Published in final edited form as:

J Intellect Dev Disabil. 2009 September ; 34(3): 258–265. doi:10.1080/13668250903083332.

A content analysis from a US statewide survey of memorable healthcare decisions for individuals with intellectual disability

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Abstract

Background—Little is known about surrogate healthcare decision-making for individuals with intellectual disability (ID). This study examined healthcare decision-making by residential-agency directors to learn their process and the extent to which the individual is included.

Method—Content analysis of qualitative data from a mailed survey of residential-agency directors in a large US mid-Atlantic state.

Results—Narrative comments of 102 directors (65% of respondents) are reported. Three themes emerged: (a) Identifying someone else's "best interest" is challenging; (b) Perceptions of the healthcare community, especially related to quality of life, can influence care provided; and (c) Surrogate decision-making is a team effort.

Conclusions—With knowledge of how decisions are made, the healthcare community can better interact with the complex array of service agencies and persons who determine care for this vulnerable population.

Keywords

surrogate healthcare decision-making; intellectual disability; healthcare decision-making; qualitative methods; content analysis

Background

One of the most successful health advances in the United States during the second half of the 20th century has been the increase in life expectancy of persons with intellectual disability (ID). Improvements in public health, medicine, education, technology, and scientific research have all contributed to progress in healthcare and increased longevity for those with ID (Harris, 2006). As their life expectancy increases (Temple, Frey, & Stanish, 2006), there is a growing population of older adults with a growing list of chronic medical problems. The life expectancy of these older adults has risen to 66.1 years, and younger adults, especially those who do not have severe disabilities and significant medical comorbidities, now have a comparable lifespan to their peers in the general population (Hartley & MacLean, 2007). Down syndrome, the most common genetic and the first intellectual disability described, has experienced dramatic changes in life expectancy, with some individuals now living into their 70s (Harris, 2006).

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This work was presented in part as a paper presentation at the Council for the Advancement of Nursing Science, 2008 State of the Science Congress on Nursing Research in Washington, DC, on 4 October, 2008.

As individuals with ID age, they confront the same chronic illnesses that affect the general ageing population, including heart disease, hypertension, diabetes, arthritis, and stroke (Harris, 2006; Rubin & Crocker, 2006). In addition, these individuals are at higher risk for obesity, epilepsy, thyroid disease, visual impairments, and oral disorders (Harris, 2006), but they continue to have less access to quality healthcare than the general population. Such issues were identified in the recent report, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* (U.S. Department of Health and Human Services, 2002), which emerged from the U.S. Surgeon General's conference on Health Disparities and Mental Retardation.

Concurrent with this trend has been the deinstitutionalisation movement implemented in the 1960s to improve the quality of life for those with ID and encourage their transfer into community-based facilities. As a result, nationwide the number of individuals with ID living in nursing facilities and institutions has decreased steadily and the proportion of individuals with ID living in group homes has continued to increase. In the year 2000, 61% (263,359 residents) were living in group homes compared with 29% (34,743 residents) in institutional placements (Braddock, Hemp, Rizzolo, Parish, & Pomeranz, 2002). Persons with ID now live in diverse community settings, often needing assistance and supervision with decision-making and routine activities of daily living.

Surrogate decision-making

In these varied residential environments, persons with ID increasingly require decisions to be made on their behalf for a variety of health-related issues (Rubin & Crocker, 2006). So-called surrogate decision-making—decisions made on another person's behalf—are difficult and profoundly challenging, especially for individuals with long-term inability (decisional capacity) to express an informed choice (Lyden, 2006; Rich, 2002; Wong, Clare, Holland, Watson, & Gunn, 2000). While surrogate decision makers may value their clients' wishes, it is often challenging to know what they want, and surprisingly little is known about how surrogates make healthcare decisions for this highly vulnerable population.

Problems with communication make consent difficult, if not impossible (Rubin & Crocker, 2006). One study noted that in the urgent-care environment an estimated 40–50% of individuals with ID had difficulty with communication (Sowney & Barr 2007). Cognitive limitations, lack of information and support appropriate to their needs, and limited experience with making choices are all challenges to effective decision-making for persons with ID (Freedman & Chassler, 2004). But, while it is often assumed that these individuals lack the ability to participate in *any* medical decision-making (Sowney & Barr, 2007), many have enough cognitive capacity to engage in at least some of the decision-making process (Wong et al., 2000). In one study comparing decisional capacity among adults with no, mild, and moderate ID, adults with mild and some with moderate ID could consent to common and low-risk health-related treatments (Cea & Fisher, 2003). Since only a small percentage of individuals with ID are severely or profoundly impacted (e.g., IQ below 35), this suggests that many or most have at least some ability to participate in discussions relevant to their care (Cantor, 2005; Harris, 2006; Lyden, 2006). How often and to what extent the individual with ID is included in decision-making is unknown, as there has been little research in this area. In general, research has been limited by concerns about including “vulnerable” populations as subjects in research studies (Levine et al., 2004). Clearly, people with permanent cognitive impairments, such as those with profound ID, require special protections for inclusion in research (Levine et al., 2004), as issues with decisional capacity and consent will be problematic.

The ethical standards that inform surrogate decision-making include the use of “substitute judgment” and “best interest.” Substitute judgment requires the surrogate to draw on their knowledge of the person's values and priorities to make decisions as the person would (Rich,

2002). Recognising that this standard can rarely be met for individuals who have never had decision-making capacity, most courts allow the surrogate to make decisions based on what would be in the “best interests” of the person (Rich, 2002). Application of a “best interest” standard requires that healthcare decisions are based on the patient’s interests, as assessed by a “reasonable person” (Cantor, 2005), allowing for considerable judgment and leeway on the part of the surrogate.

While the standards for surrogate decision-making have been clearly articulated in the ethics and legal literature, little is known about how surrogates actually make healthcare decisions for this highly vulnerable population. Consequently, we surveyed residential agency directors, a group who are frequently required to make decisions on behalf of individuals with ID. The survey was conducted in Pennsylvania, a state whose population-health characteristics are generally similar to those of the US (U.S. Census Bureau, 2009). The state’s *Office of Developmental Programs* provides guidance for decision makers in the form of a bulletin entitled, *Procedures for Substitute Health Care Decision Making*. According to this document, which was issued in 1998 and still in effect at the time of this study, the choice of a surrogate decision maker for individuals with ID who are over the age of 18 should follow a strict hierarchy: (a) the health care proxy or attorney, (b) court-appointed legal guardian, (c) next of kin, and (d) the agency director (Mental Retardation Bulletin #00-98-08, 1998). In the absence of an appointed surrogate decision maker or willing next of kin, the facility director becomes the decision maker in this state, based on the Mental Health and Mental Retardation Act of 1966 (MH/MR Act, 1966).

Study purpose

The purpose of this study was to explore how residential-agency directors who serve as surrogate decision makers for individuals with ID make decisions for and with their ID clients. We posit that with increases in life expectancy and ageing, many with ID will outlive their family caregivers and will increasingly need community-residential agency placement. Increasingly, their healthcare decisions will be made by surrogate residential-agency directors. As part of a larger project on surrogate decision-making, we asked agency directors several open-ended questions about their approach, and here we report our findings from an analysis of their narrative comments. The quantitative aspects of the survey are reported elsewhere (Fisher, Orkin, Green, Chinchilli, & Bhattacharya, 2009).

Methods

After receiving Institutional Review Board (IRB) approval, we surveyed directors of licensed residential facilities for individuals with ID in a large US mid-Atlantic state. The sample included all residential agencies listed in *The Web Index of Mental Retardation/Developmental Disability & Other Service Providers in Pennsylvania* (Pirmann, 2000). We compared this list to others maintained by the state’s overarching administrative entities (Health Care Quality Units) to verify the Web Index for accuracy.

Development and management of the survey

The research team developed an exploratory descriptive survey that was reviewed for face validity by a panel of five nurses with training in ID. The survey included an open-ended question asking respondents to describe a memorable decision they made for an individual with ID. In addition, respondents were asked to describe other influences on their decision-making which were not specifically addressed in the survey. Additional comments were sought, and responses to these open-ended questions comprise the qualitative data that were analysed in this study.

In conducting the survey, we followed Dillman's Tailored Design Method (Dillman, 2000). 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 a five-dollar bill to thank participants for their time. Two weeks later, we sent a second survey to non-respondents.

Analysis of the qualitative data

Written responses to the three open-ended questions were transcribed verbatim and were coded, aggregated, and analysed as anonymous group data to maintain confidentiality. Three nurse researchers, experienced in qualitative data analysis and in working with people with ID, examined and coded the narrative data independently and concurrently; they iteratively reviewed and modified their categories using content analysis, until consensus was reached on identified themes. Content analysis organises subjective descriptions of feelings, behaviours, and experiences into non-overlapping meaningful categories. The categories were developed through a process of identifying and coding the primary patterns from ideas found in the narrative data, each of which reflected distinct themes (Macnee & McCabe, 2008; Polit & Beck, 2008).

Emerging themes were validated by having individuals who initially coded data and another nurse researcher reach agreement on all thematic categories. In addition, preliminary findings of these qualitative data were presented at a disability nurses' continuing education meeting for discussion and feedback. In attendance at these meetings were nurses from the Health Care Quality Units who have responsibilities for health promotion and capacity building in community agencies that provide services and residence for those with ID. In their consulting role with agency directors, they assist in assembling information, researching health conditions, and interpreting health care language and reports for the residential agency team. This corroboration is used in qualitative analysis to give confidence in the validity of the data and is referred to as "investigator triangulation," which requires more than one investigator to analyse data through consensus between or among investigators (Russell, 2003) or experts in the field.

Results

Response rate

From 262 state-licensed facilities surveyed, 158 useable forms were returned (60% response). In addition, 14 blank surveys and another 20 agencies were removed from the final sample because the mailing addresses were either incorrect or the agency no longer served the target population.

Summary of quantitative results

Characteristics of the respondents and their settings—The mean age of the respondents was 49 years (range 41–56), 95% were Caucasian, and 53% were female. The respondents were experienced: mean number of years working with ID was 21 years (range 12–30), and they spent on average nine years in their role as agency director (range 2.8–16.2). Their agencies administered a variety of living arrangements, with the most prevalent being group homes and supervised apartments. There was wide variation in the number of persons served by each director's agency at the time of survey completion (0–1200 clients) (Table 1).

As reported elsewhere in greater detail (Fisher et al., 2009), the vast majority of respondents rated the following three factors as "very important" in their decision-making process: the wishes of the individual (85% of respondents), assessment of the individual's best interest (84–85%), and recommendations of medical experts (84%). Less emphasis was placed on benefits

and risks of the intervention (61–71%), wishes of family (50–63%), and the individual's health status (29–53%), and little emphasis on religious affiliation (22–39%), and extra cost to the agency beyond what the individual's health insurance covered (11%).

Qualitative findings

Surveys from 102 agency directors (65% of respondents) included a written response to one or more of the open-ended questions. If an individual responded “no” or “none” to one of the questions, we counted this as a response; however, if a question was left blank, it was not counted as a response.

Recall of a memorable surrogate healthcare decision

Directors were asked to describe a memorable example of a healthcare decision in which they included an individual with ID in the process. Responses ranged from brief descriptions of experiences such as “decided against aggressive further care with an elderly consumer” or “obtaining dental care” to detailed accounts of decision making. In all, there were 90 responses to this question, including descriptions of dental (3 comments), medical (18), and surgical (21) procedures, and decisions related to cancer care (8), kidney disease (4), end of life care (6), and residential placement issues (7).

The following representative response describes the process of using a supportive team approach to involve the individual with ID in decision-making:

We recently dealt with an individual regarding an issue of obtaining treatment (chemotherapy and radiation) for esophageal cancer. We met with the individual, family, team, hospice, physician and nurses regarding the inoperable tumor that presented itself during a routine examination. Since this individual has Barrett's Esophagus and Cornelia de Lange syndrome along with a Peg tube for feedings, it was determined that surgery was not an option based on the size and location of the tumor. The individual along with the entire team met several times regarding treatment, diagnosis and prognosis. The individual and his family were fully informed and supported regarding the decision-making process.

Family involvement in the decision-making process varied, sometimes easing and sometimes adding to the burden, as expressed by these three representative responses:

Family involvement tends to limit an agency's involvement in making the decision. This is the case even when the family member has not been an active team member supporting the individual.

Fortunately to date family members and/or individual with ID have been available and able to participate in health care decisions.

The hardest part in doing this is when there are no family members to help discuss the appropriate decision to be made. I sometimes second guess myself.

The decision-making burden was summarised by one director in the following comment:

The most important decision is always trying to determine what the individual would want especially if they can't communicate effectively and if there is no family and how the decision will affect their quality of life. One never wants to make a decision that goes against who they are just because medical or other people feel it is the right thing to do medically.

Thus, surrogate decision makers described a variety of characteristics of memorable decisions. These included a wide variety of medical illnesses, a shared decision-making process, varied

family involvement, and attempts to include the individual with ID in the decision-making process.

Other issues influencing the decision-making process

The second open-ended question asked respondents to describe issues that influence their decision-making process which were not otherwise included in the survey. Sixty-five directors responded to this question. Common concerns and influences included legal issues, ageing, and care in terminal conditions; general misunderstanding related to ID; and negative attitudes on the part of physicians, hospitals, and care staff. Table 2 presents selected salient written statements representative of additional concerns of agency directors.

Themes emerging from content analysis

Three themes emerged from the content analysis: (a) Identifying someone else's "best interest" is challenging; (b) Perceptions of the healthcare community, especially related to "quality of life," can influence the care provided; and, (c) Surrogate decision-making is a team effort.

Identifying "best interests."—It was apparent that identifying a person with ID's "best interests" can be quite challenging. As one director noted, "clients with ID often do not make the best healthcare decisions for themselves, usually out of fear of the needed procedure." Further, impaired cognitive ability may limit these individuals from participating in the decision-making process. Still, directors emphasised that they placed great importance on representing the person's wishes when making a decision for them and with them. Their responses also reflected conflicting opinions of family members, providers and the individuals themselves in trying to identify what "best interest" really means, as evidenced in the following remarks:

An individual needed eye surgery to correct a vision problem. The individual's family felt the surgery would cause him pain and was unnecessary because "he sees well enough for the life he lives." Residential staff and medical personnel felt he was not seeing as well as he could be seeing. The individual is unable to speak for himself, so we made the decision to have him have the surgery. The surgery was successful and the individual became more mobile because of being able to see better.

A 62 year old male with Parkinson's required kidney dialysis due to kidney failure. After speaking with the individual it was determined that he felt well overall with the therapy and that he enjoyed his life. He did not mind going to the hospital and was cooperative with the treatments. The consent was signed to initiate the dialysis even though the physician questioned the advisability of this therapy. The gentleman lived to enjoy another Christmas with his friends.

Some people are unable to understand, so even when included with discussion, they don't have ability to indicate one way or the other.

Healthcare providers' perceptions—The second theme—that perceptions of the healthcare community regarding quality of life can influence care provided—reflected the concerns of agency directors that the stigma associated with the diagnosis can impact medical care and access to services. This is illustrated in the following written responses:

We also encountered nursing staff who did not recognize that quality of life does not necessarily mean recovery to a state beyond his previous level of health. It was often difficult to make them understand that he had indeed progressed and was on the road to FULL recovery. They could not understand what FULL recovery would be for him not having known him before his illness.

It is a “need” for hospitals to become educated on individuals with Intellectual Disability and the ID system. Doctors, hospital social workers, etc. must realize that individuals with ID deserve the same treatment as others in their facility. They must also become aware of the various regulations that involve our ID citizens regarding medical treatment.

Many agency directors noted that healthcare providers often presume that individuals with ID have a poor quality of life. Ultimately, they felt, this belief affects the quality of care they received. To the directors, such a mindset not only compromises individuals’ chances of receiving optimal care, but also compounds the challenges of making surrogate decisions. As this director surmises:

All too often physicians felt that individuals who are intellectually disabled do not have “quality of life” and they base their decisions accordingly. Substitute healthcare decision makers must consider if the individual’s quality of life can be maintained with appropriate treatment.

A team effort—The final theme—surrogate decision-making is a team effort—frequently emerged through descriptions of the importance of a shared, collaborative process. It was clearly explained by one director who stated, “There is really never a decision that is made by one person who is the decision maker—it is always a team decision.” In addition, there is an expressed understanding of individual wishes and a suggestion that experienced staff, functioning as “family” can represent individual wishes even when the individual is identified as “incompetent” or is unable to provide input, as reflected in the following two examples:

Most recently a person for whom we cared for more than 24 years was transferred into hospice care with less than 1 month to live. She had no family (other than us) and the healthcare provider deemed her incompetent to give informed consent. I personally have known her for 17 years and the staff where she lived until hospitalization also have known her for 20 years. It was clear in many ways that she did not want further treatment that would prolong her death by 3–6 months. We [name given], the Doctor, the social worker, the staff, discharged her home. All agreed to a DNR and hospice placement. As during her hospital stay we would visit every day to comfort her and provide support and love until she passes.

Unfortunately to this point each case has been with someone who has not been able to provide input. The input from the individuals who know the person best was considered—the staff, the family—the people who were best able to interpret the individual’s feelings about what was happening. Because staff know the individuals so well, we felt we were complying with what they would want.

Thus, many directors advocated for greater understanding of ID as well as the decision-making process, while promoting a good “quality of life” and improved training on legal issues for directors, support staff, hospitals, and healthcare providers. As requested by one director: “I would like to see increased training opportunities around substitute healthcare decision-making —[surrogate decision making] is not something that I fortunately have to do too frequently, but depending upon circumstances do not always feel well prepared for [legal issues].”

Discussion

This study identified some of the real-world challenges faced by agency directors when making healthcare decisions for and with individuals with ID. They described a team approach to decision-making that included input from the individual but inconsistent support from the family. They confronted negative perceptions from the healthcare team and expressed feeling burdened when needing to make decisions based on the “best interests” of another person.

Directors said they included the individual with ID in the decision-making process to “the best of their ability,” yet many individuals with ID had limited capacity to participate. Artnak (2008) points out the difficulty of caring for decisionally incapable persons, especially those who lack advance care documents and no living relatives to speak for them. The decision maker and healthcare providers, while attempting to plan care in the best interest of people with ID, can be faced with a number of less than ideal options (Artnak, 2008).

Directors remarked that they attempted to provide thorough explanations and education related to healthcare decisions, and they sought input from the individual with ID, their family (when available), the medical staff, and direct care-team members. A team approach to shared decision-making was highly valued, but it was often difficult to reach consensus among all parties.

While a team approach may reduce decision-making burden, it also raises a number of questions. For instance, how do surrogate decision makers know the person’s wishes? By what methods do they elicit such wishes, and how reliable are they when the person lacks decision-making capacity? Likewise, 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 surrogates 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 decision (e.g., routine care vs. end-of-life care)? While such questions were not directly addressed by this study, future research could help clarify these aspects of decision-making by surrogates for this vulnerable population.

The qualitative findings also suggest that the healthcare community could benefit from additional education about the needs of this vulnerable population. Individuals with ID are often not involved in their healthcare decisions, and healthcare staff in acute care settings are generally unfamiliar in caring for them (Artnak, 2008). Rubin and Crocker (2006) point out that the healthcare needs of people with intellectual and developmental disability have not been considered extensively in medical education, and that healthcare for adults with ID was largely ignored for decades. They argue that, for many years, individuals with ID have been “almost invisible in the medical world” (p. 3). The decision-making process, which plays a pivotal role in accessing healthcare services and treatment, deserves the focus and attention of researchers and the health care community.

Limitations

While this study advances our understanding of surrogate decision-making for individuals with ID, some limitations should be addressed. First, this research was not designed as a stand-alone qualitative study, but rather the responses reported here were obtained from a limited number of open-ended questions appended to a larger quantitative survey on surrogate decision-making. Additionally, these questions were asked of one type of surrogate decision maker for this vulnerable population (agency directors providing residential services for those with ID in one US state), and not a broader group of surrogates. It is possible that different responses would have been obtained if the survey had been distributed to other types of surrogate decision makers (e.g., family, healthcare practitioners), if the focus was a different form of debility (e.g., dementia, stroke, or head injury rather than what had been termed intellectual disability), or if the survey had been conducted in another geographic region. Moreover, while the response rate (65%) was rather typical of that reported for other health surveys (Asch, Jedziewski, & Christakis, 1997), we cannot know whether or how the views of the non-respondents might have differed. Despite these limitations, we had a high percentage of participants who took the time to answer one or more of these open-ended questions, and their responses suggest a

common and pressing set of themes and issues that enhance, contextualise, and add depth to our quantitative findings.

Conclusion

Decision-making on behalf of individuals with ID is complex and challenging. Agency directors described a dynamic, uncertain, and variable process that resembles a shared decision-making model but may change in response to the particular situation faced by the individuals with ID. As parents and other traditional caretakers for this ageing population become progressively unable to continue their caregiving responsibilities, the surrogates and service agencies will play an increasingly important role in making healthcare decisions and in accessing medical care. If these surrogates are to perform their responsibilities well, they will need greater support and education to assist them in their role.

Acknowledgments

This study was funded and supported by US NIH grant NINR #521NR008798-02. The National Institute for Nursing Research (NINR) has placed no restrictions on the publication of this data, and there is no conflict of interest or financial gain for any of the authors listed.

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Table 1

Characteristics of respondents and residential settings overseen by their agencies

Characteristic	<i>M, (SD) or Percent</i>
The respondent	
Age, years	49.1 (8.0)
Gender (% female)	53.5%
Race/ethnic group	
White	95.1%
Black or African American	2.8%
Hispanic or Latino	0.7%
Other	1.4%
Time working with individuals with ID, years	20.9 (9.1)
Time as proxy healthcare decision maker, years	9.0 (7.2)
The setting	
Number of individuals receiving residential and support services	126 (196)
Living arrangements provided by each agency	
Group home	91.7%
Family living	49.0%
Supervised apartments	45.5%
Intermediate care facility	16.9%

Table 2

Selected representative statements of additional concerns of agency directors

Ageing:

“My concern is with the ageing family members, there will be increasing need for substitute health care decision making.”

General misunderstandings related to ID:

“In relation to the medical community and their ability to understand the limitations of those ‘for whom they are caring’ often times they mistake smiles and agreeable ways for understanding and/or their disagreeable ways for a rejection of their treatments.”

“The fact that many hospital staff are not aware of the specific guidelines regarding consent and the ID populations. Many times consent is received from family members who do not have the best interest of the individual receiving the services.”

Care in terminal conditions:

“We have been forced to put elderly ID individuals through treatments which prolonged Suffering. We would not have done same for self or family members.”

“Sadly even if family & key direct support professional advocate for a person in a way that they felt the individual would want, but is in conflict with the bulletin [state guidelines], I must follow the guidelines in the bulletin.”