



**Volunteer-Supported Decision-Making for People with
Cognitive Impairments**

**A Report on the San Angelo Alternatives to
Guardianship Project**

Prepared in Response to House Bill 1454,
81st Texas Legislature, Regular Session, 2009



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Executive Summary

H.B. 1454, 81st Texas Legislature, Regular Session, 2009, directed the Health and Human Services Commission (HHSC) to create a volunteer-supported decision-making advocate pilot program for persons with an intellectual or developmental disability (IDD) who live in a community setting and for persons with other cognitive disabilities who also live in a community setting. The goal of the pilot is to offer an alternative to guardianship that does not impede self-determination and helps maintain person-directed lives.

In accordance with H.B. 1454, the purpose of this document is to report on the effectiveness of the pilot and to make recommendations to continue, change, or eliminate the pilot program.

HHSC delegated responsibility for the pilot program to the Department of Aging and Disability Services (DADS). Subsequently, DADS developed a formal agreement with the Texas Council for Developmental Disabilities (TCDD), which funds and manages the pilot.

A Request for Proposals (RFP) was issued, inviting organizations to participate. Only one acceptable proposal was received. The proposal was submitted by the Arc of San Angelo. Project funding was approved in March 2011. The project has made significant accomplishments, overcoming several barriers and difficulties expected in a developmental project.

The project has established an advisory committee that has provided key guidance and has built on connections with local academic and community leaders. The project has provided basic training to a group of volunteers and is implementing an initiative to use iPads as tools for further training and for interaction with persons with disabilities.

The project is training volunteers and seeking ways to appropriately match them with individuals with disabilities. The model being used has faced challenges, as only one ongoing relationship between a volunteer and an individual with a disability has been established. The volunteer-supported decision-making model has been only one strategy used by project staff to prevent unnecessary guardianships. Using short-term relationships with volunteers or staff intervention, the project has enabled other individuals to remain independent, avoid guardianship, or have an unnecessary guardianship removed.

To ensure that the project can benefit more individuals, staff has begun working to increase community understanding of the potential for self-determination and independence among individuals with cognitive impairments. These efforts will build local support for ongoing volunteer activities.

Recommendations

The project should be continued for its remaining funding period.

As the end of the project term approaches, agencies and others concerned with the project should consider the following to capitalize on progress to date:

- Seek resources to develop documentation and other tools to disseminate the project's findings and allow other communities to develop similar projects;
- Develop or identify continuing education materials for physicians, attorneys, and judges concerning contemporary thinking about disability rights, self-determination, and independence; and

- Consider seeking funding to other sites for similar projects

Background

H.B. 1454, 81st Legislature, Regular Session, 2009, directed HHSC to:

- Create a volunteer-supported decision-making advocate pilot program for persons with IDD who live in a community setting and persons with other cognitive disabilities who also live in a community setting;
- Convene a work group to develop the rules and structure of the pilot program;
- Contract with one or more entities to administer the pilot program and to recruit and train volunteer advocates to provide supported decision-making services; and
- Before each regular session of the Legislature, publish a report that includes an evaluation of the effectiveness of the pilot program, recommendations for changes to improve its operation and a recommendation to continue, expand, or eliminate the pilot program.

HHSC delegated implementation of the pilot program to DADS. However, DADS received no additional funds to implement the bill and received approval by the bill's author and HHSC to collaborate with the TCDD to implement the pilot program.

DADS and TCDD signed a Memorandum of Understanding (MOU) in May 2010, whereby TCDD agreed to provide funding to implement the pilot program. TCDD approved up to \$75,000 per site over three-years, pending annual review and approval by the TCDD Executive Committee.

DADS convened a workgroup comprised of individuals and family members of persons with IDD or cognitive disabilities and advocate organizations to develop the rules and structure of the pilot program. The workgroup provided guidance and input to TCDD on the development of an RFP. The workgroup also suggested potential locations for pilot sites across the state and recommended on the types of training that volunteers should be required to receive to increase their understanding of the individuals who participate in the pilot.

TCDD released the RFP in July 2010, and received two applications that were reviewed by a designated panel and the TCDD Executive Committee. In addition, DADS offered comments to TCDD per the requirements of the MOU.

Only one proposal that was received was determined acceptable. That proposal, from the Arc of San Angelo, was funded in March 2011.

Organizational Structure

The Arc of San Angelo, a public, non-profit advocacy and service organization, operates the project. It is a chapter of The Arc, a national advocacy and research organization. According to its mission statement:

“The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.”

The San Angelo chapter serves Tom Green County (population 110,224) and the surrounding rural counties.

The Arc has recruited, trained, and supported volunteers for the past 10 years. The organization operates a guardianship program but uses strict acceptance criteria for inclusion in that program. The Board of Directors refuses to accept guardianship of individuals who have capacity to build skills and exercise rights on their own behalf. The goal of the existing Arc guardianship program is to avoid guardianship, except in extreme instances where guardianship can be used as a tool to access preventive medical and dental services, or to advocate for rights by accessing protected information such as abuse reports.

The Arc has supported families to attend statewide conferences and training opportunities. The Arc has co-sponsored legislative forums, community leadership development programs, and “sibshops” (events designed for the brothers and sisters of children with an intellectual disability). The organization provides information, referral, and individualized consultations, including attendance and participation at service planning meetings for adults and for children in special education programs.

The Arc of San Angelo has a staff of three, including the director who is a parent of an adult with autism and other disabilities. This individual founded the guardianship program and has more than 25 years’ experience with advocacy and service.

The project advisory committee (PAC) provides overall direction to the project. The PAC includes individuals with disabilities, family members, service providers, and academic faculty. The PAC has provided guidance to the project on volunteer outreach, eligibility criteria, training techniques, and relationships with local providers, among other topics.

The project also receives advisory assistance from a Texas Tech University professor of law who has significant experience with the legal issues associated with disability. Faculty from the Angelo State University social work program and the Howard College nursing program also worked with the project.

Implementation

As an innovative project in a medium sized community that is somewhat remote from large metropolitan areas in the state, the project has encountered both successes and difficulties. The project has developed innovative responses to the issues noted below, while continuing to work toward preventing unnecessary guardianships.

Legal Liability Issues

As the project was being organized, staff and others expressed concerns about whether volunteers or organizations would be vulnerable to legal liability over decision-making.

Legal assistance and research led to the discovery that volunteer liability is not a concern for this project. The Charitable Immunity and Liability provisions of the Civil Practice and Remedies Code (Chapter 84.004 (b).) make volunteers acting on behalf of charitable organizations immune from civil liability. To assure that volunteers act within the scope of the program and do not engage in willful acts not covered by the immunity, the project adopted risk management activities.

Project staff drafted policy to address these issues. Procedural steps are in place to enforce quality standards and practices, criteria and screening procedures for volunteers, value-based quality training activities, staff monitoring, individual evaluations, and liability insurance.

Early Emphasis on Medical Power of Attorney

Early in the project, staff emphasized the development of a medical power of attorney for individuals with IDD and/or other cognitive impairments. Project staff assumed that the medical power of attorney allowed the individual with a disability to designate a trusted person to make medical decisions.

As the effort moved forward, project staff and advocates learned that physicians and, to a lesser degree, attorneys were unwilling to accept the documents. Medical professionals assumed that the medical power of attorney was only valid if the individual was capable of fully understanding the relevant medical procedure. The determination of the individual's ability to understand the procedure is made by the physician, operating independently.

Generally, physicians assumed that an individual with an intellectual disability was incapable of understanding medical procedures, and therefore incapable of assigning a medical power of attorney. It appeared that physicians did not consider the individual's functional level, history, communication skills, or other factors that would demonstrate competency. If the physician did not believe that the individual was competent, the medical power of attorney had no effect.

Attorneys who did not have significant experience with persons with disabilities were likely to make the same assumptions about competence, further complicating efforts to establish a medical power of attorney.

Because key professionals have not accepted them, medical power of attorney arrangements are no longer a priority for the project.

Recruiting and Educating Volunteers

After consultation with the local PAC, project staff began to focus on identifying and educating volunteers to work with volunteer-supported decision-making.

Identification, recruitment, and education of volunteers were rooted in the potential volunteers' experience with people with disabilities and familiarity with the San Angelo area. Project staff and the PAC identified the following important characteristics of volunteers:

- evidence of integrity;
- knowledge of services for people with disabilities and the options available; and
- knowledge of the community and the specific strengths and weaknesses of the local service system.

People volunteering for the project need considerable knowledge, skill, and experience working with vulnerable individuals in difficult situations. The project has used targeted and specific outreach for volunteers. A broadcast approach was thought likely to bring in inappropriate people.

The project has depended largely on word of mouth and informal interviews for recruiting potential volunteers. This method, while time consuming, allows for early screening for some important characteristics. Staff reached out for volunteers to student interns in the social work program at Angelo State University and nursing students at Howard College.

Staff has developed an extensive education process for volunteers. It begins with an evening session based on the "Partners in Policy Making" model developed by the Minnesota Council on Developmental Disabilities. Training includes the value of people first language, the history of people with disabilities, and the self-determination movement. Volunteers are trained regarding what constitutes informed consent, the difference in substituted judgment and best interest versus supported decision-making. Training includes information on guardianship and the risks of establishing an unnecessary guardianship.

Volunteers then participate in problem-solving scenarios using decision-making strategies that they will use with participants. The real-world problems presented give volunteers an idea of the scope of the commitment being asked of them. Some volunteers decide that the demands of the program are too great and leave as a result. Their responses to the problems give project staff information that is useful in matching volunteers with specific individuals with disabilities.

Further training is provided on a one-on-one basis. This approach allows staff to concentrate on the needs of specific individuals. One-on-one training also encourages candor when discussing very intimate needs and issues. One-on-one training is enhanced by the use of iPads. The iPads were purchased with donor funds and savings from the elimination of printed materials. The tablets are loaded with a growing list of applications, videos, and PowerPoint presentations. The contents include training materials for volunteers and tools for interaction with people with disabilities.

Participation by Individuals with Disabilities

In consultation with the PAC, the project staff determined that the priority population should be individuals identified by guardians ad litem as being at immediate risk of guardianship. The project also serves those who can benefit from an ongoing relationship that will help to build their decision-making capacity.

The project team concluded that individuals at imminent risk of guardianship are not necessarily well served by volunteer-supported decision-making in the short term. Project staff may need to act as the "first responder" to the situation to evaluate the needs of the individual with a disability

and provide information to forestall guardianship. Once the situation is stabilized, the individual with a disability can be matched with a volunteer as soon as possible.

Recruiting other individuals with disabilities to participate in the project has been challenging. Project staff reports that providers of DADS-funded services are wary of the project, fearing that a volunteer will interfere with the established service system. Project staff believes that providers often see themselves as the appropriate source of guidance for the individual with a disability. The project has had greater success in working with individuals who do not receive DADS services—individuals who live alone or with families, or receive private-pay services. Most recent efforts focus on working through MHMR Services for the Concho Valley (the local authority) to reach out to providers.

Changing Community Expectations

The project's experience with volunteer recruitment, outreach to people with disabilities, contacts with providers, and contacts with legal and medical professionals all shows difficulties with community acceptance and support. There is room for greater understanding about disability rights, individual choices and the strengths of persons with a disability. The project's most recent efforts at reaching volunteers and individuals with disabilities aim to raise awareness that people with an intellectual and other cognitive disability can often make their own choices and decisions.

Working with a service provider who is not a DADS contractor, the project recruited 15 individuals with disabilities to participate in a leadership academy, learning about choices, self-advocacy, and decision-making. The participants were individuals living with families or living independently, or were individuals new to the San Angelo area. The project staff members say participants were generally enthusiastic about the academy, but no formal evaluation was conducted.

The project is now trying to establish the area's first self-advocacy group, enabling individuals with disabilities to work on decision-making and choices in a peer-to-peer learning environment. Project staff is also developing ways to help individuals with disabilities become more actively involved in choices about lifestyle, diet, activities, and health. Such a program, developed in conjunction with local university faculty in the fields of dietetics and kinesiology, may help improve health while building individuals' capacity for making their own decisions.

The project is working with MHMR Services for the Concho Valley to reach out to providers for DADS programs and make a presentation on the project, its goals, and its value to individuals with disabilities.

Project Effectiveness

The San Angelo Alternatives to Guardianship project is near the midpoint of its planned three-year term. The project has resulted in significant accomplishments in preventing unnecessary guardianships but has encountered barriers to the development of a sustainable approach using volunteer-supported decision-making. The project continues to make progress, but outcomes will be different from those originally planned.

Findings

The project has diverged from the original proposed schedule, but staff and the PAC efforts have been directed to overcoming the procedural, legal, and practical problems affecting the project in its early months.

H.B. 1454 calls for an evaluation using criteria similar to the National Core Indicators (NCI), a widely recognized tool for measuring individuals' satisfaction with their services. At this time, the project has only provided volunteer-supported decision-making to one individual and has not yet begun using measures based on the NCI. Evaluation measures such as these will be used in the future.

As a developmental and innovative activity, the Volunteer-Supported Decision-Making project has emphasized the development of policies and operational tools. This has resulted in some unanticipated accomplishments, including:

- The project researched and documented issues relating to possible legal liability for volunteers;
- The project identified the issues associated with medical power of attorney instruments and changed direction because of those issues;
- The project developed the use of iPads as a training and interaction tool—an innovative approach that is quite different from what was originally proposed; and
- The project is developing the community's first self-advocacy group, in order to increase understanding of the opportunities for self-determination available to people with an intellectual disability.

The project has been able to assist three individuals, thereby preventing two unnecessary guardianships and ending another. These accomplishments balance the difficulties in meeting the project's originally scheduled milestones.

Recommendations

The project should be continued at the current site for the remainder of the planned term (three-years, ending in 2014). This will allow the project to capitalize on the existing momentum, community support, and commitment to the goals of the project.

As the end of the project term approaches, agencies and others concerned with the project should consider the following to capitalize on progress to date:

- Seek resources to develop documentation and other tools to disseminate the project's findings and allow other communities to develop similar projects;
- Develop or identify continuing education materials for physicians, attorneys, and judges concerning contemporary thinking about disability rights, self-determination, and independence; and
- Consider seeking funding to other sites for similar projects