

Wisconsin Council on Children's Long-Term Supports

Date: December 16, 2013

To: Kitty Rhoades
Brian Shoup
Beth Wroblewski

From: DHS Council on Children with Long-term Support Needs

Topic: **Recommendations for Supporting Families through CLTS Redesign: Short and Long-Term Strategies**

The Children's Council is very pleased to hear your announcement about your leadership for a renewed focus on quality improvement of the children's long-term support system. We strongly support the department's efforts. As members of the Council, we are committed to working closely with the department to come up with workable solutions that will empower and support families using the CLTS.

We believe that families are the lynch pin to achieving desirable outcomes for children and young adults with disabilities and are critical partners in the systems change process. Values about work and contribution come from families. Families who have access to three key strategies for support are better able to play key roles in identifying and securing opportunities for their family members to participate in meaningful ways within their community and ensuring access to self-determined lives. These proven strategies for supporting families: 1. information and skill-building opportunities; 2. emotional supports and 3. needed goods and services, should be integral components of all current and new initiatives advanced through CLTS.

CLTS is critical to assisting families to achieve their long-term outcomes. The overall goal of CLTS should be to support families to maximize their capacity, strengths, and unique abilities so they can best support their family members while facilitating achievement of self-determination, independence, productivity, and inclusion in all facets of community life.

The following recommendations are intended to advance DHS systems change efforts to support families and can be accomplished, in many cases, through prioritization and refocusing of existing federal, state and local resources. These recommendations will support families as they endeavor to support their children to have meaningful self-determined lives.

1. Focus on Family "North Star" Outcomes by:

- a. Using system outcomes identified by the CLTS Council, counties and families, design and implement a periodic family evaluation tool and process to obtain information from families about the effectiveness of supports and services. Use this information to guide quality improvement efforts.

- b. Providing ongoing family-centered CLTS service coordinator training that is reinforced by DHS technical assistance activities. This training should include a focus on increasing skills and knowledge of current CLTS service coordinators to partner with families to identify family outcomes and increase family access to generic community and natural supports, Medicaid covered services, private insurance, school supports and futures planning.
- c. Supporting opportunities for families to acquire skill and knowledge to be effective partners and advocates by supporting parent leadership training.
- d. Assuring families have access to information that is understandable, reliable and culturally appropriate by working with family organizations and advisory committees to develop and review all materials directed to families. Consider a family consumer handbook, modeled after *A Consumer's Guide to Family Care, "Being a Full Partner"*.
- e. Assuring that annual planning for current and future needs of a child and family is based on the family identified outcomes, not a menu of services. Shift conversations from services to supports for the family's vision.

2. Rebalance System to be *Equitable* for all Children by:

- a. Increasing funding to reduce and eventually eliminate waiting lists for access to the CLTS for all children waiting, regardless of diagnosis. Any new funding should reduce the inequity between children with different disabilities. This is best accomplished by eliminating waiting list which will assure that families have the best match to needed supports rather than having to choose the only open door, even when this does not meet their needs.
- b. Assuring that all children have equal access to eligibility determination using the functional screen with particular attention to children with severe emotional disturbance.

3. Grow *Self-Determination* within CLTS by:

- a. Providing learning opportunities for families and service coordinators to assure families are supported to focus on strengths, interests, possibilities and opportunities. These opportunities should include contact with families who have older children as well as adults with disabilities.
- b. Supporting and encouraging family-to-family networks and connections to provide emotional supports, information and a more expansive vision for the future.
- c. Increasing access to one-to-one service coordination supports for families who are seeking assistance and those on the waiting list for CLTS.
- d. Convening discussions with families and counties to understand the barriers, reduce complexity and improve access to family-directed supports within the children's waivers.

4. Improve *Efficiency* and Reduce Duplication of CLTS services by:

- a. Building on efficiencies experienced in counties using a single point of entry and expand COMPASS Wisconsin-Threshold statewide to improve access to information, supports and eligibility determination.
- b. Addressing barriers that prevent service coordinators from creative problem-solving which in turn facilitates inclusion for the child and family and maximizes access of neighborhood and community supports.
- c. Developing an integrated and web-based CLTS information technology system that improves data reporting that can be used to describe CLTS including elements such as numbers served and on waiting lists; costs; spending trends; service utilization and demographics.
- d. Reducing burdensome paperwork and regulatory processes for counties to allow them to redirect their time and resources to direct support to families.
- e. Making self-directed personal care available to families.

5. Eliminate Resource *Waste* by:

- a. Improving access to and coordination with Medicaid prior authorization, private insurance and EPSDT to reduce cost shifting to CLTS.
- b. Providing training to service coordinators on working with school and community partners to assist families to increase community capacity to support and include children with disabilities. Improve skills needed to integrate a variety of funding sources to meet family needs.

6. Increase *Employment* For Young Adults with Long-Term Support Needs by:

- a. Starting early and continuing often to help families shape a positive vision for the future and actualize that vision as partners and advocates with schools, CLTS, and their communities.
- b. Ensuring that CLTS interactions between providers and families, as well as ongoing training for families focuses on vision setting, future possibilities, partnering with professionals, and maximizing school and community resources.

We appreciate your consideration of these recommendations. We would very much like an opportunity to work together to advance the recommendations of interest to you. Please contact us for a meeting at your earliest convenience to set up a time to meet and discuss your priorities and the plan for moving forward. Please contact Liz Hecht, 608-239-1364, to schedule a meeting with Council representatives.

Thank you,
Liz Hecht
Chair