

Section 1

Overview of the Philosophy and Values Underlying Self-Directed Services in Dane County

In 1998, Dane County received a three-year pilot, self-determination grant from the Robert Wood Johnson Foundation. While the pilot has ended, the implementation of self-directed services continues, with the intent to:

- expand choices for people with developmental disabilities;
- give people and their families control over the allocation of their service dollars.

Self-Directed Services aims to:

- do no harm;
- provide people the freedom to choose their brokers and services providers, as well as, the type of supports they purchase and how providers get paid;
- have the bureaucratic system as invisible as possible to people with disabilities and their families;
- keep the process simple;
- have people and their families define and assess quality;
- spend no more on services than the county would have under a contracted system.

Section 1 of this resource manual provides an overview of the history and values that created and sustain self-directed services in Dane County.

GUIDING PRINCIPLES of SELF-DETERMINATION

Dignity and Respect

All people have the right to be treated with dignity and to be respected as a whole person. All people have the right to “the dignity of risk.” Many of our greatest lessons are learned when we make choices that we later realize were mistakes. The network of support makes risk possible by providing safety and supporting growth.

Choice and Control

People have the right to choose what they will do with their lives. When people need help, friends and family can be most effective in assisting them to broaden their experiences and to exercise their right to make their own choices.

Relationships

It is essential that relationships are maintained and expanded. Paid services can isolate people. Relationships provide everyone with strength, support and security. The development of new relationships is crucial.

Giving and Community

Everyone has the ability to give to his or her community in a meaningful way. When we give of ourselves, we feel a sense of belonging. Community membership includes having your own home, a job, involvement in your community and making a difference in the lives of others.

Dreaming and Planning

All people have hopes and dreams for the future as well as goals they want to achieve. A supportive team helps people identify these dreams, then creates a plan to prioritize and realize these dreams.

Fiscal Responsibility

When there is control over how funds get spent, there is also responsibility to live within a budget. There is an obligation to those waiting for services as well as others needing government funding.

Making things happen does not always require money. To find the best quality for the most reasonable price, people are able to purchase in and out of the service system.

The Role of Professionals

Professionals become partners with the people who hire them. They assist people in understanding what their choices are and realizing their dreams.

Choice Has Limits

Public funds will not be used to support choices that are illegal or harmful to the person or others. The choices must be available to all.

Self-Determination is Not Abandonment

Self-determination is not an excuse for abandoning someone in an unsafe situation on the grounds that he or she “chose” it. There are limits to the level of risk society will allow people to take with their own lives and physical well being. It is not acceptable to offer a “choice” of either excessive restrictions or no support at all. Self-determination means becoming more creative in helping people find ways to learn decision-making and manage their actions.

Whatever It Takes

An answer of “No, we can’t” is replaced by “How can we make this happen?” There is a commitment to help people determine their dreams, respect their dreams, and help their dreams come true.

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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.

DRR 4/05

Integrity and Accountability:
Addressing Safety and Quality while Assisting
People with Developmental Disabilities in Dane County to
Author Their Own Lives

December, 1998

*Updated January, 2001

*What matters most to people's safety is the extent and quality of their relationships. People are safer the more others care enough about their safety and well-being to keep a close eye on their situation, to stand up to difficult situations with them, to act imaginatively in response to their vulnerabilities, to negotiate on their behalf with others who control important opportunities, and to struggle with them over situations in which they are contributing to their own problems.**

* From *Assistance with Integrity*, John O'Brien and Connie Lyle O'Brien

We are continuously learning to better support people with developmental disabilities and their families within our Dane County communities. In less than 25 years, our county has made huge strides in replacing a century of segregation, congregation and institutionalization with a system of support and services increasingly focused on helping each person we serve create a life within their neighborhoods in Madison, Waunakee, Mt. Horeb or another of our cities, towns or villages. An essential foundation of our work has been and will continue to be an emphasis on paying attention to people's potential vulnerabilities as we break down the barriers to inclusion and participation within our communities.

It is difficult to define these issues clearly without using old words which were born in a previous age. The word "quality" has historically been used as an adjective in our system, usually placed in front of terms such as "compliance" or "assurance." In such contexts, quality typically refers to issues of safety, and most often to being safe from abuse or neglect within facilities or by caregivers. More recently quality has been discussed in terms of "quality of life," with a growing understanding that the people we serve are citizens within a country that places high value on each individual defining what quality means in his or her life. For now, we will continue to use the concept of quality in both contexts, while our vocabulary struggles to keep up with our learning.

It is important to be clear about our intent to support people in ways which account for their disabilities, which account for the inexperience which many people have had in living in our communities, and which account for the presence of people in our society who will willfully or neglectfully harm or exploit others. We have developed a system that begins with enforcement of the laws which protect all citizens and which place additional safeguards on top of them. We have learned, as noted in the paragraph on the title page, that what matters most to people's safety is the extent and quality of their relationships, and we are continually working towards creating a system that enhances rather than limits people's relationships.

We have also learned, both from those we serve and from reflecting upon our own lives, that what matters most *in life* is the extent and quality of our relationships ... our relationships with one another and our relationships with other elements of this wondrous world in which we live. We want our system of support and services to enable people to have lives rich with experiences and relationships. The "quality" of our system will be directly related to the extent to which we are successful in this regard.

The following summary describes key elements of our system of "safety and quality" for people with developmental disabilities who we support in Dane County:

Developing an individual support and services plan

All people receiving support and services do so utilizing a planning process that identifies needs and describes how those needs will be met. The elements of this process listed below set the framework for paying attention to the important issues in a person's life. The last two items have been added to the planning process specifically for people who will be utilizing an individual budget to obtain support:

- A description of how the person wants to live (What are the person's goals? Where does he/she want to live? With what type and amount of support? How would the person choose to spend time, given the opportunity?);
- a budget describing what goods, support and services will be purchased;
- a description of how support will be provided (both paid and unpaid);
- identification of existing and potential issues of risk;
- identification of and response to health care needs;
- the "outcomes" a person expects from people and agencies providing paid support; and
- those elements of a person's life which are "non-negotiable."

Using Existing Laws

While other citizens (including provider and county staff) may assist and support a person in our system who has been harmed, law enforcement officers and prosecutors throughout Dane County have become more sensitive to the potential vulnerability of people with significant disabilities. Harming and stealing from people is against the law and is expected to be investigated and prosecuted by law enforcement officials. Dane County Department of Human Services quality assurance staff participate in the Dane County Commission on Sensitive Crimes Task Force and on the Victim Outreach Subcommittee of that task force. Staff will be involved in further training of law enforcement agencies, as well as in additional training of service provider agencies to more effectively work with law enforcement.

Roles of County Administration and Staff

A number of procedures have been implemented to address issues that may compromise the well-being of a person receiving services. Other activities relate to proactive measures that are designed to decrease the likelihood that people will intentionally or unintentionally harm or neglect someone receiving support. These procedures and activities include:

- Clearly stated rights and grievance procedures;
- Requirements in contracts with service providers to:
 - notify the County of incidents which may compromise an individual's well-being, whether or not the incidents are a criminal offense;
 - follow all county abuse and neglect guidelines;
 - investigate and resolve the incident, and provide a written report to the county of their review and resolution; and
 - check past employment records of direct service providers, and share information on past employees with other agencies.
- A variety of ways for county staff to respond to incidents which may compromise a person's well-being, including:

- referring the incident to law enforcement officials;
 - completing a direct investigation of the incident;
 - referring the investigation to an outside consultant;
 - using consultant services to assist in conflict resolution or mediation of complex situations involving people with disabilities, families, guardians, advocates and providers; and
 - using county staff to assist in conflict resolution or mediation of complex situations involving people with disabilities, families, guardians, advocates and providers.
- Monthly meetings of the Dane County Elder Abuse and Vulnerable Adult Team, which reviews specific examples of potential abuse or neglect and works to help agencies better prevent and respond to their occurrence;
 - Quarterly meetings with all agencies to problem-solve around both systemwide and individual issues;
 - Monthly meetings to provide special attention to and address Adult Family Home issues;
 - The capacity of Dane County Case Management to provide extra support if needed as a result of a problematic situation;
 - The process to use the courts in evaluating the need for guardianship and mandatory serviced orders;
 - The availability of a crisis response for people who may need another place to live or additional support in their own home during a problematic situation;
 - Annual evaluations by County staff of how things are going for a number of people living within each residential services agency, using a format described within the County “Guidelines for Supportive Home Care Agencies for Adults with Developmental Disabilities”;
 - Annual evaluations by County staff of how things are going for a number of people supported by each vocational services agency;
 - The recent addition of an Ombudsman position within the Dane County Department of Human Services; and
 - Support to a newly created Quality Assurance Board (described below).

Role of the Quality Assurance Board

A Quality Assurance Board has been established which consists of volunteers who are interested in improving the quality of our developmental disabilities services system. The Quality Assurance Board plays a number of significant roles, including:

- Reviewing, analyzing, and providing feedback on the manner in which providers, support brokers and county staff respond to identified problems with services;
- Identifying and publicizing patterns and trends which enhance or impede the quality of life experienced by the people we serve;
- Overseeing a new system of continuous quality review and improvement of the support and services people are receiving individually and collectively;
- Developing and reviewing outcomes from satisfaction surveys and focus groups on particular issues; and
- Assisting in the resolution of individual conflicts by offering an informal opportunity for mediation.

Roles of Support Brokers for People Who Have an Individual Budget

Support brokers play an important role in facilitating effective interdependence among people with developmental disabilities who depend upon the county human services system, agency and individual providers of support and services, family members and guardians. Roles that relate directly to quality and safety include:

- An active role in helping identify “non-negotiable” outcomes and issues of health, safety and rights for each person; and in assuring those outcomes and issues are addressed on an ongoing basis;
- An active role by Support Brokers in affirming they have current personal knowledge of each person’s living situation and that either a) they can affirm that the person is living in safe and decent conditions, that the person’s human rights are respected, that the person’s money is appropriately managed, that the person is receiving needed health and dental care, and that the person is receiving adequate assistance to deal with the consequences and vulnerabilities of her or his particular disability; or b) if one or more of these conditions is not met that they are personally involved in efforts to assure that they are met; and
- A requirement for support brokers to notify county staff if issues arise which place a person at risk.

The efforts summarized above do and will contribute towards helping the people we support live fuller and safer lives within Dane County. They do not stand alone as a series of mechanisms to assure quality. The quality of the system we are continuously

working to improve attempts to build and strengthen relationships among people with developmental disabilities; their families and friends; individuals who are paid to support them; and other citizens of our communities. As a part of our larger human services system, it both contributes to and relies upon continuous learning by all of us together.

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Guardianship and Self-Directed Supports

Who is this paper about?

This paper is concerned with self-determination initiatives as they affect adults who are either under guardianship or for whom guardianship may arguably play a useful role. In order to be able to talk about people who have a functional need for a high degree of support in decision-making and assertion of rights, I refer to them in this paper as “people in need of substitute decision-making.” I am not particularly happy with either the word “need” or the word “substitute,” and use the phrase with the following qualifiers:

- Everyone has some level of ability to have and communicate preferences, hopes and dreams and therefore a central role to play in decisions affecting his or her life.
- The real issue is not the ability of the person, but the ability of the rest of us, first, to help the person understand life choices and, second, to discern the person’s preferences, hopes and dreams.

The real functional need might better be described as “joint” or “supported” decision-making. However, I use the word “substituted” to indicate that these are situations where most people would agree that there is a need to turn to others who know the person well in order to determine what the person would most likely choose for himself or herself, or to decide where to start in providing the person with an experiential base on which choices can be made.

Why put guardianship on the self-determination agenda?

The names *self-determination* and *self-directed supports* send a clear message of people taking charge of their own lives and of their own supports. Guardianship, on the other hand, involves giving legal power over decisions affecting the person’s life to someone else. Despite the fairly obvious threat to self-determination posed by guardianship, self-determination initiatives have focused primarily on shifting power away from the formal service system, while treating guardianship as a given beyond their control.

The problem on which self-determination initiatives have largely been focused is reducing *the concentration of power held by the service system* over a person's life. This problem is real and important: the service system has traditionally controlled the money, set budgets, chosen forms of support, chosen and contracted with service providers, and either directly provided or strongly controlled support planning and coordination. If we are serious about *self-determination*, however, we should be paying attention not only to the concentration of power in the service system, but to *any major concentration of power outside the person himself or herself*. With this in mind, we have a responsibility to look at the concentrations of power outside the person that self-determination initiatives, as currently designed, either do not address or may actually promote. For people in need of substitute decision-making, whether or not under guardianship, reducing the power of the service system may do nothing to increase their power over their own lives, and may in some case make matter worse, unless we pay attention to the other places where power lies.

Does guardianship serve a useful purpose that justifies its existence?

One possible approach to the apparent conflict between guardianship and self-determination is to advocate abolition of guardianship. This approach has some advantages:

- It is clear and ideologically consistent.
- It creates a barrier to the systemic bias towards overprotection. If guardianship exists, the legal and human service systems are likely to persist in overusing it.
- It challenges the system and support circle to always look to the person as the decision-maker, and to find imaginative ways to support him or her to understand choices and indicate preferences. For the person surrounded by people who care about him or her and are committed to discovering and realizing his or her hopes and dreams, guardianship can be an impediment rather than a useful tool.

On the other hand, there are some people for whom guardians play important and useful roles:

- Some people are genuinely unable to understand or assert their legal and human rights, and are at risk of being exploited or dominated by other people or by agencies and institutions. The risk is particularly great for people where a person, group or institution is in a position to intimidate or isolate the person. Where the guardian takes advocacy for the person seriously, he or she can be an essential bulwark against abuse, neglect and exploitation, and an essential advocate for the right of the person to a real life. Often, that advocacy is only possible with the legal access to information and the power to act for the person that guardianship confers.
- Access to needed services may depend on informed consent. For example, a surgeon may refuse to perform elective surgery without a guardian to give

informed consent, or a landlord may refuse to rent an apartment without a guardian to sign the lease.

Unfortunately, transferring power over individual budgets to individuals and their brokers does not eliminate the danger that other people or agencies will take advantage of their power over a person who is not in a position to assert his or her own rights. The decision of the service system to relinquish its control over budgeting and service planning, in the context of a person who is not in a position to take that power on, may well create new concentrations of power outside the person. For example:

- If there is no one in the circle other than the broker and the person, the broker ends up with almost total power over how funds are used, if the person is not in a position to question or challenge the broker's decisions.
- If the family or some other person has a high degree of influence over the person, they can end up with almost total power over all aspects of the person's life. In practice, some families have used this kind of informal control to increase their domination and the person's isolation. At least with guardianship, there is some form of court oversight and the possibility of seeking court relief; this is lacking where the domination is real but informal and the person has no legal spokesperson.

We can be reasonably sure that if we build a system where people are vulnerable to exploitation, exploiters will come, especially if large sums of money are in play. For at least some people, guardianship may be a necessary support to prevent exploitation. The question then becomes whether guardianship can be implemented in a way that helps people who need it without taking away rights they can exercise themselves, and that avoids imposition of guardianship on people who are quite capable of making their own decisions, on their own or with the support of others committed to identifying and realizing their hopes and dreams.

Can we reduce overuse of guardianship?

If we accept that guardianship does serve a useful function for some people (or that we are going to have to live with it for awhile whether we like it or not), anyone serious about self-determination must address the overuse of guardianship. At least in Wisconsin, guardianship has been imposed on many people able to make their own decisions. For those people for whom guardianship arguably plays a useful role, unlimited guardianships have been imposed where limited guardianships could have better met the need. This overuse of guardianship has great costs:

- The process of establishing that a person is legally incompetent is often a painful one, not only for the person but also for friends and family members who are called upon to publicly label the person incapable.
- A person found incompetent loses many basic, day-to-day rights, and a loss of dignity and respect because he or she must seek the consent and assistance of

another person for many activities that other people perform themselves. Other people are likely to see the person as less capable than he or she actually is.

- Loss of decision-making power reduces the persons' opportunity to learn to make choices, and thus to develop or keep decision-making skills.
- Guardian authority in an area where it is not needed creates extra work for the guardian, who will feel responsible for any area where he or she has been given authority, and creates fertile ground for unnecessary conflict between the person and the guardian.

One approach that may be helpful is to treat decision-making and assertion of rights as important issues in the person's life that must be addressed by the person and his or her support circle in the process of planning the person's future and determining what kind of support he or she needs. Arguably, it is the issue that should be addressed first, because it is so important to the validity of the rest of the planning process. In this context, *guardianship* is no longer a given imposed by the legal system, but rather *one form of functional support* that may (or may not) be an appropriate path to giving the person a life that best reflects his or her preferences, hopes and dreams, and to protecting the person from abuse, neglect and exploitation. If some level of guardianship is an appropriate support, the person, support circle, broker and service system would then be responsible for seeking a court order for the kind of guardianship appropriate to the person's life-plan.

The goal of the process should be to design supports for decision-making around the situation and needs of the person, to restrict use of guardianship to people for whom it is a necessary tool, and, for those people, to use the tool of limited guardianship to restrict use of guardianship to those decisions and rights where it is the most appropriate form of support, given the situation and goals of the individual. The personal futures planning process can be the source of the kind of information that psychologists, court social workers, lawyers and judges need to make better use of limited guardianship.

One way of approaching the analysis of whether guardianship is useful for the person, and to what extent, is to analyze the need for substitute decision-making separately in the context of each of the major functional areas in the person's life where the person may need support in decision-making or assertion of rights. These include issue areas such as: management of money, contracting, making a will, choosing a place to live, having freedom of mobility, consenting to medical treatment, consenting to support services, choosing friends, consenting to sexual contact, consenting to marriage, etc. For each issue area, it can be useful to ask the following questions:

- What decisions or need to advocate rights does the person face in this issue area? What decisions is s/he likely to face in the future?
- For decisions and rights relevant to his or her life, is the person able to understand significant information on the nature, risks and benefits of the various options, or

on the nature and significance of his or her rights, if explained in a form the person is most likely to understand?

- If no, what is the level of risk to health, safety, rights, possessions and access to a desired life created by the inability to make informed decisions or understand and assert rights?
- Has the person had the opportunity to develop decision-making capacity through training and practice? Has the person had needed evaluation and support to develop a functional means of communication? If not, would this be likely to develop or restore decision-making ability?
- Does the person have a strong informal network of support committed to identifying and realizing his preferences, hopes and dreams? If so, is the person able and willing to work with this network of support in a way that will allow decisions to be made on a cooperative basis that will meet the goals of the life plan without use of guardianship? (This may include the use of alternatives such as dual-signature checking, power of attorney, etc.)
- Do the benefits of guardianship outweigh the costs? If so, can guardianship be limited to only those decisions and rights where the risks justify the use of guardianship?

Can “self-determination” increase concentration of power in the guardian?

“Self-determination,” as we know it, seeks to place powers formerly held by the service system in the hands of the person himself or herself or, where the person lacks ability to speak for himself or herself, “as close to the person as possible.” In other words, there is a fairly explicit (and probably correct) assumption that, for people who need substitute decision-making, *decisions will generally better reflect the person’s hopes and dreams if made by family, friends, or others who know the person well than if made by the service system.* Where the person has a guardian, the respective roles of the person and the guardian have often not been defined or clearly communicated to either the guardian or the person. By default, this has sometimes resulted in an unspoken policy of accepting the guardian as the person’s representative, i.e., the person who chooses the broker, takes the lead in planning and makes final decisions.

This model, which could be called “guardian-determination”, creates an extraordinary concentration of power in the guardian. The major checks on the guardian’s power are the individual, who is unlikely to be in a position to protest even if he or she understands the process for doing so, and the broker, who can be hired and fired by the guardian. Guardians interested in having unchallenged authority are likely to choose brokers who will follow their wishes, and dismiss those who do not.

While the assumption that the guardian is more likely than the service system to reflect the person’s hopes and dreams is accurate in the majority of cases, it is inaccurate for too many people to allow the exceptions to be ignored:

- People willing to act as volunteer guardians are in short supply. Many people have guardians who work for state agencies or private agencies that contract with states or counties. In other words, power shifts from one bureaucracy to another.
- Many guardians, while well-meaning, do not have personal knowledge of the person. I dealt for some time with a case where the volunteer “guardian” saw his job as signing papers; he had never met the person and saw no reason to do so.
- Even guardians who are family members may lack appreciation of the person’s potential to have a real life. Particularly for people substantially able to speak for themselves, people under guardianship are as likely to see themselves as held back by their guardians as they are to see themselves as held back by the service system.

Self-determination initiatives do not create these problems. However, they may sometimes make them worse, at least incrementally. Under the traditional service system, the system itself held more power in the process of planning services, and at least in some cases could use this power to negotiate or advocate for the person’s preferences and goals. If the system backs off and leaves the guardian with total authority, the person loses an independent voice and potential ally in the planning process.

How can the system support guardians to fill their roles?

It bears repeating that the vast majority of guardians will be working in good faith to try to help the person have as full a life as possible. Their concerns about taking risks and trying new things may will reflect past experience and a realistic assessment of the capacity of the service system to (1) screw up what it is trying this year and (2) change its mind next year anyway. It is important for the service system to start from a position of listening to and respecting the views of the guardian and trying to understand the reasons behind them. Essential components of a functional guardianship system that are often lacking include:

- A system for recruiting guardians who have a commitment, ability and energy to fulfill their role, and who are a good match for the people they are working with.
- A system for training guardians on issues such as guardian responsibilities, people’s rights, people’s potential, and the way the service system operates, and for providing ongoing, independent support for guardians.
- A system of peer support so that guardians facing decisions or advocacy needs can benefit from the experience others (parents, guardians and people with disabilities) who have dealt with similar decisions and advocacy needs in the past.

What guiding principles should govern decision-making affecting self-directed supports for individuals who have guardians?

The standard set of guiding principles being used in various forms by self-determination initiatives around the country does not squarely address the question of the distribution of authority when the person involved has a guardian. Attachment A provides a draft of some possible guiding principles. Setting clear expectations at the outset, and having principles to which to refer, may:

- Influence how guardians, brokers and individuals go about making decisions.
- Serve as a mechanism to identify problems early in the process, or to convince some guardians that the self-directed support option is not what they are looking for.
- Provide guidance to the system on how to respond when things go wrong from its perspective. For example, how should the system respond to a guardian who uses control over the individual budget to increase the person's isolation and lack of access to typical life experiences, when there is no evidence that the guardian is following the person's preferences?

DRAFT--Guiding Principles Related to Guardian Roles--DRAFT

All individuals have the same basic rights of citizenship, including rights to safety, freedom of speech, freedom of association, privacy rights, and freedom of mobility. A guardian's decision to restrict these rights should be respected only where the guardian has a compelling health or safety reason for the decision. Guardian decisions that discourage or inhibit the person from learning choice-making and expressing preferences, that isolate or restrain the person, that restrict the person's rights, or that place the person at risk of abuse or neglect, indicate the need for the system to play an active role in assuring that supports are designed and provided in the least restrictive manner and that the person's safety and rights are assured.

Decision-making is both a human right and a functional skill. Some people have a functional need for support in decision-making, due to age, inexperience, or cognitive disabilities, in order to protect the individual's health, safety or rights. The support, including appointment of a substitute decision-maker, should be planned and implemented as part of person-centered planning, in a way that retains as much personal control and dignity for the person as possible, continues to involve the person in decisions that affect his or her life, and builds his or her decision-making skills.

Self-determination requires aggressive efforts to learn and respect the preferences of the person. Where the planning process relies on substitute decision-making, the support plan must show that there are strong grounds for believing that the goals and methods of support chosen reflect the person's preferences, or that they are based on what is known about the person and are part of a process designed to learn more about the person's preferences. Part of a guardian's role is to learn and respect the person's preferences, and promote the person's rights as a citizen. The performance of that role requires finding ways for the person to indicate choices and preference, and to find ways to respect those preferences consistent with the person's overall best interests. This includes preferences related to the planning process and membership in the person's support circle.

A guardian of the person has a right and duty to be a partner in service planning and to ensure that the person's best interests are served. This includes the power to have access to records and service planners, and the power to give or withhold informed consent in the areas of the guardian's authority. Guardians often have knowledge of the person, a personal bond and commitment and continuity over time that the service system should value and cannot replace. To perform his or her role appropriately, a guardian must make a commitment to knowing the person and his or her situation, and to active involvement in decisions for which the guardian has legal responsibility.

The individual has a right to meet and talk with other people as he or she chooses. This includes the right of a person under guardianship to meet and talk with his or her support coordinator, an advocate, or other members of his or her support circle, without the presence of the guardian.