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ARTICLES:


2. “How to Determine Competency,” by Edmund G. Howe from The Journal of Clinical Ethics, Vol. 12, No. 1: Explains that capacity is fluid and should be assessed over time, and argues for the use of a “sliding scale.” Article does not focus specifically on people with DD and “The Developing and Piloting of a Capacity and Assessment Tool” by Maria Torroella Carney from The Journal of Clinical Ethics, Vol. 12, No. 1. Focus is not specifically on people with DD. Author does research in geriatrics. http://www.clinicalethics.com


Prepared by H&W Independent Solutions, Inc. for The Quality Trust, Updated 8-06, chayes@hwisolutions.com
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This is a comparative study between those without mental retardation and those with mild and moderate mental retardation. The study looked at ability to give consent and found it was positively related to level of intellectual functioning. Results underscore need to educate individuals with mental retardation about treatment situations and to balance protection from harm with self-determination.


BOOKS:

1. “Ensuring Choices,” Chapter Five of A Good Life For You and Your Relative With Disabilities, by Al Etmanski. Published In Canada by PLAN. Suggests the use of a Supported Decision-making Agreement for people with DD and their families. Excellent discussion of choice and the importance of alternatives to guardianship and most importantly contains a capacity assessment tool. www.plan.ca


MISCELLANEOUS:

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http://www.fordham.edu/general/Undergraduate/Research_on_Consent_8209.html


5. The American Bar Association’s (ABA) Commission on Law and Aging focuses on strengthening and securing the legal rights, dignity, autonomy, quality of life, and quality of care of elders. It carries out its mission through research, policy development, technical assistance, advocacy, education, and training. Many of the issues cross over and there are numerous resources available at their web site. http://www.abanet.org/aging/home.html

6. The National Guardianship Association (NGA) has an extensive web site with lots of valuable resources. Their goal is to support excellence in guardianship, when it is chosen as an option. They have documents you can download including “A Model Code of Ethics for Guardians” and “Standards of Practice”. http://www.guardianship.org/

7. The ARC’s web site has an extensive list of publications and resources on Estate Planning, Guardianship and Futures Planning. After going to the following web site, scroll down a few pages to find the listings. http://www.thearc.org/futplan.html

STATE SPECIFIC RESEARCH

California:

1. Information Related to Informed Consent Bulletin, August 2003. Developed by the Department of Health Services, Licensing and Certification division, State of California. Developed to give providers and surveyors a better understanding of “informed consent” as it applies to people living in ICFs/MR in the state of California. This bulletin includes information regarding various options for representation that are acceptable under California law, depending on the specific circumstances. This bulletin
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also includes general information about informed consent, and suggestions for facilities regarding relevant “positive practices.” Not available online. Contact Information: Cathy Clark, Policy and Research Branch, Licensing and Certification, Department of Health Services, 1501 Capitol Ave, MS 3001, PO Box 997413,Sacramento, CA 95899-7413. Telephone number is 916.552.8642.

Florida:


Illinois:

1. Family Futures Planning Project: Training, Support, and Advocacy Program for Adults With Developmental Disabilities and their Families. Developed by Illinois Council on DD, Chicago ARC, University of Illinois, Dept. of Disability and Human Development: A curriculum for assisting individuals and their families to plan for the future. Includes training materials specifically for individuals that are to help the individual develop plans for the future that are driven by their needs and preferences and help them learn how to make informed choices about their future. (Feb. 2002) http://www.state.il.us/agency/icdd/online/includes/Helping%20Families%20Undestand%20Options.pdf


Louisiana:

Developed 10 guiding principles to govern practices related to decision making. Not available online.

Maryland:


Massachusetts:


North Carolina:

1. The Guardianship Capacity Questionnaire resulting from The Capacity Assessment Consent project. In North Carolina, the County Clerks of Courts are the officials who make the determination about guardianship. The Guardianship Capacity Questionnaire was designed to be used by anyone who is thinking about guardianship for another person. It designed to encourage the identification of alternatives to full guardianship. The Carolina Legal Assistance (CLA) coordinated the project and the tool and additional information can be found at their web site. http://www.cladisabilitylaw.org/

Texas:

1. “Capacity Assessment for Self-Care and Financial Management,” from the Texas Dept. of Mental Health and Mental Retardation. The effort started with a public process of comments/input in 1991, a report was published in 1992 and TX revised its probate code in 1993. This legislation authorized the development of the tool and process. It then took 6 years to develop the Capacity Assessment tool. The focus was to have a uniform tool and process for guardianship and not just have a doctor making the recommendation as to the competency or incompetency of the individual. It takes
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several hours of face to face interviews or telephone interviews with people who know or work with the individual to complete this assessment. The assessor must try to obtain assessed persons view of relationship with informants. Person should assess the individual’s awareness, level of understanding and functional abilities in targeted areas. This is not a legal document but a standardized screening tool. The assessment can be viewed at the following link.
http://www.dhs.state.tx.us/providers/ltc-policy/forms/cap-asmt/CAPASSE.PDF

Washington State:

1. A “Functional Assessment” chart from the Guardianship Services of Seattle from www.proguard.org/guardianship/functional_assessment.htm It has a chart with places to rate person’s abilities in several different categories.

Wisconsin:


Note regarding websites: Many of the web sites listed take you to the overall web site for the organization. You will then need to click on resources or publications to find the specific document.

End Note/Disclaimer: This is a working document and not meant to reflect all the current research or work regarding guardianship and informed consent for people with developmental disabilities. It is meant to serve as a resource tool for those who wish to find additional information. Web link information is included. If you find it is out of date, please let us know. Those wishing to share information or suggest additions to the content, please send the information the Quality Trust 5335 Wisconsin Ave NE, Suite 825 Washington, DC  20015 in care of Phyllis Holton pholton@dqualitytrust.org or to Catherine Hayes at H&W Independent Solutions chayes@hwisolutions.com

Thank you!

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