

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

FINAL MINUTES

June 10, 2008
LaQuinta Hotel
10:00 – 3:00 p.m.
Madison WI

Chairperson: Liz Hecht

Members Present: Keith Keller, Sally Mather, Beth Wroblewski, Julie Turkoske, John Shaw, Pilar Guzman, Hugh Davis, Sue Gilbertson, Lynn Breedlove, Fredi Bove, Julie Bryda,

DHFS Staff Member: Katie Sepnieski

Guests Present: Kelli Betsinger, Susan Younger, Waushara County, Becky Boyea, DHFS, Tara Johnson Parent Respite, Joyce Binder, I-Care, Amy Whitehead

- I. Welcome and Introductions-Liz Hecht
 - a. Members introduced themselves
 - b. Review of the agenda and a change to the agenda. The Secretary was unable to join the Council meeting.
- II. Secretary and DHFS Update-Beth Wroblewski
 - a. How can the children's section move forward with the momentum of FamilyCare taking priority at the Department?
 - b. The Secretary is very interested in moving the CLTS issues forward. She has discussed this desire at the LTC conference in April. She has met with staff internally to discuss how things can move forward.
 - c. The Secretary has been given the next two meeting dates in order for her to attend one of the meetings.
- III. How to positively make change around the State?
 - a. There is a need to work with new county staff on the best practice for the children's long-term support programs. The infrastructure at counties has changed within the last year due to the implementation of FamilyCare. Staff with experience and knowledge may no longer be at the county. New staff working with children may not have a history and understanding of what is needed in the CLTS system.
 - b. Counties are trying to create an efficient infrastructure which supports all areas within human services. Counties are beginning to combine the children's sections together. The pilot counties such as LaCrosse and Brown have worked to combine the sections in a thoughtful way. They spent much time and energy to develop a structure that would serve all children in the best way for the families.

- c. The children's services system has lost many strong advocates due to infrastructure change within county and state agencies.
 - d. The DHFS is planning on a two day training/conference in the fall to discuss the philosophy of the CLTS changes. DHFS will focus on the barriers that counties are facing and how to move them forward.
- IV. Effective CLTS Management During Change
- a. Thoughtful Planning
 - i. Does staff know what is needed for families and children? Are counties utilizing the appropriate staff in planning for the counties?
 - b. Organizational Capacity
 - i. Is there anyone in the system that can responsibly think through what children and family need?
 - c. Staff Expertise
 - i. Staff knowing and maintaining relationships with families, community providers, etc.
 - d. Impact on Change
 - i. The CLTS System may no longer have staff with the ability to make an impact within the counties. These senior staff members could make decisions or advocate for the needs of CLTS families and children. They have the history, knowledge, and expertise on the best way to make change in a positive way.
- V. Discussion with the Council on what issues they are facing.
- a. Families report being abandoned by the county service coordinators. The system is not connecting families to the right services. Crisis slots are not being utilized for families that are truly in crisis.
 - b. Personal care for children is not adequate. Not all counties serve children the same, access has been limited. The guidelines seem to be different across the state.
 - c. Coordination between programs (intensive in-home, PC services), coordination between divisions within the Department (BLTS, OFCE, HCAA). How to assure quality input on a short timeline?
 - d. The inflexibility of PC services is difficult for families. The difficulty of switching the duties of the PC services while in the home for families is almost impossible for them.
 - e. Families, service coordinators, and providers are expected to know so much about the different systems in order to get any service. The stress families are facing makes it difficult to know what questions to ask and who to ask. With the system changing it makes it difficult for service coordinators to know the right answer.
 - f. The rural counties have difficulty finding staff to support families. In the past the children's staff was combined with an adult service coordinator. With the expansion of FamilyCare the adult service coordinator is no longer available and is unable to take on the children's system. Rural counties can not justify hiring a new staff for children, it may be necessary for counties to work together in order for appropriate staff to work with CLTS programs.

- g. To work with counties that are transitioning what is the best place for CLTS programs. It is important to learn from lessons that the western part of the State has accomplished with the expansion of FamilyCare. While counties are planning for FamilyCare it is important to also plan for CLTS programs. Counties making the decision of where CLTS programs should be could be involved with a self-assessment.
 - h. There is fragmentation between the divisions at DHFS and with the separation into the two Departments. It may be more difficult for efficiency within the system. Children with complex needs (mental health, other disabilities, child protective services, etc.) cross systems and the complexity of the systems continues to increase.
 - i. A summit on kids, where does the Council want the focus for kids to go in the next ten years. The summit would include the two Departments and the divisions within the departments that work with children.
 - j. Lack of holistic thinking at the state level has an impact of what happens at the county level concerned that the new Department will further fragment the system.
 - k. Develop a subgroup to assist with DHFS for input.
 - i. How do we train new staff on the philosophy and structure of the CLTS programs? Identifying concerns and issues with the personal care services. How does DHFS establish tools to do thoughtful planning for CLTS programs at a local level at counties?
 - 1. Keith Keller, Sue Gilbertson, John Shaw, Liz Hecht, Barb Katz, Julie Turkoske
 - 2. Cindy Zellner (Door County), Tom Englebrecht
 - ii. PCS statutory change may occur in the next budget. Having input from the CLTS Council could be beneficial with what is happening in the children's system.
 - 1. Sue Gilbertson, Lynn Breedlove (would provide someone from DR-W), Liz Hecht
 - 2. Ask Amy Whitehead
 - 3. Lynn will email another person that may be interested
- VI. The creation of a new name for the new initiative – Kelli Betsinger
- a. Who needs to know about the council and the re-design?
 - i. Legislators, the Department, families, parents, counties
 - ii. Families really need to know what is going on. There is misinformation and misunderstanding of what all the programs are.
 - iii. Having one name that pulls together all the programs. Having only one doorway, one package.
 - iv. It is important for the public to understand that families with a child with a disability do not always “get taken care of.” There continues to be a need for the public to realize that many families have needs that are not being met.

- v. The name needs to grab attention for the general public, and people will pay attention. The word or phrase should be friendly. To become an acronym takes away from the purpose.
 - vi. Making it clear and concise for people to understand what CLTS all entails.
 - vii. By creating a new name it needs to be known that the “old” re-design was not bad. But there does need to be a change.
 - viii. Re-design was a reaction to FamilyCare. It has been an 11-year process.
 - ix. Families having better information that could help them, not just the public supports. What is provided through public supports needs to be more flexible. The services would be coordinated better, pieces fit better, more cost-effective.
 - x. Families are doing it, but we can help.
 - xi. Funding needs to be available, by utilizing the MA card, private insurance, and school services. Accessing the services when funding is available can be an obstacle.
 - xii. Addressing that the number of children waiting for services is equal to the number of children receiving services.
 - xiii. Legislators need to be aware of what is actually occurring. Having such a fragmented system makes it difficult for them to understand what the funding would be used for.
 - xiv. Special needs is a term that is used often for families. Families have a difficult time using the word disabled.
- b. What is the outreach that is occurring?
 - i. There is a need for effective outreach and coordination. The access for information is needed.
 - ii. A fragmentation of services makes it difficult for a coordination of services and the most cost-effective way to utilize the services.
 - c. You can do it, We can help. Some type of synonym of this phrase.
 - d. The Foundations Paper and using the term Foundation. Possible Family Foundations.
 - e. Naming Subgroup
 - i. Sally Mather, Beth Wroblewski, and Liz Hecht
- VII. Budget Initiative Workgroup – Lynn Breedlove
- a. In order to get the Council’s recommendations into the 2009-2011 budget it must go through a process.
 - i. DHFS develops budget
 - ii. Division of Administration (DOA)/Governor Decide on budget (September)
 - iii. Joint Finance Committee (JFC)
 - iv. Each house decides
 - v. Conference Committee
 - vi. Vetoes

- b. The Council needs to make a recommendation to Secretary Timberlake. By developing the recommendations early it will help to move the initiative forward.
- c. The budget initiative workgroup drafted a memo to Secretary Timberlake regarding recommendations for moving ahead with formulating an initiative for CLTS programs.
- d. The memo could also be developed for the legislature. Having the same message through all the stages of the budget process will assist with moving the recommendations forward.
- e. It would be helpful to work with the Autism Council on the recommendations in order for the CLTS Council to be able to move forward.
- f. The Autism Council may make a recommendation for additional funding dollars to eliminate the waiting list. This would be in conflict with the CLTS Council recommendation for additional funding.
- g. The memo is currently three pages but will need to be edited down for legislators.
- h. The three solutions that need to be funded are intertwined, each issue needs to be addressed in order for the system to work in a cost-effective, and coordinated way.
- i. The term coordinated services was a bit confusing. Is it at a family level, or macro/systems level? At the beginning of the document it was very general but was flushed out later on in the paper. Having that definition of each point flushed out a bit in the beginning would be understood through out the paper.
 - i. Coordinating for each family and on a systems level should be addressed. The medical issues are not part of the managed care plan. The medical piece should be addressed as to why it is not being included.
 - ii. By having coordinating supports for families that meets their needs will affect the system by having a cost-effective way to use resources.
 - iii. The paper will need to distinguish between managed care and coordinated supports.
 - iv. Coordinated supports are essential to meet the needs of families. It is important to stress that the supports are essential, it is not the niceties, it is the core of what the family needs.
- j. Sitting on Ready is an important message to get across. The CLTS system has been trying to move forward for 11 years and “it is our turn now.”
- k. It would be important to focus on the funding that has been given for FamilyCare and to remove the language for children with autism. Families that have children with autism could be interested in being a part of the new initiative.
- l. In the solution paragraph it should state that we have experience with the three prongs (Information, New Funding, and Coordinating Supports). The children’s system has worked on the three prongs separately and

knows what works. Developing a new system that will incorporate all three prongs will make a very strong system.

- m. The story in the memo was created to give a face to the issue.
 - i. The story is “light-touch.” It doesn’t speak to re-design. Most families that are involved with the CLTS system have more needs than are addressed in the story.
 - ii. Are there elements of the story that could change to address all three prongs? Adding a bit more confusion or another layer of issues and having managed care organization come in and coordinate the services effectively. The story could address private insurance, school services, and how to coordinate the services and how to pull in the last funding piece of public funded services.
 - iii. Split up the story. Discuss what could happen today if things happened. At the end of the story discuss what would happen if re-design were in place.
 - iv. The current story addresses that if it everything was coordinated then the family would be successful. It doesn’t address that there might not be services available or funding available.
- n. The paper did not want to address ADRCs or CYSHCN Regional Centers as the only possibilities for the information and access piece. The paper does address that a family-centered approach is needed and to have expertise in the children’s system. There are multiple options that can be explored; any viable options will need to be able to deliver the expertise that is needed in the children’s system. A statewide, regional, and county level infrastructure needs to be addressed. Multiple entities may be needed for the children’s system since there are different needs.

VIII. Funding Requirements-Lynn Breedlove

- a. If reasonably calculated there may be a more effective way to provide services to children and families.
- b. Approximately \$11 million dollars would be needed for resource centers for children based on the funding for the ADRCs. However if it was piloted in a few regions or counties how much funding would be needed?
- c. In the last biennium the children’s system received \$9.6 million. The Council should not ask for anything less at this point.
- d. The FamilyCare program received a large sum of money. The children’s system needs additional funding to continue to move forward.
- e. Demonstration sites were asked for in the last budget were not linked together. In the new budget the demonstration sites would be tied together. It would be a system change in which all the sites would need to work together within a new state infrastructure. Having regional consortia could be used in order to get a diverse pool of families and it would also address statewide consistency.
 - i. Counties that would be interested in participating would need to agree to a number of programmatic necessities that are needed in the demonstration sites.
 - ii. The counties would not need to be geographically located together.

- iii. The families in the demonstration site counties would need to all be enrolled in the managed care pilot.
 - iv. Within the five regions of the state there would be the ability to learn about the different issues within each region. Also by having all five regions involved the legislature would be interested.
 - v. To support the infrastructure it may cost approximately \$3 million for each year of the biennium. The resource center funds need to be included.
 - f. In the last budget \$9.6 million was given to DHFS to assist with eliminating waiting lists. The Council will need to ask for more in order to continue to serve more children and create demonstration sites.
 - g. To create the demonstration sites it is important to fund them adequately. This could cost approximately \$10 million.
 - h. The Council determined the Budget subcommittee would need to continue to work on budget recommendations.
- IX. John motioned to accept minutes from last meeting. Sue 2nd
- X. Approved
- XI. Future agenda items
- a. Continued budget issue discussion
 - b. ADRCs/Regional Center clarity-need subgroup
 - c. Eligibility determination where would that fall for information, access