Published in final edited form as:

Am J Intellect Dev Disabil. 2009 November ; 114(6): 401–410. doi:10.1352/1944-7558-114.6.401.

Proxy Healthcare Decision-Making for Persons With Intellectual Disability: Perspectives of Residential-Agency Directors

Kathleen M. Fisher,
Drexel University

Fredrick K. Orkin,
The Pennsylvania State University College of Medicine

Michael J. Green,
The Pennsylvania State University College of Medicine

Vernon M. Chinchilli, and
The Pennsylvania State University College of Medicine

Anand Bhattacharya
Drexel University

Abstract

Directors of residential agencies for persons with intellectual disability in one U.S. state completed a self-administered, mailed survey to assess relative importance of information sources and decision factors in proxy healthcare decision-making. The most important sources were physician recommendations and input from the person; family input, care staff recommendations, and medical records were less valued. The person's wishes and best interests and recommendations of medical experts were the most important decision factors. Less important were benefits and risks of the intervention, family wishes, and health status; little emphasis was accorded to religious affiliation and extra cost to agency. More research is needed on how best to elicit the wishes and determine what constitutes the "best interests" of these vulnerable individuals.

As the life expectancy of people with intellectual disability increases and approaches that of the general population (Foster & Turner, 2007; Sowney & Barr, 2007; Temple, Frey, & Stanish, 2006), such individuals are increasingly experiencing chronic conditions associated with aging, such as hypertension, heart disease, arthritis, mental illnesses, and obesity. Although innovations in medical science and public health have improved health throughout the general population, those with intellectual disability disproportionately experience medical problems that impair the quality of their lives (Beange, McElduff, & Baker, 1995; Fisher & Kettl, 2005; Harris, 2006; Horwitz, Kerker, Owens, & Zigler, 2000; Lennox & Kerr, 1997; Rubin & Crocker, 2006; Sowney & Barr, 2007). To address such problems, professionals inevitably must make a variety of health-related decisions. However, the principal challenge is that individuals in the intellectual disability population frequently lack the capacity to make healthcare decisions for themselves (Arscott, Dagnan, & Kroese, 1999; Cantor, 2005; Freedman, 2001). Because healthcare providers have both a legal and ethical obligation to

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Correspondence regarding this article should be sent to Kathleen M. Fisher, College of Nursing and Health Professions, Drexel University, Mail Stop 501, 245 North 15 St., Philadelphia, PA 19102-1101. kmf43@drexel.edu .

Portions of this paper were presented at the 18th annual Scientific Session of the Eastern Nursing Research Society, Philadelphia, April 2006, and the annual meeting of the Society for Medical Decision Making, Boston, October 2006.

assure consent for medical treatment (Sowney & Barr, 2007; Wong, Clare, Gunn, & Holland, 1999; Wong, Clare, Holland, Watson, & Gunn, 2000; Zimring, 2006), two issues arise: how to determine whether an individual can provide consent and how to make care decisions when he or she cannot.

Although there are no universally accepted standards for establishing the ability of individuals to consent to medical treatment (Arscott et al., 1999; Zimring, 2006), researchers and clinicians have developed a number of measures to assess decision-making capacity (Moye & Marson, 2007; Zimring, 2006). Such assessment typically involves determining an individual's ability to understand and retain relevant information, appreciate the nature and consequences of the decision at hand, and express or communicate a decision (Cantor, 2005; Foster & Turner, 2007; Johnston & Liddle, 2007; Wong et al., 1999). Additionally, the decision must be voluntary and free from coercion or other forms of undue influence (Morris, Niederbuhl, & Mahr, 1993).

Individuals with intellectual disability face several challenges that threaten to undermine their capacity to make decisions. They often have verbal and memory deficits, difficulties with problem solving, a tendency towards acquiescence and suggestibility, and problems with abstract thinking and being overly concrete (Arscott et al., 1999; Cantor, 2005; Harris, 2006; Lyden, 2006). Furthermore, an estimated 40 to 50% of these individuals have some difficulty with communication (Sowney & Barr, 2007).

Such challenges often lead to the misconception that individuals with intellectual disability lack the capacity to participate in any medical decision-making (Sowney & Barr, 2007). However, many of these individuals have sufficient cognitive capacity to engage in at least some of the decision-making process (Wong et al., 2000). Cea and Fisher (2003) compared decisional capacity among adults with no, mild, and moderate intellectual disability. They found that many adults with mild and moderate intellectual disability could consent to common and low-risk health-related treatments. Because only a small percentage of individuals with intellectual disability are severely or profoundly affected (e.g., IQ below 35), this suggests that many or most have at least some ability to participate in discussions relevant to their care (Beirne-Smith, Ittenbach, & Patton, 2002; Cantor, 2005; Harris, 2006; Lyden, 2006).

Even so, when illness occurs, individuals with intellectual disability typically depend on family members or other surrogate decision makers for a wide range of healthcare decisions, and ethical standards for such surrogate decision making have been established. If the wishes of a previously competent individual are known or had been clearly expressed at a time when he or she had decisional capacity, the task of the surrogate (or proxy) is to represent those wishes as the individual would if he or she had been able, a process known as *substitute judgment* (Leo, 1999). In the more likely scenario where the individual never had decision-making capacity (or there is no prior knowledge of their wishes), proxies are given wide latitude to make decisions based on an assessment of the individual's best interests (Cantor, 2005; Leo, 1999; Lyden, 2006). Because this process unavoidably involves value judgment and subjectivity, along with an evaluation of what a "reasonable" person might select under such circumstances (Cantor, 2005; Leo, 1999; Lyden, 2006), the role of the proxy decision maker is both important and challenging.

Adding to the complexity of the issue are the substantial differences among proxies' experience, knowledge, training, and background, which often lead to variation in healthcare decision making. For example, Freedman and Chassler (2004) found significant differences in the provision of preventive services according to the place of residence (e.g., parent/relative home, community residence, institutional facility). Specifically, dental and physical exams were less likely when individuals lived with a parent or relative, and gynecological exams were

less likely when females lived with a parent or relative compared to other community-based settings.

This combination of dependence on proxies and variation in decision making contributes to the vulnerability of individuals with intellectual disability. As this population ages, nonfamily caregivers are increasingly called upon to assist with healthcare decision making, a situation exacerbated by a deinstitutionalization movement that has resulted in a large and growing number of individuals moving into community-based systems (Braddock, Hemp, Rizzolo, Parish, & Pomeranz, 2002). In this context, directors of residential facilities where individuals live often become default healthcare decisions makers and are empowered to make a myriad of healthcare treatment decisions and provide consent for medical treatments and procedures. As the number of individuals residing in community housing increases (Braddock et al., 2002), the role of proxy decision makers will continue to expand.

Despite the central role of proxies in decision making, few investigators have explored how these surrogates make decisions on behalf of individuals with intellectual disability. On what do they base their decisions? What sources of information do they find valuable? What factors in the decision do they rely upon? Do they include the individual in the decision-making process? What obstacles do they face in making critical decisions? Such questions led us to explore the process by which proxies make medical decisions for individuals with intellectual disability. Because we were particularly interested in learning about agency directors who cared for individuals in community residential settings, we focused on the following issues for agency directors in one state in the United States: (a) the characteristics of the proxy decision makers and their settings, (b) the perceived importance of information sources that informed their decision making, (c) the relative importance that proxies attributed to various factors used in their decision making, and (d) whether and how they involved the individual with intellectual disability in the decision-making process.

Method

Participants

Our study population was the universe of licensed residential-agency directors for persons with intellectual disability in Pennsylvania, a state whose population-health characteristics are generally similar to those of the other states in the United States. We identified 262 agencies in an Internet-based index of mental retardation/developmental disability providers in the state (Web index, 2000). To verify that our list was complete and accurate, we compared it to lists provided to us by the state's healthcare quality units, which are overarching administrative entities that maintain independent lists.

Materials

A self-administered survey instrument (available from the first author) was developed by the investigative team with the assistance of both a literature review and an expert panel of nurses with training and clinical experience in intellectual disability. The panel reviewed the instrument for face validity, and the survey underwent several iterations and pilots before the investigative team agreed on a final version. An initial section covered each agency director's demographic characteristics and intellectual disability-related experience, including length of time working in the field, length of time as a decision maker, and number of clients with intellectual disability for whom the agency provided services. Then, using a five-point, graduated Likert-type scale, we asked directors to indicate their level of confidence that their healthcare decisions were aligned with what their clients would want, how emotionally burdensome the decision-making process was for them, how often they involved the individual

with intellectual disability in decision-making, and the relative importance of 13 information resources and 25 specified decision factors in their decision-making.

Design and Procedure

Upon approval from participating universities' institutional review boards, we followed Dillman's tailored design method (Dillman, 2000) in designing and distributing the survey. One week prior to the survey mailing, each director received a letter describing the project and alerting him or her to the imminent arrival of the survey. Next, we mailed the survey and included a prepaid return envelope and \$5 to thank participants for their time. Two weeks later, we sent a second survey to nonrespondents.

Analysis

Survey responses were entered into a computer-based spreadsheet, verified (a 5% sample of spreadsheet entries was compared to written survey responses), and then analyzed. Summary statistics were computed and rankings of "importance" were prepared for both the 13 information sources and the 25 decision factors. We used exploratory factor analysis to distill the Likert-type ratings of the 25 decision factors into a smaller number of broad categories or latent domains of "importance" for the directors' decision making. To obtain this simpler structure, we used a principal-components method with an orthogonal (varimax) rotation that would provide a solution with minimal or no correlation among domains. We also allocated the directors to subgroups whose members shared a decision-making pattern identified by applying cluster analysis to their ratings. We then explored the possible relationship between subgroup assignment (decision-making pattern) and experience (director's age, years working with individuals with intellectual disability, years in proxy decision-making role) with ANOVA.

Results

Survey Response

From 262 state-licensed facilities surveyed, 158 useable forms were returned (60% response). In addition, we received 14 blank surveys and another 20 agencies were removed from the final sample because the addressees indicated that administrators were not involved in healthcare decisions ($n = 18$) or the envelopes had incorrect addresses ($n = 2$). Thus, the results reported here reflect 158 sets of responses.

Characteristics of Respondents

The directors were middle-aged, white, and mostly female. They reported many years of experience with individuals who have intellectual disability and with the role of proxy healthcare decision maker (see Table 1).

Characteristics of Residential Settings

Respondents reported a wide variation in the number of persons (0 to 1,200) served by each agency at the time of survey completion. The directors' agencies administered a variety of living arrangements, with the most prevalent being group homes and supervised apartments; most agencies reported several types of arrangements (Table 1).

Proxy Healthcare Decision-Making Experiences

Almost half of responding agency directors reported that they made surrogate healthcare decisions at least once each month. The great majority of directors indicated that they *always* or *usually* involve the person with intellectual disability in the decision-making process, usually in a one-on-one discussion (95%) and often with videotapes (46%). Although a

similarly great majority of directors also felt *extremely* or *very* confident that their decisions are aligned with what they perceive the person would want, the directors found decision-making emotionally burdensome in varying degrees (Table 2).

Information Sources Perceived Important in Proxy Healthcare Decision Making

Table 3 lists the relative importance of 13 information sources available to support the directors' decision making. Physician recommendations (rated *very Important* by 83%) and input from the individual with intellectual disability (80%) were regarded as most valuable, with family input, nurse and other care staff recommendations, medical records, and other written materials (47 to 62%) deemed less important. Least helpful were a variety of sources external to the residential setting.

Factors Perceived as Important in Proxy Healthcare Decision Making

The exploratory factor analysis, based on 123 complete sets of directors' ratings of the 25 decision factors, unraveled the correlations among their ratings: seven latent domains with eigenvalues greater than 1.0 and containing two thirds of the statistical information (variance) in the set of ratings were identified. Table 4 presents the domains and decision-factor correlations following rotation; each domain is moderately or highly correlated with one or several factors (boldfaced values with correlation $> .4$) that have minimal correlation with the other factors that are highly correlated with other domains. Using the underlying factors as a guide in naming the domains, we found that the seven domains are the person's health status, characteristics of the intervention, person's prognosis, religious affiliation, family wishes and involvement in decision-making, expert advice, and best interests and wishes of the person.

Table 5 rank orders the relative importance of the 25 factors in the decision-making process by the proportion of assessments rated as *very important* on the Likert-type scale. Directors placed greatest emphasis on factors characterizing the perceived wishes of the person, the person's best interest, and the recommendations of medical experts (all rated *very important* by 84 to 85%). Lesser weight was accorded the benefits and risks of the intervention, wishes of family, and the individual's health status; little emphasis was placed on the individual's religious affiliation, the logistics of the health intervention, and the extra cost to the agency of the intervention.

Cluster analysis facilitated allocating the 123 directors with complete ratings of the 25 decision factors to several subgroups (3 to 6) having similar decision-making patterns; however, the patterns were not markedly different, regardless of the number of subgroups used. Mean years of experience, whether characterized as age, years working with individuals with intellectual disability, or years having a proxy decision-making role, did not differ by subgroup (decision-making pattern).

Discussion

We surveyed agency directors overseeing residential homes where proxy healthcare decisions are commonly made on behalf of individuals with intellectual disability. To make such decisions, proxy decision makers said they relied principally on physician recommendations and input from the person with intellectual disability. To a lesser extent, they used input from the family. They placed little emphasis on information sources external to their settings, such as other directors' opinions or educational materials. When ranking specific factors used in their decision making, they placed greatest emphasis on their perception of the client's wishes, what they perceived to be the client's best interests, and physician recommendations. Although the directors did consider the benefits and risks of the proposed healthcare intervention, family input, and the client's health status, they noted that they did not rely on considerations external

to the client's well-being (e.g., logistics of intervention, extra cost to agency) when making proxy decisions. Thus, these directors' avowed decision making was other-oriented, emphasizing the needs and wishes of their clients over most other considerations.

Our survey illustrates the challenge of proxy decision making, which inevitably requires the decision maker to make healthcare choices for individuals who lack the ability to make autonomous decisions on their own behalf. Although proxy decision makers may indicate that they value their clients' wishes over all other considerations, knowing their wishes is not simple. For example, Sowney and Barr (2007) found that in the emergency environment, the biggest perceived challenge faced by nurses caring for people with intellectual disability was communicating effectively with them. In the absence of standardized and valid measures for assessing wishes, proxies (as well as healthcare providers) must deduce the desires of the individual. Time, experience, and familiarity with the individual certainly helps, but in healthcare settings, these are typically scarce commodities.

For such reasons, proxies often resort to decisions based on the perceived "best interests" of the individual, but doing so carries its own set of risks. Best interests are difficult to determine and inevitably involve value judgments and assessments about what matters most (presumably to the decision maker), which can be difficult when one does not (or cannot) know the individual's preferences, goals, and aspirations. Relying on physician recommendations has its appeal because doctors have clinical experience regarding prognosis and likely outcomes, but their medical training does not qualify them to judge whether a particular set of outcomes should be considered more desirable than any other, and physicians are also at risk for interjecting their own values and preferences into the decision-making process.

Thus, proxies might benefit from guidance about how to make these difficult decisions. Determining another person's best interests is difficult under the best of circumstances, but when that other person has chronic medical problems, limited communication, and little understanding of the rationale for a healthcare intervention, this task can be daunting. One way to cope with this uncertainty is to focus less on the outcome of decisions and more on the process. Procedural fairness in this context depends on input from physicians, a balance of burdens and benefits, and participation of stake-holders. Although doing so does not assure a good outcome, it does share the burden of decision making and reduce the isolation of these decisions.

Relying on a process-driven approach to determining best interests gives rise to a number of questions. For example, what constitutes a person's best interests and how is this determined? Are such judgments made by intuition, by a systematic analysis, or by some other method? To what extent do proxies interject their own values and preferences into the decision-making process? How do they decide when they are not able to determine the person's preferences or best interests? Is their decision making affected by the nature of the healthcare decisions (e.g., routine care vs. end-of-life care)? Although such questions were not addressed in this study, future researchers could help clarify these aspects of decision making by proxy for this vulnerable population.

Another interesting finding was that families had relatively little input in the proxy decision-making process. This is contrary to healthcare decision making for the rest of us. When a previously competent individual becomes unable to make an immediate decision in medical care, typically substituted decision making is made by next of kin or family members. The relative absence of family input into decision making for individuals with intellectual disability living in community agency settings is curious and needs further investigation. Although absence of family input may merely reflect separation from the residents of these community agencies, other factors may be involved as well. This issue also warrants further investigation.

Limitations

This study has several limitations. Our survey was limited to agency directors and may not be generalizable to other decision makers, such as family and healthcare personnel. We conducted the study in one state (albeit rather representative of the United States), and it is possible that if conducted in other states and geographical areas, different results might be obtained.

Although the survey response rate of 60% was reasonably high and is consistent with that of other health-related surveys reported in the medical literature (Asch, Jedrzejewski, & Christakis, 1997), we know nothing about the beliefs or characteristics of the 40% of agency directors who did not respond. In addition, the survey relied on self-report, without direct observation. Although we know what directors *say* they do, perhaps they were providing socially desirable responses (self-report bias); we were not able to ascertain how they actually make decisions for individuals with intellectual disability. Our inability to relate directors' decision-making patterns to their experience may reflect the homogeneity of the directors' demographics, perhaps a limited sample size, or true lack of such a relationship. Finally, we focused on individuals with intellectual disability living in community settings and, thus, did not include those residing in nursing homes or mental health institutions, where disease severity may be greater and other influences on proxy decision making may be at play (Rimmer, Braddock, & Marks, 1995).

Despite these limitations, this study provides valuable new information about proxy decision makers, the settings in which they work, and how they say they make decisions on behalf of individuals with intellectual disability. The main factors that agency directors use in making decisions are the individual's wishes, best interests, and the advice of physicians. More research about how best to elicit those wishes and what constitutes the best interests of individuals with intellectual disability are needed.

Conclusion

Healthcare decisions made by agency directors on behalf of individuals with intellectual disability are based largely on three factors: what the individual would want, what is in the best interest of the individual, and medical input from physicians. Little information is available for two of these factors, namely, how proxies determine what the individual wants and what constitutes the best interest of a person with intellectual disabilities.

As individuals with intellectual disability acquire chronic medical illnesses, healthcare decision making by proxy will become increasingly common. Consequently, it is imperative to understand the process of proxy decision making, with the goal of developing guidelines to improve the quality and consistency of the healthcare delivered to this vulnerable population.

Acknowledgments

This paper was supported by National Institutes of Health Grant NINR 5R21NR008798-02. The second author is now an adjunct faculty member in the Department of Anesthesiology, Yale University School of Medicine.

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Table 1

Characteristics of Respondents and Residential Settings Overseen by Their Agencies

Characteristic	Mean ^a /%	Range
Respondent		
Mean age	49.1	47.7–50.5
Gender (% female)	53.5	
Race/ethnic group (%)		
White	95.1	
Black or African American	2.8	
Hispanic or Latino	0.7	
Asian or Pacific Islander	0.0	
American Indian or Alaskan Native	0.0	
Other	1.4	
Mean time working with individuals who have ID ^b	20.9	19.3–22.4
Mean time as proxy healthcare decision maker	9.0	7.8–10.3
Setting		
Mean no. of individuals receiving services	126	92.5–160.1
Living arrangements provided by each agency (%)		
Group home	91.7	
Family living	49.0	
Supervised apartments	45.5	
Intermediate care facility	16.9	

^a95% confidence interval.

Table 2

Characteristics of Proxy Healthcare Decision-Making Process by Respondent

Characteristic	%
Frequency of such decision making	
Daily	12.1
Weekly	15.0
Monthly	20.7
A few times a year	40.0
Annually	12.1
How often do you involve the individual with intellectual disability in the process?	
Always	51.8
Usually	31.2
Sometimes	13.5
Seldom	3.5
Never	0.0
How confident are you that decisions are aligned with what individual with intellectual disability would want?	
Extremely	22.8
Very	58.9
Somewhat	14.9
A little	0.7
Not at all	0.0
How emotionally burdensome is this decision-making process?	
Extremely	14.2
Very	28.2
Somewhat	39.0
A little	10.6
Not at all	7.8

Table 3

Relative Importance of Information Sources in Proxy Healthcare Decision Making

Information source	% rating source as <i>very</i> <i>important</i>
Physician consultant	83
Input from individual with intellectual disability	80
Medical records	62
Nurse consultant	56
Family input	54
Residential care staff	49
Written material or health education information	47
Patient advocate	29
Contact with state agencies	25
Healthcare quality units	22
Internet	14
Other residential agency director or substitute healthcare decision maker	12
Video tapes	9

Table 4
Factor Analysis of Decision Factors: Correlation Matrix of Rotated Factor Loadings by Putative Domain

Decision factor	Putative domain						
	1	2	3	4	5	6	7
Person's health status		Characteristics of intervention	Prognosis	Religious affiliation	Family wishes & involvement	Expert advice	Person's best interests & wishes
Assessment of best interest	.33	-.04	.13	-.00	-.01	.04	.74
Knowledge of individual wishes	.09	.09	.04	.11	.52	-.35	.58
Opinions of other team members	.06	.14	.06	-.07	.28	.66	.13
Recommendations of medical experts	-.03	.22	.18	.17	.11	.61	-.09
Wishes of family	-.08	.07	.08	.19	.71	.25	-.02
Guidelines from state policies/regulations	.36	-.32	.02	.08	.22	.47	-.15
Individual's level of functional ability	.69	.16	.12	.09	.17	-.14	-.01
Individual's level of health	.79	.17	.12	-.04	-.12	.19	.13
Individual's other medical problems	.78	.13	.04	-.00	-.03	.35	.14
Individual's level of agitation	.80	.19	.16	.18	.02	-.06	.10
Presence of depression	.71	.25	.12	.29	.11	-.01	.18
Age of individual	.62	.41	.09	.17	.00	-.01	.21
Individual's quality of life	.26	.34	.08	.40	-.21	.11	.42
Involvement of family members	.09	.15	.12	.02	.78	.22	.02
Presence of barriers to accessing services	.42	.44	.16	.39	.05	-.02	.07
Religious affiliation of individual	.11	.08	.21	.89	.7	.01	.05
Religious affiliation of family	.25	.15	-.22	.72	.37	.15	-.04
Individual's prognosis	.19	-.05	.67	.06	-.07	.25	.20
Agency cost for treatment	.31	.70	-.15	.11	.12	.01	-.17
Individual's ability to cooperate with treatment plan	.48	.47	.33	.20	-.03	.11	.21
Complexity of intervention	.30	.67	.11	.03	.13	.24	.33
Risk of intervention	.16	.51	.48	.20	.01	.15	.17
Potential benefit of intervention	.07	-.02	.76	-.05	.15	.10	.09
Length of treatment	.34	.65	-.02	.08	.28	.11	-.18
Ability of individual to provide consent	.27	.16	.67	.17	.17	-.21	-.31

Note. Boldface numbers are significant factor loadings.

Table 5**Relative Importance of Decision Factors in Proxy Healthcare**

Decision factor	Rated very important
Your knowledge of the individual's wishes	85
Your assessment of what is in the individual's best interest	84
Recommendations of medical experts	84
Potential benefits of the proposed intervention	71
Individual's quality of life	66
Wishes of the family	63
Risks of the proposed intervention	61
Opinions of other team members	55
Individual's prognosis	54
Individual's general level of health	53
Involvement of other family members	50
Guidelines from state policies and regulations	50
Individual's other medical problems	49
Individual's level of functional ability	46
Ability of the individual to provide informed consent for the intervention	40
Spiritual beliefs and/or religious affiliations of the individual	39
Complexity of the proposed intervention	36
Presence of barriers to accessing services	34
Individual's level of agitation	34
Individual's ability to cooperate with the treatment plan	33
Presence of depression	29
Age of the individual	23
Spiritual and/or religious affiliations of the individual's family	22
Length of treatment or number of healthcare visits	21
Costs to the agency for treatment (beyond any insurance coverage)	11