

Wisconsin Council on Children's Long-Term Support Needs  
Council Meeting

**Minutes**

Tuesday March 21, 2006

Sheraton Madison Hotel

10:00 a.m. – 3:00 p.m.

Madison, WI

Members Present: Liz Hecht, Chair – Members: Cheryl Berg, Hugh Davis, Sharon Fleischfresser, Melanie Fralick, Sue Gilbertson, Glenn Johnson, Barbara Katz, Keith Keller, Sally Mather, Carrie Pomije, John Shaw, Michelle Sturz, Julie Turkoske, Michelle Urban, Beth Wroblewski

Guests: Dan Bier - Waisman Center, Joyce Binder - I Care, Amy Whitehead – Children with Special Health Care Needs Regional Centers, Helene Nelson, Department of Health and Family Services (DHFS) Secretary

Staff: Kristina Stuart, DHFS

Minutes for December 9, 2005 – Council Approved

I. Opening Comments, Announcements

- Welcome
- Sharing of Long-Term Care Council Resolutions relating to Children's Long-Term Support

II. Information, Assistance and Advocacy – CLTS Council has three outcomes relating to information, assistance and advocacy for families. Keep these outcomes in mind as we discuss these different information, assistance and advocacy enterprises, which currently include:

- Children with Special Health Care Needs Regional Centers
- Aging and Disability Resource Centers (ADRC) – Recipients have information and assistance services, eligibility determination and service planning
- Division of Vocational Rehabilitation Counselors – Kids with transition needs
- Pathways Navigators – Kids with transition needs

Question for group: How should different Information and Assistance Advocacy organizations work for children as an infrastructure component of children's long-term support redesign? ADRCs are being considered as that entity for children by the Long-Term Support Council. Comments from members:

- How do these tie into the work of private non-profit agencies; DHFS is supplanting non-private not for profit.

- How does the school transition affect the other transitions that a child experiences?
- ADRCs would seem like a faster way in to the county based services – within a few counties is good.
- Services could be available within a school district for ongoing information and assistance? Teacher or educational professional could connect them with that? Could there be a single place located within the schools from birth to 21? Need to be engaged more in process at school level.
- All points of entry for a family—doctors, home health agency or others.
- Children’s services are more complicated than adult services.
- Information, Assistance and Advocacy should start before school.
- Good not to have information, assistance and advocacy NOT tied into eligibility.
- Could the ADRCs be the administrative infrastructure for IA&A services?
- Just adding onto the ADRCs puts kids at risk for being marginalized by numbers.
- Might be good to tie into Department resource commitment to ADRCs.
- Regional Centers are already doing a lot of what is being suggested for information and assistance.
- Should LTS be thinking about regionalization for long-term support and other services, including IA&A?
- Language and Marketing is so important...because agencies may not want to promote services if only waiting lists are available: same information given multiple times is important. Families may not identify their children as children .

## II. DHFS Initiatives for Long-Term Care Reform

- Governor Doyle has promoted success of Family Care – managed care options for frail elders, adults with physical disabilities and adults with developmental disabilities.
- ADRCs are being included as the front end of long-term supports – within three years they need to be providing IA&A for adults with mental health needs too.
- Governor Doyle announced a 5 year timeline for implementation of long-term care reform.
- Proposals for LTC planning grants shows regionalization – different county consortiums are being implemented.
- Most of these proposals are a 1915 (b)(c) Waiver combination.
- DHFS has acknowledged that if a consortia has a different plan than b/c; than a 1115 demonstration waiver could be sought.
- Much of this information is available on the DHFS website.
- No decisions have been made to date for children’s services...all options are on the table.

- Secretary Nelson is committed to meeting the principles of LTS reform in the Children's Foundation paper
- Questions from members:
  1. Will this adult system want to take on kids? Adult system in small county may also serve kids currently...what will happen to kids while adult infrastructure changes?
  2. Where are children in this system? Pace of children's redesign needs to be accelerated – how can this be done most efficiently?

### III. Long Term Care Options Lunch Presentation

See Powerpoint presentation: Long-Term Care Options

### IV. Long Term Care in Other States – John Agosta and Gary Smith, HSRI

Comments from HSRI guest speakers: Wisconsin has always been a leader... the system there is not necessarily starting from scratch; what can be sustainable going forward in tight times?

- Look at state demographics – where are caregivers?
- What can government do? This will be more modest than it was in the past...what can Medicaid (MA) do is frequently a question for supporting families. MA beneficiary is child, not family. Changes nature of discussion (i.e. Dad may need tires) – not allowable under MA!
- Recasting role of government – not just what government can do to support people. One role is better financing and collaboration; Getting public agencies to coordinate better: schools, MA, county, DD, etc. sitting down together. This cannot be the only part of the system, however.
- What can families do to help each other? Peer mentoring, exchange networks – instill a culture of cooperation and collaboration among families. EX: Lynn Time Bank, Lynn, MA (collecting info for MA DMR and DPH on what respite, other services they offer each other). AK & OR have small tests with respite care delivery. State in AK – helping people to help each other.
- Mine assets in the community. Family Stipend Fund that businesses can donate to. 1. Families must give back to the Stipend Fund (in-kind time, etc). 2. Solicit funds to give back to fund.
- How to help do this? Case worker spending time building relationships in community – Kiwanis club, churches, etc. Building relationships with family and looking outside of government services to things in the community. WA funded Community Guide – it wasn't about MA services, it was supporting child and family around community based needs. Nurture professionals who did that?
- System has become service oriented versus family support.
- Medicaid Options to explore:
  - New Waiver application is a better pathway for Family Directed Services.

- b/c combination Waivers – not widespread use. Start reaching into state plan side. Can fund different types of services...community reinvestment funds, one time supports. One of 3 or 4 b/c combos only.
- 1115 Waivers – Started to reemerge in long-term care. Not yet much for kids system. VT and KY: wrap around long-term care services...more seamless types of approaches. KY has more long-term support elements and linkages to health care. Most powerful tool...hard to get through Centers for Medicaid/Medicare the approval for 1115. Holds most opportunities to create what you want.
- Family Opportunity Act – MA to kids with Disability Determination Bureau without institutional limits

V. Secretary Nelson visits CLTS Council

- Gov. Doyle and DHFS Secretary's Office want to pursue reform
- Helping children and their families with long-term support redesign; a system that is fair and makes sense across all systems, addresses waiting lists, and helps families get services that they choose.
- Consider role of parents and families, schools, other partners
- Could think about expanding options
- Early in next biennial budget process; 2009-2011 is the timeframe for Children's Long-Term Support Redesign. Have a thoughtful process...what direction are we steering reforms? Second, if some funds are there; what is best benefit for the dollar? Key time for the Council to give input – early in the process
- Big picture reform – national level – could cash and counseling could work? How could prior authorization fit into this picture better?
- Choice, flexibility, increasing funds to make it more flexible

Questions to Secretary Nelson, and her responses:

Q: Adult care happened fast. Will this happen for kids?

A: Gov. Doyle has said 5 years reform for adults, end of waiting lists in 5 years...would like a similar time frame for children. Of course, Family Care had been in demo for 5-8 years...Sec. would like 5 year framework. Planning grants are still place for adult system...figuring out how private partners work with counties. All but 9 counties have come into adult planning phase; hope similar interest for children

Q: Will all Human Services ultimately be regionalized?

A: No secret master plan to do so; many counties have voluntarily entered into consortia in the past. Most counties are involved between 1 and 10 voluntarily collaborations. State is encouraging without mandating.

Q: Will all this regionalization be confusing?

A: Whatever system is developed should have a user friendly front door. It should be convenient for families with person centered care planning...maybe more ADRCs than other systems. Behind the curtain, service collaboration can be bigger, broader.

Q: What is oversight role for regional planning grants?

A: Local officials still responsible; family care can appeal, raise issues, etc. DHFS ultimately does have oversight. Some counties have advisory boards for the new planning grant consortiums. Must have consumer voice input...program design factor.

Q: When Family Care started, looked at Community Aids and county contribution and made a trade.

A: State "bought out" county share. Family Care supported by federal and state funds, no county match. Milwaukee County made \$11 million this year. County must serve within that rate. Theory of family care is to manage within budget, save money by member per month, put savings into serving people who are waiting. Budget neutral for counties, not a property tax relief plan. The intent is to deliver more equitable access to services.

Q: What is DHFS' capacity to pilot different models for kids with quality measures?

A: If that is Council advice, DHFS could try it. Wouldn't probably want a statewide system that is different. If piloting, could do that. If ready to go to scale, could do that as well.

Q: How do you survive the day to day stuff to figure out how to make it better?

A: What we do in next budget must address current needs and future reform. Open to advice about how to do that. Where are we going? If there is money, how could it best be spent? Without new money, what could we do within that context?

Q: Have we increased complexity of system with new initiatives and programs. Multiple initiatives sometimes lead to lack of integration (transition related issues). No sacred cows in terms of programs!

A: Great to give ideas – better to have a system that responds individually, based on choices, coordinates and is more holistic. MA fee-for-service form was written not to honor those principles. How can waivers be leveraged to create family friendly and people friendly systems? Some models are already out there are established and could be applied easily.

Q: Desire to reduce waiting lists and soon as possible and maintain values of long-term system.

A: With Family Care – eliminating waiting lists AND system reform in 5 years. Children should be heading toward that same thing.

Q: Having a child with a disability has such a huge impact on the whole family. Family Care is working and saving money? Can we glean money to work on waiting list for families.

A: If we have some funds; what is best use of that? Should we end the “slot lottery.” Help us set priorities, and will be presented to Gov. Doyle in form of options.

Q: Can we have equity in resources comparable to the adult side to kick start this initiative? Children’s staff is small and carries many burdens.

A: Thank you for comments.

Q: How can Division of Disability and Elder Services and Division of Public Health work collaboratively to address the needs of children with special health care needs and Health Care Financing?

A: Mission of our Department is all about Public Health. Managerially and philosophically, we believe it. Are trying to claw back at the complexities. Going to merge 3 or 4 health care programs into BadgerCare Plus. Complexity of Regionalization is going to be a good way to go, if people think they can work together. The planning grant regions are locally designed-logical and coherent in their areas. These new regions are not state designed.

Q: from Secretary Nelson: ADRCs are like public libraries. People come to learn...may get referrals, may not. Will this work for kids?

Q: How do we make services work better?

A: from Secretary Nelson: Let’s make sure we use all the resources available for system. Time of optimism to do things better. Let’s use this group to construct something that’s better.

## VI. Discussion on Long-Term Support Options

- How do we begin thinking and doing the work for information, assistance and advocacy?
- How do we make recommendations for choosing a model for long-term support committee?
  - Children’s services have always been a tag along...who’s thinking about kids when the consortiums come into play? We could hear from counties who are part of the consortiums?
    - Meeting of Children’s Pilot counties and consortium and CLTS Council representatives to consider impact on children in next several months.
  - Group to look at card covered services and what could and could not get pulled into a b/c waiver? Pro or Con of pulling in each different service. DHFS is working on gathering this information internally. Other data being gathered: have SSI eligibility, but have needs like a KBP child, or needs like a Waiver eligible child to estimate child. Costs are not reported consistently to Medicaid if private insurance paid; so that is a challenge to estimate.
- What information do members need on what to recommend? Next meeting: moving a model forward, addressing issues of current system.

- Need: to hear what other pilot counties are doing...critical questions so each pilot is answering questions on access and other points. What are they learning, what's working, what are challenges?
- BadgerCare Plus – Ask Dianne for a rundown to present at mtgs.
  - Get rid of doorways to MA (not Healthy Start, Pregnant, etc.); to determine if there are new people who should come through the door
  - Can there be flexibility in MA beyond medically necessary to include more social public program funding? Federal Directors are trying to make it more difficult, though...
- Health Check as a service? Could the plan become a prior authorizing document?
- Priorities or guidance about short-term things most helpful for families?
- Focus on system supports...no discussion about informal supports. Need training for Service Coordinators on how to make the family's life more meaningful. Isolation from your community; lack of community inclusion. Have to be at table together working together so that families don't feel that agencies are trying to "wiggle" out of providing services!
- Informal Breaks for meetings...

General other comments:

- Consider using a CLTS Council intranet...webcast information from other states where relevant.
- Other pre-sessions ideas for next time:
  - Managed care for kids?
  - Self-determination
  - What would process for managed care look like for kids?
  - Quality indicators, satisfaction with services delivered? Outcomes in managed care
  - Reports on family care satisfaction surveys
- Meeting ideas for next time:
  - What are children's pilot counties doing?
  - Dane County self-directed model?

**NEXT MEETING: May 18, 2006**