

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

Approved Minutes

September 9, 2005

Department of Health and Family Services,
1 W. Wilson St. Rm. 751
10:00 a.m. – 3:00 p.m.

Present: Liz Hecht, Chair - Members: Cheryl Berg, Hugh Davis, Sharon Fleischfresser, Melanie Fralick, Pam Garman, Sue Gilbertson, Glen Johnson, Barb Katz, Sally Mather, Marge Pifer, Carrie Pomije, Michelle Sturz, Julie Turkoske, Michelle Urban, Beth Wroblewski, Deana Yost

Guests: Judith Frye, Associate Administrator, Division of Disability and Elder Services, Sinikka Santala, Administrator, Division of Disability and Elder Services Jamie Schlecter, Family Support 360 Project, Amy Whitehead, UW-Madison Waisman Center

Staff: Kristina Stuart

I. Opening Comments, Announcements

Meeting Location: Will not always be at DHFS – maybe somewhere on the East Side so that parking is more accessible.

Announcements/Information:

- Will have a public comment period at each meeting.
- A broad e-mail will go to all counties, to Council members, etc. will be sent in the near future informing members of which counties were awarded a Children's Long-Term Support Pilot.
- Should we address any gaps in membership? Issue for the future in terms of ethnicity.
- Reimbursement for non-state employees: Travel reimbursement is available. Need to fill out a W-9 if never had state reimbursement before. Reimbursement for breakfast is for \$9.00 (must leave before 6:00 a.m.) and dinner is for \$17.00 (must leave before 7:00 p.m.). State reimbursement is 38.5 cents per mile. Please ask Kristina Stuart if you need a copy (stuarkc@dhfs.state.wi.us or 608.235.6636).

II. Background and Other Partners

- Previous Children's Redesign Committee: See Liz Hecht's Powerpoint presentation: "Building a Family-Directed System of Long-Term Supports for Children and Families."
 - Note: 2005-2007 biennial budget required that Functional Screen be implemented as well as the Children's Long-Term Support Parental Fee.
- Council on Long-Term Care Reform - Liz Hecht is liaison is to the Council on Long-Term Care Reform from the Council on Children's Long-Term Care Needs to ensure cross-over.

- State Family Support Advisory Committee - This committee disbanded in hopes of participating in this Council. Can this Council be responsive to the questions that face Family Support Program?
- Autism Council - Need to set a method to formalize a liaison system between the Council on Children's Long-Term Support Needs. The role of the Autism Council is advisory to the DHFS, just like this Council. Much overlap on policies and procedures.

III. Council Scope and Charge

Council is Advisory to the DHFS. The Council will connect to children in other systems: children with special health care needs, mental health needs, etc. Peer groups also advisory to the DHFS: Birth to 3 Program Interagency Coordinating Council, Autism Council

Q: How would we define this group? Response: Could be determined by the Functional Screen, but does not need to be that precise for the Council's consideration.

Q2: What is the definition of long-term support needs? Response: There is a continuum of support for children as they move into and out of this group; we should consider that population broadly.

Council Membership: DHFS Government Agency Liaisons will be non-voting. This is so that decisions to the DHFS will be neutral. Difficult at times to get representation from youth members due to school commitments, challenge to group how we can get youth participation. Appointments have been for 2 or 3 years terms initially so that there would be staggered participation of new members. Low-income areas, members from different ethnic backgrounds, etc.

Council Meetings: Quarterly, more as needed. Can do subcommittees through distance technology to save on travel costs.

Council Recommendations: Secretary Nelson prefers action oriented decisions from Councils. If an issue is identified, think about solutions that the group would prefer. Recommendations do need to be consistent with state and federal regulations.

Council Responsibilities: See Section 3 of "Establishing the Council for Children with Long-Term Support Needs" document.

Children's Services are now part of the Children's Services Section. Will send Bureau of Long-Term Support organization chart.

IV. Overview of Children's Long-Term Support System

Mental Health Services: Alice Mirk, presenter. Alice is Section Chief in the Bureau of Mental Health and Substance Abuse Services. Her section works to integrate services among Children's Services, Women's Services, transition services, and adult community services. The Bureau of Mental Health and Substance Abuse Services has a recovery based model of holistic wrap around services. Whatever the diagnosis, an assessment pulls in functional and treatment needs in a recovery based system. Some key programs:

Children's Wraparound Services – Dane, Milwaukee Co. Children with Severe Emotional Disturbance; this is a County-private enterprise with wraparound model.

Previous Intensive Services and wraparound case management – Drawback; never seen ongoing funding to these initiatives. ISP, CST, etc. These initiatives all supported resiliency based models, never any ongoing funding.

Comprehensive Community Services (CCS) –County matched service through Medicaid. A recovery based model plan must be submitted and approved by a county before they can implement it. Children and adults with mental health and substance abuse issues are eligible. CCS is billed not under individual services; you bill for a package of services that a county designs in conjunction with Health Care Financing; the per diem of this cost is billed. It can include outpatient services, home services, ADL coaching, peer support and peer coaching, etc. This all falls under the psychosocial definition per the Centers for Medicare and Medicaid services. Local government must find the local match for the CCS program, so it is a financial consideration before participation. Many counties find they are paying 100% of substitute care for some children that could yield a cost-saving if participating in CCS. Marathon County has been a leader in CCS services.

Q: How are children determined eligible? Response: Children's Functional Screen determines eligibility for the CCS service, and person needs a diagnosis from a licensed diagnostician.

Q: How does this differ from Wraparound Dane County? Response: It is not managed care, it is built around true costs of service. Children do not need to meet the same Level of Care as kids for the Waiver. Can be a transitional support between child and adult system.

Q: Can counties choose to implement this service? Response: Yes.

Q: What is difference between this program and Children's Waiver? Response: Benefit package may not be that different, but less stringent than Waiver for eligibility. Not meant to be a substitute for more intensive services under the Children's Waiver or Community Support Program (CSP).

Q: Can you get other card services while in CCS? Response: Yes.

Counties already participating: Marathon, Outagamie, Winnebago, Green Lake, Washington, Waukesha, Kenosha, Richland, LaCrosse (coming soon: Marquette, Brown).

Public Health Services: Sharon Fleischfresser, Division of Public Health. Powerpoint presentation: Children and Youth with Special Health Care Needs." Brochure:" Does your Child Have Special Needs?"

Q: What percent of children with special health care needs have long-term support needs? Response: About 10,000 children have long term-support needs. About 120,000 children have special health care needs as identified by the national SLAITS survey (13% of children).

Q: How do we provide input to the Children with Special Health Care Needs Program. Response: Every 5 years the Division of Public Health seeks input into how to allocate Title V funding. For Regional Centers, there is a competitive cycle to be a Center also every 5 years.

Q: Is there a breakdown of which special health care needs children have who are served? Response: Yes, this is tracked. Asthma is #1. Sharon will send this information to Kristina.

Medicaid Services. Marge Pifer, Division of Health Care Financing. Presentation notes: One in seven people in Wisconsin in on Medicaid (MA). Wisconsin has a broad array of services for children with disabilities, with broad MA eligibility categories. Services are as broad as any other state in the country. Medicaid is running a deficit, but all parties are still committed to maintaining MA program (unusual nationwide). Not many EPSDT services have been added in Wisconsin (Health Check) in Wisconsin, because so many services are covered. Constant challenge of operating within a budget; \$70 million dollars short currently. How do you have savings without hurting people? Ideas are welcome. Wisconsin Medicaid works closely with other Divisions to implement services, such as CCS and the Birth to 3 Program. Broader than any insurance program in the country.

Q: Difficult to find providers in some areas who accept Medicaid reimbursement; dental, mental health, transportation. Response: National problems with some of these issues. Brokerage for transportation services is probably going to go through now; better coordination of rides coming; Gov. Doyle approved this in the last budget.

Issue: Private insurance buys one wheelchair and MA used to buy a back-up? Now MA won't buy back-up. Maybe disincentive for families to use private insurance.

Q: Health Check Over Services – Providers don't understand how to access this? Response: MA is going to a new publications system in 2007. MMIS Database information system.

Q: Give families a print-out of Medicaid costs; families helped monitor their expenses in MA utilization and understand all that Medicaid pays for. Response: One mailing is \$80,000 - \$90,000. Some other states have ability where families can log in electronically. Maybe new MA system could allow this in the future.

Notes from Council Members on their personal/Council interests:

Issues identified by members:

- Don't know why the mental health system doesn't support families like the DD system.
- Sometimes the mental health and DD system fight each other when children need services.
- Important not to duplicate system, and to involve the public health system as well.
- Systems perspective – how each part of the system interacts with other. Reach consensus and provide solutions.
- How can we affect real change through real solutions?
- Parents can help teach people about what children need. Children are not little adults; they are unique family members.
- Would like the system to work better for families who participate in multiple programs.
- The access part of the system seems most key; sometimes information does not seem to be disseminated about how to access services in rural areas.
- Very difficult to tell parents about the differences across the state, and lack of services.
- The system is so complex; difficult to explain to families everything that is or could be available.
- Transition issues are key personally and system wide.
- Learn and empower other parents from what has been heard.
- Advent of Children's Waivers has raised priority for children in the county. Has a big ripple effect through behavioral effect and child welfare; has raised children's visual status.
- Concerns about children with SED, ends at age 22. There are no services for these kids even if there is a funding source. Then at 22 the funding goes away.
- How can we support families who are on waiting lists with some kind of assistance?
- Coordination issues included children's mental health are key; would like to add children's mental health issues to our charge.
- Inequity of knowledge among parents; need to help parents know how to advocate for their children. Look to Council to fix a mix between process and outcomes.
- Group will be able to share their unique perspectives and will also keep our big picture in mind for broader Children's Long-Term Support Redesign. Challenge is to ensure that theoretical discussions get to practical recommendations.
- The Council serves as a reality check, and can help guide policy discussions.
- Making sure that system is not just family-focused but family-friendly. Not asking for the moon by asking for help. Make sure that everyone knows that parents know their kids the best.

Comments from Sinikka Santala, Division Administrator for Disability and Elder Services

Here on behalf of Secretary Nelson, who is out of town for a family wedding. Secretary Nelson is extremely pleased to sponsor the Council; she has a real commitment and interest in Council membership. Thanks to Beth Wroblewski for her commitment to making this happen. Thanks to Chair Liz Hecht for her long-term commitment to these issues. There are so many things that are coming together at this time.

Long term reforms have been happening on 3 fronts: Family Care, Children's Long-Term Supports Reform & Mental Health AODA Reform. All 3 initiatives have been making headway; unique part of children's initiatives were so much family-driven. Initial commitment for these services was through tremendous input from families; makes this redesign effort really unique.

Service system is needed to be family-driven, seamless from childhood to adulthood, a variety of community partners are needed. Three new home and community-based waivers are a huge new benefit to help provide assistance to children. Difficult transition for autism system transition, but worked through these issues. Also Governor's Council on Autism, we want to make sure there is a great deal of information sharing and coordination. Very proud of children's functional screen, statewide April 1, 2005, especially as there were different challenges in writing it for children. Also coming very soon – pilots are to be awarded to counties to implement systems change. Advisory to the Secretary's Office; issues that are raised here we will be taken very seriously and under full consideration. We respect your time and commitment very seriously.

Upcoming Council Meetings:

Friday, December 9, 2005

Tuesday, March 21, 2006

Council could solicit input at Circles of Life Conference for subcommittee meeting.

Outcomes

Small groups considered outcome statements. See document: "Qualities and Outcomes of the Long-Term Support and Service System for Children and Families in Wisconsin." Groups reported back.

Report Back for Small Groups - Recommended changes/additions to all outcomes. Will be reflected in revised "Qualities and Outcomes" document at next meeting.

Executive Committee Interest

Barb Katz

Michelle Sturz

Sue Gilbertson

Redesign Pilot Counties

Deanna Yost

Sally Mather

Marge Pifer

Quality Improvement/Assurance

Michelle Urban
Sharon Fleischfresser
Michelle Sturz
Hugh Davis (perhaps)

Policy and Procedures

Sue Gilbertson
Cheryl Berg
Pam Garman

Program Coordination and Funding

Carrie Pomjie
Pam Garman
Glenn Johnson
Marge Pifer
Barbara Katz

Access to Information, Assistance and Referral

Sharon Fleischfresser
Julie Turkoske
Cheryl Berg
Glenn Johnson
Barbara Katz

Hugh Davis – willing to float

Next Meeting Topics

Adult Disability and Resource Centers – Up to the Minute report
Medicaid Waivers – what is a slot, how do families access available slots
Functional Screen – a demo and background, what it does and does not do
Web Resources – The Manual, FS Overview