



**HRTW PHASE II PROJECT PROFILES:  
TRANSITION AND THE  
NATIONAL PERFORMANCE MEASURES  
SPRING 2005**

Project period: 6/30/01 to 6/29/05

Statistics are cumulative

**BLOCK GRANT – 6 NATIONAL PERFORMANCE MEASURES**

To help states develop effective mechanisms to achieve a system of care for all children with special health needs and their families by 2010, MCHB developed six national performance measures (NPM).

NPM 6 BLOCK GRANT GUIDANCE: New Performance Measures (p.43)

<ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf>

1. Screening
2. Family
3. Medical Home
4. Health Insurance
5. Community Base Services
6. Transition

**GOAL 6:** Youth with special health care needs (YSHCN) will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

*Desired Outcomes:*

1. State Title V CSHCN Programs Include Transition Programming
2. Informed Decision Making & Youth Involvement
3. Health Care Insurance/Coverage
4. Medical Home
5. Education, Employment, Recreation, and Independent Living

**HRSA/MCHB-DIVISION OF SERVICES FOR CHILDREN WITH SPECIAL HEALTH NEEDS,  
HEALTHY & READY TO WORK INITIATIVE, PHASE II:**

Grant projects were awarded to the State Title V Maternal and Child Health Programs (or a designee) in Arizona, Iowa, Maine, Mississippi, and Wisconsin to develop State models of children with special health care needs programs focused on transition outcomes, 2001-2005. Kentucky's HRTW Phase II Project, funded from 1999-2003, is included in this report.

Each HRTW Project reports annually on progress toward project goals in March. In September, projects provide an interim report that includes data on project participants and a summary of activities on each of the Desired Outcomes. These are profiles of the HRTW Projects for September 2004.

**\*\*\* Please note that all Projects do not focus on all of the Desired Outcomes**



**Arizona**

Racing to the Future:  
Youth Centered Model of  
Transition for Arizona  
YSHN

- Medical Home
- Person Centered Planning

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<b>Desired Outcomes</b>	<b>Activities</b>
<p><b>1. State Title V CSHCN Programs</b></p>	<p>AZ Racing to the Future is a collaboration among Title V OCSHCN Programs, Arizona Bridge to Independent Living, St. Joseph’s Hospital, Phoenix Children’s Hospital, Phoenix Pediatrics, and the AZ Network of Medical Homes. In response to this project’s activities, Title V has hired staff responsible for working statewide to meet the transition needs of YSHN. Project staff train CRS nurses on transition procedures and care coordination. Project staff train middle and high school transition personnel on self determination and transition. The SWI steering committee, with representatives from all the state, local, public and private agencies concerned with CSHCN, is working to increase communication across agencies regarding transition issues.</p>
<p><b>2. Informed Decision Making &amp; Youth Involvement</b></p>	<p>483 youth have participated in the project with 95 in Youth Transition Training Programs and RAPID TRANSIT. For two years, three groups of youth and parents collaborated on Participatory Action Research (PAR) teams. Based on the work and products of these groups, three programs were developed:</p> <ul style="list-style-type: none"> <li>• Youth Leadership Training program-- focused on developing interpersonal and social skills, peer mentoring and community opportunities, community advocacy and resources, and health care maintenance and communicating with doctors. The final product for each youth is a PowerPoint presentation on an issue – including careers, accessibility, advocacy. Youth who completed the program were offered opportunity to participate in the Tsunami program of paid participation in community activities.</li> <li>• FAST TRACK (six weeks/4 hours weekly), a hands-on, activity-centered self-determination program in which youth use PAR to develop goals and strategies in health care, education and vocation, housing and money management, and social skills. FAST TRACK is offered 4 times yearly and is promoted to middle/high schools statewide. SWI employs youth in the FAST TRACK program to serve as paid group leaders on subsequent FAST TRACK sessions, and as paid interviewers on a transition follow-up study.</li> <li>• RAPID TRANSIT Transition Fair: St. Joseph Hospital, CRS and SWI sponsor four one-day transition fairs yearly for youth aging out of CRS services. FAST TRACK participants make presentations describing their transitions to college and work experiences.</li> </ul> <p>Available are the following materials:</p> <ul style="list-style-type: none"> <li>• The PAR training manual was designed for youth and parent groups to systematically address the issues they identify. The AZ youth focused on topics like accessibility of local venues, but the manual’s intent is to maximize others’ capacity to solve personal or local issues.</li> <li>• The Leadership Training Manual, FAST TRACK curriculum, the medical teaching exam, the Systematic Transition Plan, and the HIP-YIP also are available.</li> <li>• The HIP-YIP is a comprehensive durable medical record that includes past and present health status, PAR data, and transition plans. When feasible, youth acquire skills in using personal data assistants and electronic transmission of data for record keeping and communication with providers, peers, and the internet. Barriers to using this technology include visual, coordination, literacy, and computer literacy skills.</li> <li>• Documentary film produced by a youth in the PAR and FAST TRACK groups (77-min.) youth interviews participating youth and parents (experiences, barriers and strategies)</li> </ul>

<p><b>3. Health Care Coverage</b></p>	<p>Identifying adult care providers remains a significant barrier to transition. The SWI Project has pursued a variety of avenues for transition to adult health care. First, we developed a matrix of health care plans in AZ with cross-reference of physicians in those plans. One MD in each plan was identified to serve as a PCP for YSHCN in that plan, and tools for documentation were developed. Most of the adult providers in the Phoenix metropolitan area do not accept ACCESS, the insurance carried by most YSHN. To address this issue, the project has begun a discussion with ACCESS management to pilot differential reimbursement for adult providers. In addition, the project has opened communications with the AZ AMA and AAP in order to develop a resolution supporting differential reimbursements for adult providers willing to serve YSCHN. Until there is a systems change at the HMO level, adult providers will not be willing to provide services.</p>
<p><b>4. Medical Home</b></p>	<p>The SWI Arizona Network of Medical Homes (pediatricians, sub specialists, adult primary care) meets monthly to address problems related to transition to adult health care. Barriers addressed include perceived lack of expertise by adult PCPs, inadequate reimbursement, lack of standards of care for YSHCN as health conditions interact with problems of aging. Until these issues are addressed, it will be difficult for youth to transition to adult care in the numbers hoped or with ease.</p> <p>The AZ Network of Medical Homes developed an 8-hour/8-module videotaped medical home training series. The participating physicians include pediatricians and family practitioners. The Medical Home series includes modules on transition, health care coverage and reimbursement, care coordination, community resources as well as assessment and documentation forms (which define medical exams and procedures for obtaining additional resources). OCSHCN is paying for the physicians CMEs.</p> <p>Tressia Shaw, MD, developed a training series for medical pediatrics while a resident at St. Joseph's Hospital. She is now developing a Transition clinic and resident training at St. Joe's. Training residents is clearly a major step toward alleviating the shortage of physicians willing to serve CYSHCN. Maggie Haugen, care coordinator, trains CRS nurses on transition with a videotaped training module and training package developed by the project.</p>
<p><b>5. Education, Employment, Recreation, and Independent Living</b></p>	<p>The Medical Teaching Exam, Systematic Transition Plan and FAST TRACK curricula are processes that guide youth in making informed decisions in these areas. The PAR/FAST-TRACK groups participate in social and recreation activities and have done accessibility surveys of community malls, movie theaters, and baseball stadium.</p> <p>Families and youth are provided extensive information about local, state and federal resources. Family support for transition and independence is developed through family group activities. Transportation remains a major issue; a driving education curriculum has been developed and parents conducted a study of transportation options.</p>
<p><b>Youth Advisory Council</b></p>	<p>The AZ YAC meets bi-monthly to plan PAR group meetings. Compensation is \$12 per hour. The AZ YAC has been institutionalized as part of the Title V program. Youth signed up to participate in the program are qualified to serve in the OCSHCN "tsunami" parent program.</p> <p>AZ YAC members have presented at the state and national conferences.</p>
<p><b>Miscellaneous</b></p>	<p>The SWI evaluation database has produced its first report on youth PAR. The report shows the benefits of PAR for youth in achieving personal and group goals. Participant satisfaction data currently are being analyzed.</p> <p>In addition, a phone interview study of youth aging out of CRS is being conducted to determine whether these youth have identified adult providers, insurance, set goals for employment, and how these youth are faring socially.</p> <p>Project staff has given multiple community and professional presentations.</p> <p>List-serves have been established for youth and families and health care providers.</p>



**Iowa**

Adolescent Transition:  
Healthy and Ready to Work

- Medical Home
- Work Preparation

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Desired Outcomes	Activities
<p><b>1. State Title V CSHCN Programs</b></p>	<p>The project is a collaboration of Iowa's CSHCN organization, Child Health Specialty Clinics (CHSC), with Iowa's Center for Disabilities and Development at the University of Iowa. Iowa's HRTW project serves the Waterloo area. Considerable effort has gone into making sure that program and evaluation efforts in Waterloo are integrated among programs. HRTW youth are served by a Title V Care Coordinator.</p> <p>The project collaborates with the Statewide Implementation of the Medical Home Concept for Children with Special Health Care Needs (ISIMH). In turn, ISIMH is collaborating with the Community Integrated Service System (CISS) project – Family Physicians and Communities Partnership for Kids, administered by the IA Chapter of the American Academy of Family Physicians.</p> <p>The Director CHSC is the Principal Investigator for HRTW and ISIMH. This collaboration positions Iowa to advance the medical home concept throughout the state with focus on all ages of CSHCN.</p> <p>Local service providers now address employment-related issues for HRTW participants. Using local service providers such as the Waterloo Employment Development Council has been a more successful strategy as they have a better understanding of the Waterloo community, know which employers are hiring, and use community supports for working YSHCN in the area. The project has a dual emphasis on a smooth transition from pediatric to adult health care <i>and</i> career planning/workplace experiences. A cornerstone of Iowa's HRTW project is the presumption that health promotion and meaningful, satisfying employment mutually support each other.</p>
<p><b>2. Informed Decision Making &amp; Youth Involvement</b></p>	<p>48 youth are participating. Iowa's project is designed to provide intensive, customized care coordination for YSHCN involving regular, ongoing contacts with youth and families and with medical providers, schools, and community supports on their behalf. Care Coordinators place special emphasis on integrating health into the IEPs in the schools. <i>Make All the Right Moves</i> is a resource book created by young adults with disabilities intended for middle and high school students for futures planning.</p> <p>Iowa's YAC piloted <i>Living Well and Staying Healthy</i>, a 10-session health and wellness program incorporating career planning and preparation, intended to reduce the incidence of secondary conditions for YSHCN. Eight HRTW participants and advisors participated in all sessions and invited their parents to attend a celebration ceremony at the end of the course. The <i>Living Well and Staying Healthy</i> curriculum for adolescents is being tested in other Iowa communities and is expected to be available in 2005.</p>

<p><b>3. Health Care Coverage</b></p>	<p>All HRTW participants have insurance. Youth and family members work together to develop a portable medical binder with specific health information pertaining to that youth so they understand their health condition(s) and needs, their medication, when and how to contact their health care provider(s), and information about their insurance/funding.</p>
<p><b>4. Medical Home</b></p>	<p>HRTW project physicians associated with University of Iowa Health Care are incorporating relevant medical home strategies into their own pediatric and family clinics, resulting in valuable first-hand medical home experience. These physicians, along with other relevant HRTW Project staff comprise a sub-group of the HRTW project team -- the HRTW Facilitation Team -- so named to reflect the goal of facilitating movement of clinics toward the medical home model. Using the Medical Home Index as an assessment or diagnostic tool, HRTW Facilitation Team members work with interested clinics and provide on-site technical assistance to advance their respective practices in alignment with medical home standards.</p> <p>A large general pediatric and family physician practice that serves most of Waterloo's lower-income patients requested the HRTW Facilitation Team's assistance building medical home capacity for their adolescent patients with Attention Deficit/Hyperactivity Disorder first, as those patients comprise a large share of the practice.</p>
<p><b>5. Education, Employment, Recreation, and Independent Living</b></p>	<p>To build linkages between medical providers, employers, and educators, HRTW sponsored presentations on adapting school and work settings for students using medical technology. Waterloo's Transitional Alliance Program (TAP), a joint effort between the Waterloo Community School District and the Department of Rehabilitation Services, serves many HRTW participants and provides career assessment, career exploration, job search assistance, job coaching, and follow-up as needed until participants reach age 25. Through these efforts, approximately 20% of HRTW participants either work or have experienced a work-based learning experience.</p> <p>Via an Employment Development Council facilitated agreement, Waterloo area schools and the regional Area Education Agency support work efforts and allow HRTW-involved youth to be excused from school to participate in workplace and community experiences <i>and</i> be given school credit for their efforts.</p>
<p><b>Youth Advisory Council</b></p>	<p>12 young adults with diverse medical conditions and cultural backgrounds serve on IA YAC. Pay is \$50 per quarterly meeting plus expenses and/or accessible transportation.</p> <p>The group provided considerable feedback concerning medical and educational practices they feel would benefit from change and advised on issues related to blended funding for the Waterloo SSA Youth Transition Team, personal finances to a Waterloo credit union, and issues related to employment (including disability-friendly employers in the Waterloo area).</p> <p>HRTW youth advisors were asked to participate on the local RWIB Board that oversees implementation of the Workforce Investment Act. Parents have remarked that as a result of serving on YAC their sons or daughters are more outspoken and seem more self-confident.</p>
<p><b>Miscellaneous</b></p>	<p>HRTW evaluators have developed a quasi-experimental evaluation design, allowing comparison of system-level and individual changes with a matched comparison group, over time, and within groups to study processes and outcomes that are most useful to program planners.</p> <p>A half-time MSW Care Coordinator was hired to expand the project's ability to serve youth with emotional or behavioral issues. Disability Mentoring Day activities included Waterloo youth this year. Regional networking with contiguous states about medical home and HRTW best practices is a focus.</p>



**Kentucky**

KY TEACH

Kentucky Youth Transitioning to Employment And Comprehensive Healthcare

- Title V Transition Programming

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*Project Period:* 6/1/99 to 9/30/03

Desired Outcomes	Activities
<p><b>1. State Title V CSHCN Programs</b></p>	<p>The KY TEACH Project was based in Kentucky's CSHCN agency. Transition services are now at the "branch" level in the organization's structure. Services are expanding into the Louisville community through Transition Resource Centers in Neighborhood Places. The Commission has developed strong liaisons with local and state education agencies, family groups, centers for independent living, vocational rehabilitation and workforce development agencies, juvenile justice, and universities. Transition liaisons in each of the 14 regional offices outreach to local agencies and physicians to improve transition.</p> <p>Addition of a transition checklist in the computerized record system helps staff guide families and youth in developing skills and connecting with resources to improve transition to adulthood.</p>
<p><b>2. Informed Decision Making &amp; Youth Involvement</b></p>	<p>Over 10,000 children and youth are affected by the systems changes yearly. Staff promote development of skills in management of self-care and involvement in school and community activities.</p> <p>Youth are involved in day and overnight camps, work experiences, mentorship programs (with the Spina Bifida Association), work preparation workshops and peer support groups at the Centers for Independent Living, and planning and participating in family-professional conferences where they have opportunity to explore careers, self care and risk taking behaviors, decision making, and resources.</p> <p>In addition to advising state Girl Scout leaders, Commission staff established a Girl Scout Troop with both girls with SHCN and typical girls ages 7-18. Included are activities outside the home, exploring interests, personal assets and careers, transportation skills, health self care and finding health services, independence in home skills, sports and recreation, money management, personal awareness and social interaction.</p> <p>On Disability Mentoring Day in 2001 22 youth and in 2002 120 youth, and in 2003 102 youth participated in work shadowing experiences in community agencies and businesses or in school programs involving working adults with disabilities and community resources to help youth work. These activities improved attitudes of parents, youth and employers toward work abilities of youth with disabilities.</p>
<p><b>3. Health Care Coverage</b></p>	<p>Health care coverage is a topic clarified at each visit and on the Transition Checklist for planning during the teens. Care Coordinators discuss insurance coverage and give information on issues to consider.</p> <p>Fewer physicians in KY are accepting Medicaid or are limiting their caseloads - problematic for the Commission's population. The percentage of graduates with no insurance has remained at about 30% (similar to typical youth ages 18-24 in KY) over the 4 years of the grant, but the number of graduates with insurance through their own jobs declined as KY's unemployment rate rose.</p>

<p><b>4. Medical Home</b></p>	<p>Care Coordinators assist families in finding primary care providers in their communities; visit summaries are sent to these PCPs. Over 91% of patients have a PCP. Many of the PCPs are family practices so transition to adult primary care is not difficult. 86% of graduates in the past 2 years report a PCP but only 51% name a physician; some name a clinic. Consistently across the years about 45% of graduates say they have visited the ER in the past year, twice the rate of that found in typical youth.</p> <p>Hearing impaired youth express concern with finding physicians who have interpreters so they can see their physician independently. Materials have been developed to help young people learn how to take more responsibility for their own health and work with their physicians (see website).</p> <p>The Commission collaborated with Shriners Hospital and 32 other community organizations to debut the AAP's Medical Home Training in Dec. 2000. District staff visit local physicians to discuss Commission services and the medical home concept, offer assistance, educational materials and information on community resources, and enlist their willingness to see youth and young adults with special needs.</p> <p>Transition information is published in medical association newsletters.</p>
<p><b>5. Education, Employment, Recreation, and Independent Living</b></p>	<p>Through the Project over 165 youth attended camps, 63 youth had paid work experiences and many others worked and were involved in community activities because of encouragement they received from staff. Over 200 had work, mentorship, and/or skills development workshop experiences.</p> <p>Through staff development efforts and the computerized Transition Checklist, skill development in health and independence areas is a focus in all care coordination services for all patients and their families.</p>
<p><b>Youth Advisory Council</b></p>	<p>A youth advisory council was not an element of the grant guidance for this project.</p> <p>A youth consumer of Commission services is now a member of the Commission Board that guides the work of the agency.</p> <p>Several youth have been employed at the Louisville Commission office and offer advice and guidance in planning Project activities. Youth coordinate writing the quarterly newsletter.</p>
<p><b>Miscellaneous</b></p>	<p>In the new edition of the Transition Handbook developed by the University of Kentucky's Interdisciplinary Human Development Institute, for the first time there is health content because a KY TEACH liaison contributed. The transition focus has had an impact on most staff.</p> <p>As part of the project evaluation staff were surveyed. Over 90% say they now make a greater conscious effort to focus on transition issues, have much more information to share with families, and know more about resources in the community. Staff have offered many recommendations for improving transition to adult health care and services for youth with disabilities that can be found in the final report.</p>



**Maine**

Maine Works for Youth!  
(MWFY) Maine HRTW  
Phase II Project

- Youth Leadership
- Interagency Collaboration

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**Desired Outcomes**

**Activities**

**1. State Title V CSHCN Programs**

MWFY! is a collaboration of Maine's Title V CSHCN program, the University of Maine Center for Community Inclusion & Disability Studies (CCI) and the Maine Support Network. MWFY!, in partnership with CSHN staff, including case managers and care coordinators is developing a web-based protocol consistent with the database needs of the CSHN program and which will link the existing newborn screening and birth defects registry with the newly designed CSHN database. The system also contains project management tools and has potential for tracking outcomes.

Regional review teams continue to monitor and update the database of resources (Service Tapestry) from their parts of the state. MWFY! staff conducts follow up with the teams on a quarterly basis. Project staff provide information about the Service Tapestry at community forums and through wide dissemination of the service tapestry brochure. A tutorial has been developed to support the use of the Service Tapestry.

Collaborations include: the Maine Chapter of AAP; the Hood Center at Dartmouth Hitchcock Medical Center; CHOICES, Maine's Medicaid Infrastructure Grant; Maine APSE; Maine Medical Center's SAMHSA transition grant; Maine Departments of Education, Labor, Health and Human Services; parent, advocacy and youth organizations across the state including the Family Advisory Council to the CSHN program, the Maine Transition Network and the Maine Youth Action Network.

**2. Informed Decision Making & Youth Involvement**

Over 1000 children and youth are affected by the CSHN systems changes.

A Youth Advisory Group to the CSHN program meets regularly with the Program Director and is involved in policy and practice decisions.

YOUTHSPEAK is a speakers' bureau of youth with special health care needs who disseminate youth-developed information about their strengths and needs to employers, providers, educators, policy makers and parents. YOUTHSPEAK 2.0 is available on CD and PowerPoint presentations are on the website.

Care Maps are being adapted as screening tools by CHSN case managers and integrated into the developing informatics system. "My Life Map" is being developed as a "needs assessment" that youth can complete and includes a planning component to help youth realize their dreams and goals. Members of YEA ME have played a significant role in the design.

The Maine Health Care Notebook has been completed and is now being distributed to new CSHN program enrollees, through specialty clinics, early intervention programs and physician offices as well as available on the web.

<p><b>3. Health Care Coverage</b></p>	<p>MWFY! is actively involved in Maine's Medicaid Infrastructure Grant funded under TWWIIA and will continue to be involved in the MIG II (a Comprehensive Employment Opportunities Grant application has been submitted to CMS). Effective October 1, 2002, MaineCare (Maine's Medicaid program) began enrollment in a non- categorical, single adult category and to date more than 5,000 youth aged 18-24 have been enrolled (the single largest enrollee group). A health insurance "primer" was developed by project staff and is available on the web.</p> <p>The CSHN Program is involved with the New England Serve (Massachusetts) and Dartmouth Hitchcock's (New Hampshire) MCHB's Insurance grants and has begun implementation of care coordination in four pediatric practices.</p>
<p><b>4. Medical Home</b></p>	<p>The project's Medical Home Advisory Committee planned and presented the Medical Home Training in October 2003. 60 individuals including family practice physicians, pediatricians, nurses, parents, youth and representatives from organizations that serve the CSHN population in Maine participated. Monique Fountain, MCHB Director of the Medical Home and HRTW Initiatives, delivered the keynote address. Parents and youth participated on all of the panel presentations.</p> <p>MWFY and CSHN are currently working with the Maine Chapter of AAP to conduct a statewide needs assessment related to the status of medical home-ness as well as to support them in their effort to disseminate best practice materials and resources using funds from a Champions for Progress Center state mini-grant.</p>
<p><b>5. Education, Employment, Recreation, and Independent Living</b></p>	<p>Systemic work regarding employment and inclusion continues to be a focus of our work in collaboration with multiple state partners. Collaboration with Maine Transition Network's Transition Outcomes Project involves systematic review of the IEP's of participating schools for consistency with IDEA regulation. Jesse Bell, YEA ME member will present at the Maine APSE conference in October and discuss his supported employment experiences.</p>
<p><b>Youth Advisory Council</b></p>	<p>The Youth Advisory Council, Youth Educators and Advocators of Maine (YEA ME) expanded to 8 youth and young adults from across the state. The group has adopted by-laws and elected officers. The group meets six times a year with the CSHN director and all members have email addresses to communicate between meetings. The youth advise the CSHN program on policy development and designed a youth version of the CSHN application. Youth are compensated \$10 per hour plus expenses.</p> <p>YEA ME members have given multiple presentations including Maine School Nurses Association Conference, Maine Youth Action Network conference, TASH and the Maine Support Network annual conference. YEA ME members facilitated a workshop for youth at the 21<sup>st</sup> annual Special Family Weekend retreat and participated in the statewide Kids Law Conference. A focus group of YEA ME members was convened by U of Southern Maine faculty to ascertain the recreation needs of youth.</p> <p>MWFY! works with the Maine Youth Leadership Network to infuse diversity into their efforts to support youth leadership in Maine. Educating multiple interest groups about the experience and how to meet the needs of transitioning youth with special needs is likely the greatest contribution that MWFY makes in Maine.</p> <p>YEA ME provided testimony on their needs to the Maine Legislature's Youth Advisory Council in June 2004. The project is respected for valued roles that parents and youth maintain in all project activities.</p>
<p><b>Miscellaneous</b></p>	<p>Resources and materials have been added to the website and a web site for the CSHN program is nearing completion.</p> <p>Mallory Cyr, a founding member of YEA ME and a student at Univ. of Maine at Farmington, was awarded the University of Maine's Maryann Hartman Young Women's Social Justice Award in 2003.</p> <p>A joint meeting of the Family Advisory Council and the Youth Advisory Council was held recently and collaborative activities for later this fall are planned.</p>



**Mississippi**

Mississippi  
Healthy Futures

- Independent Living

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**Desired Outcomes**

**Activities**

**1. State Title V CSHCN Programs**

Healthy Futures (HF) is based at the Coalition for Citizens with Disabilities, a statewide, consumer-controlled, non-profit organization composed of 28 cross-disability constituent organizations. HF contracts with MS Title V Children's Medical Program (CMP) for activities related to training and collaboration with health care professionals.

CMP reaches into communities to identify medical service providers and link them with families. CMP offers a needs assessment and referral clinic for adult myelomeningocele patients. HF is involved with CMP in the MCHB Block Grant Needs Assessment planning. Collaboration is high with family organizations, professional organizations, independent living councils, education, SSA, Vocational Rehabilitation and ARC of MS.

The Healthy Futures Adult Advisory Council (composed of 32 members representing Title V Children's Medical Program, MS Chapter of AAP, state agencies, advocacy groups, community colleges and universities, parents, and others) meets on a quarterly basis and plays a prominent part in all activities.

HF is proud of the collaborations established with consumers and their families -- one of Healthy Futures' greatest strengths, utilizing the Coalition for Citizens with Disabilities' and LIFE's extensive network of contacts with families. HF has succeeded in reaching YSHCN and their families who have never before received transition assistance.

**2. Informed Decision Making & Youth Involvement**

228 youth are participating. 82 are over age 21; at least 39 of these are employed and/or in college. HF contracts with LIFE, MS's state system of independent living centers, to provide skills training (especially with a health focus), peer counseling, advocacy, and information and referral by five Independent Living Transition Specialists. LIFE provides service coordination and follow-up through age 25. A survey of transition needs is distributed biannually to youth to determine perceived transition needs and knowledge of medical conditions, current treatment plans, and preventive health care issues.

Transition Specialists match as many consumers as possible with mentor adults with the same or similar type of disability and encourage YSHCN to be mentors to younger children with disabilities. Over 30% of transition consumers are matched with mentors. Finding qualified and willing mentors is a challenge; transportation and time are issues. Explorations with colleges and universities and Big Brothers/Big Sisters are in process.

HF offers retreats for youth and parents (concurrent, not together) twice yearly (41 youth attended the spring retreat), employment exploration days in October, and a yearly summer leadership conference with 150+ youth. Healthy Futures assists YSHCN and families to attend the Annual Coalition for Citizens with Disabilities and LIFE Conference which focused on independent living philosophy and participating in the electoral process from the local district to the national arena. Four consumers have received Achievement awards recognizing their exceptional increased enhancement of independent living skills.

Family Support Groups have been established in 5 areas of the state. Each meeting has had an average of 10 YSHCN and family members in attendance. Topics have included goal setting, employment, self-advocacy, health issues, etc. HF provides transition information to parent groups funded through grants to Family Voices of MS. HF will create new support groups for parents of young children in areas without such.

<p><b>3. Health Care Coverage</b></p>	<p>A critical need for more adequate and affordable private healthcare coverage remains.</p> <p>CMP accepts calls from physicians, agencies and families regarding resources and referrals related to YSHCN.</p> <p>CMP continues to inform their physicians of CMP's role in providing support to their practices and assisting in identifying local resources.</p> <p>There is discussion with Medicaid and equipment vendors regarding the evaluations for custom fitted durable medical.</p>
<p><b>4. Medical Home</b></p>	<p>HF works closely with Title V CSHCN (CMP) and the MS Chapter of the AAP to identify consumers in need of medical homes and dentists and to match them with providers. Pediatricians and family medicine physicians are offered transition support from HF and CMP. CMP offers assistance with CME programs. A program on ADD has been offered. CMP hosts opportunities for practicing pediatricians to visit a multi-disciplinary specialty clinic to obtain information on resources and treatment for children with special health care needs.</p> <p>Through an agreement between CMP and UMC Department of Pediatrics and Department of Family Medicine, third year pediatric residents/ped-medicine residents participate in CMP's Blake Clinic.</p>
<p><b>5. Education, Employment, Recreation, and Independent Living</b></p>	<p>Each HF participant receives not less than one contact per month from the Independent Living Transition Specialist to implement the individualized Independent Living Plan. Participants have been provided wide ranging services including assistance in improving housing, home modification projects with donated labor and materials, preparing for college and finding employment, finding linkages with post-secondary education and GED programs, and acquiring assistive technology. The goal is that by age 25 each consumer is as independent as possible.</p> <p>HF is collaborating with education-based transition pilot projects in 5 school districts. HF Independent Living Transition Specialists are working with Part C early intervention program support groups for parents of young children to assist with futures planning.</p> <p>All five IL Transition Specialists had employment exploration days in October 2003 with the MS Department of Environmental Quality Control, Jackson Fire Department, Handi-capable Vans, Wal-Mart and a carpentry shop in the Jackson area.</p> <p>HF collaborates with MS Department of Voc Rehab and the MS Department of Employment Services for YSHCN and their mentors to meet and learn from private and public employers. The same is planned for Oct. 2004 Disability Mentoring Day.</p>
<p><b>Youth Advisory Council</b></p>	<p>Youth Advisory Council consists of 10 members who are compensated \$50 for attending meetings plus travel expenses and lunch. Meetings are held every other month to plan retreats, the Youth Leadership Conference and other activities and discuss transition issues. Project goals and activities are always discussed at these meetings.</p>
<p><b>Miscellaneous</b></p>	<p>A representative sample of case files of active YSHCN consumers are reviewed by LIFE supervisory personnel and an evaluation specialist at least every six months to assure thoroughness of services, timeliness, and accuracy of reporting, etc. Changes are made to project methodology as warranted by the results of these evaluations. Healthy Futures has contracted with the University of Southern Mississippi, Institute for Disability Studies, to conduct a final cost benefit analysis.</p> <p>HF Director has appeared on television and radio programs increasing awareness of transition needs and activities. HF has presented posters and sessions at variety of local and state organization meetings and the website is updated.</p>



**Wisconsin**

Wisconsin - Healthy and Ready to Work

- Community Development
- Person Centered Planning

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**Desired Outcomes**

**Activities**

**1. State Title V CSHCN Programs**

Wisconsin HRTW is based at the Waisman Center at the University of Wisconsin-Madison. The Waisman Center has been designated by the Wisconsin Title V Program to serve as the Southern Region CSHCN Center. In that role it partners with four other Regional Centers to provide (1) information and assistance, (2) parent to parent support and (3) service coordination to families with CSHCN using the Asset-Based Community Development and person-centered planning models. Each regional center develops a plan for how staff will work with HRTW to address transition in work plans.

With leadership from Wisconsin HRTW, all 5 WI CSHCN Regions are actively engaged in HRTW community development, skills training, person-centered planning for youth, information and assistance and data collection. Each Region has a transition liaison focusing on transition events and information sharing with local public health nurses and others. A state CSHCN staff member attends most project meetings and acts as a liaison between the CHSCN program and the project. The State CSHCN Program is developing a web-based data system for all WI MCH funded programs. The CSHCN Regional Centers are using the database that includes transition questions and HRTW Project data. HRTW-WI works with SSA and the Division on Aging and Disabilities to include transition questions in a new functional screen for children with long-term care needs. Under development is a HRTW toolkit that will allow other state CSHCN programs to look at what has worked in Wisconsin and choose tools that strengthen their state's ability to address transition across all six performance measures.

In 2004, HRTW staff participated in a panel presentation during the annual Maternal and Child Health Leadership Conference in Chicago.

**2. Informed Decision Making & Youth Involvement**

384 youth are participating in various aspects of the project. During the past six months, more than 15 emerging youth leaders presented on panels or at conferences around the state about their transition experiences. A youth committee coordinated and ran the second annual Gathering of Youth statewide youth leadership conference. This two-day youth training that was held in the spring pulled together empowerment, self-determination and content about programs and services. HRTW has hired two "community connectors" who work with youth who have had person-centered plans, linking them to opportunities and activities in their communities. In a Latino community and a suburban neighborhood in Milwaukee, community connectors facilitate the person-centered planning process (PATH), so youth can increase independence in decision-making in aspects of adult life, including health.

HRTW supported a week-long summer camp for 18 transition-aged youth at the University of Wisconsin-Whitewater (UWW) co-sponsored by the Council on Developmental Disabilities, UWW, Department of Vocational Rehabilitation and the Great Lakes Inter Tribal Council. A subcontract with the Department of Public Instruction's State Improvement Grant provides parent leadership training for about 25 parents of transition-aged youth. This initiative is so successful that DPI expanded its regional parent leadership training options to include training for parents of youth in transition. Of the 6 Parents in Partnership trainings this year, 4 are for parents of transition-aged youth, (nearly 100 parents). Multiple single workshops have been conducted across the state in response to local capacity building efforts, particularly in the areas of guardianship and regional transition forums focusing on self-determination.

<p><b>3. Health Care Coverage</b></p>	<p>Insurance coverage and planning for change is included in all transition plans. HRTW collaborates with Bridges to Work, funded by CMS, to improve implementation of the Medicaid Purchase Plan to strengthen coordination of employment-related health and long-term care services.</p> <p>HRTW works with SSA to explore ways to make transition from Katie Beckett waivers to SSI a more seamless process.</p>
<p><b>4. Medical Home</b></p>	<p>HRTW meets regularly with the State CSHCN Medical Director and participates on the MCH State Advisory Committee allowing HRTW to join efforts with the CSHCN statewide Medical Home plan. HRTW is partnering with the state CSHCN program and its Medical Home Learning Collaborative to provide medical practices with transition-related information.</p> <p>HRTW National Center, Patti Hackett, has been invited to present on transition at the upcoming Medical Home Learning Collaborative meeting in December, which includes nine medical practices around the state.</p> <p>HRTW is creating resource folders on transition-related topics for the practices.</p> <p>HRTW continues to work with the University of Wisconsin Hospitals and Clinics to explore ways to integrate transition concepts into training of health care professionals.</p>
<p><b>5. Education, Employment, Recreation, and Independent Living</b></p>	<p>The person-centered planning process (PATH) has resulted in self-determination trainings in public schools; guardianship training; sexuality and health safety training in the community; state and local list serves; and new employment, recreational and health connections for individuals.</p> <p>Several trainings on guardianship and alternatives to guardianship are offered in the pilot sites and associated materials and a video and website page are being developed.</p>
<p><b>Youth Advisory Council</b></p>	<p>The 10-member Young Adult Advisory Group meets regularly and provides ongoing input to the project including reviewing project materials, planning for a speakers bureau, and participating in conferences, classes and panels at the Statewide Transition Consortium. Compensation is \$25 per meeting plus expenses. The youth are leading the group themselves.</p> <p>The Group is the constituent voice that keeps HRTW work focused on the needs of the youth. They are developing a fact sheet series on issues of interest to them, including participation in the IEP process, SSI, DVR and other topics. Youth are collaborators in the work of a nurse researcher and local developmental disability trainers. A youth is partnering with a parent to develop and co-teach a health training in two parts for youth and their parents.</p> <p>Champions Incentive Award funds have assisted HRTW in holding three problem-solving sessions with youth to jumpstart CSHCN's ability to collect information from youth with special health care needs, including Spanish-speaking youth.</p>
<p><b>Miscellaneous:</b></p> <p><b>Statewide Transition Consortium</b></p>	<p>The Wisconsin Statewide Consortium on Transition with about 40 individuals from a wide range of agencies reviewed and recommitted to their mission which is an important step toward sustainability beyond the HRTW grant.</p> <p>The Consortium is a forum whereby information is shared, statewide initiatives are aligned, best practices are promoted and new collaborations and projects are formed. Their current focus is on how the group can be involved in public policy around transition issues.</p>