

Health Care Decision-Making by Adults With Mental Retardation

Christine D. Cea and Celia B. Fisher

Abstract

Abilities of adults with mild, moderate, or no mental retardation to understand hypothetical treatments was investigated using the Assessment of Consent Capacity–Treatment developed for this study based on Appelbaum and Roth's psycholegal consent standards. Performance in all groups decreased with increasing psycholegal complexity of consent decision-making. Most adults with mild and no mental retardation and almost half of adults with moderate mental retardation were able to make and justify treatment choices and fully or partially understand treatment information. Most adults without mental retardation, 50% with mild, and 18% with moderate mental retardation were able to partially appreciate relevance of treatment choice to patient's situation and weigh treatment risks against benefit. Implications of findings for patient rights are discussed.

Almost 2 decades ago, The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982) urged practitioners to avoid determining an individual's capacity as a decision-maker simply by his or her status as having mental disabilities. In response, over the years, institutional policies regarding the rights of adults with mental retardation to make health treatment decisions has shifted from a protectionist stance, based upon presumptions of decisional incompetence, to an emphasis on the promotion of consumer autonomy through increased opportunities to make choices about health-related treatments (Ellis, 1992; Freedman, 2001; Freedman, 1998; Knowlton, Turnbull, Backus, & Turnbull, 1988; Morris, Niederbuhl, & Mahr, 1993; Turnbull, 1977). This has been especially true for persons living in residential settings, in response to federal regulations requiring all capable individuals in Intermediate Care Facilities to make choices for themselves for treatments they receive (Conditions of Participation, 1988). Enhanced opportunities for adults with developmental disabilities to make such decisions raises complex challenges for residential staff, practitioners, and family members who are responsible for determining circumstances in which such independence is or is not in the consumer's best interest (Dinerstein, 1994, 1999).

Broadly conceptualized, autonomous consent

to health-related treatments requires that (a) an individual is informed about the nature and purpose of the treatment, (b) the decision to be treated is voluntary; and (c) the person has a rational understanding of the treatment risks and benefits (Ellis, 1992; Grisso, 1986; Turnbull, 1977). At the current time, there is little agreement however, on a generally accepted definition of *consent capacity* nor are there clear standards for its determination (Fisher, 1999; Lidz et al., 1984; Morris et al., 1993; Saks & Litt, 1999). Abilities relevant to consent capacity have been considered in both the clinical and legal literature (e.g., Appelbaum & Grisso, 1988; Berg, Appelbaum, & Grisso, 1996; Grisso & Vierling, 1978; Roth, Meisel, & Lidz, 1977). Appelbaum and Roth (1982) developed the most influential theoretical taxonomy for evaluating capacity to consent based on a consideration of the practical context in which clinical and legal decisions are made. According to this taxonomy, the ability to consent can be evaluated within four increasingly intellectually challenging psycholegal standards of consent capacity. The first and least stringent of these standards is the ability to communicate a choice concerning treatment. The second standard pertains to the ability to understand factual information about the nature of the disorder and the risks and benefits of the proposed treatments. The third, appreciation of the situation and its consequences, requires that the in-

dividual not only understand the risks and benefits of the proposed treatment but also the cognitive and emotional implications of the treatment for his or her own circumstances. The fourth standard, rational manipulation of information, is the most cognitively complex and requires the ability to weigh the risks and benefits of the proposed treatment when making a choice and to arrive at a “reasonable” outcome of choice.

To date, despite a small cadre of pioneering studies (e.g., Lindsey, 1994; Lindsey & Luckasson, 1991; Morris et al., 1993; Shapiro & Sheridan, 1985), the extent to which these standards can be applied to the consent capacity of adults with mental retardation remains sufficiently unexplored (Boggs, 1986). In recent years, courts responsible for the legal protection of the rights of people with mental retardation have not required an absolute threshold for decision-making, looking instead for consent capacity that does not deviate substantially from the norm (Appelbaum & Grisso, 1988; Friedman, 1998). However, little empirical information is available about conditions under which the treatment decisional capacity of individuals with varying degrees of mental retardation is similar or different from that of individuals with typical intelligence.

In the present study we examined the ability of adults with mild and moderate mental retardation living in residential facilities, as well as those with typical intelligence (no mental retardation), to understand the elements of informed consent for health-related treatments within the four psycho-legal standards proposed by Appelbaum and Roth (1982). Through the presentation of hypothetical treatment vignettes, the general hypothesis tested was that the treatment consent capacity of adults with mild or moderate mental retardation, in relation to that of adults with typical intelligence, would vary according to the intellectual level of participants and the test of competency applied.

Method

Participants

We interviewed 90 participants equally distributed among three groups (no mental retardation, mild mental retardation, moderate mental retardation). The majority of the sample were Caucasian (54%); 29%, African American; 7%, Hispanic; 3%, Asian; and 7%, “other.” The mean age of the individuals with mild mental retardation was 43.4 years (standard deviation [*SD*] = 11.4, range = 23

to 65) and the mean for those with moderate mental retardation was 40.6 years (*SD* = 11, range = 25 to 65). They were recruited from community residences of a large nonprofit agency serving people with disabilities in the New York Metropolitan area. Individuals without mental retardation, whose mean age was 30 years (*SD* = 9.4, range = 19 to 49), were recruited from a local 2-year community college. Thirty-eight percent of the sample was male and 63%, female. The greater proportion of female to male participants is typical of the distribution of students enrolled in the community college program in which participants without mental retardation were recruited and to a slightly greater percentage of women with moderate mental retardation served in the community residences of the participating agency. The majority of individuals with mild mental retardation (90%) were reported to have an “unknown” etiology, with the remainder of this group reporting “other” etiologies. Of this group, 30% were competitively employed, 27% worked in sheltered workshops, and 33% attended day treatment or day habilitation programs. Of the participants with moderate mental retardation, 70% had an etiology of unknown origin, 13% had Down syndrome, and 17% had other etiologies. The majority of individuals in this group (77%) attended either day treatment or day habilitation programs, and 23% worked at a sheltered workshop. Approximately half of individuals without mental retardation (53%) were competitively employed.

Levels of functioning were determined from psychological evaluations conducted within 3 years of the date of testing by qualified psychologists employed by the agency using standardized psychometric intelligence tests (e.g., Wechsler Adult Intelligence Scale-Revised, Wechsler, 1981) and scores on adaptive behavior scales (Vineland Adaptive Behavior Scales, Sparrow, Balla, & Cicchetti, 1984). The IQs for individuals with mild mental retardation ranged from 55 to 80 (*M* = 65) and from 36 to 54 (*M* = 45) for participants in the moderate mental retardation group. The Kaufman Brief Intelligence Test (Kaufman & Kaufman, 1990) was administered to students without mental retardation at the time of interview. Their scores ranged from 80 to 117 (*M* = 100.8).

Instrument

Assessment of Consent Capacity-Treatment (Assessment of Consent Capacity). This instrument, developed for this study, measured the capacity of

adults to reason about treatment-related information. It consists of three standardized treatment vignettes developed in consultation with agency staff and medical practitioners serving patients with mental retardation. The treatment vignettes were designed to represent situations for which consent was sought for low-risk elective treatment. The development of the questions and format for the Assessment of Consent Capacity-Treatment were drawn from treatment consent capacity measures developed for children (Weithorn & Campbell, 1982), adults with psychiatric disorders (Grisso & Appelbaum, 1991), and adults with mental retardation (Morris et al., 1993).

The first vignette describes a psychiatrist's recommendation for psychopharmacological treatment (with minimal side effects, such as drowsiness and dry mouth) for behavioral outbursts jeopardizing an individual's work placement. The second vignette describes a dentist's recommendation for orthodonture work to correct misalignment of teeth. The third vignette describes a physician's recommendation for a series of injections to prevent an allergic reaction to pollen and dust.

Each vignette contains eight paragraphs of similar length, written at a fifth to sixth grade level in accordance with Grunder's (1986, 1978) reading ease formula. The interviewer reads each paragraph to the respondent one at a time using what Grisso and Appelbaum (1991) have termed a *single-unit disclosure format*. The questions that follow each paragraph make up a 13-item questionnaire designed to test the four psycholegal standards of consent capacity proposed by Appelbaum and Roth (1982). Illustrations of these questions for the behavior vignette are found in the Appendix. Communicating a choice is assessed with questions requiring the examinee to demonstrate understanding of the voluntary nature of treatment and indicate whether the hypothetical patient should say yes or no to the treatment proposed in the vignette and give a reason for the decision. Understanding factual information is assessed with questions regarding the nature of the disorder, role of the practitioner, nature of the treatment, treatment benefits, treatment risks, benefits of treatment refusal, and risks of treatment refusal. Appreciation of the situation and its consequences is evaluated with questions directed at the ability of the examinee to understand the consequences of accepting and refusing treatment. Rational manipulation of information is assessed with questions requiring the ability of the

participant to take into account treatment risks and benefits and weigh risks against benefits to make a treatment decision.

Procedure

Recruitment of potential participants with mental retardation was limited to individuals identified by a residential supervisor or program coordinator as having a primary diagnosis of mild or moderate mental retardation. All participants were English-speaking and had at least moderate expressive language and adequate hearing ability. Individuals with active psychoses were not included in the study. Legal guardians and correspondents for consumers provided informed permission. Potential participants were initially approached by agency staff, who assessed their willingness to participate. Those who demonstrated an interest were then approached for their consent by the investigator in the presence of an agency staff member. Community college students, 18 years and older, were recruited through announcements in class. Informed consent was obtained from those who wished to participate.

Each participant was interviewed individually in a quiet space at the residence or the community college. At the residence, a trusted staff person was present during the interview. The presentation of each vignette took approximately 15 minutes to complete, resulting in no more than a 45-minute testing session per participant. The gender of the hypothetical patient in each vignette was matched to the gender of the examinee. Responses to each question were scored as full, partial, or no credit. If the participant gave a no-credit response, the examiner repeated the question. If a no-credit response was again given, the paragraph was repeated and the question asked one final time. Partial credit responses were further probed by the examiner stating, "Tell me more." Participants with mental retardation received McDonald's gift certificates and college students, the cash equivalent of the certificates as tokens of appreciation for their participation.

Coding and reliability. All interviews were audiotaped, transcribed, and independently scored by two trained raters using a 3-point coding system (2 points = *full credit*, 1 point = *partial credit*, 0 points = *no credit*). Interrater agreement across the three vignettes was high, 97% to 98%. Alpha coefficients on the 7 items representing understanding of factual information for each treatment vignette were as follows: behavior = .85; dental = .88; allergy = .82. Pearson correlations between the 2 items repre-

senting the other psycholegal standards were significant for each treatment vignette: Appreciation of the situation and consequences (behavior, $r = .54$; dental, $r = .63$; and allergy, $r = .63$, $p \leq .01$); rational manipulation of information (behavior, $r = .45$; dental, $r = .50$; and allergy, $r = .48$, $ps \leq .01$); communicating a choice (behavior, $r = .26$, $p < .05$; dental, $r = .55$; allergy, $r = .45$, $p < .01$).

Results

Preliminary analyses indicated no significant effect for gender. Therefore, gender was not considered in the subsequent analyses. Table 1 provides mean scores for each of the four psycholegal standards of consent capacity and the percentage of participants who gave no-credit, partial credit, and full-credit responses to questions on the three treatment vignettes. The possible range of scores attainable for each of the four standards is 0 to 4 points for communicating a choice, 0 to 14 points for understanding factual information, 0 to 4 points for appreciation of the situation and consequences, and 0 to 4 points for rational manipulation of information. As illustrated by the percentages in Table 1, the ability of adults with and without mental retardation to provide full-credit responses to questions decreased as the level of cognitive complexity of the standard associated with the question increased.

Univariate analysis of variance comparing differences in responding between the groups in each treatment context and each psycholegal standard were also found to be significant, $p < .001$ (see Table 1). Using planned comparisons we further explored group differences of significant univariate tests. Significant differences, $p < .001$, were found on the communicating a choice standard between (a) participants without mental retardation and those with moderate mental retardation and (b) participants with mild or moderate mental retardation. Significant differences, $p < .001$, were also found among all three groups on both understanding factual information and appreciation of the situation and consequences standards for each treatment vignette. No differences were found in the ability of participants without mental retardation and those with mild mental retardation to communicate a choice about treatments in each treatment vignette and between participants with mild and moderate mental retardation in their ability to rationally manipulate treatment information.

A comparison of the percentage of no-credit,

partial-credit, and full-credit responses (see Table 1) shows that adults with mild mental retardation (86%) performed almost as well as adults without mental retardation (95%) across treatment contexts on the communicating a choice standard of consent capacity. Although these questions appeared more difficult for adults with moderate mental retardation, almost half (45%) were able to give full credit responses, and 40% were able to give partially adequate responses.

Although adults with mild mental retardation found factual information about treatment more difficult to comprehend than did their counterparts without mental retardation, approximately 85% demonstrated partial or full understanding of factual information tied to medical treatment choices. Approximately half of those with moderate mental retardation indicated at least partial comprehension on this standard.

Although adults with mild mental retardation were less able to appreciate the situation and consequences of the treatment proposed and rationally weigh the treatment risks against benefits in making a treatment choice, more than half (65%), compared with 85% of adults without mental retardation, demonstrated at least partial appreciation of the relevance of treatment choice to a patient's situation. Furthermore, approximately half of the adults with mild mental retardation (52%) were able to at least partially rationally weigh treatment risks against benefits. Adults with moderate mental retardation had greater difficulty with both of these tasks.

Discussion

In the present study we examined the ability of adults with mental retardation, as compared to the ability of adults with typical intelligence, to understand elements of informed consent using vignettes that described elective, low-risk psychiatric, dental, and medical treatments. Participants provided responses to questions designed to tap abilities according to four increasingly demanding psycholegal standards of consent capacity (Appelbaum & Roth, 1982). Irrespective of their intellectual status, all individuals' responses decreased with the increasing complexity of the psycholegal standard.

Psycholegal Standards and Consent Capacity

The first and least stringent of the four standards is communicating a choice. This research showed that many adults with mild mental retardation and some

Table 1 Means, SDs, Percentage of Responses and Univariate *F* tests for the Psychological Standards of Consent Capacity by Treatment Vignette and Level of Functioning

	Levels of functioning ^a												<i>F</i> (2, 85-87) ^c			
	No MR				Mild MR				Moderate MR							
	Credit (%)				Credit (%)				Credit (%)							
	Mean	SD	Par- tial	Full	Mean	SD	Par- tial	Full	Mean	SD	Par- tial	Full				
ACC-T ^b treatment vignettes																
Behavior treatment																
Communicating a choice	3.67	.76	10	0	90	3.55	.56	0	15	85	2.68	.78	5	45	50	16.73
Understanding factual information	11.03	2.50	5	30	65	8.23	3.30	20	45	35	4.75	2.40	40	50	10	38.42
Appreciation of situation/consequences	2.87	1.25	15	25	60	1.30	1.26	55	25	20	.28	.46	85	15	0	42.95
Rational manipulation of information	1.70	1.15	35	45	20	.83	1.02	65	30	5	.28	.60	85	15	0	16.11
Dental treatment																
Communicating a choice	3.88	.39	0	0	100	3.37	.67	0	20	80	2.27	1.20	20	40	40	26.77
Understanding factual information	12.00	1.57	0	25	75	7.80	3.20	20	50	30	4.14	3.20	50	40	10	59.87
Appreciation of situation/consequences	3.10	.84	0	40	60	1.70	1.21	0	20	80	.52	.83	75	20	5	51.61
Rational manipulation of information	2.60	.85	5	60	35	1.60	1.03	30	55	15	.48	.69	75	20	5	43.32
Allergy treatment																
Communicating a choice	3.82	.52	5	0	95	3.53	.69	0	20	80	2.71	1.10	15	35	50	14.70
Understanding factual information	10.60	1.87	5	40	55	7.47	2.90	20	55	30	4.71	2.35	40	40	20	43.10
Appreciation of situation/consequences	2.63	1.21	15	35	50	1.50	1.20	40	45	15	.28	.53	85	15	0	36.80
Rational manipulation of information	2.40	.97	15	45	40	1.23	1.20	50	35	15	.25	.52	85	15	0	37.70

Note. Possible range of scores for each standard: 0 to 4 Communicating a Choice, 0 to 14 Understanding Factual Information, 0 to 4 Appreciation of Situation and Consequences, 0 to 4 Rational Manipulation of Information (0 = no credit, 1 = partial credit, 2 = full credit).

^a*N* = 30 in each group. ^bAssessment of Consent Capacity-Treatment. ^cAll significant at the .001 level.

adults with moderate mental retardation were able to make and justify a treatment choice and understand the voluntary nature of the decision in the hypothetical vignettes. The majority of participants with mild mental retardation and almost half of those with moderate mental retardation provided adequate responses. It has frequently been the practice to consider failure of a person with mental retardation to object to treatment as an indication of voluntary agreement (Ellis, 1992). Our data demonstrate that when queried directly, many adults with mental retardation have the capacity to actively indicate agreement to participate. These data suggest that requiring practitioners to document that a patient with mental retardation has been given the opportunity to communicate his or her acceptance or refusal of treatment, may offer consumers enhanced protection from excessive paternalism.

The second standard, understanding factual information, pertains to the ability of a person to comprehend specific information about the proposed treatment during informed consent disclosure. This includes understanding the nature of the problem, the treatment and its risks and benefits, and any alternative treatments. Patient comprehension is expected to be that of a reasonable person, given the same amount of basic information, not necessarily the technical aspects of the procedure or treatment (Hurley & O'Sullivan, 1999; Roth et al., 1977). Most participants with mild mental retardation were able to adequately or partially comprehend factual information about the treatments proposed in the vignettes, and one half of those with moderate mental retardation were able to do the same. It is important to note that factual understanding is not simply dependent upon intellectual capacity but is linked to the degree to which an individual has had previous experience with the proposed treatment, the type of information and the manner in which it is given, and the extent to which the practitioner educates the patient about aspects of the treatment and his or her options. As such, advocates for the rights of persons with impaired decisional capacity have suggested that practitioners be required to make "reasonable disclosure" of information essential for an informed decision to be made (Tepper & Elwork, 1984). The single-unit disclosure format utilized in the Assessment of Consent Capacity-Treatment may be helpful for making such information more accessible to persons with mental retardation.

The third standard, appreciation of the situation and consequences, requires an understanding

of the risks and benefits of the treatment, the cognitive and emotional implications of each, and the ability to apply this information abstractly for the individual's own situation (Appelbaum & Grisso, 1995). Irrespective of intellectual status, participants in all three groups generally showed a lesser capacity on this standard than on standards requiring their ability to communicate a choice or understand disclosure information. However, the majority of adults with mental retardation demonstrated at least a partial grasp of the relevance of the information to a personal situation, suggesting that a more educational consent format might increase capacity for this type of information.

Finally, rational manipulation of information, the most stringent of the four psycholegal standards, includes the ability to rationally weigh treatment risks and benefits in making a reasonable treatment choice (Appelbaum, Lidz, & Meisel, 1987; Appelbaum & Roth, 1982; Grisso & Vierling, 1978; President's Commission, 1982). Adequate responses on this standard were lowest across all groups. However, the relevance of this psycholegal standard to judgments regarding a person's capacity to consent has been questioned. Roth et al. (1977) warned that holding persons to a standard that requires the calculation of risks and benefits poses legal and ethical problems because it is difficult to demonstrate that the preference is directly related to the rationale that he or she gives, and rejection of an individual's rationale can justify widespread substitute decision-making for those with cognitive impairments. Moreover, for adults with mental retardation who may not have experience making decisions based upon rational calculations, applying a risk-benefit analysis as a standard of moral agency can deny them freedom of action and consensus-making, both of which are considered rights of personhood (Fisher, 1999).

Regarding the generalizability of findings, disclosure information was presented to participants in the form of hypothetical treatment vignettes about "other" individuals. One might reason that consent capacity would be greater in "real world" treatment settings, where information is personally relevant and where health-care providers have the opportunity to more concretely demonstrate procedures. Further, the treatments proposed in the hypothetical vignettes were of low risk and high benefit to the patients. Due to limitations in abstract reasoning skills, as the risks of treatments increase and outcomes are more uncertain, the capacity to con-

sent of adults with mild or moderate mental retardation will need to be evaluated with increasingly stringent standards (Hurley & O'Sullivan, 1999; Morris et al., 1993).

The findings in this study underscore current legal and ethical recommendations that professionals respect the fundamental rights of persons with mental retardation by not assuming that their disability automatically deems them decisionally incompetent (Bersoff, Glass, & Blain, 1994; Dinerstein, 1994; Ellis, 1992; Freedman, 2001; President's Commission, 1982). This research shows that many adults with mild mental retardation and some adults with moderate mental retardation do indeed have the ability to provide adequate consent to standard, low-risk health-related treatments. Moreover, the high proportion of partially adequate responses to understanding factual information questions suggests that consent capacity of adults with mild or with moderate mental retardation could be enhanced with supportive decision-making or educational techniques in preparation for treatments or procedures requiring their consent.

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Authors:

Christine D. Cea, PhD (E-mail: Cea@Fordham.edu), Associate Director, Developmental Disabilities Project, Fordham University Center for Ethics Education, Department of Psychology, and Dealy Hall, 441 East Fordham Rd., Bronx, NY 10458. **Celia B. Fisher, PhD**, Professor of Psychology and Director, Center For Ethics Education, Dealy Hall, Fordham University, 441 E. Fordham Rd., Bronx, Ny 10458 (E-mail: Fisher@Fordham.edu).

Appendix A

Psychopharmacological Treatment Vignette for Aggressive Behavior

Disclosure 1: Nature of Disorder: Susan has a problem. She has been getting mad, shouting and starting fights at the place where she works. Susan has tried to control her behavior and has asked people at work for help, but she can't stop these behaviors. If she does not stop these behaviors, she will not be allowed to come to work.

Question 1: Something is wrong with Susan's behavior at work. What is wrong with her behavior?

Disclosure 2: Role of Practitioner: Susan goes to see a psychiatrist. A psychiatrist is a doctor that helps people with behavior.

Question 2: Susan goes to a psychiatrist. What is a psychiatrist?

Disclosure 3: Nature of Problem: The psychiatrist tells Susan that she could take medicine that might help her stop these behaviors. The medicine is called Sentaril. Susan would take 2 pills, one in the morning and one at night for many weeks.

Question 3: What can the psychiatrist do to help Susan with her problem?

Disclosure 4: Treatment Benefits: The psychiatrist says that the good thing about taking the medicine is that it can help Susan by keeping her calm. She won't feel like shouting or starting fights as much as she does now and she will be allowed to come to work.

Question 4: What are the good things that could happen if Susan takes the medicine?

Disclosure 5: Treatment Risks: The psychiatrist tells Susan that the bad thing about taking the medicine is that it might make Susan feel a little sick. When she starts the medicine, she might feel dizzy or sleepy and her mouth might feel very dry.

Question 5: What are some of the bad things that might happen if Susan takes the medicine?

Disclosure 6: Benefits of Refusal: The psychiatrist tells Susan that if she does not take the medicine, she will not feel sick, get dizzy or sleepy, or have a dry mouth.

Question 6: What is the good thing that would happen if Susan does not take the medicine?

Disclosure 7: Risks of Refusal: The psychiatrist also says that the bad thing about not taking the medicine is that Susan will still get mad, shout and fight, she will have to work even harder to control her behavior, and she may not be allowed to come to work anymore.

Question 7: What are the bad things about not taking the medicine?

Disclosure 8: Voluntary Nature of Treatment: The psychiatrist tells Susan she has a choice—she can say “yes” she wants to take the medicine or “no” she doesn't want to take the medicine.

Question 8: What choices does Susan have?

Question 9. Consequences of Accepting Treatment: Why would Susan want to take the medicine?

Question 10. Consequence of Refusing Treatment: Why would Susan not want to take the medicine?

Question 11. Appreciation of Both Risks and Benefits: What should Susan think about before she makes a choice about whether or not to take the medicine?

Question 12. Rational Manipulation of Risks and Benefits:

(a) There are good and bad things about taking the medicine and not taking the medicine. What are the most important things for Susan to think about before deciding whether or not to take the medicine?

(b) What things are not so important for Susan to think about before deciding whether or not to take the medicine?

Question 13. Communicating a Decision to Accept or Refuse Treatment: What do you think Susan should do? Should she tell the psychiatrist “yes” she wants to take the medicine or “no” she does not want to take the medicine? Why?