



Forging A Partnership:

Individualizing Funding and Increasing Choices for People with Developmental Disabilities in Dane County, Wisconsin

April, 2005

Review & Update

Beginning in 1996 and culminating in December 2004, Dane County, Wisconsin, entered into a systems redesign for adults with developmental disabilities based upon the principals of Self-Determination. For the past 8 years Dane County has engaged in a careful planning and learning effort aimed at strengthening the public system of services and supports, while building upon the current and potential strengths of its communities. As of January 1, 2005 more than 1,100 adults with developmental disabilities are accessing services provided through that redesigned system.

The Purpose of the continuous changes in our system is simple:

*To help the people we support to create the lives they want,
connected to and supported by our communities.*

There are three key elements of the Purpose of our work together: *To help the people we support* refers to the core of the work we have been doing and will continue to do in providing professional and personal assistance to people with developmental disabilities in Dane County who need our support. We know how to do this work and do it well; although ongoing fiscal issues and more recent human resource shortages have compromised our ability to do it as well as we know how.

To create the lives they want recognizes that we have historically created programs, services and slots and "placed" the people we support into them. Our system is evolving in a manner in which the people we support, allied with others who care about them, may not only choose from among available services, but will have the opportunity to compose their own supports and services as well.

Connected to and supported by our communities reflects the historic and continuing reality that many people with significant disabilities are disadvantaged by rejection, segregation and isolation from ordinary community life. This rejection stems in great part from our long history of institutionalizing people with disabilities outside of our communities, and from the early history of providing services almost exclusively in segregated settings within our communities. A key element of our Purpose is to more vigorously work to remove the physical, program and attitudinal barriers that distance the people we support from others in our communities.

The following Principles guide our pursuit of that Purpose. These Principles are not absolutes. Some may challenge another. Taken as a whole, together with our Purpose, they form the basis for the evolving structure and practices within our system of services.

- Support of Individual Freedom
People ought not to lose basic human rights because they need assistance as a result of having a disability.
- Support of Individual Choice and Control
Exercising freedom within the day-to-day constraints of a human services system requires people to have the power to make decisions and freely control their lives. This translates specifically into the authority to decide *how* to receive needed support and to decide *who* will provide that support.

- Support for Relationships
 In many ways the historic and continued discrimination towards people with significant disabilities and the nature and complexity of the human service system have made it difficult for the people we serve to develop and maintain personal relationships. At this point in our history an important role of the system is to provide support to maintaining and strengthening the relationships between each person we serve, and those who care about him/her.
- Support to Strengthen Community Connections
 The too frequent isolation of the people we serve from typical community membership and opportunities for contribution continues to limit the potential for people to create the lives they want. The system must passionately pursue the multi-faceted work of “building community” for the benefit of the people we serve, and the benefit of all others in our communities.
- Support for Partnership and Collaboration
 In addition to strengthening important relationships for each individual being served, the long-term well being of all requires active attention to strengthening the historic collaboration among public and private agencies, families, and individuals and groups representing people with disabilities.
- Support for Increased Decision-Making
 Active support and learning opportunities must be provided to people as they begin making different kinds of decisions in their lives. This support must be directed towards the individuals we support, towards family members, and towards individuals who serve as legal guardians.
- Support for Self-Advocacy
 People with developmental disabilities have had relatively little experience individually or collectively in playing an active role in helping create or influence policies and practices. Active support to strengthen self-advocacy is a necessary part of a system which hopes to increase the interdependency among the people we serve and others in our communities.
- Being Explicit About the Limits of Choice
 The intent of individualizing funding and increasing choices is to enable people to obtain the support they need to compose their lives as typical members of our communities. Funding cannot be used in ways which jeopardize a person’s well being, or which reinforce segregation and isolation from others in our communities.
- Maintaining Fiscal Responsibility
 The natural evolution towards individualizing funding and increasing choice is occurring within a period of diminishing fiscal support for human services by the state of Wisconsin. It requires individuals, agencies and the county to work within and continue to address budgetary constraints.
- Maintaining a Strong Public Human Service System
 Helping the people we serve to create the lives they want will continue to require an active public role in providing leadership to and management of our system of services. Individualizing support and services does not diminish the importance of maintaining and even

strengthening the public human service system which has a primary responsibility to lead and manage an effective system of support and services.

Over these past eight years the Purpose and Principles stated above have been widely discussed and substantially supported by people in Dane County who have developmental disabilities and those who care about them as family, friends, neighbors, agencies and political representatives. We have attempted to adapt the organizational structure and day-to-day practices of our service system based upon the guidance of that Purpose and the Principles which flow from it.

Virtually every aspect of services and supports for people with developmental disabilities has experienced some degree of change. The following list describes essential structural components or practices which we have established based upon our guiding Purpose and Principles:

- Each person in or entering the adult services system has an individual rate of funding and supports to use it to obtain services.
- Each person chooses a person to assist him/her in obtaining and coordinating supports (a support broker). A support broker cannot provide “direct services” to the person receiving support, or work for an agency that does. Nor can a support broker speak on behalf of the individual (guardian, representative payee, etc.).
- Each person's support and services are derived from an initial and ongoing planning process guided by the person and those who are important to him/her.
- Quality assurance and quality of life has received increased focus, in part through the guidance and support of the Quality Assurance Board initiated in 1999.
- Payment structures allow ease of payment for both agency services, and for other needed goods or services.
- System changes are continually communicated across all parts of the system.
- System changes emphasize maintaining and increasing the connections between the people we serve and others in our communities.
- The voice of individuals and of families has been strengthened and that of providers and of county administration maintained.

Our progress in effective implementation of these practices is perhaps best evaluated “in the eye of the beholder.” We believe that our strategy of combining planning, piloting, reflecting and adapting has allowed gradual evolution of change, while maintaining stability within our current system. We are also aware that the evolution of these changes at a time of continued fiscal constraint and growing human resource shortages has contributed to feelings of stress and at times frustration within our system.

The day-to-day feedback we have received from the great majority of the individuals and their allies who are using an individual rate of funding has been positive. A growing number of people are using the new options available to them to individualize the manner in which they receive support where

they live and where they work. People selecting current or different agencies to provide services and support typically report a stronger sense of satisfaction with the agencies providing that support. Payment for services has, for the most part, been prompt and is more flexible than was possible through our county-administered fiscal system. At another level, the system changes that have occurred in Dane County have influenced the changes made by the Department of Health and Family Services in incorporating consumer-direction of services into the redesign planning for long-term care services in Wisconsin.

As we compare our progress to date with our purpose and principles, we believe there is justifiable pride in the accomplishments of people with developmental disabilities, families, provider agencies, and county administration and staff. When we compare our progress to date with the hoped-for evolution of our organizational structure and practices, the pride of accomplishment shares the stage with ongoing concerns and acknowledgement of what we have failed to accomplish to date.

We believe that the formal, informal and anecdotal feedback we receive is invaluable in identifying both where we have fallen short in meeting the Purpose of our work together, and specific opportunities to improve our procedures and practices. Several changes have been made to address concerns that have been identified, and we believe we have made progress towards:

- Facilitating a more effective relationship among the people we serve, support brokers and provider agencies;
- Increasing opportunities for input and problem-solving from all partners within the system;
- Increasing opportunities for communicating information on implementation, concerns, rumors and perceptions through written material (e.g., the *Choices* newsletter) and both routine and focused meetings (the twice monthly Friday Morning Forums);
- Increasing skills of all partners in the system in effective person-centered planning and on more effectively using such planning to help people get the lives they want. This remains an area of work that needs and will receive continued emphasis;
- Initiating the Dane County InfoShare as a regular event in which all partners in our system can gather together to celebrate, reflect and learn; and
- Further development and expansion of classes offered by the Waisman Center Training and Consultation program geared to people with disabilities and those who support them.

A New Beginning

In many respects, the efforts we have engaged in to date have only set the stage for the next transformation. Tom Nerney, a national leader in the Self-Determination movement and Director of the Center for Self-Determination has described essential elements for the system of the future:¹

¹ *LOST LIVES - WHY WE NEED A NEW APPROACH TO QUALITY*
Tom Nerney Center for Self-Determination, June 2004

“The design of the new system requires three essential elements:

- ✓ *Individual budgets which represent the translation of the person’s hopes and dreams into a budget document controlled by the person/family with assistance when needed.*
- ✓ *Independent assistance or brokering which is the provision of unbiased and competent advice and support for the person with a disability in designing and carrying out the life plan and budget provisions.*
- ✓ *Fiscal Intermediaries which are organizations or individuals who provide financial assistance with bill-paying, accountability for public funds, taxes and benefits as well as other types of financial assistance that may be needed.*

These system re-design features make it possible for any person with a disability, no matter how significant, to benefit. There can be no exceptions to the restoration of full citizenship to individuals with disabilities.”

In Dane County, we now have these three essential elements in place. We are well positioned for the future. We need to advance our system because, as Nerney goes on to point out, the future for people with disabilities will be embroiled in a “Perfect Storm” resulting from:

- ✓ The aging of parents who currently support their adult children at home;
- ✓ The increased competition for scarce Medicaid resources;
- ✓ The rapidly shrinking workforce.

In Dane County, the future is now. We have certainly felt the early affects of the scarcity of resources. We have seen our waiting lists grow; and we have struggled with the scarcity of direct care staff.

We have also seen the first experiments of people with disabilities choosing non-traditional supports and developing microenterprises; the advent of Sound Response (a system of providing support away from the person’s home using the telephone lines), decreasing the need for direct care staff while saving money; the development of a performing arts theatre company (Encore Studio for the Performing Arts) by and for people with disabilities; the development of staffing agencies (Goodwill Co-Employment, & TJS LLC); and individual payments to over a hundred vendors of atypical services and supports. We have also witnessed the ability of individuals, with support from their brokers, to find more efficient forms of support. Since 1998, individuals with disabilities have returned over \$1,000,000 of their allocated funding to help serve others on our waiting list or to assist others in need of greater support.

There are areas in which we have not made as much progress as we would like. When we ask people with disabilities what they value most, the most common response is “relationships”. And we know relationships are what keep people safe and have a meaningful life. We are currently reviewing, with the Center for Self-Determination, a Quality Protocol they are developing in hopes that this tool will help up in this process. And, we believe that no such process can replace continually bringing people together to focus on individual and collective strategies to more effectively overcome the barriers to community membership.

In the coming years, we plan to more successfully address these issues as well as to continue the learning in the other areas listed above. It is clear that individualized funding can be effective in *helping the people we support to create the lives they want, connected to and supported by our communities*. It is just as clear that individualized funding practices and procedures are only a part of what needs to happen across our county to support everyone's efforts towards meeting that purpose.

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