

Re-thinking Guardianship

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Guardianship, at one time seen as a benign way to "protect" people with disabilities, is now seen as an intrusion into a person's basic civil and human rights and a legal process to be avoided. Guardianship was originally used to handle and control property and property rights for individuals considered incompetent (or in the language of most statutes prior to the 50's - "imbeciles, idiots, feebleminded, insane and cretins" - "gamblers and ner-do-wells" were sometimes also included). Guardianship of the Person was added as an afterthought to the duties of a Guardian of the Estate.

Change has come about as part of questions that have been raised since the 70's about the way our society in general views and treats individuals with disabilities. It was in the 70's that the first class-action suits were filed regarding the deplorable conditions in institutions. Such legal actions highlighted the general abuse of the rights of individuals with disabilities. Courts all over the country began ordering community-based services and concerning themselves with the enhancement of dignity and the protection of basic civil and human rights of individuals with disabilities. New laws were passed in recognition of the need to integrate citizens with disabilities into our communities, including the Developmental Disabilities Assistance and Bill of Rights Act (DD Act)¹, the Individuals with Disabilities Act (IDEA)², and the Americans with Disabilities Act (ADA)³, the most significant civil rights legislation ever passed for people with disabilities. All these laws have promoted inclusion of individuals with disabilities into their own communities and brought new awareness of the abilities and contributions of people with disabilities to our society.

Guardianship laws began to change as well. Many states introduced a list of due process protections for people who became subject to guardianship petitions such as the right to hearing, lawyers, and independent evaluations. Most revised laws also express a clear preference for **partial** guardianships for limited decision-making power rather than full guardianship over all possible life decisions.

Even with these changes in the law, individuals with disabilities still suffer from a lack of due process because of paternalistic attitude and duplicities in guardianship proceedings that confront persons with cognitive impairment or those with difficulty in communicating. In fact persons alleged to have committed criminal acts have their due process rights far more zealously guarded prior to being deprived of their right to life, liberty or the pursuit of happiness. Before they lose their money or are incarcerated, (in sometimes remarkable similar types of institutions), they are afforded real due process protections.

While these legislative changes have been taking place, person-centered planning has become the planning process for people with disabilities. In Michigan, it has even become law.⁴ The person centered planning process is defined generally as a process of

planning for and supporting an individual that honors the individual's preferences, choices and abilities. The person-centered planning process assumes that all people have preferences, regardless of their level of disability. Through this process, the person's preferences are determined by any method possible. In some cases, observations of the individual's behavior by those closest to them are used to determine preferences. Such preferences are then honored as long as they are not harmful to the individual. This process of determining preferences and choices enhances the dignity and self-determination of individuals and is far more reliable than having a court-appointed, single person to make all decisions with or without the input of the individual with a disability.

As the law established person-centered planning and individuals' rights to make decisions about their treatment options, Self-Determination Initiatives began developing. The Robert Wood Johnson Foundation provided funding to 19 states for Self-Determination Initiatives demonstration projects. The projects sprung from reforms that question the almost total control public funders and providers have over the life choices of individuals with disabilities and their families. In that system, funds and decisions are allocated to providers. Individuals with disabilities and their families have little or no say about which providers are to supply services or what those services should be. Changing this imbalance of power and control is the goal of self-determination. Decision-making by the individual is key to this effort. Obviously, appointing a guardian to make decisions for the individual can defeat this process. However, asserting that each individual should make their own decisions doesn't mean that each individual doesn't need help, assistance and support.

The Iowa Supreme Court has recognized that outside supports for an individual may negate the need for guardianship.

In making a determination as to whether a guardianship should be established . . . the court must consider the availability of third party assistance to meet a . . . proposed ward's need for such necessities . . .⁵

Tom Nerney, Executive Director of the Center for Self-Determination has stated: **We have to reject the very idea of incompetence. We need to replace it with the idea of "assisted competence". This will include a range of supports that will enable individuals with cognitive disabilities to receive assistance in decision-making that will preserve their rights . . .**⁶

Thus, just as supports have evolved since the 70's to assist individuals with disabilities to participate in education, employment, housing and other community opportunities, supports are now evolving to assist people in decision-making. "Assisted living" has replaced institution living, and "supported employment" has provided more job opportunities. "Assisted competence" is now continuing the evolution that enables people with disabilities the dignity and freedom to develop and participate in the lives they want and choose.

Stanley S. Herr, Professor of Law, University of Maryland School of Law has studied guardianship laws over the world. He states:

A number of countries have adopted new legislation in recent years to minimize the use of guardianship, to impose only its least restrictive alternatives, and to introduce other innovations . . . The imposition of guardianship posed important ethical, legal and practical problems for the disability rights community . . . The ethical questions involve ideas of paternalism, liberty, prevention of harm and exploitation, beneficence, and the power relationships between guardian and ward. Finding better answers will implicate vital principles of self-determination, including freedom, authority, support and responsibility.⁷

Thus, support systems in most states are exploring alternative means to guardianship and ways to restrict the effects of the imposition of guardianship on the choices of individuals with disabilities.

These efforts have resulted in the development of many alternative methods to handle decision-making that assist individuals with disabilities and their advocates. For instance, the use of durable powers of attorney are used in order to designate a person to discuss and make decisions about medical decisions, living situations, confidentiality issues and other areas of concern. In this way, family members or others who have always assisted the individual in making such decisions can continue to do so without filing a petition to become guardian and actually take away the right of the individual to make such decisions. The power of attorney allows the individual to give that power to someone, and they can also take away that power if they become unhappy with the decisions being made. Many state laws will allow for such powers of attorney and also recognize that the level of informed consent needed to execute such a document is lower than that needed for other legal arrangements under law. As an example, in Michigan the standard for executing a medical power of attorney is that the individual must be "of sound mind", which is the same standard as seen in the realm of Michigan wills and testaments. In order to execute a will, "average mental capacity at the time of the execution of the will is not necessary to its validity. A less degree of mind or capacity is requisite to execute a will than to make a contract covering the same subject matter."⁸

Another example of devising alternatives is the concern about who will take care of the individual's money if they are totally unable to handle it themselves. The majority of people with developmental disabilities are recipients of Supplemental Security Income. (SSI) For these and other governmental benefits, the government will designate a "payee" - someone to receive and disburse the money for the individual if the person is determined incapable of managing the funds him/herself. A guardian of the estate or conservator would be a duplication of this function. If a substantial amount of money comes into the individual's life, there are trust documents that can be drafted that can protect the governmental benefits and still use the funds to provide an enhanced life for the individual. A trustee or co-trustees can be designated to distribute the funds and see that the individual's needs and desires are met. Such a trust can specify that someone visit the person and assure that the individual is satisfied with their living situation and support systems. This is more than the imposition of a guardian or conservator can do for an individual and gives more peace of mind to parents who worry about what will happen to

their child when they are gone. A knowledgeable attorney should be consulted about these trust documents.

The above are major alternatives to guardianship, and there are many more that can be devised. There are as many alternatives as there are issues. Education of those recommending guardianship is needed as many professionals and lay people, as well as court personnel believe guardianship is the only way to resolve many issues that can be handled through less intrusive methods. We need to stop applying a legal solution to personal issues that can be handled through a person-centered process.

Putting an end to the systematic removal of rights and the concomitant removal of protections for people with disabilities needs to be a priority. This would mean a different way of doing business. Those who care about an individual with a disability and those who make their living because of individuals with disabilities, have an obligation to discover what people like and don't like, what their desires and preferences are. We should employ the many alternatives which currently allow people to avoid guardianship altogether. Ultimately, we can use the framework of person-centered planning and self-determination to obtain the optimum choice making. We can assure individuals with disabilities, including those with cognitive disabilities and disabilities that impair their communication, access to life, liberty and pursuit of happiness. Plus, we will have eliminated an unnecessary barrier to individuals' opportunity to seek their piece of the American dream.

¹42 U.S.C. § 6012

²20 U.S.C. §1400 et seq

³42 U.S.C. 12101 et seq

⁴MCL 330.1712; MSA 14.800 (712)

⁵In the Matter of Hedin, Iowa Supreme Court, (1995)

⁶Common Sense, Issue 6 - 1999; a publication of the National Program Office on Self-Determination, University of New Hampshire, Insititute on Disability, funded by the Robert Wood Johnson Foundation

⁷Id

⁸Bean v. Bean, 144 Mich 599, 108 NW 369 (1906).