



Comments to the House Select Committee on Individuals Eligible for ICFMR Services

Topic: Guardianship

May 21, 2008

Independence, respect, and equality are values important to all people. These values help define the concepts of autonomy (independence and freedom) and self-determination (the right to make decisions for one's self). Because these rights are so valued in our society and are something that most of us would value for ourselves, the "least restrictive alternative" should always be considered before taking away a person's civil and legal rights to make decisions for him or herself.

The least restrictive alternative is an option which allows a person to keep as much autonomy and self-determination as possible while providing only the level of protection and supervision that is necessary

The Texas Center for Disability Studies at The University of Texas at Austin offers the following information and recommendations regarding guardianship for residents of state institutions.

Guardianship

The first reaction to the abuse, neglect, and exploitation of residents of state institutions may be that guardianship is the solution to the problems; some see guardianship as the only way to protect vulnerable residents of state schools. We ask that you not rush to the assumption that guardianship is the logical remedy.

Many organizations, universities, state agencies, and non-profits around the country have come to the conclusion that guardianship should be a last resort with less restrictive alternatives being considered first. Policymakers from around the nation have come to understand that, while many individuals may need assistance to make appropriate decisions, it should not result in allowing another individual to control all aspects of their lives.

"One of the most prevalent assumptions is the belief that if you have an intellectual or developmental disability you are, by definition, incompetent and someone else should be appointed to make your decisions. As a result, guardianship systems have evolved which are overprotective, do not honor the ability of individuals with disabilities to choose and be responsible for their own lives, and ignore the importance of social support. Most painful, when people are declared incompetent for decision-making purposes, they lose their status as citizens." (Leadership Institute, the Council on Mental Retardation, Louisville, KY)

"Even when people have guardians, they can be abused, exploited and hurt by others." The best and most respectful way to minimize harm, increase the prospect of a quality life and provide advocacy is not the removal of someone's rights." (The Rural Institute, The University of Montana; Marsh Katz, Project Director)

Instead of focusing on guardianship and presumed incompetence, we suggest that you consider various options from the perspective of "assisted competency." Assisted

competency assumes a need for support in decision-making, but allows an individual to retain the civil rights that most of us take for granted.

Alternatives to guardianship are almost universally stressed as the preferred option when individuals need assistance in decision-making. These include supports such as power of attorney, limited guardianship, temporary guardianship, health care proxy, person-centered planning, representative payee, special advocates/mentors, and more.

Recommendation:

Develop and implement a pilot program of “appointed special advocates” for individuals residing in State Mental Retardation Facilities (SMRFs) who do not have legal guardians. This program could be modeled after the successful CASA Program used in the Child Protective Services System, with individual advocates serving as guides/advisors/mentors to assist and support the residents in understanding and conducting person-centered planning, developing their support plan, identifying appropriate services, identifying preferred living options, and other assistance as requested or needed by the individual.

Basic concepts of the program should ensure that:

- The appointed special advocate would act as an advisor, a mentor to the state school resident.
- The program authority is independent of state schools.
- An appointed special advocate would provide on-going support as needed by the individual, assist individuals with understanding information, and advocate for the individual’s preferences. The appointed special advocate would not make the decisions on behalf of the individual unless directed otherwise by a court
- Each volunteer advocate would be assigned to only one resident at a time.
- Volunteers should make a 1-year commitment to allow sufficient time to build a relationship and get to know the individual, learn the individual’s preferences, attend inter-disciplinary team (IDT) meetings, consult with MRA staff responsible for the Community Living Options Information Process (CLOIP), attend court hearings as needed, and simply act as an advocate as needed by the individual.
- Minimum training requirements of the appointed special advocate must include comprehensive information on:
 - Intellectual/Developmental disabilities
 - Self-determination
 - Person-centered planning
 - Community-based services and supports
 - Person’s with Mental Retardation Act, Olmstead Decision, Americans with Disabilities Act.

This method of *supported decision-making* could be easily piloted in both rural and urban areas of the state that have state schools. Policies and procedures could be developed using the CPS CASA Program as a model, making adjustments for the different population, statutory issues, and the decisions being considered. One option would be for the state to contract with local Mental Retardation Authorities (MRAs) to recruit volunteers, provide training, assign volunteers to SMRF residents, collect data, supervise activities, and monitor outcomes. For individuals needing more significant support, a court could expand the “appointed special advocate’s” responsibilities. This program would be a logical addition to the current Community Living Options Information Process and Permanency Planning responsibilities of the MRA.

This new program for supported decision-making would certainly require financial resources, but would likely cost less than the cost to provide guardianship to all SMRF residents. It would also provide more ongoing support, supervision, and monitoring (often not readily available in the guardianship programs) that would better protect the rights of the individuals.

Summary

Texas would not have to start from an empty slate when developing such a program. We currently have a Court Appointed Special Advocate Program in place. Other states have implemented programs incorporating the concepts of “assisted competency” and “assisted decision-making” by using client advocates. The country of Sweden uses mentorship in place of “administrators” (our equivalent of guardianship). Mentorship has been in existence in Sweden since 1976 when 30,000 Swedes were under guardianship. By 1985, the availability of mentorship had decreased that number to 17,000. In 1989, the Swedish parliament restricted guardianship to minors under the age of 18. By December 1999, approximately 40,000 Swedes had mentors while only 3,500 (mostly minors) were appointed administrators (guardians).ⁱⁱ

In summary, the Center recommends restraint be used when considering guardianship and other decision-making support options for residents of state institutions. When it comes to individual civil rights and freedoms, we believe less control translates to more self-determination. We are hopeful you will develop policies not based on a presumption of incompetence, but based on a presumption of the need for supported decision-making that translates to “assisted competency.”

“Guardianships, because they are so powerful, should be used sparingly. Other less restrictive forms of assistance may be more appropriate.” It [guardianship] is the most restrictive choice when decision making assistance is needed. There are many more ways help can be given before proceeding to guardianship.”ⁱⁱⁱ

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ⁱ *Alternatives to Guardianship and Conservatorship for Adults in Iowa*, The Substitute Decision-Makers Task Force for the Iowa Department of Elder Affairs, 2006. Funded by the Iowa Department of Elder Affairs and the Iowa Governor’s Developmental Disabilities Council.

ⁱⁱ *Self-Determination, Autonomy and Alternatives for Guardianship*, Stanley S. Herr, Professor of Law, University of Maryland School of Law.

ⁱⁱⁱ *Alternatives to Guardianship*, NebGuide, The University of Nebraska – Lincoln Extension, Institute of Agriculture and Natural Resources, November 2005.