

BACKGROUND PAPER INFORMED CONSENT/GUARDIANSHIP PROJECT

In October 2003 representatives from Washington D.C.'s Mental Retardation and Developmental Disabilities Administration (MRDDA), Corporation Counsel, the Quality Trust and Providers of services to people with mental retardation and developmental disabilities (MR/DD) came together to discuss guardianship and informed consent concerns for people being supported by the service system in Washington D.C. Participants used actual case studies and worked in break out sessions to identify the array of areas where informed consent issues arise and the systemic root causes that underlie these issues. Out of this day long meeting came a commitment from group members to work together and identify specific activities on which we could collaborate.

Our goal is to identify solutions that will decrease the number of individuals at risk of losing their rights through a full guardianship. We worked together to identify key issues and barriers, to define common ground and to develop recommendations. We want to identify viable strategies for supporting individuals as the primary decision maker in their lives.

DRIVING FORCES: Through discussions, the workgroup identified a number of driving forces that led to its formation and the need to address informed consent and guardianship issues in Washington DC. These include the following:

- Lack of knowledge about the process to obtain medical consents.
- An increasing number of ICF/MR citations regarding informed consent that drove providers to seek full guardianship.
- Lack of knowledge about alternative and legal mechanisms that support decision-making.
- Questions regarding the provider and government's role in allowing or supporting decisions that are not in the person's best interest (as determined by the team) and a lack of assessment to address.
- The need to identify alternatives to guardianship to give individuals an array of supports and options for involvement in decision making.

WORKGROUP FINDINGS: The workgroup agreed that guardianship is a neutral concept, neither good nor bad. Some people need intensive supports in making decisions and benefit by having a guardian. Others do not need this level of intervention and would benefit by a less intrusive alternative. Further, some individuals have the potential to learn to make decisions for themselves if provided the support, assistance and opportunity to learn. We identified several critical issues providers and individuals face when trying to make decisions about consent. There are other circumstances where consent may be an issue but our goal was to identify the most pressing barriers that exist. Below is a brief review of the issues discussed. Additional detail is discussed in a separate paper.

- Dental treatment: Individuals who need routine or urgent dental work often require sedation for which consent is required.
- Individual bank accounts: Banks require a signature or consent, but are unwilling to accept the individual's signature.
- Gaining consent for medical care (urgent): Individuals who need urgent (important, but not a medical emergency) care often have problems obtaining services in a timely manner due to problems with securing needed consents.

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- Emergency medical consent: Although a process exists, it is not widely understood or used.

BARRIERS: Once we identified the various issues, we outlined what we perceived to be the barriers contributing to the problem. Below is a list. These are outlined in more detail in a separate paper.

- The presumption of “incompetence”.
- Confusion between commitment process and guardianship intervention procedures.
- Limited use of less restrictive strategies and alternatives to guardianship.
- Lack of advocates as required by law.

WHAT WE AGREE ON NOW: There are numerous points of agreement that form the foundation of our collaboration. Below is a brief overview of some of these.

- Functional Competency should be the basis of making a decision about guardianship and not “mental status” or label.
- An assessment or guide is needed to determine the person’s ability to understand or “consent” to specific issues.
- Guardianship is the most restrictive form of decision-making assistance. A substitute decision maker, like a guardian, should not be appointed for a person with mental retardation until that person is given the opportunity and support to make his or her own decisions, except in emergencies.
- There are numerous alternatives to full guardianship available.
- Guardianship is only one of an array of choices. It is the most extreme option but is occasionally necessary to protect someone who needs the support and protections it offers.

RECOMMENDATIONS: The Informed Consent/Guardianship workgroup met several times. We developed a list of recommendations and potential projects. Our first joint project is the development of this series of issue papers, which we will use as a vehicle to share our findings and to solicit input from various stakeholder groups. We agreed to host a Summit to further explore the issues. We identified three key areas to address:

1. Clarification of the Law and the Process for obtaining needed consents.
2. Education on a range of topics related to informed consent and guardianship, including identifying or developing training and resource materials.
3. Coordination of efforts by all the stakeholders with an emphasis on maintaining open communication and the sharing of work products.

We request that those who would like to provide input or suggestions do so by submitting comments in care of the Quality Trust by writing to: The Quality Trust, 5335 Wisconsin Avenue, NW, Suite 825, Washington DC 20015. Attention – Informed Consent/Guardianship Project.