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Goodness-of-Fit Ethic for Informed Consent to Research Involving Adults With Mental Retardation and Developmental Disabilities

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This article reviews current theory and research on informed consent policies for adults with mental retardation within a relational ethics framework that re-conceptualizes consent vulnerability in terms of the goodness-of-fit between participant decisional capacities and the specific consent context. Conceptualizing informed consent competence as a product of the relationship between person and consent context shifts assessment of decisional capacity away from an exclusive focus on a research participant's cognitive deficiencies to (a) an examination of those aspects of the consent setting that are creating or exacerbating consent vulnerability and (b) consideration of how the setting can be modified to produce a consent process that best reflects and protects the hopes, values, concerns, and welfare of adults with developmental disabilities.
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Social policy and civil law regarding the self-determination rights of persons with developmental disabilities has shifted considerably over the years. Historically, many adults with mental retardation were presumed incompetent and restricted from opportunities to make decisions for themselves. Disregard for the rights of institutionalized persons with mental retardation resulted in abuses like the now infamous case at Willowbrook State Hospital where biomedical researchers infected children identified as "mentally defective" with viral hepatitis without their knowledge, and with the questionable voluntary consent of their parents [Katz, 1972].

In the wake of Willowbrook, advocacy for persons with mental retardation came to national attention and forged great legal gains for individuals with decisional impairments. The movement led to policies requiring deinstitutionalization, normalization into human services, regulations governing intermediate care facilities, and recognition by the courts that a diagnosis of mental retardation cannot be accepted as presumption of decisional incompetence [Wolfensberger, 1972; Rennie v. Klein, 1982; Rogers v. Okin, 1982; Conditions of Participation, 1988; Lindsay and Luckasson, 1991; Bersoff et al., 1994; Dinerstein, 1994].

Today practitioners, residential supervisors, educators, and family members demonstrate respect for individual autonomy by encouraging persons with mental retardation to take part in everyday decision-making [Ellis, 1992]. Despite these gains, scientists studying the neurological causes or psychosocial correlates of mental retardation or empirically evaluating skill promoting interventions or treatments for dual diagnosis have few ethical and empirical guideposts for constructing respectful and protective informed consent procedures. An ongoing informed consent challenge for developmental disabilities scientists is balancing the obligation to respect the rights of those with mental impairments to be treated as autonomous members of the moral community, with the need to ensure that ill-informed or incompetent decisions will not place their welfare in jeopardy [Ellis, 1992; Bersoff et al., 1994; T.D. v. New York State Office of Mental Health, 1996; Fisher, 1999; Cea and Fisher, 2003a].

In 1982, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research urged scientists to avoid determining an individual's incapacity as a decision-maker simply by his or her status as mentally disabled. Extending this recommendation, the National Bioethics Advisory Commission [NBAC, 1998] recently called for investigators to study the consent capacity of people with intellectual disabilities and to explore techniques to enhance their decision-making performance. However, determining the proper standards and procedures to govern this assessment poses a major challenge in research involving subjects with mental retardation. Currently, there are no empirically based guidelines to help scientists evaluate research consent capacity in developmentally disabled prospective participants. Thus, researchers applying the scientific method to describe, explain, and enhance the status of persons with mental retardation may be inadequately prepared for the ethical and legal challenges associated with including persons with limited decision-making capacity in their studies,

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adequately informing such individuals of treatment risks, or seeking appropriate surrogate consent [Fisher, 1999].

This article first reviews current theory and research on informed consent policies for adults with mental retardation and then presents a relational ethics framework that re-conceptualizes consent vulnerability in terms of the goodness-of-fit between participant characteristics and the consent context [Fisher, 1999; 2003][1].

DEFINING CONSENT COMPETENCE

All persons with mental retardation are unique individuals. While some are capable of making decisions for themselves, others may lack the capacity or experience to do so. Those in the mild and moderate classifications can often speak intelligibly, comprehend the speech of others, and reason; and many have more in common with those with typical intelligence than those classified with severe (extensive) or profound (pervasive) mental retardation. Moreover, mental retardation affects a range of cognitive and adaptive abilities characterized by significant within-person variability. For example, while impaired decisional capacity is more likely to emerge as severity of mental retardation increases, cognitive levels of functioning do not directly predict differences in levels of communicative, interpersonal, or activities of daily living adaptive functioning. At the same time, many with mental retardation share limited educational opportunities and social experiences that may impact their ability to consent to research [Hill and Lakin, 1986; Ellis, 1992; Hayden et al., 1992; Cea and Fisher, 2003b].

Informed consent for research involves a series of interrelated concepts, many of which may be unfamiliar to persons with mental retardation and/or require perspective-taking, critical reflection, or recursive thinking skills that are known to be difficult for individuals with intellectual impairments. First, a prospective participant must understand that the purpose of research is to produce general knowledge and not to provide a direct benefit to the participant. Many adults without intellectual disabilities find this is a difficult concept to grasp [Appelbaum et al., 1987]. In addition, prospective participants must understand the specific purpose and procedures of the study for which they are being recruited. This may include examination of the neurophysiological correlates of mental retardation, or the efficacy of psychopharmacological agents. It may require psychological testing, observations of behavior, discussions with informants, the use of placebo, and random assignment to different arms of a randomized clinical trial. Truly informed consent also requires an understanding and appreciation of human subjects protections designed to insure participant rights including: risk-benefit assessment, confidentiality procedures, and the voluntary nature of participation.

How to judge whether an individual is competent to understand these multiple components of informed consent continues to be debated in ethical, legal, and scientific arenas [Appelbaum et al., 1987; Rosenfeld, 2002; Fisher et al., 2003]. Some have found that intellectual classifications of adults with mental retardation are predictive of global indices of consent capacity [Lindsay and Luckasson, 1991; Tustin and Bond, 1991; Morris et al. 1993]. However, few studies tell us about the particular aspects of consent that may be easy or difficult for individuals with mental impairments to understand [Arscott, 1998; Cea and Fisher, 2003b].

Reframing informed consent as a goodness-of-fit between person and consent context shifts responsibility for consent capacity away from the participant's mental status to examination and enhancement of those aspects of the consent setting that can reduce consent vulnerability.

The MacArthur Scales

Appelbaum and his colleagues have developed the most influential taxonomy for evaluating capacity to consent based on a consideration of the practical context in which clinical and legal treatment and research decisions are made. According to this taxonomy, consent competence can be evaluated in terms of four psycho-legal standards: evidencing a choice, factual understanding of issues, appreciation of the situation, and rational manipulation of information. This model has been empirically tested through the development of the MacArthur instruments for consent capacity in treatment and research [Appelbaum et al., 1999; Grisso et al., 1995]. However, at present this model has only been validated on adults with typical intelligence suffering from schizophrenia, depression, or Alzheimer's disease [Kim et al., 2001]. Thus the extent to which distinctions between psycho-legal capacities measuring choice, factual understanding and appreciation are applicable to adults with mental retardation and whether or not a standard of rational manipulation can be fairly applied to persons with developmental disabilities is an important matter for ethical inquiry and debate.

Communicating a Choice

The first and the least stringent of the four standards, is *communicating a choice*. When obtaining consent to treatment from persons with mental impairments, it is common practice to consider failure to object as an indication of voluntary agreement [Ellis, 1992]. Thus, a minimum psycho-legal standard requiring documentation that a research participant has communicated a choice orally, nonverbally, or in writing protects the individual against excessive paternalism. However, the ability to express a choice does not mean that the choice is either rational or voluntary. Thus, even for minimal risk non-therapeutic research, communicating a choice as a psycho-legal threshold for consent comprehension is not an adequate standard of consent capacity [President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982].

Factual Understanding

The second psycho-legal standard, *factual understanding*, pertains to comprehension of information about the nature, timing, and potential risks and benefits of treatment. However, for adults with mental retardation, factual understanding may not simply depend upon intellectual capacity but may be linked to the amount of previous experience with the specific procedures to be implemented and decision-making in general, and the extent to which the informed consent presentation

[1]The goodness-of-fit concept developed in this paper draws upon theories of person-context fit first proposed by Thomas and Chess [1977].

is sufficiently educative regarding research rights.

Appreciation

The third psycho-legal standard, *appreciation of the situation*, requires that an individual not only understands the procedures and risks and benefits of the research, but the personal implications of the study for his or her own circumstances. In some instances this may be difficult for persons with dual diagnosis who may understand they have a developmental disability, but lack insight into the psychiatric disorder that may be the focus of the research [Cea and Fisher, 2003a]. Some, however, have questioned whether denial of mental illness in adults with and without mental retardation is sufficient justification for a finding of incompetence [Kirk and Bersoff, 1996; Saks and Litt, 1999].

Rational Manipulation

The fourth psycho-legal standard, *rational manipulation of information*, is the most stringent, requiring the ability to calculate risks and benefits to arrive at a "reasonable" outcome of choice. Roth et al. [1977] warn that holding adults with mental retardation to such a standard presents legal and ethical problems. First, whether or not an individual can apply logical reasoning to a research participation choice does not necessarily mean that such reasoning was responsible for the final decision to consent or dissent to participation. Second, since the decision-making styles of those without mental retardation are rarely evaluated, adults with known developmental disabilities may be unfairly held to a higher standard of competency than commonly applied to the general population [Drane, 1985; Morris et al., 1993; Fisher, 1999; 2002]. Third, applying a risk-benefit analysis as the primary standard of moral agency can deny persons with mental retardation freedom of action based upon more concrete or emotional factors that are equally legitimate expressions of the rights of personhood [Merleau-Ponty, 1945; Widdershoven and Smits, 1996; Fisher, 1999; McKenzie, 2002]. Finally, holding persons to this last standard of cognitive competence has often justified widespread substitute decision-making for those with mental impairments, especially when the disabled person disagrees with the risk-benefit assessment of the investigator, the local institutional review board, or the consumer's physician or family members [Cea and Fisher, 2003b].

ENHANCING CONSENT CAPACITY

The National Bioethics Advisory Commission [1998] has called for research on procedures that can help adults with decision-making deficits attain a level of functioning to enable them to participate in a valid consent process. Yet, techniques for enhancing decisional competence for research have rarely been examined. Preliminary findings on the efficacy of brief oral, written, or video presentations on improving understanding of rights in treatment and research have been encouraging for child, adolescent, and developmentally disabled populations [Grisso and Vierling, 1978; Tymchuk, 1992; Bruzzese and Fisher, 2003].

The Roeher Institute [1996] has used a supported decision-making model to help adults with intellectual deficits exercise self-determination for health care decisions. Adults with decisional impairments are asked to select a family member, friend, or other trusted person to be present during an informed consent discussion to help review information, and together decide whether or not the individual will consent to participation. Supported decision-making is a procedure that holds great promise for investigators seeking consent from adults with developmental disabilities who do not have legal guardianship, but have established relationships of trust with others and whose competency to independently consent is questionable. For these individuals, supported decision-making can avoid the risk of triggering a legal competency review solely for the purposes of a single research participation decision [Fisher, 2002; 2003]. As new techniques for assessing and enhancing consent capacity evolve, investigators must remain sensitive to individual variation in the strengths and vulnerabilities that each person brings to the consent context.

A GOODNESS-OF-FIT ETHIC OF INFORMED CONSENT

Adults with mental retardation, like all persons, are linked to others in relationships of reciprocity and dependency [Walker, 2002]. A relational ethic calls for scientists to construct informed consent procedures based upon moral principles of respect, care, and justice guided by responsiveness to the abilities, values, and concerns of research participants and awareness of the scientists' own competencies and obligations [Fisher, 1997; 1999]. Conceptualizing informed consent competence as a product of the relationship between person and consent context shifts assessment of decisional capacity away from an exclusive focus on a prospective research participant's cognitive deficiencies to (a) an examination of those aspects of the consent setting that are creating or exacerbating consent vulnerability and (b) consideration of how the setting can be modified to produce a consent process that best reflects and protects the consumer's hopes, values, concerns, and welfare [Fisher, 2003].

From a relational perspective, morally responsible informed consent practices require actions that go beyond simply evaluating whether a prospective research participant understands the nature, risks, and benefits of procedures for which consent is sought, toward a reframing of the consent context itself. This person-context reframing involves remedial efforts to enhance consent comprehension coupled with efforts to attain mutual understandings and support among consumers, their care providers, and the investigator.

Vulnerability as a Relational Construct

A goodness-of-fit ethic views vulnerability as a relational construct [Goodin, 1985; Fisher, 1999; 2003]. Research vulnerability is defined in terms of a susceptibility to harm that does not rest solely upon the physical, psychological, or social characteristics that society views as disadvantageous, but upon the degree to which an individual's ability to provide informed, rational, and voluntary consent is dependent upon the specific actions of scientists within a specific experimental context. From this perspective both the specific susceptibility to research risks and the specific ability of scientists to help alleviate these risks defines an obligation that is morally binding [Fisher, 2003].

When developmental disability is the focus of scientific inquiry, investigators must consider the special life contexts that render prospective participants more or less susceptible to the harms associated with recruitment procedures and participatory requirements for each particular experimental design. For example, susceptibility to coercion and exploitation may be a particular risk for adults with mental retardation living in institutions or community residences with limited experience in making independent choices, or for whom acquiescence to authority has been a means of survival [Fisher, 2003].

Individuals with mental retardation and their care providers often assume permission from a non-disabled guardian

is required for consent decisions, regardless of whether guardian consent is legally mandated [Ficker-Terrill and Rowitz, 1991; Ellis, 1992]. For these persons, recruitment and consent procedures drawing upon institutional authority or the influence of legal guardians may increase their vulnerability to undue persuasion and involuntary participation [Fisher, 1999]. On the other hand, respectful and trusting relationships between developmentally disabled adults and their immediate caregivers may be a positive life feature that investigators can draw upon to reduce susceptibility to research risk [Fisher, 2003].

For research involving persons with developmental disabilities, a goodness-of-fit ethic obligates scientists to take actions that go beyond simply protecting participants from physical or psychological risks associated with research procedures. Investigators must be willing to reconfigure experimental procedures to reduce or eliminate research vulnerability. This may include re-conceptualizing traditional assumptions regarding the standards by which an individual is considered competent to give informed consent and the role of guardians in consent decisions. It may also include new ethical responsibilities, including an obligation to educate prospective participants about general and specific scientific concepts and procedures, human subjects protections, and research participant rights [Fisher, 2003]. From a relational perspective the investigator sees such efforts not in terms of paternalism or condescension [Goodin, 1985], but as contextually defined obligations of the research contract [Fisher, 2003].

ENHANCING INFORMED, RATIONAL, AND VOLUNTARY PERSON-CONTEXT CONSENT

Informed consent to research represents a mutual agreement between an investigator and participant, the validity of which rests on the requirements that the consent is informed, rational, voluntary, and competent [Faden and Beauchamp, 1986]. The informed aspect of consent requires that practitioners provide information about the purpose, procedures, potential risks and benefits, and alternative options of treatment or research sufficient for an individual to make a reasoned decision. For some individuals with mental retardation, such information may not be sufficient if they lack general knowledge about research procedures and participant rights or have not had the opportunity to make autonomous decisions. In these situations, a goodness-of-fit between person and consent context might require modifying consent procedures to include "reasonable disclosure" of practical information about general aspects of research essential for a knowledgeable decision to be made [Tepper and Elwork, 1984].

To meet the rational requirement of informed consent, an individual needs to be able to understand the information presented and appreciate the consequences to oneself of agreeing to or declining treatment or research participation. Although impairments in abstract reasoning can limit this ability, matching the language level of consent information to the prospective participant's intellectual status, repeating information, presenting information in multiple modalities, and modifying those aspects of the consent setting that may be stress-provoking for that particular individual can reduce person-context consent vulnerability. For example, providing pictorial illustrations of consent information may increase attention to and comprehension of research procedures and participant rights beyond that elicited by textual or verbally presented material.

A goodness-of-fit ethic of informed consent obligates investigators to consider how the consent setting can be modified to produce a consent process that best reflects and protects the participant's rights, concerns, and welfare.

The voluntary requirement of consent is meant to insure that individuals are not coerced into participating and are free to withdraw from research at any time. In some contexts people with mental retardation may be particularly vulnerable to coercion and exploitation. For example, they may fear disapproval from doctors or residence supervisors, or feel they must be compliant in deference to the authority of the requesting practitioner [Fisher, 2003]. Some may have little experience in exercising their rights, or if they are living in a community residence, may be fearful of discontinuation of other services. Modifying the consent setting to reduce the perception of power inequities, to provide opportunities to practice decision-making, and to construct concrete ways of demonstrating that other services will not be compromised can strengthen the goodness-of-fit between person and consent setting [Fisher, 2003].

AUTONOMY AS CONNECTEDNESS TO OTHERS

Understanding of informed consent embedded in law and federal standards is too often grounded in a narrow definition of autonomy that is limited to respect for the rights of persons to self-governance and privacy [Faden and Beauchamp, 1986]. However, the ideal of autonomy must be distinguished from the conditions for autonomous choice [Childress, 1990]. Within a relational framework autonomy need not be conceptualized as isolated or isolating [Walker, 2002], but as an expression of connectedness to others. From this perspective, when efforts to create a goodness-of-fit between the person and consent context are insufficient to insure adequate consent, individuals with mental retardation should be encouraged to select a consent partner or to yield decision-making to a consent surrogate who can help them arrive at a decision best fitting the prospective participant's wishes and concerns [Fisher, 2002; 2003].

AN INFORMED CONSENT ETHIC OF MUTUAL OBLIGATION, RESPECT, AND CARE

This article has argued for the importance of seeking goodness-of-fit between a person with mental retardation's decisional capacities and the consent context. To do so involves the creation of respectful and compassionate consent procedures. All persons are unique individuals. Thus consent procedures should be based upon an understanding of each prospective participant's special characteristics, their consent strengths and weaknesses, life experiences, and practical concerns. Such understanding can be achieved through the development of valid and individually sensitive consent assessment and enhancement techniques to insure that consent procedures reflect an ethic of mutual obligation, respect, and care. ■

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