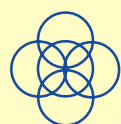


Wisconsin Healthy & Ready to Work:
A Series of Materials Supporting Youth with Special Health Care Needs

Statewide Leadership for Youth in Transition: A Person Centered, Asset-Based Community Development Approach

**Potential Roles for Title V
Children/Youth with Special Health Care Needs Programs**

Asset-Based
Community Development
Person-Centered Planning
Community Improvement



Waisman Center
University of Wisconsin–Madison
University Center for Excellence in Developmental Disabilities



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The Waisman Center is dedicated to the advancement of knowledge about human development, developmental disabilities and Neurodegenerative diseases. It is one of 9 national centers that encompass both a Mental Retardation/Developmental Disabilities Research Center (MRDDRC) designated by the national Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities (UCEDD) designated by the Administration on Developmental Disabilities.

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In cooperation with the Wisconsin Children/Youth with Special Health Care Needs Program

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Voices of youth with special health care needs were a driving force within the Wisconsin Healthy and Ready to Work Project. It is appropriate to begin with some of them.

"How will I be five years from now? Will I be sick? Will I be able to continue working? Those are the kind of questions that keep running through my mind."

"It's important to look ahead to what you want to do and know where you want to go. But you also have to put in a lot of effort. I think I may try a different job as I get older, but it's too early to tell now. Right now I like where I am."

"I've grown up with medical issues, and my mom says I'm good at talking to people, so a career as a doctor makes sense."

"Yes, I want to, yet no, I don't either because... because I'm going to have to go to my own doctor, my parents are not going to be there in the waiting room.... Yeah, this is what we wanted for a long time, but no, this is not what we want right now."

"My aides and the people who come in and take care of me – I have to work around their schedule, and they don't have to work around mine."

"Since I've gotten to college, I've been able to take my medication.... I'm very proud of that."

"...you don't know where you start, and you kind of bounce around until... you find somebody in a good mood... that's willing to give you some information."

"In ten years, I'll be married and driving a Mercedes-Benz convertible."

Part I: Introduction

Purpose of this Report

The purpose of this report is to provide information that State Title V Children/Youth with Special Health Care Needs (CYSHCN) Programs can utilize as they design and support services to meet their mandated responsibility to address Core Outcome Six of the National Agenda for Children with Special Health Care Needs that reads: *All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.*

The information in this report is drawn primarily from the experience of the Wisconsin Healthy and Ready to Work Demonstration Project that was funded by the federal Maternal and Child Health Bureau between 2001 and 2006 and implemented by the Waisman Center in cooperation with the Wisconsin Title V CYSHCN Program.

What's Health Got to Do with Transition? Everything!

Health impacts all aspects of life. Success in the classroom, within the community and on the job requires that youth understand their own health status, and that they are trained and supported to assume responsibility for their own health along with other members of their health care team. State CYSHCN programs are ideally positioned to assume a leadership role to create and nurture a wide array of policies, programs and other opportunities that can assist youth to better understand and assume responsibility for their health related needs. In recent years, the area of youth transition has received increased attention for several reasons.

- Due primarily to advances in medical science, approximately 90% of children with special health care needs are now expected to reach adulthood. Over the past 30 years, survival rates for spina bifida and leukemia have increased 200%, cystic fibrosis rates 700%, and congenital heart disease rates by 400%.¹
- While more children with special health care needs are living into adulthood, young people with serious chronic conditions and disabilities are less likely than those without special health care needs to graduate from high school, enter into employment, or to pursue postsecondary education. A Harris Poll found that 68% of Americans with disabilities age 16-64 were unemployed, compared to 19% of those without disabilities.²
- Many young and middle-aged adults who grew up with chronic health conditions continue to receive their health care by pediatricians. They are not receiving the necessary training and support to assume responsibility for managing their own health care. This continued reliance on pediatric providers often results in the neglect of adult health care issues such as routine primary health care for adults, reproductive health care, and effects of aging on special conditions.³

The Healthy and Ready to Work Initiative: National Perspective

States and territories throughout the nation have been committed to promoting the health of families since passage of Title V of the Social Security Act in 1935. However, the more recent emphasis on children with special health care needs has occurred since 1989 and 2001 respectively.

The 1989 Omnibus Budget Reconciliation Act was important because it set stricter requirements for how a state could use Title V MCH funds. In addition to requiring that 1/3rd of those funds be utilized to support programs and services for CYSHCN, the legislation specified that the intent of such programs should be to promote family-centered, community-based, coordinated care, and to facilitate the development of community-based systems of service for such children and their families.

In order to promote the development of this system of services, the federal MCH Bureau created the levels of service framework for key public health services that is shown in Figure 1. Now known as the “MCH Pyramid” it is important because it points to the fact that direct services to youth in transition are built upon an array of infrastructure building, population based and enabling services. In order to support youth, state programs must consider what needs to be accomplished at each level of the MCH pyramid.

Throughout the 1990’s, legislative mandates affecting CYSHCN focused heavily on support for young children’s educational and health needs. One such federal initiative was called “Healthy and Ready to Learn.” This was a catchy title that helped to focus attention, but as it was being advanced, advocates for older children began to ask, “What happens when these same children become youth with special health care needs? Where are the programs and services to support the other end of the spectrum?”

In response to these questions the MCHB created the “Healthy and Ready to Work” initiative in December 1996. Over the initiatives two phases, grants were awarded to 12 states to design and apply different HRTW methodologies. A HRTW National Center was funded to promote the success of the HRTW grantees, strengthen the leadership role of Title V CYSHCN agencies, and otherwise work to develop strategies that ensure a successful health transition in ways that involve youth as full partners in creating and sustaining change.

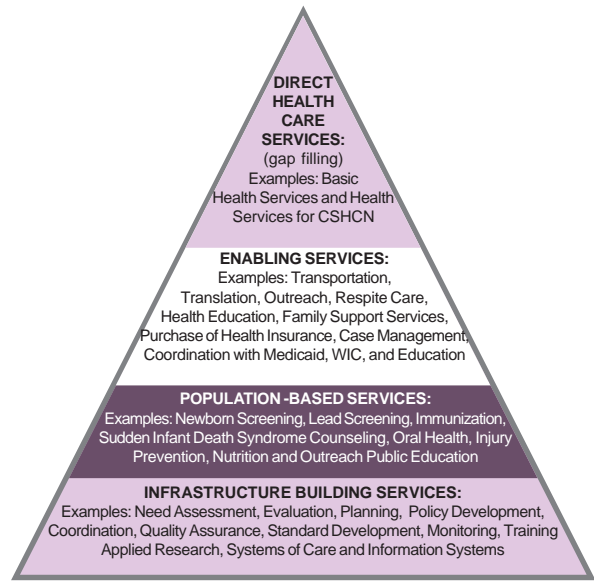


Figure 1: MCH Pyramid of Health Services

“...Now known as the “MCH Pyramid” it is important because it points to the fact that direct services to youth in transition are built upon an array of infrastructure building, population based and enabling services.”

In February, 2001, President Bush announced the New Freedom Initiative – “a comprehensive program to promote the full participation of people with disabilities in all areas of society by increasing access to assistive and universally designed technologies, expanding educational and employment opportunities, and promoting increased access into daily community life.” Following announcement of that initiative, federal agencies conducted a one year self-evaluation in order to identify barriers to community living for persons with disabilities. That evaluation culminated in a special report to the President that identified action steps that federal agencies would take to overcome those barriers. Titled *Delivering on the Promise*, the report was a compilation of reports from 9 federal agencies including the Department from Health and Human Services. Chapter III, Section C of that report is an *Action Plan for Children with Special Health Care Need and their Families* that charged the MCHB to take the lead in developing a plan to achieve appropriate community-based services systems for children with special health care needs and their families. *The six components of the Action Plan then became The National Agenda for Children with Special Health Care Needs, which was then adapted to create the MCH Block Grant Performance Measures, both of which are spelled out below.*

**Core Outcomes to be Achieved:
National Agenda for Children with
Special Health Care Needs**

1. All CYSHCN will receive coordinated ongoing comprehensive care within a medical home.
2. All families of CYSHCN will have adequate private and/or public insurance to pay for the services they need.
3. All children will be screened early and continuously for special health care needs.
4. Services for CYSHCN and their families will be organized in ways that families can use them easily.
5. Families of CYSHCN will partner in decision making at all levels, and will be satisfied with the services they receive.
6. All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

**HRSA/Maternal & Child Health Bureau
MCH Block Grant
Performance Measures**

1. The percent of newborns who are screened and confirmed with conditions(s) mandated by their State-sponsored newborn screening programs who receive appropriate follow up as defined by their state.
2. The percent of CYSHCN age 0 to 18 years whose families/youth partner in decision making at all levels and are satisfied with the services they receive.
3. The percent of CYSHCN age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.
4. The percent of CYSHCN age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need
5. Percent of CYSHCN age 0 to 18 whose families report that community-based service systems are organized so they can use them easily
6. The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life.

Part II: The Wisconsin Healthy and Ready to Work Approach

The Wisconsin Healthy and Ready to Work Approach is based on two overall premises:

- ✓ Young people with special health care needs thrive when their gifts and passions are recognized, supported and used in communities.
- ✓ Communities thrive when all of their resources and assets are connected and utilized

Thus, all communities benefit when youth with special health care needs are full and active community participants.

Why a Person Centered, Asset-Based Approach?

In an era of decreasing resources and increasing demands on systems, programs need to look at existing resources in different ways. A person centered asset-based approach starts with outcomes in mind – outcomes that are based on the young person's vision for his or her life. It draws from both formal and informal resources, often making use of opportunities that are easily overlooked when the focus is limited only to the family and the narrow range of school and service providers. Asset based approaches increase family confidence in systems and communities and give youth decision-making power they may never have experienced before.

As described by Kretzmann and McKnight at Northwestern University, an asset-based approach *affirms and builds upon what is working within families and within our community based systems*. It “focuses upon the capacities of community residents and workers, the associational and institutional base of the area; not with what is absent or with what is problematic.”⁴ An asset-based community approach is particularly important to address transition issues because the circumstances that young people and their families are working from are so highly individualized. These circumstances include such issues as the young person's health status and disability, family resources, quality of educational programming to date, community support options available, including the availability of relevant training and employment opportunities.



Observations & Tips about implementing an asset-based approach to youth transition.

1. There needs to be a willingness to work together. A spirit of confidence and trust must prevail.
2. All who are invited may not choose to participate, but recognize and value all who come.
3. Help people do what they want to do more effectively. Recognize what is there, and take advantage of what is working.
3. Give and take relationships are more successful. Each interaction and relationship should be mutual.
4. The beauty of this approach is that you don't have to do it all yourself.
5. Work where people and systems are at. Unwanted or unsolicited structure cannot be imposed upon individuals or systems.
6. Systems in and of themselves will always be inadequate; but keep a positive attitude and rely upon the parts of the system that work well to help you move forward. As one person said in our project, “If the system itself says ‘no,’ find a ‘yes.’”

Within an asset-based approach, each of the stakeholders share the commitment to do what is necessary to support young people and their families through the transition period. But, the manner in which the roles are performed by each stakeholder will vary depending upon the relationships and partnerships they have negotiated (formally and informally) within each community and with each family. This approach expects and relies upon our education, health and social services agencies to meet their assigned and mandated transition responsibilities. However it also acknowledges that while these mandated responsibilities are vital, in and of themselves they are likely to be insufficient when dealing with the transition challenges of many youth with special health care needs. This is so because the unique needs of these youth related to their special health care status may not be easily met by traditional services, supports and opportunities. However, despite that insufficiency, those who are involved in an assets based approach recognize that there is cause to be confident if citizens look to one another and build upon their individual and community capacities to include everyone in the community. When this occurs, the transition period for young people with disabilities and other special health care needs moves away from being a period characterized by limitations and barriers and becomes what it is for most youth and families—an exciting period of time to struggle with the question of what it means to grow up, move away, and develop lives of their own.⁵

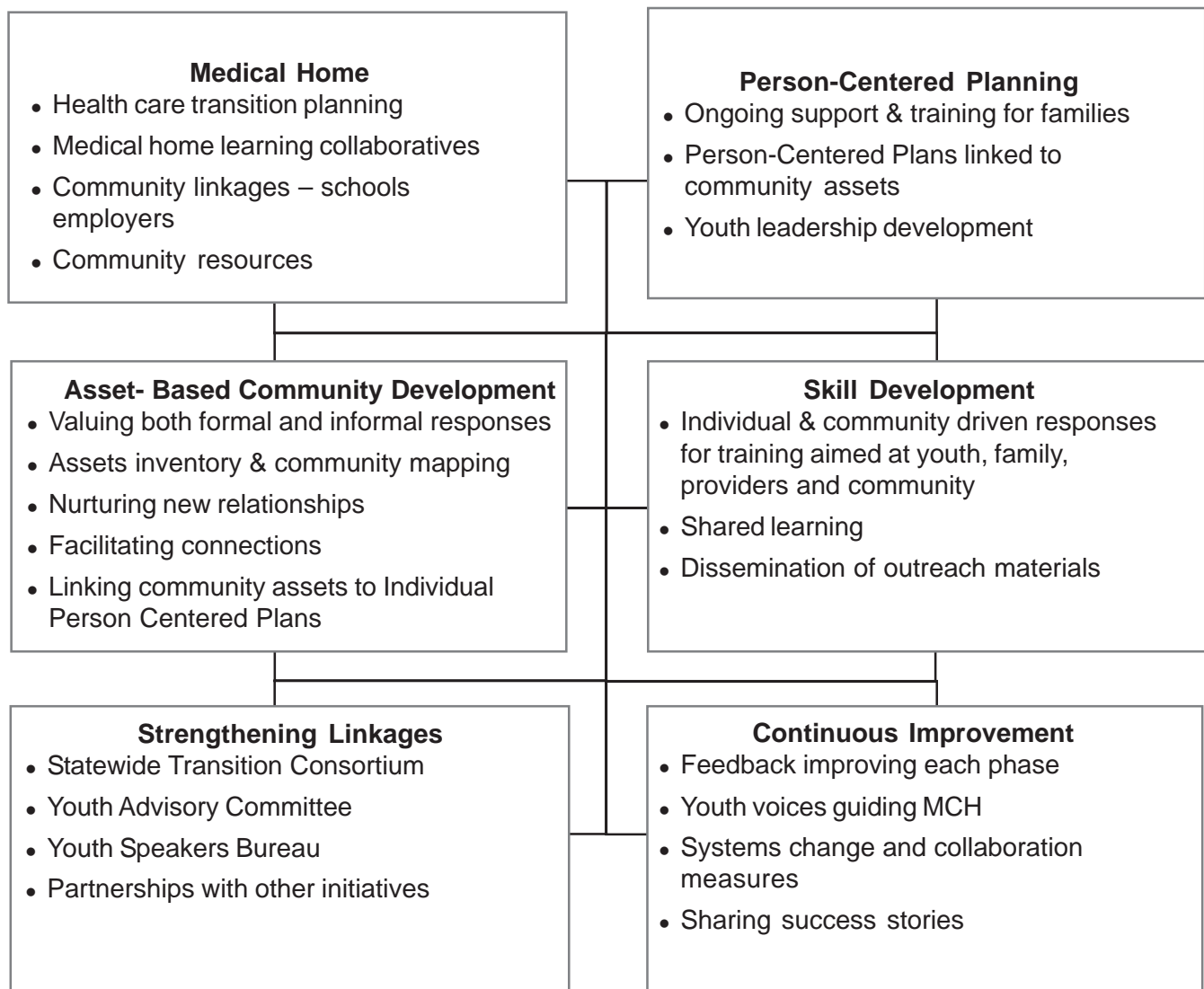
“ . . . Asset-based approaches increase family confidence in systems and communities and give youth decision-making power they may never have experienced before.”

“ . . . those who are involved in an asset-based approach believe there is cause to be confident if citizens look to one another and build upon their individual and community capacities to include everyone...”

Elements of the Wisconsin Healthy and Ready to Work Approach

The approach that Wisconsin implemented to support youth in transition was drawn from the experience of the HRTW projects that MCHB funded between 1996 and 2001, the transition framework and literature reviews completed by Kohler, Chapman and others at the National Transition Alliance,⁶ the principles of asset-based community development that have been described and advanced by the Asset-Based Community Development Institute at Northwestern University, and person centered planning techniques described by O'Brien, Pierpoint and Forest.⁷ As shown in Figure 2, the Wisconsin Healthy and Ready to Work Approach has six elements, each of which include a number of activities that are carried out in separate, but most often inter-related ways. Collectively these elements work to promote successful transition.

Figure 2: Elements of the Wisconsin HRTW Approach



“Transition is a process, not an event. The actual process should be gradual, occurring in harmony with adolescent and family development. While there is not one correct model, whenever it occurs, communication among pediatric and adults providers, parents and youth is critical.”

— National Center for Youth with Disabilities

Definitions:

- *Medical Home:* An approach to providing health care services that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. Pediatric health care professionals, parents and youth act as partners to identify and access all medical and non-medical services. (Adapted from AAP).
- *Person-Centered Planning:* A strengths-based approach that is keyed to listening to the ideas and preferences of the young person with special health care needs and his/her family, and working with those ideas to set the direction and plan for the future.
- *Asset-Based Community Development:* A relationships based approach to community development that relies upon mapping of the wide range of local assets (in contrast to problems and needs) within the community (e.g., individuals, citizens associations, institutions, physical environment) and then matching these assets with opportunities to further enhance the community. As applied to the YSHCN it refers to matching of the community assets to support youth with special health care needs as they transition to adulthood and all levels of community life.
- *Skill Development:* Refers to the series of methods that are taken by individuals, agencies and organizations to continually provide opportunities to individuals and groups to increase their knowledge and skills through information and assistance, trainings and self study materials.
- *Strengthening Linkages:* A process that agencies in leadership positions exercise in order to engage representatives of various venues in discussions that affirm their commitment to common interests, permit sharing of information on current issues, challenges and opportunities, and otherwise works to promote effective and efficient utilization of resources to support youth in transition.
- *Continuous Improvement:* Refers to a variety of quality management techniques that are incorporated into the ongoing processes of a program that result in the collection of information on program performance that is utilized to design continuous program improvements based on what is learned.



State Comparison: The Wisconsin Experience:

Wisconsin is a midwestern state that has a population of 5,234,350. Ninety percent is White, 5.5% African American, 2.1% Hispanic, 1.4% Asian American and .9% American Indian. The state has rural, urban, tribal and farm communities, all of which vary significantly in transition services.

According to the Association of Maternal and Child Health Programs (AMCHP) State Profile for the Wisconsin 2004 Block Grant, Wisconsin MCH serves 4,076 children with special health care needs.

A 2001 summary of SLAITS data from the National Survey of Children with Special Health Care Needs included information about 110 Wisconsin children with special health care needs specific to MCH outcome 6. The parent or guardian who knew the most about the child's health and health care provided answers to the questions asked. Adults acquainted with youth reported that of the 110 Wisconsin youth:

53 percent of children reported on had doctors that talked with them about changing needs as the child becomes an adult.

65 percent of children had a plan for addressing changing needs.

36 percent of children had doctors who discussed the shift from the child's provider to the adult provider.

16 percent of children received guidance and support in transition to adulthood.

29 percent of children received vocational or career training.

Taken from Summary Tables from the National Survey of Children with Special Health Care Needs, 2001

Leadership for implementing this model in your state

The Wisconsin Title V CYSHCN program designated the Waisman Center at the University of Wisconsin-Madison as its partner to serve as the lead agency in the state to develop and implement transition support for CYSHCN. The Title V Program selected the Waisman Center based on the fact that it is the federally designated University Center for Excellence in Developmental Disabilities within the state and consequently has a great deal of experience in providing training, technical assistance and outreach across Wisconsin communities. The Center had earlier been designated by the Wisconsin Title V Program to serve as the Southern Region CYSHCN Center. In that role the Center partners with four other funded State Title V CYSHCN Regional Centers to provide (1) information and assistance, (2) parent to parent support and (3) service coordination to families with CYSHCN.

The point to consider here, is that while responsibility to assure that the State is effectively addressing youth transition rests with the State CYSHCN Program, the manner in which the program meets that assurance can vary from state to state, depending upon the preferences of the program and options they have to choose from within their state. States that choose to partner with outside agencies can consider such groups as:

- University-based programs, including University Centers for Excellence, or specialized centers within schools of education, medical or nursing schools that are focused on adolescence.
- Medical Home learning collaboratives that are well established.
- Consumer leadership organizations such as Centers for Independent Living, family leadership organizations such as Family Voices and Parent Information Training Centers.
- Voluntary civic and community groups, especially those interested in supporting youth and advancing employment.
- Other state agencies including community development, public instruction, vocational rehabilitation and others with a youth focus.

“Over the past several years we have been involved in a major restructuring of our CSHCN Program, and our outside partners have been the key. They’ve expanded our pool of talent and helped us access resources that we would have likely overlooked working only from the perspective of the state agency. I would urge other State CYSHCN programs to look to outside partners – particularly to address performance measure six related to youth transition.”

*Sharon Fleischfresser, M.D.
Medical Director, Wisconsin CYSHCN Program*

Structure of this Report

The remaining sections of this report describe each element of the Wisconsin approach including:

- Definition of element
- Relevancy of element to core outcomes and performance measures
- Self assessment suggestions for State CYSHCN Programs
- Brief summary of Wisconsin activities with featured resources
- Tips and Lessons Learned



How Wisconsin CYSHCN Regional Centers Support Transition

Wisconsin’s CYSHCN Program does not provide direct services to children and youth. Rather, the state has set up a network of five regional centers across the state that provide information and assistance to families, youth, providers and community members at large. The centers also conduct regional trainings, provide parent-to-parent support, and are involved in health benefits counseling.

With leadership, training, technical assistance and resources from Wisconsin HRTW, all WI CYSHCN Regions became actively engaged in HRTW community development, skills training and person-centered planning activities.

Each Region identified a transition liaison who focuses on transition events and information sharing with local public health agencies and other community partners. The transition liaison worked with project staff to identify areas of need and interest related to youth transition in each part of the state; to recruit participation in trainings and person-centered plans; and to disseminate materials from the projects to youth, families and community partners. The transition liaison also helped identify local youth to participate in youth leadership opportunities through the project, and disseminated information to youth and families about upcoming opportunities related to adolescent transition topics and events.

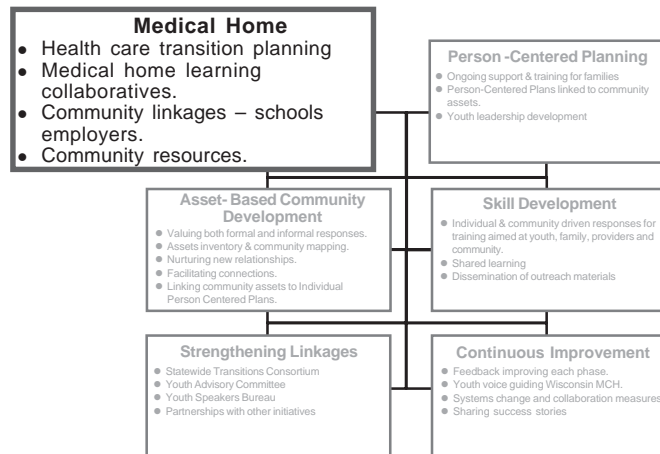
★ CYSHCN Regional Centers

Part III: Applying Wisconsin HRTW Approach

The Medical Home Element

Definition: An approach to providing health care services that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. Pediatric health care professionals, parents and youth act as partners to identify and access all medical and non-medical services. (Adapted from AAP.)

Elements of the Wisconsin HRTW Approach



Medical Home is relevant to the following core outcomes and performance measures:

Core Outcome #1: All CYSHCN will receive coordinated, ongoing, comprehensive care within a medical home.

Core Outcome #2: All families of CYSHCN will have adequate private and/or public insurance to pay for the services they need.

MCHB Performance Measure #1: The percent of newborns who are screened and confirmed with condition(s) mandated by their state-sponsored newborn screening programs who receive appropriate follow-up as defined by their state.

MCHB Performance Measure #3: The percent of CYSHCN age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

Self-Assessment suggestions for State CYSHCN Programs: The overall purposes of this assessment should be to determine what is currently occurring with regard to Medical Home, how current activities can be enhanced or expanded upon, and what new activities might be planned for the next one to five years. While most states have some level of Medical Home activity in place, very often those activities do not include specific actions steps related to planning for youth transition to adulthood. Consider the following activities and questions:

- 1) Identify current activities that are linked with the AAP Medical Home initiatives within your state, including MH learning collaboratives.
- 2) Review SLAITS and other data sources to formulate an estimate of how many CYSHCN are receiving health care within a Medical Home framework.

- 3) Identify existing Medical Home practices in your state and gather information from youth, families and health care providers to identify areas of strength and gaps. What are these Medical Homes specifically doing to address the needs of youth in transition?
- 4) Ask families and youth what types of materials/information they would find useful to strengthen their partnerships with their health care providers. From their experience, how comprehensive are services and connections? What are families and youth most satisfied with? What suggestions do they have for improvement?
- 5) If your state CYSHCN program does not have a consumer/youth advisory group, consider forming one so that it is positioned to offer advice to Medical Home learning collaboratives and others in the state who are working to promote Medical Home.

Summary of Wisconsin Activities

From our assessment, we learned that while Medical Home was not a generally recognized term statewide, several pediatric practices had some exposure through promotional efforts of the Wisconsin Chapter AAP and the state Title V CYSHCN Program. Both the Medical Director of our CYSHCN Program and our Title V MCH Director are very active in the state chapter of the AAP, so those contacts were very helpful to our promotional efforts. Our state was also fortunate because several pediatric practices were participating with the National Medical Home Learning Collaborative sponsored by NICHQ - National Initiative for Children's Healthcare Quality. Since these practices were already well versed on Medical Home, we chose to make a special effort to work with them, feeling if we could assist them to acknowledge and perform the work necessary for successful transition, then they could serve as model practices that others could emulate. We took a consultation and technical assistance approach and asked them – "What are you currently doing to facilitate successful transition?" Are there ways that we can help you be more successful?" Their answers pointed us in a number of directions.

Legal Decision Making: When the young person turns 18, he or she is an adult with all the rights and responsibilities that come with that status, including their assuming responsibility for arranging their own health care. Families and care providers asked us for information on a full range of guardianship options, from independence to full guardianship. We focused on building partnerships between families and medical, legal, financial, social service and HRTW professionals. We did not limit these discussions to youth transition but focused the discussion on all who influence decision-making related to guardianship. We worked with attorneys and other advocacy groups to develop a series of materials which served as the basis for content presented at nine workshops around the state. These were attended by youth and families, transition teachers, local attorneys and judges, Independent Living Center staff, county case managers and others in social service fields.

Tools From Wisconsin HRTW

Legal Decision-Making



This set of resources explores all legal options for youth with special health care needs at age 18, from full independence to different types of power of attorney and guardianship. Since it is based on Wisconsin law, portions of the content will not directly apply outside of Wisconsin. But, it will provide a helpful overview of the primary issues to be concerned with as a young person turns 18. (Note: Content of this video is also included as a separate track on Caleb's Story video described on page 26.)

Tools From Wisconsin HRTW

Transition to Adult Health Care: A Training Guide in Two Parts



This training guide is intended to serve as a framework for anyone interested in helping young people with special health care needs and their parents prepare for the transition to adult health care.

Transition to Adult Health Care

Management. Youth must know about their medical condition, their care and treatment regimens and the medications they require. Parents who have provided and coordinated care for their children from very young ages often have a difficult time knowing how to gradually increase youths' independent involvement in their health care. In order to encourage a shift in responsibility, both parents and youth need support. Wisconsin HRTW identified a parent with a health care background who was interested in developing two-pronged health-care management training: one workshop focused on parents and caregivers, and another set of trainings for youth themselves. The curriculum was presented with both parents and youth at a statewide families conference called Circles of Life, a statewide vocational rehabilitation conference, and at youth peer mentoring sites.

Throughout the project HRTW staff met with the faculty of the University of Wisconsin Pediatric Pulmonary Center (UW-PPC). They were a natural group to partner with given the UW-PPC is funded by MCHB. Their mission is to provide an interdisciplinary training program to develop leaders who will improve the health of children with respiratory conditions. The UW-PPC, like many specialty clinics and programs throughout the country, recognizes the need and opportunity to do more to help patients transition to adulthood in a coordinated way that feels safe for patients and families. During our partnership with the PPC, they completed a comprehensive transition program, called *“Moving On...Transitioning from Pediatric to Adult Care”*. This program provides a booklet and educational tools that focus on assisting youth with cystic fibrosis to gain skills at various developmental stages from ages 8-21. The goal of this program is to help youth to take on more responsibility as the move through the developmental process to become informed young adults who are able to take care of their health and medical care.⁷

Tips and Lessons Learned about Medical-Home

Nurture Partnerships. As you work to promote Medical-Home it's easier if you start your work with partners who have already shown an interest in practicing in the ways that Medical-Home intends. Don't just rely upon physicians, but also look for like minded people who are nurses, care coordinators in managed care organizations, youth, families and others who want to learn more and improve the ways they work with families and other agencies.

Commit to the Relationships. If Medical-Home is going to be successful, then like any home, the partners must be committed to a working relationship that is mutually created, defined and played out.

Expect Roadblocks. People and health care systems are complex and dynamic and it's always a "work in progress." Don't get discouraged if things look a little messy along the way. Keep your eyes on the vision and be open to changing the plan as new challenges and opportunities are presented.

Specialists can enhance the Medical-Home team building. While Medical-Home is designed primarily from the perspective of the primary care practice that is serving the young person, specialty practices and clinics focused on specific disabilities or conditions are key partners to have involved, especially for youth with complex medical conditions such as pulmonary diseases, cerebral palsy, etc. Specialty practices can often be used to work with the family and the primary care provider to convene initial discussions with the various community partners to get roles clarified and everyone working together.

Encourage youth to stay connected with their Medical-Home. Medical-Home practices are often asked to fill out school and/or employment related paperwork that speaks to the abilities and strengths of the young person. Physicians and nurses will be more accurate and thorough in these reports if they have been able to know the person beyond the routine interactions. Encourage youth to work towards establishing a close and trusting relationship where they are comfortable sharing who they are beyond their specific medical or health condition.

Identify practitioners who consider capacity for decision-making in their patient population as routine part of their daily work. Without making gross generalizations about subspecialties, some physician practices, by virtue of their training, may have an enhanced awareness of decision-making capacities of patients. For example, because family practitioners work with people across the lifespan and often discuss durable power of attorney with their senior patients, they and other specialists may be poised to work with YSHCN on a range of issues regarding their decision-making.

Long-term benefits occur when consumers are informed. Youth with special health care needs may be better prepared to deal with health issues than youth without special health care needs because they have had more health care consumerism experience. Youth need to start participating in their health care from their early teens or even as pre-teens. Curricula to help develop skills are important, as are opportunities to practice applying those skills in the health care setting and with family members at home.

Encourage informed decision-making. Help families be proactive in supporting their youth with special health care needs to make their own decisions. Support skill-building for youth and parent training that teaches families how to build choice-making into youths' lives.

Remember to communicate *directly* with the youth you work with--using a variety of strategies. Some YSHCN may be cognitively capable to make their own decisions but their abilities may be masked by mental illness, an insufficient communication system or a physical disability that affects communication. Affirm what you can of their decision-making abilities. Patience and extra time may be necessary at first, but will pay off as relationships form, and as you understand each other's communication styles.

Be aware of your state laws around guardianship. A young person's options and responsibilities related to how they exercise decision making may be limited if some form of guardianship is in place. Work with individuals well-versed in your state's laws regarding guardianship. If some form of guardianship is in place with a given young person, still make a special effort to support the young person in knowing about and exercising their rights and to speak out.

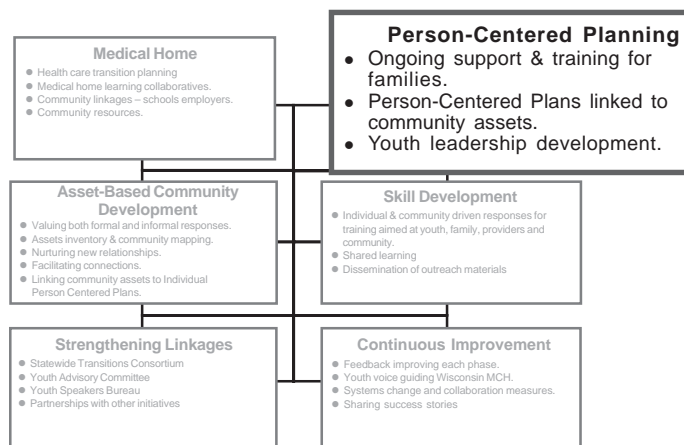
Contact other agencies involved in legal decision-making range of options. Identify groups in your state, (Arc Office, Department on Aging , Protection and Advocacy Agency)⁸ that may have useful materials about this topic. Attorneys who specialize in elder law may be good contacts about the range of options available concerning guardianship. There may be more of these attorneys readily accessible in your state than attorneys well-versed in disability law.

Consider communication styles more common to youth interactions. Those in conversation with YSHCN need some familiarity with the language of that youth. Some situations may be more nuanced and complicated than communications requiring a formal interpreter. Encourage the youth to write down or email questions in advance, with support from a caregiver or other involved person if necessary. When working with youth from a culture other than your own, consider the use of “cultural brokers”⁹ who help participants to understand meeting dynamics such as terminology, processes, roles and responsibilities.

Person-Centered Planning Element

Definition: A strengths-based approach that is keyed to listening to the ideas and preferences of the young person with special health care needs and his/her family, and working with those ideas to set the direction and plan for the future. A number of person-centered planning approaches have been developed including Planning Alternative Tomorrows with Hope, known as PATH,¹⁰ Making Action Plans, known as MAPS,¹¹ and Group Action Planning, known as GAP.¹²

Elements of the Wisconsin HRTW Approach



Person-Centered Planning is relevant to the following core outcomes and performance measures:

Core Outcome #6: All youth with special health care needs will receive the necessary services to make appropriate transitions to adult health care, work and independence.

MCHB Performance Measure #2: The percent of CYSHCN age 0-18 years whose families/ youth partner in decision making at all levels and are satisfied with the services they receive.

MCHB Performance Measure #6: The percent of youth with special health care needs who received the services necessary to make transition to all aspects of adult life.

Self-Assessment suggestions for State CYSHCN Programs: The overall purpose of this assessment should be to determine what is currently happening with Person-Centered Planning in your state, how current activities can be enhanced or expanded upon, and what new activities might be planned over the next one to five years. Since Person-Centered planning has been defined and advanced throughout the country primarily to serve those with developmental disabilities, a good place to begin your assessment is with potential partners in your state DD System. Consider the following questions and activities:

- 1) What, if any, philosophies or approaches support Person-Centered planning in your state?
- 2) Which agencies and programs are currently doing Person-Centered planning? What models are they utilizing? Who are the champions of the process in your state? How might they be engaged in efforts with your CYSHCN Program?
- 3) How are the plans used by the individual with special health care needs, the family, health care providers, school system and others in the community? What efforts can be taken to show others how this process has been successful?
- 4) If no Person-Centered planning process is used, how do agencies identify the strengths, resources, priorities and concerns of individual youth? What organizations and people are invited to the table for and with the youth connected with program? Who is missing who and should be invited next time?
- 5) How does your program tie the strengths, interests and goals identified in person-centered planning to goals and outcomes in youths' health plans? How does or could the collective experience of what is learned in the various individual plans inform ongoing planning for CYSHCN related activities?

Summary of Wisconsin Activities

Wisconsin efforts with Person-Centered planning evolved through three phases of activity, with each phase building upon what was learned in the previous phase. We learned as we were doing.

Phase I: We began by initiating separate but parallel sets of activities around Person-Centered planning and Asset- Based community development (which will be more fully described as the next HRTW element). Person-Centered planning was an effective starting point in transition planning for youth because it engaged staff in working directly with the youth and families in order to learn firsthand of their interests, abilities and dreams for the future. Likewise, asset-based community development was considered important to address early on because it offered possibilities to tap under-utilized and overlooked opportunities for youth to connect to activities and groups in their communities that could help them realize the goals they identified in their individual plans. One FTE, which was divided among two staff members, was dedicated to work with these aspects of the project. Their time was also used to support the efforts of the HRTW Youth Advisory Committee, skill-building responsibilities, and some product development. An outside facilitator who had been trained in person-centered planning processes was secured to assist with training and technical assistant related to creation of individual plans following the PATH process.

Youth and families were invited to participate by the respective CYSHCN Regional Center serving their location of the state. Each young person and family worked individually with the person-centered planning facilitator. Each “plan” took approximately 10 hours and included an introductory meeting, followed by the planning meeting when the plan was developed.

At the same time that these Person-Centered plans were being developed, project staff worked with each Regional CYSHCN Center to identify community stakeholders who could advise on their community’s most pressing concerns and interests related to transition to adulthood, as well as community assets related to engaging YSHCN in their communities. A “town hall” format was used where stakeholders were invited to a community forum; ideas were captured and served as the basis for a plan for that community.

During phase one, personal plans were created and a variety of community interests and assets were “mapped”. However, those plans and community “assets” were not blending to the degree that we had originally anticipated. All too often the ideas and plans that were generated by the youth did not line up with the opportunities and interests that were being identified by the community. We concluded that we needed to modify our process to find better ways to connect individual paths with community assets.

Phase 2: Rather than focus directly on the creation of individual plans for specific individuals, we decided to create a cadre of individuals who were interested in assuming a leadership role to promote Person-Centered planning on an ongoing basis in their respective communities. With training and support we felt they could become local champions and resources for the process. Teams of 12-16 individuals were recruited by the Regional CYSHCN centers to participate in a 3-day training. Participant expenses were paid and they were offered \$150 for each individual plan they completed with a youth. The project conducted 3 regional trainings and participants unanimously evaluated the training as effective and useful with the youth and families with whom they worked.

As these individuals were being trained, staff worked with others in their respective local communities to sponsor community activities that arose from concerns and dreams that surfaced in Person-Centered plans. For instance, since issues around health care and legal decision-making were common in plans, community trainings were offered that focused on legal decision-making options (including presentations by young adults and their families). These sessions were well-attended in every part of the state and participants reported that they would make use of the information they learned. However, this second phase of person-centered planning resulted in development of only a handful of Person-Centered plans. Families and training participants listed the same challenges in developing plans that occurred earlier, namely that there was a gap between the desires spelled out in the plan and the opportunities that were potentially available in the community.

Phase 3: The new factor that the project called upon in Phase 3 was a designated individual to specifically link the Person-Centered planning process to Asset-Based community development work. Referred to as a “community connector,” this person was a community resident who was active and engaged in both the disability community and in broader community life. Connectors were not only involved in the development of person-centered plans, but also extended their commitment and worked to identify community experiences for each youth to access based on his or her interests and plan. To support this work, a “mini-grant” process was created and funding in the range of \$1500-\$3000 was made available to support the efforts of the community connector over the period of approximately one year.

The community connector recruited youth and their families to take part in person-centered planning. After plans were developed, the connector went directly to the community for potential opportunities based on each youth's plan. The results were a set of different and unique community connections for each youth based on individualized goals and outcomes for each. Different youth were given different opportunities to try new experiences, and to acquire particular skills based on their transition plans. (The role of the community connector is more fully described later in this report).

Tools From Wisconsin HRTW

Whose Life Is It Anyway?



How One Teenager, Her Parents, and Her Teacher View the Transition Process for a Young Person with Disabilities

This publication is a unique exploration of the emotions and relationships between three key transition partners: Becky, the youth; her mother;

and her teacher. It includes talking points for group discussion about relationship building and best practice in adolescent transition. Outcomes include helping all partners raise expectations about what youth with special health care needs can achieve, how to meaningfully involve youth in the process and ultimately, how to better understand each participant's perspectives.

Example of Person-Centered Plan

The following page provides one example of a person-centered plan that was developed utilizing the PATH process. In this process, group members start on the far-right side of the diagram with "envisioning the dream." Participants spend 30 to 45 minutes talking about hopes and dreams for the individual's future regardless of whether those dreams are realistic. In the next step, the plan moves directly to the left to capture goals based on the dream that are both positive and possible within the next year. Then, they move left again to develop mid-year steps toward the year-long goals.

The final four steps are done quickly and move from far left to right. The team looks at what is currently happening in the individual's life, the "Now." Next, they enroll possible participants who can help the "positive and possible" goals happen. The "Strong" category captures activities and people who motivate the individual, or make him/her empowered. Finally, the team identifies first steps that will be done within a week, including a coach who will check in with the individual who is assigned a task, to see how the task went and if help is needed.

Tips and Lessons Learned about Person-Centered Planning

Help youth and families understand what Person-Centered Planning is all about. If families had never heard about Person-Centered planning, they were often reluctant to become engaged in the process and to make the commitment that was necessary. It can be emotionally risky for parents and the young person to invite others to participate in the process.

Consider how Person-Centered Planning can be carried out without compromising Family Centered approaches. Youth with special health needs, like all other youth, must use their adolescent years to begin to test and exercise independence from their parents and other family members. This transition can be especially difficult for YSHCN and their families because they have developed special bonds while addressing health and related issues up to adolescence. Continue to recognize and respect the role of the entire family, because like all families, they will continue to be very important during transition and the years beyond. But also help the young person and the parents accept that it is important to begin to create more independence from one another.

If funding can be secured, issue an RFP for “mini-grants” to support efforts in a local community. Proposals should describe the specific ways that the community connector will be utilized to support one or more youth. These proposals can demonstrate buy-in from a cross-section of the community and increase the likelihood that the community is ready to engage in a long-term process for change.

Hold Person-Centered planning sessions at neutral locations. A town hall, library or other public meeting space can be a very good place for these sessions. A school or person's home can be too personal and elicit emotions that interfere with planning.

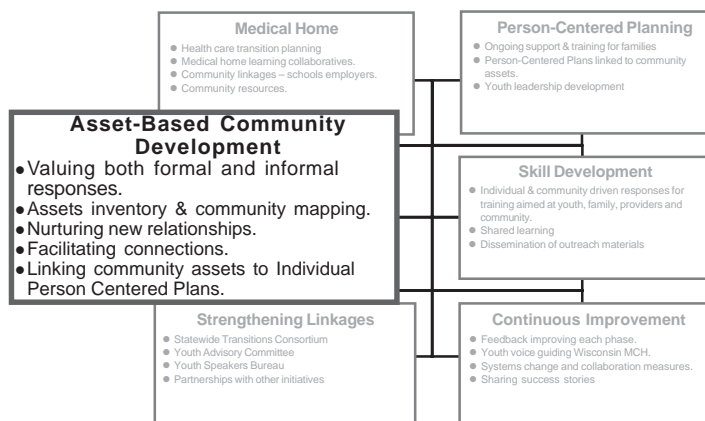
Good things take time. Allow at least one year and preferably two years to implement plans through a community connector. Relationships take time.

Follow up and support. Reconnect youth, their families and the connector every three to six months to give updates on their plans and talk about what has happened.

Asset-Based Community Development Element¹³

Definition: A relationships based approach to community development that relies upon mapping of the wide range of local assets (in contrast to problems and needs) within the community (e.g., individuals, citizens associations, institutions, physical environment) and then matching these assets with opportunities to further enhance the community. As applied to CYSHCN it refers to matching of the community assets to support youth with special health care needs as they transition to adulthood and all levels of community life.

Elements of the Wisconsin HRTW Approach



Asset-Based Community Development is relevant to the following core outcomes and performance measures.

Core Outcome #4: Services to YSHCN and their families will be organized in ways that families can use them easily.

MCHB Performance Measure #5: Percent of YSHCN age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Self-Assessment suggestions for State CYSHCN Programs: The overall purposes of this assessment should be to determine what is currently happening with Asset-Based Community Development efforts in your state, how current activities can be enhanced or expanded upon, and what new activities might be planned over the next one to five years. Consider the following questions and activities:

- 1) Is Asset-Based Community Development a recognized approach to community development that is being utilized in your state? Ask such groups as the United Way, Community Action, and Community and Economic Development Agencies.
- 2) If ABCD is being utilized in your state, who are the champions of the process? Invite them to tell their story and to join your efforts. Review “asset maps” that have been created and explore how those assets could support youth with special health care needs.
- 3) Assess the degree to which staff in your program work from an Asset-Based perspective in the context of their relationships with youth, their families and their communities. Do they focus on assets of individuals, families and communities rather than deficits?

- 4) If ABCD is not being utilized in your state, consider what role your program can take to create learning opportunities to educate others about what it is and how it can be utilized. Give special attention to connecting with the associations and informal community groups that are often overlooked.

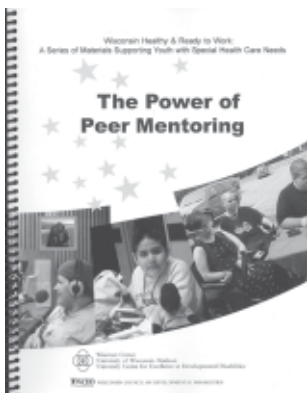
Summary of Wisconsin Activities

While a select group of Wisconsin communities had previously utilized Asset-Based Community Development approaches, those communities had not specifically directed those efforts to youth with disabilities. Therefore, one of the first steps the Wisconsin HRTW Project took was to invite consumers and representatives of community groups to a statewide meeting during which time our project consultant Jody Kretzmann, from the Asset-Based Community Development Institute at Northwestern University, gave an inspiring presentation that described what was involved in an assets-based approach. He effectively described how an assets approach that focuses on identifying and working with the strengths, dreams and what is right with individuals and communities, contrasts from the more traditional approach of health and social service programs that focus on the weaknesses, fears and what is perceived as wrong or troublesome with individuals and communities. This presentation not only reinforced how many in the audience preferred to be engaged with their respective communities, but it also provided specific tools that those individuals and communities could utilize to be engaged in this work.¹⁴ The result was that many individuals became more motivated to the possibilities and began to look upon our project as a resource to help them move forward in new ways.

As we considered next steps, we decided that we wanted to work with a community of reasonable size, so we selected a small rural community in southwestern Wisconsin where our colleagues had agency related acquaintances and where we knew a small number of youth with disabilities and their families. Over a period of a few months our staff met with members of the community to develop a listing of various community “assets” which evolved into a community assets map that listed some of the key individuals, associations and institutions - formal and informal that brought life to the community. At this same time, we identified and worked with a small number of youth to develop Person-Centered plans. But as was described in the previous section of this report, we were not able to successfully merge the two, meaning that we were not able to draw upon the assets listed in the community map in ways that supported the plans of the youth. In looking back, we concluded that the shortcoming of our original approach was that despite their good intentions, our staff were “outsiders” to the community and their efforts were not firmly grounded within the base of community relationships that characterize everyday life in that community. Therefore, the opportunities to mobilize community resources toward specific people or issues that were available to community members by virtue of their being a known, trusted and valued member of the community were not available to our staff as “outsiders.” Because of this, the project was not able to successfully leverage those community assets in such a way to apply them towards supporting the dreams and plans of the youth. At that point we decided to take a different approach and to begin by identifying community connectors. (See Germantown and Urban High School examples on pages 28 and 29).

Tools From Wisconsin HRTW

The Power of Peer Mentoring

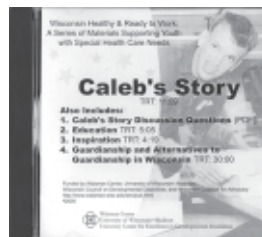


Individuals with disabilities should be recognized for who they are — valuable members of the community — and often untapped assets.

This booklet highlights the elements of one successful youth mentoring project between college-aged students with disabilities as mentors, and high-school aged youth with disabilities. Included are guidelines and strategies for building a successful youth mentoring program.

Tools From Wisconsin HRTW

Caleb's Story



An 11-minute video developed in partnership with Wisconsin Council on Developmental Disabilities and

Wisconsin Coalition for Advocacy, highlighting the work and home experiences of a young man with very involved health, cognitive and physical disabilities. It includes footage of Caleb at work, shopping and traveling in the community, and at the home he has purchased. Discussion questions included. Other tracks on this video include inspirational public service announcements.

Tips and Lessons Learned About Asset-Based Community Development

Define what you mean by “community” but stay open to change in its meaning. Taking a “community-based” approach may seem like a daunting task or like taking on too much at one time, especially if a youth and his or her family has felt excluded by community in the past. Have conversations about what youth and their families consider their community, then think of ways of expanding it beyond immediate and extended family as well as paid service providers. For some youth, community may be their school, or their church or a combination. For others, “community” might be others who are interested in computers or horseracing, or perhaps families in their neighborhood. The size and composition of the community depends on the youth and family’s perception as well as the interplay of possibilities of what community could be for the youth in transition.

Being invited in is key. When you are bringing a new or different approach to supporting youth in transition, being invited to be part of a community can be an important link to being part of the long-term work of the community. No one can force Asset-Based Community Development on a community that does not want to use the approach or framework.

Mapping of Community Assets. Compile an inventory of the key assets and resources of the community as these are represented by local individuals, associations, organizations, and institutions. The information in this inventory can be used to build strong mutually beneficial partnerships between local youth and other individuals, organizations, and associations that exist within the community. Relationship building depends upon direct knowledge of specific community resources.

Utilize Community Connectors. Because community connectors are already community members, they may have more credibility and political and social capital than someone who is unknown or someone who “jets in/jets out.”

Community Connectors have a unique set of skills and qualities. Caring for youth in transition, compassion, confidentiality, cultural competence and continuity are all elements of the work and approach of the successful community connector. If your community connector lacks sincerity, patience and passion for youth in transition, finding other community connectors will be the best choice for your Asset-Based Community Development initiatives.

Distinguish between Community Connectors and consultants. Each may have a role in your Asset-Based Community Development work. However, delineating between the two types of roles will be important for the youth and families you work with, in addition to your own initiative. Having conversations about purpose, expectations and timelines, even if they are beginning conversations, will enhance the relationship-building experience and help youth and families to direct themselves to who can best connect them to what they want and need to accomplish their goals. If a consultant’s role is to participate in periodic site visits and/or meetings, make it clear that this person has a time-limited presence in the project.

Community Connector Skills and Qualities

A Community Connector is a person who connects people to people, people to resources and resources to people. A community connector lives in the same city, community or neighborhood as the people with disabilities with whom they know, work and play. A community connector will have and make higher quality connections if she or he:

- Has an extroverted personality and welcoming attitude.
- Is a creative thinker who is willing to refine and change ideas and strategies over time.
- Knows lots of people and places in the community.
- Follows through on commitments to youth, families and community contacts.
- Understands how to fade supports as new connections emerge.
- Can relate to people from all walks of life, with all types of values, even if they are not his or her own.
- Has the ability to be comfortable in people’s homes, workplaces, community centers, churches, schools, wherever they want to meet.
- Shows comfort with asking questions.
- Takes a genuine interest in people’s lives.
- Displays patience with the process of self-and community-discovery.
- Has willingness to take risk and ask favors.
- Exhibits the creative ability to see connections between people’s interests and activities already occurring in the community.
- Holds an abiding interest in helping people and communities flourish.
- Demonstrates stamina and perseverance; does not give up easily.
- Enjoys bringing people together and acting as “host.”

Applying a Person-Centered Asset-Based Community Approach: Example - Germantown

Germantown is a small, southeastern Wisconsin community that is comprised of suburban Milwaukee commuters, farm families and small town residents. A single, medium-sized high school serves the entire community, which is primarily middle-class and white.

Community Connector: The community connector was the mother of a transition-aged son with special health care needs and has been involved in parent leadership activities at both formal and informal levels for many years. She has connections with local Department of Public Instruction staff and teachers, as well as a Milwaukee employment agency that does job development for people with significant disabilities. She has lived in the Germantown community for many years and has been active in local sports, religious organizations, school events and other organizations.

Youth and Families Involved: Although the community connector recruited participants through school, service agencies and community channels, six out of the seven families who chose to participate knew her personally. All the families had youth between the ages of 15 and 25, and all had cognitive disabilities. Some had other diagnoses as well, which required medication. All participants were connected to the project as a result of a parent receiving an email or flyer about the opportunity to be involved in the project. The parent then initiated contact with the community connector.

Process: The community connector mapped out a year-long schedule for introducing the concepts of person-centered planning to the youth and their team and community, creating plans with the youths and their teams, and finally assisting teams to implement their plans with the focus of connecting youth to opportunities within their communities. First step: The connector invited families, teachers, health providers and the community to a 90-minute meeting about person-centered planning. An experienced facilitator explained the concepts of person-centered planning. 15 people attended. From that meeting, she recruited seven families who agreed to participate in person-centered planning about a month after the informational meeting. Families and youth were encouraged to bring anyone they wanted to the planning session, including teachers and other school staff, health providers, family and friends. Most teams included 4-10 people, including the youth, immediate family, teachers and neighbors. Person-centered planning sessions were done in a group process during two hours on a week night using a multi-step planning process. Each session had three or four teams working simultaneously, and each team worked together at a separate table. Over the next six months, the community connector focused on identifying resources in the community that could meet goals in individual youths' plans by mapping different opportunities and individuals in communities with whom she could connect each youth. The connector was responsible for making introductions, accompanying youth on first visits if needed, and following up to see how things went. After six months, the teams came together for another meeting to share successes, challenges and to formulate next steps. All agreed that they want to continue to meet as a group at least twice a year in order to share experiences and resources, continue to maintain energy and commitment, and to learn from each other.

Outcomes: Life planning is a long term process but all of the youth that participated have experienced positive outcomes. Here are examples of some of the positive steps that were taken.

- One youth is now employed by a local grocery store.
- One teen is now ushering in his faith community.
- After exploring opportunities at a local animal hospital that did not work out, a youth now volunteers at the county humane society.
- A youth worked with a team member to create an exercise program for use at his high school over the summer.
- Several youths opened their first checking/savings account.

Applying a Person-Centered, Asset-Based Community Approach: Example – Urban High School

South Division has about 1,600 students on the south side of Milwaukee, with the majority speak in Spanish as their first language. Most of South Division's Latino students are of either Puerto Rican or Mexican heritage. The high school is located in a lower-income neighborhood that includes both homes and businesses, many of which are owned by Latinos. The Catholic and Evangelical churches in the neighborhood play a big role in the lives of many of the students and their families.

Community Connector: The community connector is a high school teacher who has a caseload of about 14 students, most of whom have cognitive disabilities. This teacher is Puerto Rican and bi-lingual. She is well-known at her school, where she partners with other school and community staff, and in both the Latino community and in the neighborhood that borders the high school. She makes an effort to meet and build relationships with the families of every youth she works with, making home visits and inviting families to her home. She also has developed relationships with business owners in the area surrounding the school.

Youth and Families Involved: All six of the youth involved were students of the community connector. All of the participants had been in her class for at least a year, often times longer. The youth were between age 14 and 21. Five of the six had cognitive disabilities and all of them also dealt with mental health issues and/or other major health concerns, such as seizure disorders and cerebral palsy. Many of the students were undocumented and not eligible for county, state or federal services for children and youth with disabilities. All were connected to the project as a result of having the community connector as their teacher. No participation was initiated by a parent or family member.

Process: The community connector used a person-centered planning tool with each youth a few weeks before the school team and family met for the Individual Education Plan (IEP) meeting. Interests, skills and potential opportunities were then incorporated into the IEP plan for the coming year. The teacher and other school staff then connected youth with opportunities as outlined in the IEP.

Outcomes: Like the Germantown youth, all youth in the project experienced increased connections to their communities and additional experiences related to their interests and skills. Some examples include:

- Several youth learned how to open a bank account.
- All youth applied for a library card and learned how to check out materials (many for the first time).
- One youth was linked with hospital volunteer experiences because of her interest in nursing.
- One youth joined a school dance club because of her interest in music and dance.
- Several youth became regular volunteers at the local Salvation Army and Good Will second-hand stores.
- Several youth learned how to bargain at local shops where that is an accepted practice.
- A group of youth went on a week-long camping experience. This was the first time several of them were ever away from home or their parents overnight.

“You can never close the door to relationships...with the family, with the youth or with the community. It takes a lot of time.” — Community Connector

10 Things Faith-Based Institutions can do to Include Youth with Disabilities:

- Start by asking families and youth what they would find helpful.
- Form Circles of Support around the person (4-6 people who will welcome that person, sit with them at services, possibly provide transportation to social events)
- Offer a tour and connections to new members. Introduce them to congregation members and make some personal connections to members. Involve youth with disabilities who are new in orientation classes, which will connect them with other new members.
- Offer youth with disabilities meaningful roles: ushers, greeters, food preparation, help with arts and crafts or in the nursery.
- Be direct in telling families and youth that they are welcome — in the building, in classes, and at social gatherings.
- Encourage participation in social activities as a way of including people with all interest and ability levels.
- If there is not a youth group, consider starting one for youth with and without disabilities. If a youth group exists, ask members for ideas on how to involve and include youth with disabilities (they are often the most creative innovators).
- Have youth groups think first about people and their wants, needs and abilities, and then plan activities. Starting with an activity before thinking about the people may exclude youth with special health care need or disabilities.
- Make sure transportation for all is available. When planning congregation activities and trips, discuss with the family specific support needs, especially personal care needs.
- Pull together a core team of concerned congregants (including some individuals or families with disabilities) who are interested in exploring the issue of inclusion further in their church.

10 Things Employers Can Do to Support Youth with Disabilities:

- Provide youth with opportunities to try out different skills in order to get the right job “fit.” Consider allowing youth to volunteer for a limited time, in order for them to explore skills and for the business to better understand the youth’s capabilities.
- Consider job “carving,” which is combining a certain set of duties across positions into a single job for a youth with a disability.
- Take advantage of resources that specialize in offering technical assistance on supporting people with disabilities on the job: Independent Living Centers, vocational rehabilitation, or the Job Accommodation Network website, <http://www.jan.wvu.edu/>
- Consider matching youth with mentors or role models on the job. Think of co-workers as natural supports for small issues, such as reminders, locating necessary work-related items, etc.
- Encourage connections between youth with disabilities and their co-workers: work get-togethers, eating lunch together, social outings.
- Get to know business owners who employ youth with disabilities. Ask them about issues that may arise and if they would be available to answer questions from other businesses interested in employing youth with disabilities.
- Ask your local chamber of commerce to keep a directory of organizations that employ youth with disabilities or have youth volunteers with disabilities.
- Consider alternative application methods: applying on tape instead of with a written application.
- Talk with colleagues about successes. Spread the word to other business owners and managers that hiring youth with disabilities can be both productive and mutually rewarding.
- Ask the youth and his/her family what accommodations are necessary. People with disabilities often have the most creative and least expensive solutions.

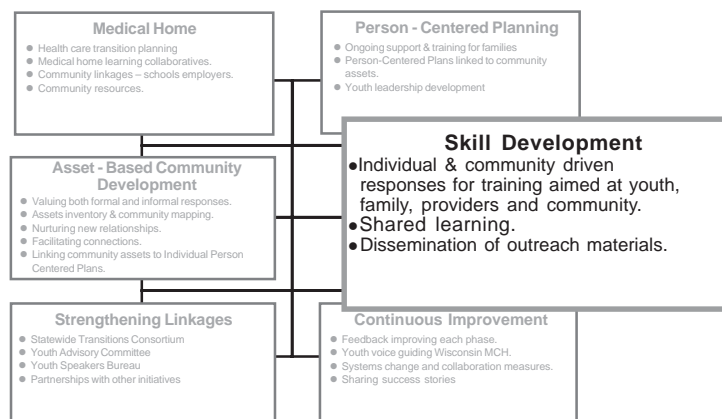
10 Things Social Organizations and Associations Can Do To Include Youth with Disabilities:

- Orient new youth members as they join to assure that they understand the purpose and the goals of the group as the group changes and grows.
- Consider providing a mentor or mentors to new members.
- Find meaningful roles and specific activities for the youth to do.
- Keep accessibility in mind when planning trips and activities. Work with the youth and family to develop accommodations.
- Consider breaking the large group into small, assigned groups for some activities, to encourage interaction across members.
- Personally invite youth with disabilities to join clubs or organizations. Don't rely on the standard recruitment tools: flyers, sign-up forms, etc.
- Ask in advance if you can assist with arranging for accommodations or accessible transportation to meetings and other gatherings or events.
- Consider universal design elements that can be used with all members, such as large print for all hand-outs.
- Pay attention to each youth's strengths and interests when planning activities, and encourage each youth to share what they are good at with the group.
- Ask youth with disabilities what your group can do to be more welcoming of other youth with disabilities.

Skill Development Element

Definition: Refers to the series of methods that are taken by individuals, agencies and organizations to continually provide opportunities to individuals and groups to increase their knowledge and skills through information and assistance, trainings and self study materials.

Elements of the Wisconsin HRTW Approach



Skill Development is relevant to the following core outcomes and performance measures:

Core Outcome #5: Families will partner in decision making at all levels, and will be satisfied with the services they receive.

Core Outcome #6: All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.

Self-Assessment suggestions for State CYSHCN Programs: The overall purposes of this assessment should be to determine what strategies are in place within the state to develop and implement skill training opportunities for the wide range of individuals that can impact issues related to the transition of CYSHCN, how current structures can be effectively utilized, and/or what new structures and activities might be planned over the next one to five years. Consider the following questions and activities:

- 1) What are the key health, education and community agencies and organizations that should be assuming a significant role to support youth in transition? What role should they be assuming and what specific set of skills should the individuals in those agencies and organizations have to perform those skills?
- 2) What trainings are currently offered for youth and families as well as health care professionals and community members? Is the focus of current training on community-level learning, individual-level learning, or both? What methods are customarily utilized in the area of continuing education and professional development? What new methods might be utilized and what assistance is available to utilize these new methods?
- 3) What new trainings should be made available to individuals within key agencies and organizations to support their role in transition? What steps can be taken to assure those trainings are developed and conducted?
- 4) What new structures, if any, should be developed to bring greater attention to supporting skill development related to youth in transition? What individuals, groups and agencies should be

targeted? Will they take ownership of these trainings and see them as a priority? If not, what steps can be taken to help them recognize the importance of such training?

- 5) What are the educational/informational desires and needs of youth with special health care needs related to their own transition? How well do they know the health and community services that are available to them? How well do they advocate for themselves as health care consumers, according to their abilities? How can this information be utilized to plan skill building opportunities

Brief Summary of Wisconsin Activities

Skill development efforts focused on two separate but closely related populations;

- Youth with special health care needs,
- Those who are involved in some aspect of providing service, training or support to those youth.

Information on values, attitudes and perceptions related to disabilities and equal rights and opportunities for those with disabilities was woven throughout these trainings.

Youth Oriented Activities: The Wisconsin HRTW Youth Advisory Committee (further discussed in next section) provided the primary input and structure for all youth oriented trainings. No formal selection process was used determine the makeup of this group because there were very few leadership opportunities available for youth with disabilities from which to recruit. Instead, staff talked with employees of the six CYSHCN Regional Centers and drew from youth they knew who might be interested. In addition, staff contacted the coordinator of Wisconsin's Youth Leadership Forum for high school students with disabilities to recruit from that group. The group began with 8 youth leaders across the state. As was stated in the previous section of this report, the committee was facilitated by a consultant who was very familiar with working to support youth to develop their leadership

For many youth, this was their first experience speaking as "experts" to their communities, and for almost all communities and groups, it was the first time they had heard directly from youth. Over time, the group took more ownership of their meetings, and sub-committees from the group worked on related projects, such as development of a youth fact sheet series and planning for a statewide two-day youth conference, *The Gathering of Youth*. With the *Gathering of Youth*, they were responsible for selecting the topics for the sessions that were relayed to the speakers; assisting with fundraising efforts and getting freebies to put in the bags the participants received at check-in; finding and distributing resources and materials youth would

Tools From Wisconsin HRTW

Youth Fact Sheets

This set of 6 fact sheets discusses topics of concern for youth, and were written by youth. Topics include:

1. Technical College: What's it All About?
2. Contacting Your Legislator
3. I Want to Work!
4. Your Individualized Education Program (IEP) and Transition
5. How to Avoid Getting in Trouble
6. University Life: What's it All About?



be interested in; designing and ordering the t-shirts, running the mini-auction; identifying fun activities to do in the evening; identifying volunteer duties; and providing input on a youth friendly evaluation for sessions and the overall conference. However, youth advisory committee participants were clear that they did not want to run their own meetings without co-facilitation with an adult who is knowledgeable about youth leadership.

In order to maintain the group's interest, it was important that the youth be real decision-makers and that all meetings have real decisions that needed advice and ideas from youth. Agendas always were sent out before meetings. Youth were able to see the effects of their opinions as programs were formed around their recommendations. Increasingly, every event planned by HRTW-WI had youth input, including a youth voice as co-presenter.

HRTW-WI offered a variety of ways for youth to provide input. Youth became increasingly busy with jobs and other activities as the project progressed. While all initial meetings were face-to-face on Saturday mornings at 10 a.m., the format shifted over time. "Hybrid" meetings included a few youth in person, and a few coming in by conference call. Some meetings were totally held by conference call, often on weekday evenings from 7-8:30. Youth were always compensated for their participation in recognition of their time and expertise. For attending meetings or speaking on panels, the rate was \$25 plus mileage or other travel expenses. For development of youth fact sheets, the rate was \$50 per sheet.

While most of the above work involved those who were directly involved in the HRTW Advisory Committee, a series of other trainings focused on the interests and needs of the broader group of youth in the state with special health care needs. These events included:

- Parents in Partnership for Transition, co-sponsored with the Department of Public Instruction.
- Nine Guardianship trainings.
- A 16-week series of "Safety in the Community" workshops for youth.
- A week-long transition camp for high school youth interested in college sponsored with UW-Whitewater.
- A Youth Leadership Forum for high school students interested in leadership.
- Transition forums focusing on self-determination and successful youth transition.
- A town hall meeting to address gaps in summer opportunities for youth.

Tools From Wisconsin HRTW

Safety Awareness for Empowerment



An eight-module curriculum to teach self-care and community safety skills to youth, particularly those with cognitive disabilities. Includes handouts, graphics, and a board game. Topics include staying home alone, safe relationships, avoiding victimization, sexuality, first aid and self defense.

As a result of the HRTW-WI partnerships with youth, a set of opportunities for youth as emerging leaders was created. These opportunities included:

- Statewide youth panel presentations at HRTW consortia meetings;
- Youth panels at regional transition forums sponsored by state Title V YSHCN programs;
- Youth presenters at Wisconsin's statewide conference for families of CSHCN;
- Youth presenters at college classes;
- Youth presenters at Wisconsin Developmental Disability Network workshops;
- Youth panels at statewide transition camp for youth;
- Youth co-presenter who piloted health care curriculum at Gathering of Youth statewide conference for youth;
- Youth co-facilitator with adult facilitator for HRTW Advisory Committee;
- Member, State Children's Long Term-Care Redesign Committee.

"I believe that the number one change that Wisconsin HRTW helped bring about was the opportunity to gain insight from young people in their own words. The HRTW team helped youth voices to be heard, and helped families to support and involve youth in their own decision-making."

*Wynne Cook, CYSHCN Western Region,
25 years experience working with families and CYSHCN*

Other Skill Development Activities: The ongoing HRTW committees and workgroups served as the primary method to design and deliver many skill development trainings to those who were working to support youth in health care settings, schools and communities. As stated earlier, many of these trainings focused on the overall Wisconsin HRTW framework, and specifically addressed the roles that various agencies and individuals can assume to support youth in transition. These trainings were very well received; however their shortcoming was that they were targeted to relatively small numbers of people. Our hope was that those who attended these training would see fit to consider what they might do to work with us to plan similar trainings locally. This occurred in many instances and we are continuing to explore ways to sustain these efforts.

Tips and Lessons Learned about Skill Development

Clarify who does what to support youth in transition. It is important to clarify the roles various agencies and individuals play to support youth, because any training that is conducted should be directed to enhance the ability of those people to perform those roles. It is also very important that individuals clearly understand their role, so that they will seek out and be more receptive to the trainings that may be made available. When thinking about who might be trained, consider individuals beyond those who work directly with youth. Help administrators, policymakers and other community representatives understand how important it is for them to see their connection with youth issues and perspectives.

Utilize the variety of training and learning methodologies that are currently available. Face-to-face trainings are very important, but the general population is becoming much more familiar and comfortable with other successful methodologies that include web-based trainings, tele-conferences, communities of practice, etc. Be open to considering them all, but continually ask what will be the most effective approach for this audience, at this time.

Solicit input from youth on the State CYSHCN Workplan. If your program has not already done so, create mechanisms for incorporating the youth voice in the CYSHCN needs assessment. Budget dollars to support youth involvement and for projects they see as important to support them in transition.

Encourage others to seek out youth input. When individuals recognize the many ways that input from youth can assist them in their designing how they interact with youth, they are often more receptive to exploring new ways of working. This new attitude then forms the basis for their being more receptive to and seeking out new learning opportunities.

Develop a Youth Speakers Bureau. Young people agree to speak on topics of their choice to organizations, committees, conferences and college classes. Wisconsin's Speakers Bureau is maintained by the partnership between the HRTW team and state Title V CYSHCN program to ensure privacy for youth participants. Organizations that are interested in youth speakers contact a HRTW staff, who contact youth based on their individual interests and how they like to present their stories. Youth receive compensation for each speaking engagement.

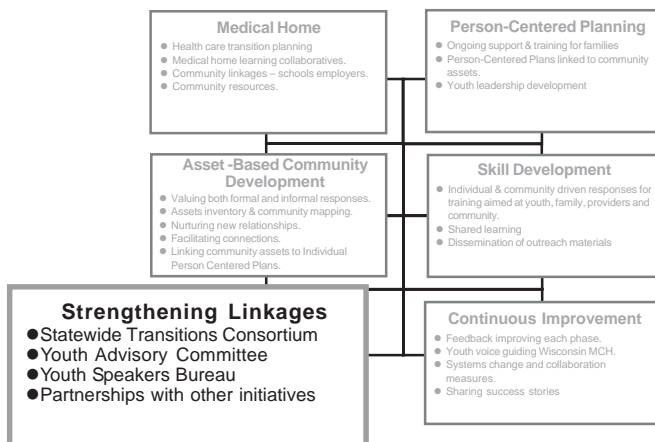
Collaborate with other agencies interested in the youth voice. HRTW-WI worked with the Wisconsin Department of Public Instruction's State Improvement Grant to include youth as paid speakers in college classes. The SIG "Parent Consultant Directory" was expanded to include youth with disabilities and their siblings as presenters. This project allows youth and their siblings to be paid an honorarium of \$50 for speaking to college classes.

Engage a group of youth to develop tip sheets on topics of their choice. This exercise can be very empowering for youth in that it positions them to consider their experience and to share their advice with peers. Topics can be related to growing up with special health care needs: talking to your doctor, getting involved in your IEP, how to advocate for yourself; navigating Social Security programs, etc. Have youth decide the topics. Give them a template for creating the fact sheet. Solicit youth volunteers to create a first draft by researching, writing and editing each others tips. Have others review and comment until they are finalized and made available.

Strengthening Linkages Element

Definition: A process that agencies in leadership positions exercise in order to engage representatives of various venues in discussions that affirm their commitment to common interests, permit sharing of information on current issues, challenges and opportunities, and otherwise works to promote effective and efficient utilization of resources to support youth in transition.

Elements of the Wisconsin HRTW Approach



Strengthening Linkages is relevant to the following core outcomes and performance measures:

Core Outcome #5: Families of CSHCN will partner in decision making at all levels, and will be satisfied with the services they receive.

MCHB Performance Measure #2: The percent of youth with special health care needs whose families/youth partner in decision making at all levels and are satisfied with the services they receive.

Self-Assessment suggestions for State CYSHCN Programs: The overall purposes of this assessment should be to determine what mechanisms are in place within the state to engage key leaders and agencies in discussions that work to promote effective and efficient utilization of resources to support youth in transition, how current structures can be effectively utilized, and/or what new structures and activities might be planned over the next one to five years. Consider the following questions and activities:

- 1) Which agencies and organizations are currently addressing youth transition issues? What are the primary factors that are motivating them to address transition, e.g., legislation, overall agency mission, currently funding projects, and/or interests of certain staff within the agency? What are they doing? What is their success? What are their plans for the next year? What assistance or support might they want and/or need?
- 2) What committees, if any, are currently in place to bring representatives of various agencies and organizations together to address issues related to children/youth with special health care? What is the charge to each these committees? Does the charge specifically speak to addressing youth transition issues? If not, what steps can be taken to bring this to their

attention so that they will consider if the charge should be modified to include transition issues? If there are multiple committees, does their work overlap? If so, is there merit to merging the committees, or to develop some other mechanism to plan and work together? If there is no committee addressing youth transition issues, what steps can be taken to organize such a committee?

- 3) Are youth with special health care needs included in a meaningful way so that they can offer input on the planning processes that agencies and organizations utilize to develop plans to address youth transition issues? If not, what steps can be taken to encourage and support those agencies to involve youth in these ways?

Summary of Wisconsin Activities

The timely opportunity that motivated the Wisconsin CYSHCN Program and the Waisman Center to make youth transition a higher priority for attention and resources was the desire to consider a joint application to MCHB under its Healthy and Ready to Work (HRTW) competition in 2000. Both agencies were very interested in youth transition prior to that time, but neither had secured sufficient resources to develop and implement a significant workplan. Therefore, the release of the RFP by MCHB was very important because it provided a reason to make transition a high priority for the short period of time that an application could be considered and prepared. The important point to note regarding this is not that it takes an RFP and dollars to motivate agencies toward action, but rather that if transition is not currently a high priority, it will likely take *some* opportunity or force to foster the change to make it a higher priority. That might come from a desire of the staff and consumers of the CYSHCN Program to put more emphasis on transition, or the availability of more resources from local community groups, school districts, or the state legislature. It might also come from the fact that more resources are available to assist states to consider what options to take – through reports such as this one and through assistance from other groups including the HRTW National Center.¹⁵

One of our first activities was to set up a series of individual meetings with representatives of the key agencies and organizations that were key players in transition. These included such groups as the Division of Vocational Rehabilitation, Department of Public Instruction, Social Security Administration, State Chapters of Family Voices and the American Academy of Pediatrics, Great Lakes Inter-Tribal Council, Parent Training and Information Centers, consumer related disability groups, the Council on Developmental Disabilities and others. During these meetings we explained that we were considering getting more involved in youth transition and submitting an application for funding, but that we wanted to do that in ways that built upon rather than competed with the work that was currently going on in the state. We found that this was a very positive approach to take because it served to recognize and validate the efforts of each organization, which in turned made them more receptive to considering how their work might be coordinated with others in the state.

These discussions led to our completing a one page inventory on each program that included a summary of what they were doing in transition, the key people involved in those activities, a listing of problems and concerns they had along with opportunities they were aware of that we should collectively take advantage of. At this time we specifically asked if they were a member of any group within the state that was assuming responsibility to bring representatives of various agencies and organizations together to address issues related to transition of youth with special health care needs. We learned one organization (DVR) had formed such a group with funding from an earlier grant, but that group was no longer in place. We learned that several groups were doing very good things, but they were often working with select agencies and organizations. Those that were working with multiple partners did not have ongoing ways to

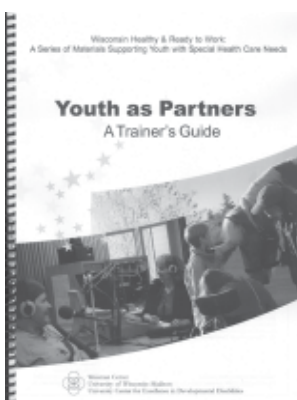
bring everyone together, nor did they feel it within their charge to address the important transition issues that fell outside of the scope of their particular projects. As a result, when we concluded these meetings, we had generated widespread support from multiple statewide agencies for exploring the merits of creating a statewide group to address youth transition. Current agency interests and activities had been inventoried, and that process helped everyone more clearly understand that successful youth transition requires the participation and commitment from multiple partners *working together*.

When final arrangements were completed to launch the Wisconsin HRTW Project one of our first activities was to convene a meeting of what was later to become know as the *Transition Consortium*. During the initial meeting we explained the overall purpose of the project and the six elements of our framework. Each agency then briefly explained what they were doing in the area of transition. Everyone found both the framework and the individual agency presentations very helpful. The individual presentations gave specific information on important projects and concerns, and the framework provided a context to better understand how various activities conceptually fit together to advance a more systematic statewide approach to addressing transition. The decision was made to convene quarterly meetings which lasted from three hours to six hours depending upon the agenda. For the first two years, a typical meeting would include in-depth discussion of one of the elements of the framework (Medical Home, Person-Centered planning, Asset-Based Community Development, etc.), and announcements/updates from agencies on anything they wanted to share about their work or concerns related to transition. A *Transition Listserv* was created to permit Consortium members and others interested in youth transition to share information about resources, meetings and other special announcements.

To assure that youth with special health care needs were closely involved in the project and the ongoing discussions, a Youth Advisory Committee was formed as a component of the Transition Consortium. Julie Sipchen (from KASA-Kids as Self Advocates¹⁶) was brought on as a consultant and offered advice and support to the committee as they were organizing themselves. While the young people would have their own meetings to talk among themselves about their common issues and perspectives (often on a Saturday morning – and away from their parents), the important role they played on the consortium was to bring a youth perspective to each topic that was discussed. It became routine practice for the Consortium to include youth on each panel presentation, regardless of the topic of discussion. Their comments were often the highlight of the discussion. Young people welcomed the opportunity to practice their skills to organize their thoughts and to present them in a public setting. Because youth input was so helpful to the HRTW Project, we explored other ways to assist youth to insert their voice into the planning processes of programs that affected them. We applied for and received a *Champions for Progress* grant to implement a *Youth on Health Project*. Youth Focus Groups were held to gather input that was advisory to the Title V CYSHCN workplan.

Tools From Wisconsin HRTW

Youth As Partners



Training curriculum on how organizations can meaningfully involve youth. This curriculum includes the history of disability, what meaningful youth leadership and involvement are, and provides activities to help adults better understand meaningful youth engagement and leadership.

Over time, consortium meetings moved away from topics created by the HRTW project, and evolved into topics suggested by participants. Time was set aside at the beginning of each meeting for organizations to give updates on transition activities, in order to maximize networking and collaboration. Eventually, consortium members would volunteer to be part of a work group for each upcoming meeting, strengthening organizational buy-in and commitment.

Tips and Lessons Learned About Strengthening Linkages

Start with sincere curiosity about what others are doing. Everyone likes to talk about the good things they are doing or thinking about. As you begin to consider what might be done to strengthen linkages, start by talking with those who you know are interested in the area of transition. Ask them to tell you their story by posing such questions as: What are they doing and thinking? What factors moved and positioned them towards these interests? What are their successes? What challenges and opportunities do they see, now and in the not so distant future? What would they like from others if anything? You can then take what comes from these interviews and begin to consider if information could be shared with others in ways that benefit everyone. This type of thinking can become the basis for designing new or more effective linkages.

Recognize and value communication as both a process and an endpoint. When the Wisconsin Consortium was being organized, the members considered whether it should be an action oriented entity that became involved in specific projects, such as advocacy or other specific projects. The members chose not to go in those directions, but rather to keep the focus of the group on communication and networking among the members. In this way, members could use the opportunity to take information to the consortium meeting, briefly share it, and then permit members to follow up on it after the meeting as they saw fit, based on their time and interests.

Set responsibility to convene meetings: Despite good intentions, time demands on everyone make it very difficult to sustain effective linkage mechanisms if specific staff and resources are not dedicated to the task of organizing meetings, developing an agenda, and dealing with logistical arrangements. It does not need to take a great deal of money or time, but the responsibilities have to be set on someone, or some group of people. While meetings (3-4 per year) will likely be adequate, also consider other ways to share information such as list serves, websites, and conference calls.

Don't create new structures if that is not necessary. Perhaps your state currently has a committee or organization in place that has already been charged to promote linkages related to transition. If it is effectively meeting the members' needs to foster communication and networking, there efforts should be applauded and supported. If not, then explore with them if they would be interested in enhancing their role to facilitate linkages.

Utilize a conceptual framework to foster discussion on transition. Because so many factors play into whether a young person is able to make a successful transition into adulthood, it is helpful to create some conceptual frameworks that identifies what those factors are so that they can be discussed individually. In Wisconsin, we developed the framework of the six HRTW elements that is described throughout this report. In and of themselves, these elements were nothing new. But we found that putting them into an inter-related framework helped Consortium members to understand each one a little better, and helped them to explore how one could potentially support the other. The HRTW framework provided a useful reference point to identify the range of potential topics for discussion within the Consortium.

Make a special effort to hear the voices of young people – and work to make that the norm. It cannot be said enough. The voices of youth are critical at all elements of the transition process, but those voices are particularly powerful during meetings when transitions issues are being discussed. Make a special effort to have youth on panels that are presenting information. Give them two or three questions to respond to well ahead of time so that they can consider their comments before the meeting. They can then talk about the questions with their peers and formulate their answers. A peer mentor can be very helpful to the young person in this process.

About the Wisconsin Statewide Transition Consortium

Mission: The Wisconsin Statewide Transition Consortium is a network of individuals and organizations that promotes the successful transition for and with youth with disabilities and/or special health care needs to all aspects of adult life.

Members: Representatives from the key stakeholder groups including:

- | | | |
|--|--|---------------------------------|
| Consumers | Families | Local community members |
| People First Wisconsin | Family Voices | Parent Training & Info Centers |
| Great Lakes Inter-Tribal Council | FACETS | Title V: CYSHCN Program |
| Pathways to Independence | WI DVR | Social Security Administration |
| WI Dept. of Public Instruction | ABC for Health | WI Council Develop Disabilities |
| Disability Rights Wisconsin | AAP – Wisconsin | Employment Resources Inc. |
| State Independent Living Council | Youth Adv Comm | WI Technical College System |
| WI Assistive Technology Initiative | Wisconsin Statewide Transition Project – CESA #3 | |
| University of Wisconsin Hospital and Clinics, Pediatric Pulmonary Center | | |

Activities: This consortium meets quarterly to exchange information and ideas about transition for youth with special health care needs. Typically each session allows for informal sharing between members with updates on initiatives and a topical content piece. The consortium has addressed the following topics in depth, with the following experts:

- Person-Centered Planning; Dennis Granzen
- Employment; Jack Hillyard
- Asset-Based Community Development; Jody Kretzman
- Celebrating the Successes: Panel of youth and young adults
- Transition from Pediatrics to Adult Health Care; John Reiss
- Medical Home; Bill Schwab
- Ensuring a Diverse Consortium; Patrice Onheiber
- Meaningful Youth Involvement; Carol Lobes
- Health Benefits Counseling: Panel of benefits counselors

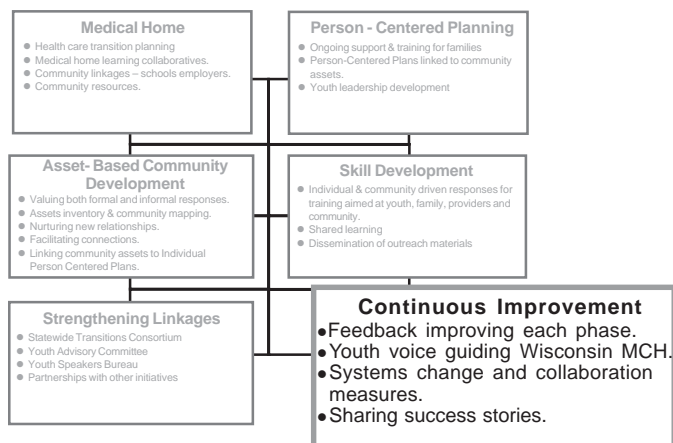
Sample Outcomes

There have been numerous outcomes from the consortium and members report a positive outcome with the following: Learning about transition initiatives and activities in Wisconsin. Connecting with other people statewide around the issue of transition. Collaborating with others on transition related issues or projects. Sharing ideas and information from the Consortium with our own organizations or groups. Making the decision to continue the Consortium following the completion of the HRTW Project.

Continuous Improvement Element

Definition: Refers to a variety of quality management techniques that are incorporated into the ongoing processes of a program that result in the collection of information on program performance that is utilized to design continuous program improvements based on what is learned.

Elements of the Wisconsin HRTW Approach



Continuous Improvement is relevant to the following core outcomes and performance measures.

Core Outcome 4: Services for CYSHCN and their families will be organized in ways that families can use them easily.

Core Outcome #5: Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.

Core Outcome #6: All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

MCHB Performance Measure 5: Percent of YSHCN age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Self-Assessment suggestions for State CYSHCN Programs: The overall purpose of this assessment should be to determine what mechanisms are in place to monitor the variety of programs and services that are working to support YSHCN to transition to adulthood, to assess how well current structures permit gathering of useful information, and/or what new structures and activities might be planned over the next one to five years to enhance continuous improvement efforts. Consider the following questions and activities:

- 1) Identify what transition related activities are occurring within your state and which of those activities might be the focus of your continuous improvement efforts. What activities do you have control and influence over that warrant your oversight and efforts towards continuing improvement? Are these activities performed by state agency staff, or those contracted to provide services, or those who are working informally together on various projects? If your transition efforts are designed within the context of a programmatic framework of activities, then that framework can serve as a template for designing your continuous improvement

processes. That is, for each of the major processes, corresponding management techniques can be designed to collect and analyze information, which may point to areas where improvements can be made.

- 2) Review current strategies that you are utilizing to evaluate and modify programs and services. Are those strategies providing credible information about your work and its results from many different sources? Is feedback from consumers a key component of program? How do you record and use the feedback you receive? What communities and groups are you not hearing from and what steps will be taken to remedy that shortcoming?
- 3) What strategies does your program take to learn more about continuous improvement theory? Do staff talk about, read or receive professional development in evaluation and quality improvement beyond what they would encounter in their daily work routine? In what ways have approaches changed in the past 10 years and why? Has this resulted in creation of a culture of continuous improvement? If not, how can such a culture be nurtured?

Brief Summary of Wisconsin Activities

Because the Wisconsin HRTW Program was designed in response to a Request for Proposals from the federal Maternal and Child Health Bureau, the initial proposal for funding included an extensive four year workplan of proposed activities and accomplishments. That workplan was approved without significant modifications, so as the project began we were fortunate to have a methodology in place to help us to monitor key processes and outcomes. That methodology included seven components; one focused on gathering information on the overall HRTW programmatic infrastructure, and the other six focused on the elements of the Wisconsin framework. Below is a summary of the type of information that was gathered throughout the project in order to help staff to assess workplan progress and determine what adjustments should be made.

Project Infrastructure:

Goal: To create and sustain the necessary infrastructure and capacity to address project goals and activities.

Outcome: The infrastructure of trained staff and consultants will enable all project activities to be completed in an appropriate, quality and timely fashion, and information continually shared with key stakeholders.

Evaluation Questions: How has the project infrastructure been established to enable the staff to carry out the HRTW project goals and objectives?

Input to Measure: Documentation of staffing pattern. Document skill development opportunities that staff and other project personnel are involved with. Interview key stakeholders throughout the project to assess satisfaction with infrastructure and their ability to work within that structure to complete project activities.

Medical Home:

Goal: To promote greater understanding and utilization of the Medical Home by youth with YSHCN and those who work with YSHCN.

Outcome: YSHCN and their providers understand the Medical Home model and utilize it to meet the comprehensive needs of YSHCN, including successful transition to adult health care providers.

Evaluation Questions: Of those youth and families who become involved with the project, how much do they and their care providers understand and utilize the Medical Home model? How does use of the Medical Home model enhance the health outcomes for YSHCN in transition?

Input to Measure: Questionnaire on medical home knowledge & utilization for youth, families and providers. YSHCN Demographics and Services Form. Questionnaire on YSHCN health related outcomes.

Person-Centered Planning:

Goal: To promote Person-Centered Planning for up to 30 youth with special health care needs, in the context of the family to identify individual goals for health, education, employment, recreation, home, social relationships and belonging to a community.

Outcome: Families and youth are connected with the appropriate services and build relationships which reflect the individualized goals of that youth and family.

Evaluation Question: How does person-centered planning improve the transition process and outcomes for YSHCN?

Input to Measure: Person-centered planning forms. Pre-post interviews/focus groups with youth, families and providers in pilot sites. Satisfaction survey completed by youth.

Asset-Based Community Development:

Goal: To build on the CSHCN regional system to promote an asset-based approach to community building to ten pilot sites, and apply that model to support transition of youth with special health care needs.

Outcome: Communities recognize their local assets and capabilities and connect these resources through a shared vision of how to include, support and accommodate youth with special health care needs and in all aspects of transition.

Evaluation Question: How have youth in pilot sites through the HRTW project impacted the local community, transition services and knowledge?

Input to Measure: Explanations of systems changes and collaboration measures. Survey of youth who participate with leadership activities.

Skill Development:

Goal: To ensure youth, families, and providers have the appropriate skills and knowledge to improve the quality of transition process in their local community.

Outcome: Youth, families, providers, and medial personnel are prepared to move from children's services to adult services with the necessary personal, professional, career and system skills and knowledge.

Evaluation Questions: What are the key skills and knowledge that youth, families and providers need to help YSHCN make a successful transition? What programs have been designed to increased skill levels? How does this skill development enhance health outcomes for YSHCN?

Input to Measures: Pre-post questionnaires testing skills and knowledge on skill building opportunities that are offered. Focus groups and/or interviews with youth, family members, providers.

Statewide Linkages:

Goal: To establish a Statewide Inter-Agency Consortium on transition, supported by a Youth Advisory Group, HRTW project staff and consultants, enabling statewide information exchange, project input and systems change.

Outcome: The state HRTW project facilitates the connections between all transition efforts with the input of key stakeholders and aligns the transition reform with other statewide redesign initiatives.

Evaluation Question: How has key stakeholder participation in the Statewide Consortium and Youth Advisory Group changed transition practices for YSHCN in the State of Wisconsin?

Input to Measures: Systems change and collaboration measures. Focus groups with Youth Advisory Group and Statewide Consortium participants.

Continuous Improvement:

Goal: To conduct ongoing project evaluation and dissemination of information that is gained in the HRTW project.

Outcome: Project will inform transition process throughout the state and assist in the development of a project model that helps youth improve health outcomes during transition.

Evaluation Question: What is the impact of the HRTW project on the health outcomes of youth in transition as well as the impact on their families and providers? How does each element of the HRTW framework contribute to success, both systemic across programs and services, and individually in the lives of youth with special health care needs?

Input to Measure: Data collected from all evaluation measures as described in above elements. Annual review of project accomplishments advisory to creation of subsequent year workplan. Focus groups with youth involved in any aspect of the project.

Tips and Lessons Learned About Continuous Improvement

Be thoughtful about outcomes and how you will measure them. Because programs and services cost a great deal of money to design and implement, they need to be able to demonstrate what is being achieved for the dollar. As you consider your transition objectives, take time to think about the specific short and long term outcomes that you will be working towards. Identify methods that you will utilize to help you assess if you are achieving the outcomes you intend.

Solicit input from staff when determining outcomes. Continuous improvement is more likely when staff members want to improve their work based on comparing them to documented results. Top-down or mandated evaluation requirements often fail to produce the information needed when staff members have little personal or professional buy-in regarding outcomes. When staff are personally invested in the results of the work, and can come to agreement on the goals of the initiative, they may be more open to reflecting upon what is working and what could be improved.

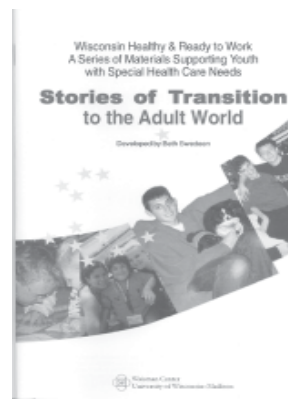
Promote a supportive and trusting environment that encourages continuous improvement. Examination of one's relationships and activities – and whether staff and community partners are accomplishing intended goals – requires trust and openness as well as an on-going commitment to building and enhancing relationships within and among members of the staff. Without trust, communication lines break down and the give and take nature of conversation can become one-sided or non-existent.

Recognize and Celebrate Success:

One of the best ways to learn about what individuals, families and communities can do together to support youth in transition, is to find ways for stories to be told. Such stories not only give recognition to the many people who were involved, but they show others what is possible.

Tools From Wisconsin HRTW

Stories of Transition to the Adult World



The road to adulthood is rarely smooth, even for young people who have had the best possible preparation. When a young person has a significant disability, that journey can be even more challenging. In this

booklet you will meet four young people with very different strengths, gifts, interests and concerns. Their stories help readers to think about a variety of possibilities.

Concluding Comments Regarding Sustainability

- The Wisconsin CYSHCN Program and the Waisman Center have committed staff and funding to continue meetings of the Statewide Transition Consortium. The *Transition Listserve* has become a valuable method to share information and continues to grow from its current 360 subscribers.
- *Family Voices Wisconsin* has been contracted to facilitate the ongoing development and activity of the Youth Advisory Committee which has become a component of the overall structure of the CYSHCN Program. This committee works closely with the Waisman Center and other organizations to promote youth leadership opportunities.
- The Wisconsin Medical Home Learning Collaborative has identified youth transition as a priority for their attention. Special meetings of the learning collaborative will focus on transition.
- Regional CYSHCN Centers in Wisconsin have been charged to provide information and assistance to support youth and their families who are transitioning to adulthood.
- Workgroups are formed as needed to consider and respond to applications for funding of research and service projects related to transition. Two 3-year federal grants have recently been received; An Integrated Community Systems for CSHCN Grant that provides resources to assist the State CYSHCN Program to implement several activities, and a university based research grant that will study the impact of summer work and volunteer experiences in the lives of youth with disabilities and special health care needs.
- Key leaders in the areas of Person-Centered Planning, Asset-Based Community Development, and Self-Directed Services are meeting to explore how their approaches intersect, and methods could be developed to foster more connected thinking and the application of new ideas in local communities.
- Large numbers of youth, their families, community associations, and care and service providers more fully recognize and appreciate the many factors that impact successful transition to adulthood for youth with special health care needs. That widespread interest, dedication and desire to participate, offers much to build upon.

Endnotes

- ¹ National Center for Youth With Disabilities, (1995), *Transition from child to adult health care services: A national survey*, The National Center for Youth With Disabilities, University of Minnesota.
- ² National Organization on Disability, (2000) *Harris Survey of people with Disabilities*, Washington, DC.
- ³ U.S. Department of Health and Human Services, Maternal and Child Health Bureau (Summer 2000), *Healthy and Ready to Work Services For Children and Youth With Special Health Care Needs*, CFDA #93-110D., p. 18.
- ⁴ Kretzmann, J., McKnight, J., (1993), *Building Communities From The Inside Out: A path toward finding and mobilizing a community's assets.*, Institute for Policy Research, Northwestern University, Evanston, Ill.
- ⁵ This vision of the future of youth with special needs during transition is further discussed in: Hanley-Maxwell, C. (1995). *The second shock: A qualitative study of parents' perspectives and needs during their child's transition from school to adult life.* *Journal of the Association for Persons with Severe Handicaps*, 20, 3-15.
- ⁶ These include:
 Kohler, P., Chapman S., (March, 1999), *Literature Review on School-to-Work Transition*, Transition Research Institute, University of Illinois at Urbana-Champaign.
 Institute for Child Health Policy, (1998), *Key Transition Issues For Youth with Disabilities and Chronic Health Conditions*, University of Florida, Gainesville.
 Clark, H., Davis, M., (2000), *Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties*, Baltimore, Brooks Publishing Co.
 Bishop, K., Taylor, M., Arango, P., (1997), *Partnerships At Work: Lessons learned from programs and practices of families, professionals and communities*, Vermont, Partnership for Change (supported in part by MCHB Project #507060).
- ⁷ *Moving On... Transitioning from Pediatric to Adult Care Team*, was developed by Craig Becker, MSSW, and Darci Pfeil, PNP in collaboration with the pediatric and adult cystic fibrosis teams at the University of Wisconsin Hospital and Clinics. For more information ca.becker@hosp.wisc.edu
- ⁸ Each state has a Protection and Advocacy (P&A) System funded by the U.S. Administration on Developmental Disabilities "to empower, protect, and advocate on behalf of persons with developmental disabilities. The P&As are independent of service-providing agencies and offer information and referral services for legal, administrative, and other remedies to resolve problems for individuals and groups of clients (taken from ADD Website)." For a listing of P & A Agencies in each state access the following link on the Internet: www.acf.dhhs.gov/programs/add/states/pas
- ⁹ For more information on cultural brokers, contact the National Center for Cultural Competence, Georgetown University, 3307 M. Street NW, Suite 401, Washington DC. Website: <http://gucchd.georgetown.edu/nccc/>
- ¹⁰ Pearpoint, J., O'Brien, J., & Forest, M. (1993). *Path: A workbook for planning possible positive futures: Planning alternative tomorrows with hope for schools, organizations, businesses, families.* Toronto: Inclusion Press.
- ¹¹ Forest, M., & Lusthaus, E. (1990). Everyone belongs with MAPS action planning system. *Teaching Exceptional Children*, 22, 32-35.
- ¹² Turnbull, A., & Turnbull, R. (1992, Fall & Winter). Group action planning (GAP). *Families and Disability Newsletter*, pp. 1-13
- ¹³ For further information on Asset-Based Community Development, contact the Asset-Based Community Development Institute, Institute for Policy Research, Northwestern University, Evanston, Illinois. Website: www.northwestern.edu/ipr/abcd.html.
- ¹⁴ The Asset Based Community Development Institute (address in previous endnote) has developed a series of helpful publications that include:
- Building Communities From the Inside Out: A Path Toward Mobilizing A Community's Assets.
 - Mobilizing Community Assets – Video training program
 - A Guide to Capacity Inventories: Mobilizing the Community Skills of Local Residents.
 - Asset-Based Strategies for Faith Communities.
 - A Workbook for Rural Asset-Based Community Development.
 - A Guide for City Officials on Building Neighborhood Capacity
 - Guides to Mapping Community Assets – Business, Consumers, Association.
- ¹⁵ The mission of the HRTW National Resource Center is to create changes in policy, programs and practices that will help youth with special health care needs transition to adult health care with funding, work, and independence. The Center is funded through a cooperative agreement from the Federal Maternal and Child Health Bureau (MCHB). For more information contact: <http://www.hrtw.org>
- ¹⁶ KASA refers to *Kids As Self Advocates* and is a national, grassroots network of youth with disabilities that is affiliated with Family Voices. <http://www.fvkasa.org/index.html>

Medical Home • Skill Development •
Strengthening Linkages • Continuous



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University Center for Excellence in Developmental Disabilities