

This discussion paper was prepared by:

Roy Froemming, Project Facilitator Wisconsin Self-Determination Learning Project
Bureau of Developmental Disabilities Services
P.O. Box 7851, Madison, WI 53707

Guardianship and Self-Directed Supports

Who is this paper about?

This paper is concerned with self-determination initiatives as they affect adults who either are 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 which 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?

Guiding Principles Related to Guardian Roles

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.