

Resource Material
Regarding
Informed Consent and Capacity Assessments
Prepared for the Quality Trust for Individuals with Disabilities

ARTICLES:

1. "Capacity Issues Related to the Health Care Proxy," by Martin Lynden from *Mental Retardation A Journal of Policy, Practices and Perspectives*, AAMR, Vol. 44, No. 4, August 2006: Discusses capacity, ethical mandates and a rationale for the assessment of capacity to execute a health care proxy.
<http://aamr.allenpress.com/aamronline/?request=index-html>
 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>
 3. "Health Care Decision-Making by Adults with Mental Retardation," by Christine D. Cea and Celia B. Fisher from *Mental Retardation*, Vol. 41, No. 2:78-87, April 2003: Demonstrates that many people with mild and moderate retardation have capacity to give consent. [http://aamr.allenpress.com/aamronline/?request=get-document&doi=10.1352%2F0047-6765\(2003\)041%3C0078:HCDMBA%3E2.0.CO%3B2](http://aamr.allenpress.com/aamronline/?request=get-document&doi=10.1352%2F0047-6765(2003)041%3C0078:HCDMBA%3E2.0.CO%3B2)
- (Note – the link above takes you to the article, which has multiple links imbedded that take you to the authors resource materials and related articles) and http://www.fordham.edu/general/Undergraduate/Research_on_Consent_8209.html
4. "The Capacity of a Mentally Retarded person to Consent: An American and Jewish Legal Perspective" by Pollack, et al, 20, New York Law School, Journal of International & Comparative Law 197 (2000). <http://www.nyls.edu/pages/581.asp>
 5. "A Modest Proposal for Self-Guardianship by Contract by Stavis, 16 Journal of Contemporary Health Law & Policy 1 (1999).
<http://www.law.cua.edu/students/orgs/ichlp/>
 6. "The Authority of a Guardian to Commit an Adult Ward" by English, 20 MPDLR (Mental & Physical Disability Law Reporter), 584 (Jul-Aug 1996)
<http://www.abanet.org/disability/reporter/home.html>
 7. "Statutory Surrogate Consent Provisions: An Overview and Analysis" by O'Connor, 20 MPDLR (Mental & Physical Disability Law Reporter), 128 (Jan – Feb 1996) <http://www.abanet.org/disability/reporter/home.html>

Resource Material
Regarding
Informed Consent and Capacity Assessments
Prepared for the Quality Trust for Individuals with Disabilities

8. "Determining the capability of individuals with mental retardation to give informed consent" by CD Morris, JM Niederbuhl and JM Mahr from American Journal of Mental Retardation, Vol. 98 No. 2, Sept. 1993 pp 263 – 272. (Abstract)
<http://aamr.allenpress.com/aamronline/?request=index-html>

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.

9. "Choices" by Ficker-Terrill & Rowitz, Journal of Mental Retardation, April 1991,
<http://aamr.allenpress.com/aamronline/?request=index-html>

10. "Symposium on Planning for the Future through Advance Directive Instruments" Psychology, Public Policy and Law, No. 3. <http://www.apa.org/journals/law.html>

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
2. A Guide to Consent, published by the American Association of Mental Retardation (AAMR). 1999. Explores legal issues of consent for people with mental retardation. <http://aamr.allenpress.com/aamronline/?request=index-html>
3. Consent Handbook for Self-Advocates and Support Staff published by AAMR. Cathy Ficker Terrill, Editor. 1999. Companion piece to A Guide to Consent. Explores options for people who cannot give consent on own and provides tools for consent issues. <http://aamr.allenpress.com/aamronline/?request=index-html>

MISCELLANEOUS:

1. Position Statements on Guardianship and on Health Care from the ARC and AAMR. Includes statement on Informed Consent and Surrogate Decision Making. 2002. <http://www.thearc.org/posits/index.htm> (note - this takes you to a list of all ARC position statements).

Resource Material
Regarding
Informed Consent and Capacity Assessments
Prepared for the Quality Trust for Individuals with Disabilities

2. Power point presentation "Assessing the Consent Capacity of Adults with Mental Retardation" presented by Celia B. Fisher and Christine Cea of Fordham University. June 2002.
http://www.fordham.edu/general/Undergraduate/Research_on_Consent_8209.html
3. Wingspan conference recommendations and related articles published in 31 Stetson Law Review No. 3 (Spring 2002) <http://www.naela.com/pdf/Recommendaions.pdf> and <http://www.law.stetson.edu/lawrev/abstracts/lawreview.asp>
4. Consent Screening Interview for Community Residential Placement: Report on the Initial Pilot Study Data, 29 Mental Retardation 119, (June 1991) By Pam Lindsey and Ruth Luckasson (not available online). A more recent tool - Competence Assessment to Stand Trial for Defendants with Mental Retardation (CAST*MR) is available but very specific for people with forensic issues. <http://www.idspublishing.com/cast.htm>
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

Resource Material
Regarding
Informed Consent and Capacity Assessments
Prepared for the Quality Trust for Individuals with Disabilities

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:

1. Governor’s Joint Work Group on Guardianship and the Developmentally Disabled, Final Report, August 6, 2003. Contains results of study and recommendations. Exhibit 5: Legal Ways of Protecting Rights” is a good chart. http://www.state.fl.us/cf_web/news/finalguardianshipreport.pdf

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%20Understand%20Options.pdf>
2. “A Guide for the Perplexed: Challenges in Reforming Adult Guardianship Systems” presented at the June 2002 ATTAC/NAPAS 25th Annual Conference. Includes the following:
 - a. Executive Summary Illinois Guardianship Reform Project – Equip for Equality report. (Complete report at www.equipforequality.org Go to Guardianship reform for report.
 - b. State Adult Guardianship Legislation: Directions for Reform – 2001, developed by the Commission on Legal Problems of the Elderly, American Bar Association. www.abanet.org/elderly - go to policy and practice center: guardianship.

Louisiana:

1. “Legally Adequate Consent Task Force Report” by the Louisiana President’s Committee on Mental Retardation Team. November 1999. Resulted from a task force named to recommend a consent policy for Louisiana Dept. of Health and Hospitals.

Resource Material
Regarding
Informed Consent and Capacity Assessments
Prepared for the Quality Trust for Individuals with Disabilities

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

Maryland:

1. "Section 4: Decision-making" from Planning Now: A Futures and Estate Planning Guide for Parents of Children and Adults with Developmental Disabilities, published by Maryland Developmental Disabilities Council, July 1999: General discussion of guardianship and alternatives to guardianship. www.Md-Council.org
2. "The Guardianship Handbook – A Guide to Adult Guardianship and Guardianship Alternative in Maryland." Author Joan L. O'Sullivan, J.D. on behalf of the University of Maryland School of Law, Law & Health Care Program. 1998. http://63.140.253.196/disability/adult-guardian/guardianship_title_page.htm

Massachusetts:

1. "Chapter 3: Personal Decision Making" from Estate Planning for Parents of People with Disabilities, by the N. Neal Pike Institute on Law and Disability, published by the MA. DD Council, August 1999, General discussion of guardianship and alternatives. Available online at <http://www.bu.edu/law/pike/textonly/estate.html>

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

Resource Material
Regarding
Informed Consent and Capacity Assessments
Prepared for the Quality Trust for Individuals with Disabilities

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:

1. "Making a Difference: Thinking About Decision-Making Support in the Transition Process," by Roy Froemming, J.D, published by the Wisconsin Council on Developmental Disabilities, July 2002, www.wcdd.org Good discussion of preserving rights and supporting people to make their own decisions.

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@dcqualitytrust.org or to Catherine Hayes at H&W Independent Solutions chayes@hwsolutions.com

Thank you!

Prepared: June 2004, Updated August 2006