office of Education and Graduate School of Social Work, University of Utah. 475 educators, professionals, and a large representation of young people and families came together to discuss and learn about transition. This sort of community collaboration has been a major goal and cornerstone of the CHOICES model.
- ❖ An outreach effort is part of the original project plan to promote transition services through education and collaborative relationships with community-based services. During the fall of 1999, representatives for CSHCN from the local health department and Vocational Rehabilitation, Education (504) counselors and a parent representative trained in transition issues gave in-service programs in 14 rural communities covering the state of Utah. The main goal of this training was to facilitate community-based agencies working together to better meet the needs of young adults in their community.
- ❖ The ICTC has developed an extensive resource guide for professionals with nine transition domains of information designed for both the rural and metropolitan areas of Utah. Parent and youth transition packets have also been compiled.
- ❖ Promotion of transition from pediatric to adult health care will be a future focus.
- ❖ Shriners Hospitals are supporting transition services by funding an expansion of services in the Intermountain Hospital to continue community-based collaboration programs developed by the ICTC project.

**Kentucky WISH (Work, Independence, Self-Advocacy, Healthcare) Project
Shriners Hospital Lexington and the Kentucky Commission for Children with Special
Health Care Needs with central offices in Louisville, Kentucky, and 13 regional offices**

- ❖ The WISH pilot project is a system change project. Interventions focus on teaching staff, young people and families the skills needed to promote and achieve successful transitions.
- ❖ A major accomplishment of the project was the development and testing of transition screening tools which help CSHCN staff nurses and hospital outpatient clinic staff to screen for developmental variances and promote transition-related health care. These Developmental Guidelines, Life Maps, and Teaching Sheets were created for patients age 0-21. The bound manual, **CHOICES Transition Resources**, is available from the project.
- ❖ Staff comments about helping with transition include, "I try to empower them to do for themselves. I discuss with parents to allow their child to become independent." " I

am more conscious about identifying these kids, more familiar with programs, give better eye contact and 1:1 time”. “I think that independence should be started early on. By the time the kids are grown it is almost too late to begin fostering independence”. “WISH raised my awareness of the need to look at transition from birth rather than 16-18”.

- ❖ Another focus of the WISH project was the piloting of computer-equipped teen resource centers with internet access, job information, college guides, and test taking software. The resource centers at the Lexington Shriners Hospital and Louisville Commission Clinic are popular with teens and create interest in developing computer skills.
- ❖ Transition camps for children were piloted. Evaluation of the camps proved the benefit of hospital-based camps geared toward building independence and social skills through educational and recreational activities. Campers can progress to camps requiring more independence from year to year.
- ❖ Building on the CHOICES and WISH project collaborative activities in Kentucky, the Kentucky Commission for Children with Special Health Care Needs has been awarded a \$1.2 million grant from the federal Maternal and Child Health Bureau. The two goals of the 4-year grant are to increase the number of Kentucky children with special healthcare needs with medical homes and coordinated health care and to increase the number of Kentucky young people with special health care needs who are prepared for employment with health benefits.

**I CAN (Independence through CHOICES and Networking) Project
Shriners Tampa Hospital and the Florida Department of Health Division of Children’s
Medical Services, Tampa, Florida**

- ❖ The major thrust of the I CAN project is to provide direct service to young adults in the area of transition to adult health care and transition to work.
- ❖ Participants in this direct service project have had the opportunity to receive a thorough vocational workup by Abilities vocational evaluators. This testing results in a comprehensive written report with recommendations on how to reach the participant’s vocational goals. The reports are also used by the Department of Vocational Rehabilitation to help write the adolescent’s ready for work plan.
- ❖ In the second direct service component of this project, young adult Shriners patients are seen by a University of South Florida Family Practice physician for their initial transition work-up in the Shriners adolescent clinic and then seen in subsequent adult visits at the University of South Florida Medical Clinic by the same physician.
- ❖ An extra benefit of this pilot program has been the involvement of medical students in these transition visits which gives students the experience of interviewing young people with disabilities and learning about transition issues.
- ❖ The I CAN project has developed multiple transition resources for teens including a video library for use by young people, families, and staff.
- ❖ Children’s Medical Services of Florida will continue to financially support the transition to adult care component of this project when the CHOICES Transition grant funding ends.

Lessons Learned from Pilot Project Experiences

- *Building expectations for being healthy and ready to work must begin at an early age and be consistent with family values.*
- *Attitudes focusing on “disability” versus “ability” are hard to break.*
- *Listen to and understand the expectations of the families*
- *Work with families must be in the context of their cultural beliefs and at the families’ pace.*
- *Planning for the future is not a high priority for teens and families--they are oriented to the “here and now”.*
- *Parents and professionals need to “let go” and to promote adulthood for teens.*
- *Losing SSI and/or Medicaid health benefits is a negative consequence of working and can be a deciding factor in pursuing and/or accepting employment.*
- *Teens need to be part of the planning for teen programs.*
- *The small peer group process (i.e. in workshops, camps, mentoring) reinforces and promotes growth experiences.*
- *Maintaining the one-to-one relationship and experiences between youth and mentor is a real commitment that requires time, patience and caring. When this commitment to the process is mutual, results can be remarkable.*
- *A vehicle to promote adult health care services for young people with disabilities is through collaboration with teaching/medical centers and medical training programs.*

CHOICES National Annual Conferences

The CHOICES Transition project conducted three annual national meetings to stimulate and promote transition efforts in Shriners Hospitals, state CSHCN and VR agencies across the country. Underpinning all three of the national conferences was the goal of promoting collaborative relationships and care coordination among Shriners Hospitals, state Vocational Rehabilitation programs, CSHCN programs, Health and Ready to Work Network participants, and others involved in transition efforts at state, regional, and national levels. The first conference, held in Washington, DC, in September of 1997, focused on the roles different systems play in transition to adult health care, employment and greater levels of self-sufficiency. Regional groups looked in-depth at ideal images of transition systems and various barriers to successful transition. The second conference, in Chicago in June of 1998, highlighted the role of private business in employing people with disabilities. Young people with disabilities shared the lived experience of obtaining education, health care, employment and self-sufficiency. The third conference in Charleston, SC, in April of 1999 presented pilot project best practices and emphasized quality of life through recreational opportunities. Each conference was designed to arm participants with information and resources to incorporate into personal and professional planning and implementation for the transition process. A theme included in all presentations is that transition is a family-driven process with cultural and philosophical influences on choices made.

The following are key concepts that were interwoven through the conferences.

Culture of Disability:

- “Special” is a disdained word in the disability community. It means different or outside of mainstream. The disability community is broad, diverse, and different, and hard to pull together to get consensus on anything.
- The medical model (something wrong must be cured or normalized) is being thrown off for the social minority model (lack of access and fit into society). Everyone benefits from knowing each other, which rids us of thoughts that people with disabilities are less intelligent or less capable.
- The Americans with Disabilities Act is the culmination of efforts of the social minority model. It represents 20% of the population. It is the disability community’s agenda to nurture and protect the ADA because it has had a profound effect on quality of life. The ADA exists to assure equality of opportunity, full participation, independent living, and economic self-sufficiency.
- People with disabilities have unique skills: acceptance of human differences; matter of fact orientation toward helping and interdependency; tolerance for lack of resolution in life; the ability to laugh at themselves and their oppressors; and the ability to grasp latent meanings and contradictory messages from people they meet every day.
- The focus of services to people with disabilities should be on primary, secondary, and tertiary prevention of disabilities, on transportation (accessible mass transit), on housing (appropriate, affordable, accessible, not nursing homes), on access to quality health care and insurance especially for the working poor, on personal assistants and job supports, and on assistive technology that is portable.

Federal Programs:

- Federal partners include the Social Security Administration, Department of Education, and the Department of Labor, specifically the Presidential Task Force on Employment of Adults with Disabilities, the National Council on Disability, and the President’s Committee on Employment of People with Disabilities. The mission at this level is to ensure that federal programs and policies are conduits for transition rather than quagmires of poverty and dependence that trap people with disabilities.
- The President’s Task Force on Employment of Adults with Disabilities is working across agencies in the federal government to look at barriers to employment of people with disabilities and increase employment to levels closer to general population. 75% of people with significant disabilities do not work; many want to, but have to say they cannot in order to receive benefits. 130 federal programs in 19 agencies work in the areas of education, training, and employment for people with disabilities. \$400 billion per year is spent keeping people out of work. 4% goes to help people get jobs. Many youth who need vocational training and supports are not getting them because they drop out in 9th grade before transition interventions begin. Most are trapped in dependency.
- Recharting the Course (www.dol.gov) describes the actions needed by 2002 for a national strategy including buying into Medicaid, economic incentives to work and

“lifelong learning”, including academic, vocational, work-related, social, and self determination skills needed for jobs. We will gain billions of dollars through economic expansion and decreased use of public funds for welfare, food stamps, and disability benefits.

- Federal policy initiatives include: 1) make work pay by providing medical coverage and eliminating economic disincentives; 2) increase access to work through training; and 3) offer employer incentives through tax credits and disability diversity training programs. The Red Book from Social Security Administration (www.ssa.gov) describes the work incentives.
- Vocational Rehabilitation agencies offer packages of services which support attainment of an employment goal. The rehabilitation counselors can help find adult health care providers based on experience with physicians and clinics in the area.

Transition Services in Schools:

- Transition has been part of the law for 10 years (PL94-142, 1990). The IEP should include plans for after public school. Children have the right to go to public school from ages 3-21 in special education. Transition planning starts at age 14 and the IEP can be changed at any time. Included in the IEP should be plans for employment, living options, vocations, education, finances, managing money, transportation, recreation, fostering personal and family relationships, legal aspects and rights, and self advocacy. Young people must “buy in” to the IEP plans in order to make connections and achieve goals. The IEP is a coordinated set of activities to look at post-school outcomes. Students must be active participants.
- Educating children with disabilities has become adversarial and litigious. Some school systems try to avoid providing services mandated by ADA and IDEA.
- Transition necessitates communication, collaboration, and coordination of services, programs and supports so that by the time students are ready to exit the school system they are prepared to make the leap into the world of adult living and work. However, less than 20% of young people with disabilities are in special education and have IEPs; it is important for transition programs to find the other young people with disabilities to offer supports for readiness for work and independent living. 504 programs support health and transition services for mainstreamed students.
- Transition services should really be started at age 10-11 so children gain knowledge and skills so they are ready to try work at age 13, the average age of first work experience. Students who have paid work experience in secondary school are more likely to find paid jobs after leaving school. Vocational education appears to have a dampening effect on dropping out as well as benefiting other aspects of students’ school performance.
- School is a child’s first job and should be a place where normalcy and wellness are insured. In school are issues of attendance, work effort, increased responsibility, and advancement. Schools and health care providers working together can impact the knowledge and abilities of young people, promote work effort, increase responsibility, teach the language, responsibility, roles, and negotiation skills needed to advance. Children need to learn to take risks and the consequences associated with them. Teach children how to defend themselves against harassment and how to retort to comments.

Children should learn to talk about what they do well to express themselves in job applications and interviews.

- Home chores are important. Kids need experiences in the community using money, buying groceries, and interacting with people.
- Sports are great integrators; kids in wheelchairs can carry things. Athletes are good bodyguards.
- Use a learning coach model of teaching and parenting; focus on the desire of parents to do the best for their kids. Letting go is important for families, health and social service workers.

Employment:

- Employers want people with work experience, communication skills, and a positive attitude toward work. They want people who are prepared to be flexible in the ever-changing workplace. Part-time work during school years can be framed with career counseling.
- The economy is a full-employment economy. Employers are looking for workers. People with disabilities can offer employers their abilities if they are healthy and ready to work. However, although businesses are convinced that they should hire them, people with disabilities have not been applying for jobs. The bigger the company the more likely it is to have people with disabilities working in it.
- The first generation of kids with inclusive education and parents with advocacy skills is coming up. People with disabilities now are better educated and have grown up mainstreamed. With technology, rehabilitation engineering, creativity and flexibility, and involving employers early in the process, most people who want to work can. People with disabilities want to be included as much as possible in all aspects of work life so they can be successful and the company can be successful.
- There has not been a landslide of litigation in the disability policy area. Inexpensive accommodations have been found that reduce workers compensation costs, injuries, and enhance the workplace for all people. The average cost of workplace accommodation at Sears was \$40. The Sears and Manpower studies show that people with disabilities can do the work and accommodations made for people with disabilities help all workers.
- Temporary agencies can channel people into temporary and permanent jobs and increase visibility of the skills of people with disabilities.

Skill Development:

- Instead of a deficiency model, assume equality and an ability model; people just function differently. Young people should learn about their disabilities and how to explain them to others. For success young people need training for development of skills, strategies and techniques as well as encouragement and high expectations to develop a sense of confidence in themselves. Sometimes creativity is needed to think up solutions to problems. Teens can practice job interviews and asking for accommodations and practice talking to the doctor.
- Motivation and self-advocacy can be developed in the family as parents learn that they can expect that their children can and will be independent and will work.

- What do kids want? A job for MONEY! They will change jobs and careers frequently. Increased education increases the probability of working. Watch overprotectiveness and lack of planning. Employers care about attitudes, communication and work experience. Start early getting into the workplace; use the family-friend network.

Health Care:

- If a person has a job the motivation for health care is often “How can I manage my medical condition so I can stay on my job?”
- A number of initiatives focus on health care of children: The American Academy of Pediatrics’ Medical Home Program offers training programs for community physicians to become medical homes for children with special health care needs.
- Medicaid’s package of benefits is a standard of care on which to judge other health care plans. Particularly important are medications, durable medical equipment, transportation, and therapies.
- Transition to adult care includes continued communication with pediatric team which is important for young person, family and health care team members!
- Mental health problems—reporting varies greatly; maybe 25% receive treatment which could help in transition to successful adulthood. Risk factors include social rejection especially at transition to middle and high school with new groups of kids. Loneliness is common for kids with disabilities because of less mobility, later incorporation into peer group, fewer role models. Depression is a major problem for young people with disabilities; prevention, recognition, and treatment are important aspects of readiness for work and independence. Victimization occurs because young people with disabilities may be less able to articulate abuse situations.

Quality of Life:

- Recreation is a big part of our lives. Through recreation we learn skills to help us handle challenges of adulthood such as cooperation, how to set goals and work toward them, courage to try new things, perseverance, and self-discipline. Recreation provides an avenue to meet people and develop friendships, identify strengths in self, identify interests, discover who I am and who I want to be, and how to live with other people. Recreation enhances quality of life for everyone.
- Through camps children live with others, establish relationships outside of family, have opportunities to be independent. Camps provide parents with respite and opportunity to see the child as more independent. Local recreation departments, the American Camping Association, Kids Camp on the internet, and groups focusing on specific conditions such as the American Diabetic Association, Muscular Dystrophy Association run camps.
- Art is about betterment and understanding ourselves and our world, tolerance, appreciation of other’s views and cultures, problem solving, and is a powerful dimension in our lives.
- For families information is power. Families need to be empowered through information, choice making and advocacy. A successful transition is a family-driven process.

Collaboration:

- Partnerships of agencies are essential. Each agency does what it can do working toward a common goal. We are all interdependent. Included can be school-to-work, welfare-to-work, mental health, mental retardation, public health, departments of human resources, protection and advocacy, community services, insurance, transportation, local businesses, and the medical community.
- Parent Training and Information Centers (PTI's) are groups in all states run by parents to support families of children with disabilities. Use state PTI's and Family Voices as resources for developing services. Parents and young people with disabilities are effective trainers.
- Participate in advisory committees—it gives opportunity to work with others on their turf and builds expectations that they will help you when you need it. Get involved with organizations that are not disability focused to help those people see the possibilities of hiring people with disabilities. Learn the language of other professional groups.

Lessons Learned from the CHOICES Annual Meetings

- *Shriners Hospital and State Agency staff are concerned about transition to successful, productive adulthood for their patients/clients and have ideas about how this might be done.*
- *Since transition issues are being approached from the educational, vocational and health perspective, a coordinated approach is essential.*
- *Interagency meetings on the national, state, and local level can lead to better coordination of services; however transition programs involve groups and agencies which may not have worked together before, speak different languages, may not be family-focused.*
- *There needs to be a central person or group of people who help to maintain interagency linkages.*
- *Parent organizations have valuable knowledge and experience.*
- *Communities vary greatly in the resources that are available and the ways that resources can be mobilized and coordinated to serve young people during transitions.*
- *Funding streams dictate services that are offered.*
- *The business community is open to hiring people with disabilities. Being able to do the job is the issue. Actual costs of accommodations are minimal.*
- *The federal government is modeling interagency collaboration, communication, and planning in relation to adolescent transition.*
- *Currently with this administration there is strong support (through programs and legislation) for people with disabilities to be employed and to maintain their health benefits.*
- *The typical transition from pediatric to adult healthcare is uncoordinated and depends on a variety of factors (i.e. availability of specialist and/or general practitioner, type of insurance benefits, priority of health care for family or young adult).*

Examples of Transition Activities in Shriners Hospitals

- ❖ **Work Program - Chicago**

For the past two summers a work program for young adults that are patients at the hospital has been conducted. The work program gives the young adults that have committed to this program a paid work experience in the Chicago Shriners Hospital which is complemented by individual and group counseling, workshops and mentoring related to key transition issues of employment, independent living, financial management, health care and psychosocial development.
- ❖ **Camps - Greenville, Intermountain, Lexington, Portland, Spokane, St. Louis**

Several of the Shriners Hospitals provided summer camping experiences for young people. Some of the camping programs have been ongoing for several years. Other camps have only been piloted in the last year or two. Generally the camps are either specialty camps for children with specific diagnoses or transition camps geared toward giving young people tools for transition to adulthood. All camps strive to improve self-esteem, independence, and recreational experiences.
- ❖ **Weekend Recreational/Workshops - Springfield Shriners Hospital**

Healthy Connections, first held last fall and in the spring is a series of interactive discussions and social activities for adolescents and young people ages 15-21 with disabilities and/or special health care needs. These sessions held on Saturday afternoons are support/mentoring meetings with recreational activities, including a Harvest Ball in October. Session topics include: Orientation/Understanding Medical Needs; Talking with Healthcare Providers; Rights to Privacy; Independent Living and Adaptive Driving; Health, Fitness and Nutrition; Sports and Recreation with a field trip to a sports facility; Relationships and Sexuality; and Transitioning to Adulthood
- ❖ **Parent Advisory Board - St. Louis Shriners Hospital**

The Parent Advisory Council established in July of 1997, meets on a quarterly basis and is composed of four families and four or five staff members from various disciplines. This council is working on a parent newsletter and a video about a family's hospital experience and it also links parent advisors with specific hospital projects and committees. Parent advisors helped with a number of projects this year, including a new hospital video and the Cerebral Palsy Transition workshop held this past May.
- ❖ **Supports for Teens with Burn Injuries – Cincinnati Burns Hospital**

Teens are targeted for successful transition into the community through the school reentry program, identifying teens needing referral for transition-related programs in outreach clinics, the Teen Connection newsletter (available on the CHOICES website) and use of self-esteem posters in the hospital.

Examples of Transition Activities in Several State CSHCN and VR Agencies

- ❖ **A plan for transitioning from pediatric to adult health care** is included in the Family Support Plan for each patient of Children's Medical Service patient age 16-21 in Florida. CMS assists patients establish relationships with adult health care providers.
- ❖ **The Alabama Teen Transition Clinic** began in 1999. Children's Rehabilitation Services Youth Advisory Council has been formed. Multi-disciplinary transition clinics are now being held. CRS works with the Alabama Governor's youth leadership forum for students with disabilities. Youth with disabilities at age 16 are referred to VR.
- ❖ **In Washington, state contractors for CSHCN assure access to rehab services at the local level.** The Adolescent Health Transition Project provides training and education to a variety of providers and information and support to youth and families through their website.
- ❖ **Several states involved with CHOICES promotion of transition** including South Carolina, Mississippi, North Carolina, Tennessee, Missouri are setting up planning groups, organizing meetings or receiving inservice trainings.
- ❖ **Healthy and Ready to Work Projects are promoting collaboration between state agencies** in several states such as Hawaii, Utah, Kentucky, Maine, Iowa, Massachusetts, California, Louisiana, Ohio, and Oregon as well as developing model programs for transition.
- ❖ **A Healthy and Ready to Work Website will be developed by 2000.** This website will describe the projects, materials, and accomplishments in participating states in detail.

Sharing the Wealth of Resources

CHOICES Web Page www.shrinershq.org/choices contains Transition Project activities, outcomes, resources, products, and links to disability related information.

CHOICES Transition Project staff:

Carolyn Keller, Shriners Hospital Transition Coordinator

Kathy Blomquist, CHOICES Co-Coordinator

Anja Peersen, Kentucky Transition Coordinator

Betty Presler, CHOICES Co-Coordinator

Amy Stone, CHOICES Administrative Assistant

Contact us at (859) 266-2101 or e-mail choices001@aol.com

References Used in Comparative Analysis of CHOICES Summary Data

Blackorby, J. & Wagner, M. (1996). Longitudinal postschool outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children*, 62, 399-413. National Longitudinal Transition Study of Special Education Students; sample of 1990 youth aged 13-21 in 1985 with wide variety of disabilities including learning disorders, blind, orthopedic. Telephone and mail surveys of parents and young people followed for 3-5 years after special education experience.

Ireys, H.T., Salkever, D.S., Kolodner, K.B., & Bijur, P.E. (1996). Schooling, employment, and idleness in young adults with serious physical conditions: Effects of age, disability status, and parental education. *Journal of Adolescent Health*, 19, 25-33. Telephone interviews with 421 youth aged 20-24 who were former patients from Illinois and Ohio CSHCN programs, mean age 22; 8% CP, 4% SB, 18% MR, 21% physical disabilities without MR.

National Longitudinal Study of Youth (1979) and (1997) Department of Labor, Bureau of Labor Statistics. The National Longitudinal Surveys (NLS) are sponsored by the Bureau of Labor Statistics (BLS) with data collection undertaken for the BLS by the US Bureau of the Census and the National Opinion Research Center. The survey provides information on employment experiences, schooling, family background, social behavior and other characteristics. (Internet address: <http://stats.bls.gov>)

NIDRR and SSA (1999). *Summary of data on young people with disabilities in the United States*. Developed by Kristine Sheri Beck and Sheila S. Newman, Conwal Incorporated and distributed at the President's Task Force on Employment of People with Disabilities meeting in Washington, DC, July, 1999. This is a compilation of the most recently published data from several different federal sources and programs designed to present basic information on the status of young people, ages 14-30, with disabilities.

PACER Center (1997). *Teens speak out: A survey of teens with chronic illness and disabilities in transition*. Report on the results of 1300 respondents to a mail survey to 11,000 teens with disabilities or chronic illness in Minnesota. 32% had cognitive disabilities; 20% had mental health conditions; 10% had physical disabilities of cerebral palsy, spina bifida, and neuromusculoskeletal (such as treated at Shriners Hospitals).

US Bureau of the Census, *Statistical Abstract of the United States: 1995* (115th Edition), Washington DC, 1995

Vogel, L.C., Klaas, S.J., Lubicky, J.P., Anderson, C. J. (1998). Long-term outcomes and life satisfaction of adults who had pediatric spinal cord injuries. *Archives of Physical Medicine and Rehabilitation* 79, 1496-1503.