This paper summarizes the Children's Committee's vision of the key elements and framework for a children's long-term support system. DHFS and the Committee are interested in your feedback to help identify areas of consensus as well as areas of concern.

Tommy G. Thompson
Governor

Joe Leean
Secretary

State of Wisconsin

Department of Health and Family Services

DIVISION OF SUPPORTIVE LIVING

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February 9, 1999

Dear Reader:

The enclosed paper represents the first phase of work of the Children's Long-Term Support Committee. It articulates a vision of the key elements and framework of a children's long term support system that is directed by and responsive to the families it serves. We are interested in your feedback and participation as this process moves forward. The committee is gathering feedback to identify areas of consensus and concern as we begin to describe the details of a new system of supports and services for children with special needs and their families.

The Committee is a unique collaborative effort co-sponsored by the Wisconsin Council on Developmental Disabilities, the Department of Health and Family Services, and the sponsoring organizations of many Committee members. Two-thirds of the Committee's members are community representatives and one-third are state agency liaisons. Nineteen of the members have children who have long-term support needs.

The focus of the Committee's work is on families whose children have functional needs who may require long-term support services. It does not specifically include children whose primary support needs are traditionally addressed by the mental health system. The Governor's Blue Ribbon Commission is addressing the needs of both adults and children with mental illness. However, several committee members represented the concerns of this group of families.

The Department of Health and Family Services will take a lead in second phase activities, in collaboration with the Children’s Committee, to develop the administrative, governing, and fiscal models for implementing the proposed system. The pilot testing phase will constitute the third phase of the initiative. The final phase will be the funding and implementation of a tested children's long-term support system.

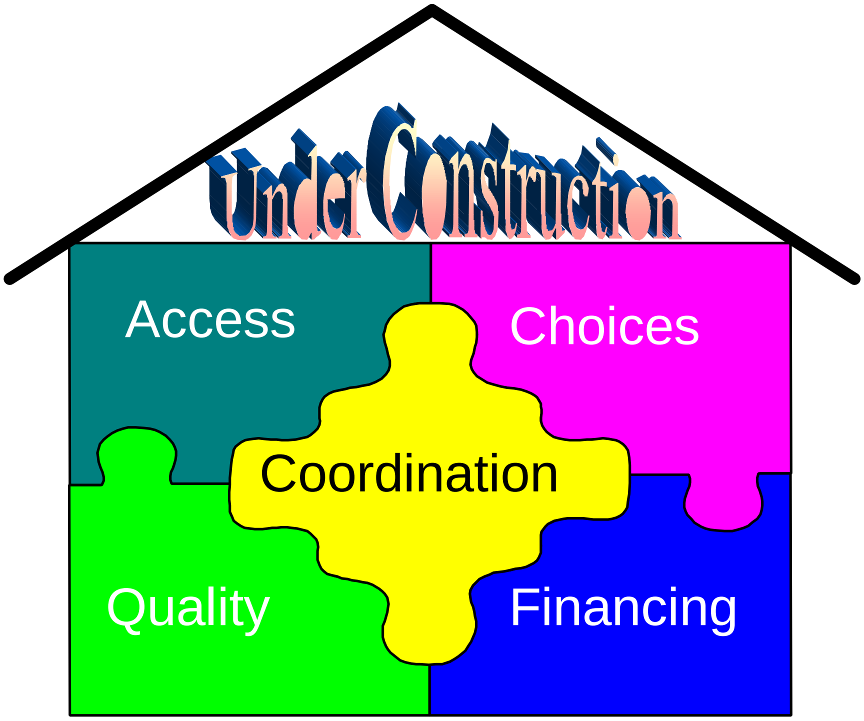
Please take some time to read this paper (it will take about 2 hours) and use the attached form to send us your ideas. Your input is very important in this process. Please share this paper with others, particularly family members, who may be interested.

Sincerely,

Liz Hecht	Beth Wroblewski
Chair	Children and Family Services Supervisor
Children's Long-Term Support Committee	Bureau of Developmental Disabilities Services

A Foundation for A System of Long-Term Support For Wisconsin Children & Families

Phase I



Best Options and Recommendations

A Report on the Work of the Children's
Long-Term Support Committee

December 1998

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The Williams Family: Fathers (and mothers) know best

Features of an improved system:

- State-level authority for effective, efficient statewide management
- Local Authority for effective, efficient local management
- Training and technical assistance for service providers and families

The Bennings: A future full of waiting lists

Features of an improved system:

- Pooling/coordination of public funding streams
- Coordination of public funds with insurance and other private funds
- Simple and fair cost-sharing policies
- An adequate funding base for long-term support

GUIDING PHILOSOPHY

OUR VISION… Children with disabilities and their families will pursue their unique hopes and dreams with assistance that:

- Is family-designed and controlled,
- Is individualized and seamless,
- Lasts as long as needed, and
- Involves a variety of community partners.

PRINCIPLES… *Children are Children First.* All children need acceptance, love, nurturing and security. The focus will first be on the child as a child, and second on the problem or disability. The developmental, social, emotional, and physical needs of the whole child must be considered in the delivery of any service.

Children are best served within their families. The best way to meet the needs of children is to support and build on the strengths of their families. Public policy will be supportive of what contemporary families need to survive and thrive. Policies and support systems will promote culturally competent practices.

Parents are the best allies in any activity that serves the child. Families have a great capacity to care for children with disabilities if given the supports they need. Families will have informed, real choices in selecting needed services and supports. They will remain in control of decisions that affect their lives.

Children and families are best supported within the context of their community. The service system will enhance the opportunities that allow children with disabilities and their families to become connected to the community. Services will focus on supplementing, not replacing, the natural support that people get from family, friends, neighbors and volunteers.

Families will have convenient access to care coordination. Children and families need a trusted person to help them find out about and make use of services and supports. This service coordinator will be someone chosen in consultation with the family with whom they can work comfortably.

Collaboration is the best way to provide comprehensive services. No single agency is able to provide all services to all children and families. Cooperation among providers is necessary to provide a flexible, seamless system.

Family perspectives and presence will be included in all aspects of the system. Families will be partners with other families, providers and policy-makers in the areas of policy and program development, professional education, and in the delivery of supports and services. Family perspectives contribute to system-wide improvements and cost efficiencies.

INTRODUCTION

INTENT… This report documents the first phase of system design and development. It articulates a vision of the key elements and framework of a children's long term support system that is directed by and responsive to the families it serves. Second phase activities will include the development of the administrative, governing, and fiscal models for implementing the proposed system. The pilot testing phase will constitute the third phase of the initiative. The final phase will be the funding and implementation of a tested children's long-term support system. Planning is underway to secure DHFS funding and staff resources for the next phases of plan development and implementation.

BACKGROUND… The Wisconsin Department of Health and Family Services is in the process of re-examining and revamping the state's long-term support system. Because of the many differences between long-term support for children versus adults, Department Secretary Leean appointed a separate Children's Committee on Long-Term Care. (See Appendix A for Committee Membership.) The Committee's charge is 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." (See Appendix B for full description.)

Public policies on long-term support affect thousands of Wisconsin children and their families on a daily basis. The focus of this report is on children who have functional needs that require long-term support services such as the Family Support Program, the Community Options Program, and the Community Integration Program. It is, however, difficult to estimate the number of children who would meet the definition of long-term support needs.

Various sources of data and analysis affect the estimate of Wisconsin children, ages birth through 21 years, included in a long-term support system. An estimated 16,225[1] - 22,200[2] children have disabilities that may require long-term support services.

The vast majority of long-term support, across the age span, is provided by unpaid family caregivers. Nationally, more than 70% of people needing long-term support rely exclusively on informal caregivers, while only 5% rely exclusively on paid support. Three-

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[1] based upon 1996 Wisconsin Council on Developmental Disabilities data from the Human Services Reporting System and waiting list data

[2] based on disability prevalence statistics of 1.0% of the population

quarters of family caregivers are women, of whom one-third have serious health problems of their own. About 10% of family caregivers gave up paid employment to provide care, and 80% spend at least four hours every day providing care. *(Source: Physicians for a National Health Plan)*

THE PROCESS….. The Committee is a unique collaborative effort co-sponsored by the Wisconsin Council on Developmental Disabilities, the Department of Health and Family Services, and the sponsoring organizations of many Committee members. Two-thirds of the Committee's members are community representatives and one-third are state agency liaisons. Nineteen of the members have children who need long-term support. Elizabeth Hecht, a parent and professional in the field, chairs the Committee. The Committee's work began in September 1997.

The focus of the Committee's work was on families whose children have functional needs who may require long-term support services. It did not specifically include children whose primary long-term support needs are traditionally addressed by the mental health system. The Governor's Blue Ribbon Commission is charged to describe a system to address the needs of both adults and children with mental illness. However, several committee member represented the concerns of this group of families.

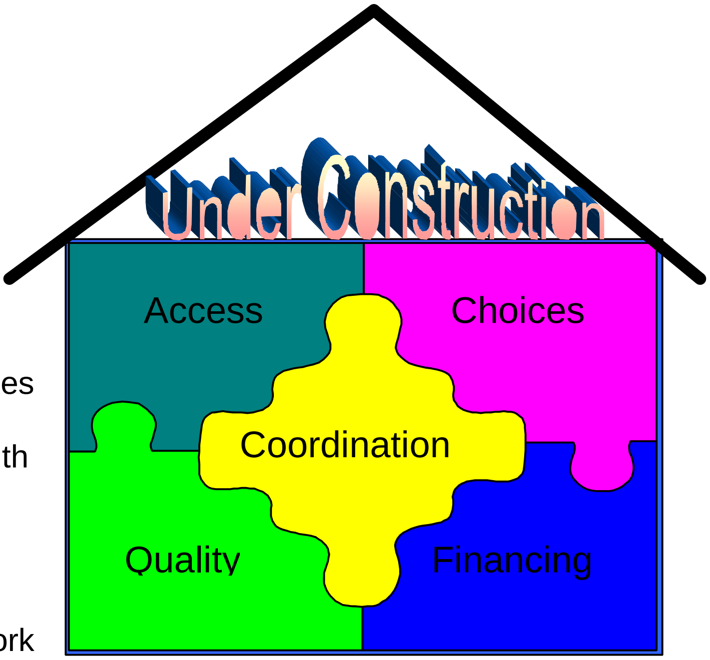
The Committee sought input from families throughout Wisconsin. More than 110 people attended a series of twelve forums throughout the state sponsored by the Committee in the fall of 1997. An additional 40 people completed a telephone or written survey. The Committee used this information to guide their discussion on various aspects of this paper.

KEY FINDINGS… The unique needs and circumstances of children and families require an approach to long-term support that is different from the adult system in several important ways. Adults generally prefer a system that they direct and that has the community as its primary context. Children typically live in families and rely on their parents for direction and the management of any supports or services they need. Children will be more likely to thrive in a family-centered system of support that acknowledges the central role of parents as planners and managers of all needed services. Therefore, the Committee favors a fundamentally different approach to eligibility, service coordination, and service delivery.

In examining the current system, the Committee found numerous examples of long-term supports that help families in meaningful ways. It also identified a number of systemic problems that should be addressed:

> ***Access*** to long-term support services is complicated and inconsistent throughout the state. An improved system will include a single source of information for families, functional eligibility criteria that are uniformly applied, and a timely response to child and family needs.
>
> ***Choice*** of services is often limited by what agencies traditionally offer, versus what families need. An improved system will include a broader definition or services and supports, give families more control in designing their services and have greater respect for the choices made by families.
>
> ***Coordination*** of services is a critical, but often overlooked, element of an efficient and responsive system. An improved system will actively link with families and their team to plan and coordinate services. It will also employ capable service coordinators who are empowered to meet family needs, and assist in the planning and coordination of resources across systems.
>
> ***Quality*** of services is greatly enhanced by good management structures and practices. An improved system will establish a state-level authority to develop and oversee a uniform, statewide system of long-term support for children and families. Local Boards will be established to plan and implement services. Families are involved in all aspects of the system, for example as staff members, system designers, and evaluators, as well as personnel development.
>
> ***Financing*** of services is highly fragmented and often inadequate. An improved system will maximize and expand resources, coordinate funding across systems, and apply family cost-sharing policies that are simple and fair.

A FRAMEWORK
FOR DESIGN



The image that emerged from our conversations with families was one of scattered puzzle pieces. It's hard for families to find the piece of the system they need, and if they do, it's usually not connected with the other parts they need. In some cases, critical pieces are missing altogether.

In response to these concerns, the Committee proposes the following framework for an interconnected and flexible system of long-term support, designed to meet the unique needs of children and their families. It has five key elements, each with desired outcomes for families:

ACCESS…….. *Desired outcomes:*

a. Families have easy access to a person who can provide complete and accurate information.

b. All eligible children and families get the supports and services they need in a timely manner. (This includes support for family caregivers.)

c. Services are accessible, coordinated and consistent throughout the state.

CHOICES……. *Desired outcomes:*

a. Families design and direct the assistance they want.

b. Families have an appropriate array of services from which to choose.

c. Universal, prevention-oriented health care is available to all children and their families.

d. Providers are responsive to each family's individual and cultural strengths and needs, and have staff and advisors who reflect the population of families served.

e. Parents have access to other parents for support, medical and educational advocacy, and mentoring.

COORDINATION.. *Desired outcomes:*

a. The service system functions seamlessly from the family's point of view.

b. Communities recognize and share in the responsibility of supporting children with disabilities and their families.

c. Families, service providers and other community members work as partners on behalf of the children.

d. Parents and providers develop working relationships that are respectful and trusting.

QUALITY……. *Desired outcomes:*

a. Quality standards for services are developed, implemented and monitored.

b. Staff, families and other caregivers receive appropriate training and support to carry out their responsibilities.

FINANCING…. *Desired outcomes:*

a. Funding is sufficient and flexible so families can choose services most appropriate to their needs.

b. All policies acknowledge the unique and hidden costs to families who raise children with disabilities.

c. Available funding follows the child and family regardless of changes of residence within Wisconsin.

The following sections outline the specific features of each element as recommended by the Committee. They describe the problems in the current system that need to be addressed, using family stories as illustrations. While the families are fictional, their circumstances are true of families we know.

ACCESS

THE HOGANS…

Bob Hogan came home from work to find his wife sitting at the kitchen table, crying. “What’s the matter?” he asked, worried and confused. “And why are you home from the office already?”

“Mom’s back went out again,” Linda said as she wiped her tears. “She can’t take care of Jason for a long time, maybe never. I’ve been on the phone all afternoon trying to find a day care provider. I found one opening for an infant, but they won’t do tube-feedings. I called another agency that helps families with disabled children find day care, but they have a waiting list.”

Bob and Linda had been managing okay since Jason was born six months ago with multiple disabilities. Linda had wanted to stay home longer, but Bob did seasonal construction work and they needed the health insurance she got through her employer. Luckily, her mom had offered to take care of Jason while Linda worked.

Now everything was falling apart. Linda wished she could find one knowledgeable person who could help her family figure out their options.

THE PROBLEMS…

Many Wisconsin families face dilemmas like the Hogans. Families repeatedly state that the lack of reliable information and supports results in tremendous frustration and family stress. Parents describe feelings of being alone and overwhelmed. They experience extreme difficulty juggling all the demands placed on them. Families report losing jobs, short-changing their other children, ending their marriages, developing health problems, and facing financial ruin. Some accumulate huge medical bills that deplete their savings and exhaust insurance coverage.

Many parents expressed a distrust of service providers, felt discriminated against because of their race, and were being “*kept in the dark, as if we would abuse the system*.” Families also expressed a feeling of pressure, a sense of urgency to get things done. “*You live in fear that when you finally do find services it will be too late to help your child. You worry, is everything you are doing enough*?”

Eligibility for supports and services is variable and inconsistent. A child with a formal diagnosis may be eligible for a program, while a child with similar needs, but either a different (or no) diagnosis will not. Family income may result in ineligibility for a long-term support service for a child with significant needs, while another child with comparable needs may be eligible. Middle income families appear to be most susceptible to a negative impact of income eligibility restrictions. Children under the age of 18 who are eligible and participate in programs often start all over again on waiting lists when they turn 18 or 21.

SOLUTIONS….. An improved long-term support system for children and families will:

Include a well-staffed information service, that

- gives free information and referrals to all requests;
- identifies and shares additional information beyond the initial request;
- is independent of service providers so as to avoid an actual or perceived conflict of interest;
- is well-publicized throughout the community;
- is staffed by knowledgeable people, who have access to other experts as needed;
- is available to all families regardless of eligibility for long-term supports;
- links people to an advocacy system when needed; and
- has extended hours, including evenings and weekends.

Have clearly defined eligibility criteria, that

- are based on functional and/or diagnostic criteria (Appendix C);
- accept all income levels, though cost-sharing may apply;
- are applied promptly and consistently;
- when used to determine continuing eligibility, take into account functional improvements that are contingent on continued support services;
- contain a simple appeals process; and
- lead to referrals to other resources for children and families who are determined ineligible.

Provide a timely response to child and family needs, that

- accurately assesses the urgency of need and intervenes appropriately;
- continues with a family when more in-depth research into a response is necessary; and
- does not put children and families on waiting lists for services they need now.

CHOICES

THE JENSENS…. *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, Joe, who is nine 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. It hurts her back to help him transfer, and it frustrates him to have to rely on her.*

Stacy has repeatedly asked the school to increase his physical therapy, but they say its not educationally necessary. She's arranged for physical therapy at home, but can't get it funded by Medicaid because it is not at a clinic. To get Joe to the clinic on time, he has to miss school and she needs to take off of work. She can't afford to take any more time off from her daytime job. The director of his after-school program has stated that they may not be able to continue working with Joe unless they hire another person for transfer assistance.

Stacy doesn't want more staff or more equipment for Joe. She wants therapy services that will help him be more mobile and more able to do things for himself. It doesn't make sense to her that the system is willing to spend more money to make him less independent.

THE PROBLEMS… Like Stacy, many parents indicate that they often get what agencies have on their "menu" or what Medicaid will pay for, rather than what they really need. In some cases, what families want is *less* expensive than what they get – like buying diapers from discount stores rather than through pharmacies and other medical providers, or hiring a teenage neighbor to provide care instead of using a home health provider. Families are often caught between conflicting rules and regulations of various systems. For example, a much needed service may not be considered medically necessary by Medicaid; not be considered rehabilitation by private insurance; not be considered educational by public schools; and not be an allowable service under the home and community-based waivers.

Families are also frustrated by the "all or nothing" nature of the current long-term care system. In some situations, getting a specific service on a short-term basis would address their identified needs. This might include one-time funding needs, time-limited services or "trouble-shooting" specific needs. A more preventive approach, driven by what families say is important to them, could avoid larger, more costly problems later on.

Families report that services are often provided at inconvenient times or distant locations. Working parents experience particular stress as they try to juggle employment with the plethora of special appointments they have for their children. While some parents are lucky enough to have flexible employers, others must give up family income in order for their children to receive certain services.

And finally, families are concerned that they have little, if any, choice about who provides services to them. Even the most intimate and intrusive services may be provided by someone who the family has never met or approved.

SOLUTIONS….

An improved long-term support system for children and families will:

Use a broad definition of services and supports, that

- provides a spectrum of services and supports, based on individual child and family need (versus the "all or nothing" type of approach);
- encourages prevention and early intervention in order to avoid more difficult and costly problems later on; and
- is fluid and flexible, enabling families to add, drop or change services as their needs change.

Give families, in partnership with the service coordinator,
the responsibility for decisions about

- definition of desired outcomes;
- what services they receive;
- the location and duration of services;
- the provider of services;
- the method (direct contract, use of a provider agency, a voucher system, etc.) of employment of support people; and
- review and problem-solving around service delivery.

COORDINATION

THE JONES….

Phyllis Jones hung up the phone and let out a sigh. That was Monica on the phone, her new case manager, the third one in two years. She was an enthusiastic young woman, fresh out of college, with no understanding at all of what it was like to raise a 6-year-old daughter with severe disabilities. She didn't mind training these new case managers. But she was tired of always watching them move on to a better job and having to start all over.

"I'd make a perfect case study for a social work class," Phyllis joked with one of her friends. "Besides our case manager, we have a social worker at my daughter's school, and a social worker here in the housing project. Wouldn't it be great if I could have only one person I had to spill my guts to?"

Phyllis is a patient woman, but she resents being treated as if her time is worthless. Just yesterday, she spent all morning waiting to see a worker at the welfare office about the food stamps she never received that month. In the afternoon, she waited for two hours at the neurologist's office for an appointment for her daughter. When she asked the receptionist how much longer it would be, she was told "You're lucky he even sees Medicaid patients."

THE PROBLEMS…

Many families have stories like Phyllis, about trying to negotiate a variety of services, each with their own rules, about working with case managers who lack experience, or about dealing with providers who treat them disrespectfully.

Families who have an assigned case manager often find that the individual is not focused on the family's identified needs. Their allegiance may be to their employer resulting in limited information and options being shared with the family. Paperwork may consume a majority of their time. Other families would welcome the support and information that a service coordinator could offer to their family but do not have access to this service.

Coordination problems are exacerbated for families who deal not only with multiple agencies, but also with multiple systems that can include long-term support programs, public school programs, health care specialists, child protective services, and others. This is compounded by families having case managers who have a narrow focus rather than helping families coordinate multiple systems and helping with problem solving.

SOLUTIONS… An improved long-term support system for children and families will:

Involve families as decision-makers in

- assessing child and family needs;
- evaluating all possible formal and informal support options;
- choosing services most appropriate to their needs; and
- determining the terms under which services and supports will be provided (e.g. provider, location, duration, etc.)

Employ qualified service coordinators, who

- are selected or approved by the family;
- conduct assessments and develop service plans in collaboration with the family;
- are non-judgmental and creative problem-solvers;
- visit the child and family in their natural environments, including home, school and community;
- are knowledgeable about community and medical resources and able to link families to the supports they need;
- will develop the capacity of families to be able to make informed decisions in purchasing services;
- facilitate communication and coordination among providers;
- provide the intensity of service coordination that the family needs and wants;
- are employed by an agency that does not determine funding levels or provide direct services; and
- can problem-solve about finding needed services and supports.

Use comprehensive and coordinated service plans that

- are developed by a team of people chosen by the family;
- are tailored to the child and family;
- include natural supports;
- identify services and supports that cut across systems to address children’s and families’ broad needs, such as education, mental health, housing, and medical needs;
- are regularly reviewed and updated; and
- are acknowledged and respected across the systems in which the child participates.

Establish formal, system-level linkages among the following:

- publicly funded long-term care programs;
- private health insurance programs;
- informal and generic community supports;
- public child welfare and family preservation support services;
- schools;
- Birth-to-3 programs;
- child care providers;
- health providers, including primary, acute and psychiatric care, mental health services and home health services;
- parent education and family resource programs; and
- transition planning with the adult service system.

QUALITY

THE WILLIAMS….. *Gloria Williams has almost the exact life she always dreamed of – a loving and successful husband, a nice home in a safe neighborhood, and good schools for her two beautiful children. The only departure from her original dream is that her youngest child has autism.*

It was both a blow and a relief to finally learn their son's diagnosis when he was almost three years old. They knew something was wrong and after they recovered from their shock and grief, they set about doing all they could to help him. After a great deal of searching, they had been quite successful in finding teachers and therapists to teach them how to support their son.

But Gloria knew she was lucky. She worried about the other parents she met at the autism support group – single mothers, low-income parents, and other parents who lived in circumstances she could barely imagine. She became angry that their voices were never heard, that they had to settle for whatever was given to them, without having a real say about how public money was spent on behalf of their children.

THE PROBLEMS… Many families who attended the public forums voiced Gloria's observations. Our current system of services has considerable variability between counties and between families. In many counties, county employees manage the planning and funding of the long-term supports and also provide the actual services. In other counties, there is a diverse mix of private, community-based organizations that contract with the county and other funders to provide services.

Entirely separate governmental bodies and industries with their own administrative and legislative requirements operate other critical services needed by families, such as education and health care. This complex system results in no one entity having the responsibility or authority to create and implement a comprehensive service planning and evaluation process for families who have children with special needs.

Monitoring and evaluation efforts are rarely comprehensive in scope or regular in frequency. There is very little in terms of requirements, money, or follow-up within the system for pro-active, continuous quality improvement efforts. Instead, there is a strong reliance on grievance procedures and appeal processes to respond to individual concerns.

SOLUTIONS…. An improved long-term support system for children and families will:

Have a state-level authority to provide effective and efficient statewide management of the long-term support system. This authority

- is composed of 51% family representatives;
- is chaired by a parent with a child currently participating in the long-term support system;
- is staffed and funded to support the financial, informational and technical assistance needs of all members, especially family members, to carry out the duties of the authority;
- oversees the analysis of statewide data on population, services and costs;
- develops statewide policies regarding eligibility, rates and quality assurance;
- provides technical assistance and training to authority; and
- ensures the availability of easily accessible, consistent, and independently funded advocacy throughout the state; and
- hears grievances unresolved at the local level.

Have local (county or multi-county) authority that

- have comparable composition and support as the state authority;
- develop and implement quality assurance processes;
- maintain a management information system with population, service and expense data;
- implement statewide policies and guidelines; and
- direct system-wide planning and capacity-building.

Provides training and technical assistance that

- involves both families and service providers, including medical, education, mental health, and other community providers;
- respond to deficiencies identified by the quality assurance component; and
- are sensitive to families with different cultural, socio-economic and religious backgrounds.

Use family identified system outcomes to monitor, evaluate and improve system quality to

- build system capacity rather than being punitive;
- assure family participation at all levels; and
- provide incentives for meeting or exceeding standards.

FINANCING

THE BENNINGS… *Carl and Martha Benning sit quietly in the County Board chambers. Tonight is the public hearing on the county budget for the coming year. They are worried about funding for the support program that provides respite services for their 12-year-old daughter. Without additional funding, the program will have to freeze additional services to children on the program and the waiting list for new children will grow substantially. While this won't affect their daughter and family right now, they are concerned about the future and other families who won't get the critical support that they need.*

The Bennings also worry about the services and supports their daughter will need in the future – integrated after-school programs, independent living and social skill development, and other supports to develop her self-reliance. They know parents of older children who have been on waiting lists for years, or who have spent their life savings to purchase services privately. The Bennings want to contribute to their daughter's services – they just can't shoulder the burden alone.

THE PROBLEMS… Families contribute an extraordinary amount of time, energy, expertise and money to the care of their children with disabilities while, at the same time, meeting their other family and work obligations. Families carry most of the financial consequences of raising a child with special needs. The current system does not always acknowledge these monetary and non-monetary contributions.

In order to meet the array of needs identified by the family, multiple funding sources must be linked together to try to completely cover the needed services. Each funding stream has a unique set of eligibility rules and requirements about how the funding can be used. This leads families to select services that may not meet their needs, but are as close as they can get. In essence, it is often funding regulations, rather than actual needs, that drive the services provided to families.

SOLUTIONS… An improved long-term support system for children and families will:

Pool or coordinate various public-funding streams in order to

- maximize flexibility and choices for families;
- avoid depleting family savings;
- reduce categorical barriers and bureaucracy; and
- provide “portable” benefits that follow the child and family if they move to another county.

Prevent cost shifting between systems:

- assure that funds saved through redesign remain in the children’s long-term support system;
- coordinate public funds with health insurance and other private dollars to assure payor of last resort status for public funds;
- prevent shifting of private insurance and other private agencies’ responsibilities to public funding;
- encourage private industries and communities to fund the types of services and supports that are important to families;
- prevent the shifting of responsibility for service payment and provision between funding sources; and
- assure adequate funding is in place in the adult system to anticipate children who will meet the eligibility criteria at adulthood.

Assure an adequate funding base for long-term support by:

- developing state and local funding budgets based on accurate and complete information about the children to be served and their needs;
- streamlining administrative processes and costs, and eliminating unnecessary regulations;
- developing a method to increase available service dollars based upon the number of eligible children;
- developing cost-saving strategies, such as a used equipment exchange program; and
- revising existing policies so that families can choose the least expensive option that meets their needs (e.g. buying over-the-counter diapers versus through a pharmacy).

Family cost-sharing policies, if developed, that will:

- be simple and straightforward;
- account for the extraordinary financial and material contributions families make in raising their children with disabilities;
- acknowledge effort-sharing, as well as cost-sharing, particularly in situations where the child's disability limits a parent's ability to work;
- prevent undue hardship for families; and
- not result in a reduction or loss of services for a child.

PHASE II – NEXT STEPS

This report describes the philosophy, framework and key features of a long-term support system that is responsive to the needs of children and families. The second phase of Children's Long-term Support (C-LTS) will focus on specific strategies for implementation. Activities will include the development of the administrative, governing and fiscal models for implementing the system proposed by the Children's Committee. Pilot testing of possible solutions to the issues within the current system of long-term care will constitute the third phase of the initiative. The final phase will be the funding and implementation of a tested C-LTS system.

The Bureau of Developmental Disabilities will continue as the DHFS lead for the C-LTS redesign efforts. Planning is underway to secure DHFS funding and staff resources for the next phase of plan development. There will also be continued partnership with the Wisconsin Council on Developmental Disabilities and the Children's Committee, as well as a Community Liaison position at the Waisman Center.

Phase II will involve in-depth research and development of all key aspects of a service and support delivery system. A detailed issue paper of each element of this framework has been developed by the Children's Committee to facilitate this phase. (see Appendix D for an example of an Issue Paper). Additionally, this phase will include continued and expanded opportunities for families, policy-makers, and service providers to work collaboratively to develop a value-based system that will provide necessary services and supports to children with long-term support needs, and their families.

The following are some of the questions that will need to be addressed in each of the five areas:

ACCESS……… *Information:* How will the single information source be designed in terms of location, staffing, funding and governance? How can we find and train competent "generalists" and assure that they have access to specialists when needed? How can we assure that reliable information is available uniformly statewide?

Eligibility: What should be the specific criteria for eligibility? Are the existing Family Support Program criteria, which focus on functional abilities, appropriate to apply to the long-term support system?

Should there be a mechanism for "limited eligibility" in terms of scope or duration of services for those families who don't quite meet the criteria, but who would benefit from services offered by the long-term support system? How would limited eligibility be determined?

When and how should eligibility be re-determined? How can we assure that people aren't penalized for the progress they make due to the support services they are receiving?

CHOICES……. *Scope:* Should an eligible family be entitled to all services in the long-term support system, or for a specified level of support as determined by their needs? How can we assure that families are given complete and accurate information about available resources so they can make good decisions for their children and themselves?

Providers: How can we assure that there is an adequate network of qualified providers throughout the state? What types of funding or other incentives should be provided to encourage service development in underserved parts of the state?

COORDINATION…. *Service coordinators:* Systems need service coordinators for management and accountability. Families need service coordinators to help navigate the system to get the support they need. Can one individual serve both roles? Who do they work for? What authority do they have to commit resources? Can families be their own service coordinators?

Service planning: How can we assure that the planning process is inclusive of other systems and resources? How can we best coordinate with other systems, such as child welfare and mental health? How can we encourage informed participation of families in the planning process?

QUALITY……… *Training:* How can we assure that the people who coordinate and/or deliver services have the right values and skills for the job? How can we open up training opportunities to be more inclusive of family members, both as trainers and trainees? What should be the mechanisms for funding and providing training and technical assistance?

Administration: What is the relationship between the proposed local authorities and county government? Counties currently play the major role in planning, developing, financing, and monitoring local services. Is county government the most appropriate focal point of responsibility for all or some of these functions? What are the alternatives, and the pros and cons of each?

Accountability: What are appropriate quality assurance mechanisms in a system that gives families greater control and decision-making authority?

FINANCING…… *Service plan funding:* Four general approaches to service plan funding were discussed and need further analysis and testing:

- Aggregate approach: Rates are used only to predict overall long-term support system costs, and are not applied to individual service plans. The family and team would develop the plan within certain guidelines, and then negotiate the funding level with the system representative.

- Individual rate approach: The maximum funding level is determined before the plan is developed, based on a formula that attaches a dollar amount to particular needs.

- Stratified rate approach: Similar to the individual rate approach, except that the authorized funding level is defined as one of several rate ranges.

- Individual savings account: Can be used in conjunction with any of the above; Allows families to “bank” authorized funds that they don’t use in the current year for use in future years.

Coordination with other funders: How do other services and resources factor into the service plan? Which resources should be directly controlled by the long-term support system, and which should be coordinated with the system? How can we guard against families gaining benefits under the long-term support system, only to have other systems reduce their benefits? What types of interagency agreements will be needed between funders?

Protection against institutionalization: How can we assure that children with extraordinary needs have access to the support they need within the community, and that high costs do not result in institutionalization?

Capacity building: How can we assure that families, programs and systems that save money can reinvest those savings in other needed services?

APPENDIX A

Children’s Long-Term Support Committee Membership

CHAIRPERSON	*Elizabeth Hecht, WI Council on Developmental Disabilities, Madison
COMMUNITY MEMBERS	*Ruth Adix, Waisman Center, Madison
	Nancy Anderson, Access to Independence, Madison
	Lynn Breedlove, Wisconsin Coalition for Advocacy, Madison
	Wynne Cook, FOR-U Program, Chippewa Falls
	*Mary Dowling, RN, Mt. Horeb
	*Sheila Durand, Lutheran Hospital, LaCrosse
	*Mari Frederick, Wautoma
	*Sue Gilbertson, Spring Valley
	*Chris Hribal, Kenosha Co. Dept. of Human Services
	*Mary Juneau, Wauwatosa
	*Gwen Lee, Ashland
	*Marlea Linse, Educator, Wauwatosa
	*Wendy Kilbey, Wisconsin Family Ties, Madison
	*Donna Loew, FOR-U Program, Chippewa Falls
	Deb McLeish, MD, UW Hospital, Madison
	*Mary Musk, MAXIMUS, Greenfield
	*Nancy Olson, RN, Respite Care Association of WI, Schofield
	*Pat Patterson, Omatayo
	*Mary Peterson, Great Lakes Intertribal Council, Lac Du Flambeau
	*Linda Rowley, WI Family Voices, Mineral Point
	*Bill Schwab, MD, U.W. Department of Family Medicine,Madison
	John Shaw, KBC Incorporated, Hudson
	JoAnn Stormer, Wisconsin Family Ties, Madison
	*Amy Whitehead, Waisman Center, Madison
GOVERNMENT LIAISONS	Sheila Chaffee, DHFS, Division of Health Care Financing
	Beverly Doherty, DHFS, Division of Supportive Living
	Sharon Fleischfresser, MD, DHFS, Division of Public Health
	Melanie Foxcroft, DHFS, Division of Health Care Financing
	Jill Haglund, DPI, Div. of Learning and Support: Equity & Advocacy
	Marge Hannon Pifer, DHFS, Division of Health Care Financing
	Millie Jones, DHFS, Division of Public Health
	Sinikka McCabe, DHFS, Division of Supportive Living
	Eleanor McLean, DHFS, Division of Supportive Living
	Juanita Pawlisch, DPI, Div. of Learning and Support: Equity & Advocacy
	Charles Wilhelm, DHFS, Office of Strategic Finance

ADMINISTRATIVE TEAM	Beverly Doherty, DHFS, Division of Supportive Living Elizabeth Hecht, WI Council on Development Disabilities Howard Mandeville, WI Council on Development Disabilities Sally Mather, Mather & Associates, Blue Mounds *Beth Wroblewski, DHFS, Division of Supportive Living
CONSULTANTS	John O'Brien, Responsive Systems Associates, Lithonia, GA Julie Pratt, The Eleanor Group, Charleston, WV

*** Indicates a parent member of the Committee**

Thanks to the many parents who attended forums and answered phone surveys regarding long-term supports for their child and family.

APPENDIX B

Charge to the Children's Committee on Long Term Care From DHFS Secretary Leean – September 1997

The Department of Health and Family Services has been working on a proposal to revamp its system of long term care for elderly and disabled citizens over the past two years. In May of this year we presented the proposal to the public. Many of the people responding to the proposal included family members of children with disabilities who expressed the concern that we had not undertaken an extensive study of how such a system would apply to children. A group of parents and advocates approached the Department and offered to seek input from other parents on a statewide basis. With the help of the Wisconsin Council on Developmental Disabilities, they also offered to convene a Children's Committee for the purpose of making an in depth investigation of this issue and recommending to the Department an appropriate course of action.

Therefore, I am asking your help in working with the Children's Committee to develop a proposal by March of 1998. I would like you to give your best options and recommendations about how services to children who have long term care needs should be designed and managed. In thinking about a potential new system, you may reflect on the current system and ask what is working well that you want to preserve and what you would like to change. To be consistent with the Department's approach to redesign, your plan should incorporate the following key principles:

- improve quality outcomes and satisfaction for children and families
- simplify access to information and services
- simplify the system and make it readily understandable
- simplify administration including the current maze of funding sources
- include prevention as an important part of the system
- make the system accessible for everyone, whether or not they can pay
- ensure choice and options, with funding flexibility available to follow the person and pay for needed services to the extent feasible
- ensure that aggregate costs do not exceed costs of the current system except for possible increases for population growth
- increase accountability of providers for serving people while making sure that consumer choice is balanced by consumer responsibility
- ensure appropriate transition to any new system.

The committee will be an independent advisory group with staff and resources funded by the Wisconsin Council on Developmental Disabilities. The Department will provide staff to assure an ongoing dialogue between the Department and the Committee as you deliberate. As often as possible, Gerry Born and Chuck Wilhelm, co-chairmen of the Department's Long-Term Care initiative, will attend the meetings. The process of developing your recommendations is one that will be designed and managed by the committee. In that process, we suggest that you seek the advice of other major managers or providers of health and long term care services such as county agencies. Our hope is that you will finish with a product on which both you and the Department can agree.

Thank you for participating in this process. I wish you well in the important work ahead.

APPENDIX C

Family Support Program Adapted Eligibility Criteria

The individual is under age 21 or has not yet graduated from high school and has a severe physical, emotional, developmental or cognitive impairment that is characterized by the need for individually planned and coordinated care, treatment, vocational habilitation, or other services and that impairment has resulted, or is likely to result in substantial limitation in the ability to function in an age-appropriate manner. The impairment must be 1) diagnosed medically, behaviorally, or psychologically; or result in an assessed substantial limitation in functioning; 2) expected to persist for a year or longer; and 3) results in substantial limitations in functioning in three or more of the following areas:

- self-care
- communication
- learning
- mobility
- family relationships
- community relationships (e.g., with peers, in school, at work)
- self-direction
- capacity for independent living (as age appropriate)
- economic self sufficiency (as age appropriate)

APPENDIX D – Sample Issue Paper
ACCESS: INFORMATION, ADVOCACY AND SUPPORT

- Families have easy access to a person who can provide accurate, comprehensive information and assistance.
- Families feel empowered to meet their children's needs with the help of the support system.
- The support system attends to the overall health and well being of children and families.
- Parents have access to other parents for support, mentorship, advocacy, and networking.
- Communities recognize and share in the responsibility of supporting children with disabilities and their families.

FEATURES OF AN IMPROVED LONG-TERM SUPPORT SYSTEM FOR CHILDREN AND FAMILIES

Families want a person to talk with who can answer questions about their experiences and give them some of the tools they need to find solutions and supports. This person is easy to find, knowledgeable about all the systems with which families interact, familiar with the laws related to children and family's rights, and knows the local resources available to a family. This person is connected to a larger network of knowledgeable people who can help them find answers. The information and advocacy this person provides is not viewed as compromised by their location or funding source. Families can be linked to the independent advocacy entity if they need legal advice.

Families find that often other families are the best teachers, mentors and creative problem-solvers. This resource will link families with each other. Additionally, opportunities to develop skills, knowledge and confidence in areas important to families will be available to support families as they work with multiple systems and providers on behalf of their child.

Families need a centralized source of resources and knowledgeable individuals to provide information, advocacy, benefits counseling, mentorship and 1:1 support to families across systems related to supporting a child with disabilities. This resource is available to all families who call whether they are "eligible" for long-term support or not. Families are referred to the long-term support entry point if appropriate. The initial contact person supports families as they move through the assessment and plan development process. Families participating in the long-term support system would be expected to use this resource on an ongoing basis; therefore, funding for this type of resource center would come from the long-term support system.

Information and advocacy can be provided by the same person or same agency as long as the agency and/or person has no gatekeeping, provision of service, or dollar allocation functions. Staff should function as a team so that a variety of information and expertise is available. Families can then determine the staff member most compatible with their family. There also should be an ability to match a family with the expertise they need (parent-to-parent, neo-natal issues, school problems, etc.).

This resource could be assisted by state of the art resource directory software, laptop computers, and a statewide 800 number that channels a caller to the right information resource based on the zip code a person is calling from. Similar strategies would enhance access in less populated areas. For example, a "real" person could answer all calls and schedule the caller with an "expert" in their area of concern either during their available office hours in their city or county, or via telephone call.

QUALITIES OF INFORMATION, ADVOCACY AND SUPPORT

1) Aggressive marketing and public awareness of this single source of information.
- Local single point of entry into the system. An 800# or a local number.
- Family knows whom to call - one number they can call for anything.
- Families can easily and readily identify a local point of contact.
- Providers can readily identify a local point of contact.
- Designated point of contact with prolonged hours of availability.

2) Resource person or community liaison is available with information right away. Always a person to answer the telephone.
- First contact will provide information and a promise for a personal face-to-face contact if wanted.
- Resource person knows the information or the right person/resource for information.
- Family can easily reach someone who really knows the system.

3) Adequate staff responds to family needs in a timely, flexible and family friendly way.
- The first person a family talks to has the role of helping design an access response.
- System is flexible enough to provide a range of information and access assistance.
- A system is in place with personnel trained to assess urgency or nature of call.
- Definition of a statewide timeline for responding to calls.
- Technology will be one of the tools available to these community liaisons.

4) The person taking the call has an in-depth knowledge of the service system and local community services.
- In an area like Milwaukee, there may be multiple access points.
- The community liaison will explore all areas of concern, including: How primary care is working for the family? Does the child have a primary physician? Dental care? Access to specialists?

5) The access/information staff has the capacity to link a family with a service coordinator.
- The generalist who answers the phone has direct access to expert technical knowledge and knows their limitations. If staff doesn't know the answer-will link to someone who does.
- Stays with a family as they find the answers together- walks along with family.

6) Anyone who needs information and assistance receives it. No eligibility criteria for this service.
- Information that is free.
- Information and access is funded by the long-term support system.

7) The information resource is independent of the long-term support provider system.

8) Information about rights and responsibilities is provided to families.
- During the initial and ongoing assessment stages.
- Would be in writing and other understandable formats for families.

9) The system informs families of advocacy options and connects families as requested.

- System is also able to connect families to advocates related to issues outside of the long-term support system.
- “Veteran” parents could mentor/guide/support families in this process.

10) Advocacy related to long-term support is outside the system providing services.

- The information/referral section of the system should assure this activity.
- May use models like Full Citizenship Initiative or Parents as Leaders.
- Should be an informal system integrated in a formal system.
- Should be funded by the long-term support

11) An advocacy/rights system focuses on both individual and system-wide advocacy.

- A family would navigate the formal system with an advocate outside of the system.
- There should be someone in the local area who tracks issues and provides oversight to provider agencies.

12) A person is available as an advocate/mentor.

- Focus on a mentor approach, someone to help navigate the appeal process.
- The advocate must respond within 24 hours.
- The advocate does not have the authority to allocate resources or correct problems; rather they link to the authority and work to resolve the issue.
- Mentors receive training and are paid for their training.
- A paid volunteer coordinator (local) who would have the network of mentor names available to share with families.

QUESTIONS FOR PHASE II.

1) Determine how to connect with and not duplicate existing community information and advocacy resources?

2) Where to locate to insure unbiased information and advocacy yet minimize system fragmentation, particularly in smaller rural areas where resources are more spread out?

3) Analyze cost and funding options.

4) Determine how to find and train personnel in the knowledge and values needed to implement information, advocacy and support functions. Explore and learn from the expertise of benefit and resource counselors such as ABC for Health and For U 2 Program.

A FOUNDATION FOR A SYSTEM OF LONG-TERM
SUPPORT FOR WISCONSIN CHILDREN AND FAMILIES

FEEDBACK FORM

We are very interested in your thoughts and reactions. Your feedback will be helpful as we move forward with Phase II. If you are interested in being considered for participation in a workgroup or would like to receive future mailings and updates, fill in your personal information in the box below. If you would like to offer your comments confidentially please use the workgroup/interest form and mail it separately.

Name______________________________________
Address____________________________________
____
____
____

Phone___________________________________
Email___________________________________

I am interested in:
___Participation on a workgroup
___Additional information
___Other:_______________________________

Affiliation (please check all that apply): ___Parent of child with LTS needs(age of child:___), ___Provider of service
___Tribe, ___County department, ___State department, ___Other:________________________________

Please indicate how important you think a particular element is based on the way it is described in the paper. Using the scale below (1=low importance to 4=highly important), circle the most appropriate number for each element. If you strongly agree with a recommendation, place a check in its corresponding box. If there is anything you want to emphasize, dislike, or found missing altogether please describe below.

	Low		High	
OVERALL AGREEMENT WITH THE CONTENT OF THE PAPER.	1	2	3	4

ACCESS (page 8 of paper)

IMPORTANCE

An improved long-term support system for children and families will:	Low		High		I strongly Agree
1. Include a well-staffed information service that is independent of the fiscal provider.	1	2	3	4	☐
2. Have clearly defined eligibility criteria, that are based on functional, and/or diagnostic criteria and accept all income levels.	1	2	3	4	☐
3. Provide a timely response to child and family needs.	1	2	3	4	☐

What do you like the most about the recommendations for ACCESS?

What specific concerns do you have ?

CHOICES (page 10 of paper)

IMPORTANCE

An improved long-term support system for children and families will:	Low		High		I strongly Agree
1. Use a broad definition of services and supports.	1	2	3	4	☐
2. Give families, in partnership with the service coordinator, the responsibility for decisions about the priorities and implementation of their child's plan.	1	2	3	4	☐

What do you like the most about the recommendations for CHOICE?

What specific concerns do you have?

COORDINATION (page 12-13 of paper)

IMPORTANCE

An improved long-term support system for children and families will:	Low		High		I strongly Agree
1. Involve families as decision-makers.	1	2	3	4	☐
2. Employ qualified service coordinators.	1	2	3	4	☐
3. Develop comprehensive and coordinated service plans that are tailored to meet the child and family needs and are regularly reviewed and updated.	1	2	3	4	☐
4. Establish formal, system-level linkages among public and private providers of supports and services.	1	2	3	4	☐

What do you like the most about the recommendations for COORDINATION?

What specific concerns do you have?

QUALITY (Page 15 of paper)

An improved long-term support system for children and families will:

	IMPORTANCE				
	Low			High	I strongly Agree
1. Have a state-level authority to provide effective and efficient statewide management of the long-term support system.	1	2	3	4	☐
2. Have local (county or multi-county) authority that have comparable composition and support as the state authority and implement statewide policies and guidelines.	1	2	3	4	☐
3. Provide training and technical assistance that involves both families and service providers and responds to deficiencies identified by the quality assurance component.	1	2	3	4	☐
4. Use family identified system outcomes to monitor, evaluate, and improve system quality.	1	2	3	4	☐

What do you like the most about the recommendations for QUALITY?

What specific concerns do you have?

FINANCING (page 16-17 of paper)

An improved long-term support system for children and families will:

	IMPORTANCE				
	Low			High	I strongly Agree
1. Pool or coordinate various public-funding streams.	1	2	3	4	☐
2. Prevent cost shifting between systems.	1	2	3	4	☐
3. Assure an adequate funding base for long-term support.	1	2	3	4	☐
4. Family cost-sharing policies, if developed, will acknowledge 1 effort-sharing, will be simple and straightforward and will not result in a reduction or loss of services for a child.	2	3	4		☐

What do you like the most about the recommendations for FINANCING?

What specific concerns do you have ?

OUTCOME RANKING (page 5-6 of paper)

As we move forward with this proposal it is important to know what outcomes from a newly designed system of long-term supports and services for children and families are most important to you. Please rank the following outcomes in order of importance (in numerical order, 1=highest importance) within each key element.

ACCESS

____ Families have easy access to a person who can provide complete and accurate information.

____ All eligible children and families get the supports and services they need in a timely manner. (This includes support for family caregivers.)

____ Services are accessible, coordinated and consistent throughout the state.

CHOICES

____ Families design and direct the assistance they want.

____ Families have an appropriate array of services from which to choose.

____ Universal, prevention-oriented health care is available to all children and their families.

____ Providers are responsive to each family's individual and cultural strengths and needs, and have staff and advisors who reflect the population of families served.

____ Parents have access to other parents for support, medical and educational advocacy, and mentoring.

COORDINATION

____ The service system functions seamlessly from the family's point of view.

____ Communities recognize and share in the responsibility of supporting children with disabilities and their families.

____ Families, service providers and other community members work as partners on behalf of children.

____ Parents and providers develop working relationships that are respectful and trusting.

QUALITY

____ Quality standards for services are developed, implemented and monitored.

____ Staff, families and other caregivers receive appropriate training and support to carry out their responsibilities.

FINANCING

____ Funding is sufficient and flexible so families can choose services most appropriate to their needs.

____ All policies acknowledge the unique and hidden costs to families who raise children with disabilities.

____ Available funding follows the child and family regardless of changes of residence within Wisconsin.

Please return to:

Liz Hecht
Waisman Center Rm 227
!500 Highland Ave
Madison, WI 53705-2280

WORKGROUP / INTEREST FORM

If you are interested in being considered for participation in a workgroup on the Children's Long-Term Support Redesign or would like to receive future mailings and updates, fill in your personal information in the box below. If you are interested in being a member of a future workgroup please note that we will include as many people as possible. However, if we have an overwhelming response we may need to limit the number of participants on each workgroup to a manageable number. If this is necessary we will select individuals representing the various regions, disabilities, cultures, and provider types to assure balanced groups. If you have a priority area that you would like to be involved with, please note this as well.

Name_______________________________

Address____________________________
____
____
____

I am interested in:
___Participation on a workgroup
___Additional information
___Other:_________________________

Phone_____________________________

Email_____________________________

Affiliation (please check all that apply):
___Parent of child with LTS needs(age of child:___)
___Provider of service
___Tribe
___County department
___State department
___Other:_________________________________

Please return this form to:

Liz Hecht
Waisman Center Rm 227
1500 Highland Ave.
Madison, WI 53508-2280