

# Wisconsin Council on Children's Long-Term Support

August 20, 2008

To: Secretary Karen Timberlake  
Sinikka Santala

From: Council on Children with Long Term Support Needs (CCLTS)

Topic: **Sitting on Ready: Advancing a Children's Initiative in the 2009-2011 Biennial Budget**

## Issue

Our system of long term supports (LTS) for children with disabilities continues to be plagued with disparities and inconsistency between counties and between families who have access to comprehensive services and information, and those who are in desperate need but lack access either because they do not have information, or are on a waiting list for services. The Children's Redesign, a DHFS initiative started in 1998, is ready to move ahead with comprehensive change in the way Wisconsin provides supports for children and families.

## Solution

The Council on Children with Long Term Support Needs proposes a 2009-2011 biennial budget initiative that advances the Children's Redesign using a three prong approach to building an integrated system for children, and youth with long-term support needs and their families. The cornerstones of this proposal are:

1. **Information, Assistance and Resource Access** that provides a quality, family-centered service that helps families maximize existing community resources and long term supports
2. **New Funding for Services** that allows a timely and flexible response to meet needs,
3. **Coordinated Services and Supports** for individual families and consolidated funding at the systems level that ensures the most cost effective use of essential long term resources and funding.

We have experience with what will work, but have not had the opportunity to put all the parts together to change the way funding is directed to achieve true systems change and a greater cost effectiveness. There have been major department initiatives in recent years: Family Care, ADRC's, and BadgerCare Plus. **We request that reform for children with disabilities also be a major initiative championed by DHS in the next biennial budget.**

## Background

The Children's Redesign began as a DHFS initiative in 1997 with a charge from Secretary Joe Leann to develop a proposal with the "best options and recommendations about how services to children who have long-term care needs should be designed and managed." A DHFS biennial budget issue paper written in 2003 states "...*The Department plans to begin implementing Children's Long Term Support (LTS) Redesign in FY 04.*" In 2005 DHFS Secretary Nelson supported the Children's Council recommendation to explore managed care as a model for serving children with LTS

needs. It is now 2008. To date, Children's Redesign has been overshadowed by the advancement of Family Care and services for young children with autism, leading to a number of failed attempts to adequately fund Redesign, and a piecemeal approach to moving forward. Many of the tools needed for reform have been developed, piloted and implemented (functional screen, CLTS waivers, county participation, parental payment liability, regional information & referral). What is needed is the opportunity to demonstrate the effectiveness of a system that integrates these tools within a coordinated framework.

### **Imagine if Children's Redesign is implemented.....**

*Stacy Jensen sits on her front steps watching her three children play in the yard. She's been raising them by herself since her husband left five years ago. She is worried about her middle son, Joey, who is 14 years old. His mobility has been declining during the past year to the point that he cannot transfer in and out of his wheelchair by himself anymore and is no longer able to climb the steps into the house. It frustrates Joey to have to rely on Stacy for help and due to all the lifting Stacy's doctor has told her that she needs to give her back a rest or she will need surgery. If Stacy has surgery, who will take care of Joey?*

*Stacy has repeatedly asked her county for some assistance to make modifications to her home so Joey can get into the house using his wheelchair and be more independent. They are sympathetic, but tell her that without new funding for services, she is still on a waiting list. They are able to offer a short term foster care placement for all three children if Stacy is unable to care for them following her surgery.*

*Her need for assistance is becoming critical because the director of his after-school program, just called to say that because of his increased needs they may not be able to continue working with Joey. They suggest she find an agency to provide care at the after school program. Stacey makes some calls and finds out that the agency that was providing personal care services is not accepting new clients and in any case they can only provide personal care in the home. Stacy can not be home after school to meet Joey; she has used up all her vacation time for the year and her boss is unwilling to allow her a more flexible schedule.*

*Stacy is scared and frustrated. What if she has to have back surgery? What if she loses her job! She wants Joey to be in the after school program with just a little help with personal care so he can stay with his friends and get some help with homework. It doesn't make sense to her that the current system is so inflexible that it will spend money for Joey to stay home with lots of help, but cannot spend less and let him stay at school with just a little help that will in the long run make him less dependent.*

Stacey feels stuck. All three elements of an integrated system are missing. Stacey does not have access to information that will let her find a workable solution, funding is not flexible or available in a timely way to meet her immediate needs, and there is no one to help her figure out a solution based her needs and preferences.

*She decides to call a number a friend gave her for **information and assistance**. They are incredibly helpful. They explain about a new program that allows more **flexibility with funding** such that they can pay for a person to provide personal care while Joey is at the after school program. Stacey calls the program and talks with a person who can help her **coordinate** with the school, Medicaid and a home health agency. The program just got **new funding** so they can also help her with modifications to her home so she does not need to lift Joey so often. Additionally they tell her about a local health club that offers an adapted fitness program that can help Joey work on his physical therapy goals so he can remain more independent. Stacy is able to get some help with lifting; keep her job and avoid back surgery. Joey is able to get in his house on his own when he doesn't have after school, be more independent at home; attend the afterschool program with his friends and is even offered "job" to develop a website for the program.*

## Proposal

We propose the DHS advance the *Family Support...Supporting Families... Roadmaps for Families...No Place Like Home...Initiative* to provide a continuum of supports for families who have children with disabilities that includes information and support, connection to resources, access to services, service coordination, and adequate funding. The cornerstones of Roadmaps are:

- A statewide infrastructure, with capacity to respond to families locally, to provide **Information, Assistance and Resource Access** helping families navigate a confusing and complex array of supports and services they need to help their child. It offers families access to staff that can provide a light touch if that is all a family needs, or if needed comprehensive assistance, eligibility determination and referral for long-term supports. Prevention, early intervention and parent education are goals of the resource center. Knowledgeable and supported parents are better able to advocate for their children and utilize resources they might already have but may not know how to maximize such as private and public insurance, school and Medicaid services, community supports and long-term supports for unique needs. There are a variety of options for delivering this service. One is the expansion of the current Regional Children and Youth with Special Healthcare Needs Center functions; another is the expansion of ADRC functions and another is to create a new structure. Whatever entity delivers this service must take a family-centered approach and have expertise in the children's system. Our recommendation is to develop an RFP process that clearly outlines the deliverables and expected collaborations and award a statewide contract to deliver this service
- **New Funding for Services** making possible a partnership between families and the children's long term support system built on trust, flexibility and responsiveness. When families trust that publicly funded services are available when they really need it, they have the opportunity to be good stewards of resources and ask only for what they need when needed. This trust requires that counties will have resources to respond in a timely way. Families won't be encouraged to "use it or lose it" and counties will have the flexibility and adequate funding from year to year to meet evolving family needs. If needs are not met families may reach a point where they can no longer cope. Children waiting to be served often are utilizing more expensive or mismatched services through other programs including Medicaid, institutions or the foster care setting. Adequate funding will support families to meet their child's needs appropriately in their homes and communities.
- **Coordinated Supports** and services for families assures the most effective use of **consolidated long-term support funding**. A family-centered managed care model using the 1915b/c Medicaid authority which allows the consolidation of Medicaid and other long term support funding creating an opportunity for choice and flexibility that allows the best fit between family needs and services. This requires a form of coordination quite different than Family Care. A new system assists families to coordinate services across multiple systems such as Department of Public Instruction, Division of Vocational Rehabilitation, Medicaid, private insurance and long term supports. It will allow families, with the support of a team, to find creative solutions which maximize community resources in addition to long term supports. This assures the most cost effective

use of long term support resources by making sure families get the services they need and increases the number of families receiving services.

Stacey was able to talk with the **information resource** where she learns about *Roadmaps*. She was able to keep her job and her family's source of health insurance. **Consolidated funding** of Medicaid services paid for the school secretary to stop into the after school program and provide personal care to Joey. This allowed Joey to find a solution that fit his preferences for inclusion and social relationships, utilized an existing community resource, the after school program, and cost less than the solution available to him, to stay home with in home personal care, using the existing system of supports. **Timely access to funding** allowed Stacy to pay for the home modifications needed for Joey to do more of his personal care himself which prevented the need for back surgery for Stacy and foster care for Joey while Stacy recuperated. Comprehensive reform of children's long term supports is only possible if all three elements of Redesign are advanced. Each aspect of the system is intertwined with the other with efficiencies only realized through full implementation of the model.

**Wisconsin's children and families are struggling with an underfunded, inflexible and fragmented long term support system. Wisconsin families and children deserve better. The DHS and Governor have set a statewide goal to eliminate waiting lists for adults with disabilities who need access to long-term support by 2011. This is the biennium to set us on the same path for children with disabilities.**