

Individuals with Intellectual Disabilities: A Review of the Literature on Decision-Making since the Convention on the Rights of People with Disabilities (CRPD)

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ABSTRACT

To achieve the basic human right of autonomy, individuals, including those with intellectual disabilities (ID), must be able to practice decision-making, that is, to make their own decisions and communicate these decisions to others. In support of autonomous decision-making, Article 12 of the United Nations Convention on the Rights of People with Disabilities (CRPD) stresses the right of individuals with disabilities to legal capacity on an equal basis with others.¹ Supported decision-making approaches may aid individuals with ID in achieving this right. The question remains whether the enactment of the CRPD indeed is translated into opportunities for autonomous and supported decision-making among individuals with ID. In order to examine this question, a systematic review of bibliographic databases since 2008, when the CRPD came into force, was conducted in order to map the current state of decision-making among individuals with ID, and to identify areas in need of improvement. Twenty-seven manuscripts were reviewed, most focusing on decision-making within the fields of residential settings, health care, and sexuality-related decisions. This review showed that difficulties in decision-making in the area of ID remain during the early years after the CRPD entered into effect. These difficulties are related to the individuals with ID themselves, to their caregivers, and to the service system. No working models on supported decision-making for this population were found. The discussion highlights the importance of developing decision-making skills among people with ID, allowing them opportunities for decision-making, training professionals in supported decision-making, and fostering the philosophy of person-centered planning.

Keywords: Intellectual disability, systematic review, decision-making, autonomy, human rights

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INTRODUCTION

Intellectual disability (ID) is characterized by significant limitations in intellectual functioning (i.e., IQ below 75); limitations in adaptive behavior which comprises three skills types (conceptual skills, social skills and practical skills), and it originates before the age of 18.² Individuals with ID are in need of specialized, integrated treatment³ and are provided for by services within the health, education, and social welfare sectors. According to Article 12 of the United Nations Convention on the Rights of Individuals with Disabilities (CRPD),¹ all individuals should have the right to legal capacity.¹ In order to exercise this basic human right of autonomy, individuals must be allowed to make their own decisions and communicate these decisions to others. Towards this end, services must employ supported decision-making approaches, which would greatly change the way in which families, professionals, service providers, and the general community perceive and act in reference to persons with ID. The aim of the present review is to map the empirical literature on decision-making among individuals with ID since the CRPD has come into force in 2008 and learn about those areas in need of improvement.

THE IMPORTANCE OF MAKING CHOICES

Autonomy refers to an individual's capacity to govern him/herself. In order to exercise informed decisions, individuals must have the relevant information, be able to reflect on their values, desires and goals so as to affirm or disaffirm them, make intentional judgments and decisions based on them, and communicate that selection to others.⁴ Decision-making is a central element of self-determination, empowerment, and social inclusion for people with disabilities. Accordingly, best-practice approaches to service delivery, such as person-centered planning, place the consumer in the role of the decision-maker regarding what service support and assistance are needed and who is best suited to provide them.⁵

THE CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES AND ARTICLE 12

The basic human right to choice is mandatory according to the CRPD¹ which was adopted by the United Nations in 2006 and came into force internationally in 2008.⁶ To date, 153 nations have signed the Convention and 119 have ratified it. Ratifying nations commit themselves to implement all obligations of the Convention. The CRPD is the first disability-specific international treaty and the first treaty to adopt the human rights approach to disability.⁷ Specifically, the CRPD promotes freedom of choice and autonomy, non-discrimination, full participation and inclusiveness in society, respect for the differences evident in persons with disabilities, equality of opportunity, accessibility to core social goods and services, and the identification and removal of barriers.

According to Article 12 of the convention, “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.”^{1(p.9)} The article states the need to “ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances.”^{1(p.9)}

Article 12 stresses the importance of supported decision-making, stating that all “parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”^{1(p.9)} As a result of Article 12, substitute/surrogate decision-making models—that is, the process by which decisions are made on behalf of adults who are judged to lack decision-making capacity—should be replaced with supported decision-making models and lead the care of people with ID. However, decision-making is not a simple task, and opportunities for decision-making are not always abundant. This article maps the current decision-making situation four years after the enactment of Article 12 which can be used as a base for comparison in future years. With this aim we conducted a systematic review of the literature on decision-making among individuals with ID since the CRPD has come into force in 2008. Studies related to decision-making within different domains of life are reviewed and challenges are described. Reviewing the literature only four years after the CRPD has come into force will allow us to map the current state of decision-making among individuals with ID in order to allow for changes in policy and practice that may advance achievement of the CRPD.

SEARCH STRATEGY

Bibliographic databases, including ERIC, Web of Knowledge, PubMed, PsycNET, Social Science Research Network, and Social Services Abstracts, were used to search for manuscripts focusing on decision-making in ID. The search was conducted within the title or abstract of the manuscript using the following search terms: “intellectual disabilities,” “supported decision-making,” “substitute-decision making,” and “decision-making.” Manuscripts were limited to those published in English since 2008. A flow chart depicting the systematic review process that was utilized is presented in Figure 1. The search strategy yielded a total of 196 potentially relevant manuscripts. After removing duplicate manuscripts and manuscripts that were not found, 48 manuscripts that appeared to meet the inclusion criteria were examined for a more detailed evaluation. Nine articles were excluded, as they were review or position papers, and 13 were excluded for other reasons (a focus other than ID, a focus on the decision-making of individuals other than those with ID, or no specific focus on decision-making). Finally, 26 manuscripts were retained for the final review and one additional manuscript was added through hand-searching, yielding a total of 27 manuscripts.

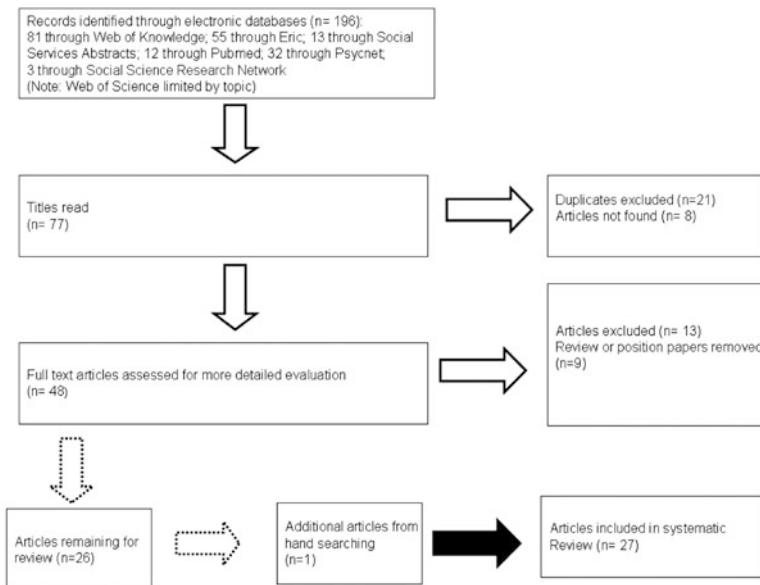


Fig. 1. Systematic review flow chart

ANALYSES OF MANUSCRIPTS

Manuscripts were analyzed according to the following criteria: The content was examined for the specific decision-making field and challenges in decision-making. Further, I examined the legal and human rights framework on which the study was based. Specifically, I concentrated on whether the literature reviewed as background for the study mentioned the CRPD, or any other human rights legal document and if substitute or supported decision-making constructs were mentioned. Finally, given the obligations set forth in the CRPD for participation, inclusion, equality and non-discrimination, the inclusion of people with ID in the research was examined, concentrating especially on whether people with ID were themselves the research participants, i.e., if their voice was heard rather than involving a proxy; and if they were involved as research partners.

RESULTS

BACKGROUND OF REVIEWED MANUSCRIPTS

Eleven manuscripts originated from the United Kingdom; eight from the United States; two from Australia and Taiwan; and one each from New Zealand, Canada, Ireland and the Netherlands. To date, the UK, Australia, New Zealand and Canada have signed and ratified the CRPD; the US, Ireland and Netherlands have signed the convention only; and Taiwan has neither signed nor ratified the convention. The reviewed manuscripts utilized different methodological designs: seven with questionnaires or surveys, three with automated computer tasks, and 17 with a variety of qualitative methods.

DECISION-MAKING FIELDS

The studies examined in this review focused on decisions within different contexts, including: transition to adulthood, self-advocacy, residential settings, employment, health care, sexuality and pregnancy and research participation. The use of a human-rights framework and surrogate or substituted decision-making is discussed within each field (for more details, see Table 1). A discussion on the inclusion of individuals with ID in the research will be presented within the discussion section.

Table 1
Summary of manuscripts reviewed

First author, country, year	Study design and data collection	Sample	Main focus of study	Main results and comments	Human rights legal framework	Supported/ substitute decision-making	People with ID as participants/ Researchers
Transition to adulthood							
Mill ¹ Australia, 2009	Life history approach using interviews	6 individuals with mild ID aged 18-25	Transition to adulthood	Identified three processes of negotiating autonomy within the family: defiant, passive, and proactive.	None specified	Implicit	P=Yes R=No
Murphy ⁹ UK, 2011	Interviews	28 individuals leaving special schools, caregivers and professional transition staff	Transition from children to adult services	Transition workers saw people with ID as adults and stressed their self-determination. Most parents positioned the individuals in space between childhood and adulthood and contested their right to self-determination.	MCA 2005	Substitute	P=Yes R=No
Self-advocacy							
Garcia-Iriarte ¹² USA, 2009	Focus group; watching of group meetings; reflexivity of group members on their participation	One focus group of people with ID; researchers attended 13 meetings	Self-Advocacy group	Highlighted three possible scenarios of how control can shift from advisors to group members (group participation with advisor control; shared control; member control with support). Participatory Action Research can be used to increase a group's capacity for meaningful self-advocacy.	None specified	Supported	P=Yes R=Yes

Residential settings						
Stancliffe ¹³ USA, 2011	Data from National Core Indicators survey	6778 adults with ID (or their proxies) living in non-family home.	Residential	Many adults with ID have little or no choice about where and with whom to live, especially those with more severe ID.	CRPD, 2006, Article 19	Supported P=Partial R=No
Dunn ¹⁵ UK, 2008	Reflection on work experience as support worker in group home	Individual personal experience	Residential	Depending on the type of decision to be made, staff may use 'strategic substitute decision-making' or 'relational substitute decision-making.'	MCA 2005	Supported and Substitute P=No R=No
Dunn ¹⁶ UK, 2010	Interviews	21 support workers	Residential	Support workers draw on their own values and life experiences to shape substitute decisions that they make on behalf of residents.	MCA 2005	Supported and Substitute P=No R=No
Chou ¹⁸ Taiwan, 2011	One group repeated interviews with ID participants; self-administered questionnaire with front-line practitioners	49 residents with ID (36 from family homes and 13 from institutions); 29 remained at fifth interview.	Outcomes of movement to new community residential scheme	41% left the new scheme and moved back to families or institutions. Choice-making was improved for residents who moved from family homes.	None or specified	None P=Yes R=No
Bigby ¹⁴ Australia, 2011	Interviews	17 clusters of ageing persons with ID, family and staff members	Residential	Decisions about the life transitions of older group home residents were dominated by a professional paradigm, which excluded the family member and failed to elicit the preferences of people with ID.	CRPD, 2006 Article 12	Supported P=No R=No

Manji ¹⁷ Canada, 2010	Case study (observations, interviews with family, staff and administrators)	4 consumers with ID and dementia	Residential – community – based group for people with ID and dementia	Two social processes: marginal- ization and supported empower- ment.	None specified	Implicit - Supported empower- ment	P=Yes R=No
Employment							
Timmons ²⁰ USA, 2011	Interviews	16 adults with ID, 13 family members, and 15 employment support staff	Employment	Influential people and factors in employment-related decision- making of people with ID are: families, school staff, community rehabilitation providers, job dev- elopors, and personal reasons for work.	None specified	Supported	P=Yes R=Yes
Healthcare							
Ferguson ²² Scotland, 2010	Interviews and one focus group	4 people with ID who take part in hydro- therapy and 13 caregivers; physiotherapy staff in focus group	Health care choices – choosing to attend/ not attend treatment	Generally identified 'others' as being responsible for making their health care choices.	None specified	Implicit	P=Partial R=No
Fisher ²⁵ USA, 2009	Survey	158 residential agency directors	Health care decisions	Important sources of information for proxy decision-making were the physician and the individual himself.	None specified	Substitute	P=No R=No

Fisher ²⁴ USA, 2009	Content analysis of qualitative survey	102 residential agency directors (from same sample as above)	Health care decisions	Identifying someone else's "best interests" is challenging. Perceptions of the health care community can influence the care provided. Surrogate decision-making is a team effort.	None specified	Substitute	P=No R=No
Wagemans ²⁵ Netherlands, 2010	Retrospective study of medical files of people who died	Of 47 medical files, end-of-life decision was made in 27.	End-of-life decisions	Capacity to make end-of-life decisions was not recorded, most likely because it was never assessed.	Dutch Contract of Medical Treatment Act	None specified	P=No R=No
Sexuality and pregnancy							
Conder ²⁶ New Zealand, 2010	Interviews	6 parents with ID	Pregnancy and parenting	Family support and appropriately responsive services are critical to the development of positive parenting.	None specified	Implicit	P=Yes R=No
Chou ²⁷ Taiwan, 2011	Interviews	11 primary caregivers and 4 women with ID	Sterilization	Almost none of the women with ID (regardless of ID level) were involved in the decision regarding sterilization, and some were not informed of the nature of the surgery.	None specified	None specified	P=Partial R=No
Dukes ²⁸ Ireland, 2009	Single subject	4 adults with moderate ID	Sexuality-related decisions	Participants in tailored sexuality education can improve their decision-making capacity.	Adults with Incapacity (Scotland) Act, 2000	Implicit	P=Yes R=No

Research participation						
Questionnaire	260 Institutional Review Board members and ID researchers	Participation in research	Questionnaire was found to have three factors: opportunities and choice; help in decision-making; beneficence. ID researchers were those with closer relationships to individuals with disabilities and who had attitudes consistent with disability-rights principles.	Belmont Report, 1979	Implicit	P=No R=No
Decision- making ability						
McDonald ⁴⁴ USA, 2008	Financial decision-making tasks and temporal discounting (half trained to use visual aid)	2 groups of 12 people with ID	Decision-making ability	Decision-making aid created a delay that prevents impulsive responding.	None specified	P=Yes R=No
Bailey ⁴⁴ UK, 2011	Symbol Labeling Intervention - Automated Iowa Gambling Task	39 adults with ID	Decision-making ability	People with ID perform advantageously on an adapted two-choice Iowa Gambling Task, showing high levels of subjective awareness about the nature of the task.	None specified	P=Yes R=No
Dymond ⁴³ UK, 2010	Three temporal discounting tasks	20 adults with ID	Decision-making ability	Half of the participants were unable to perform the task consistently. This was found to depend on executive functioning rather than IQ.	MCA 2005	P=Yes R=No
Willner ⁴⁹ UK, 2010						

Khemka ³⁷ USA, 2009	Interviews using decision-making instrument	47 adolescents with ID	Decision-making skills in inter-personal situations that involve coercion	Adolescents with ID are not well-prepared to handle situations on their own that involve coercion, especially coercion with a threat.	None specified	None specified	P=Yes R=No
Decision-making among individuals with communication difficulties							
Mitchell ⁴¹ UK, 2009	Provides examples of tools that social work educators can use	Choice and Change Project – 12 people with ID	Working with children who communicate non-verbally	Developed Talking Mats with a range of symbols. Choice is made through a range of communication modes: verbalizing, eye-pointing, signing, arm/hand movements, or facial expressions.	UN Convention on the rights of the child, 1989; CRPD, 2006	Supported	P=Yes R=No
Feiler ⁵⁵ UK, 2010	Interviews	7 teachers and 3 speech and language therapists	Involving children with ID and communication difficulties in decision-making	Staff embraced decision-making as a key priority, but found it to be a demanding task.	UN Convention on the Rights of the child, 1989; UK's Children Act, 2004 and others	Supported	P=No R=No

Knowledge and perspectives of professionals regarding mental capacity and self-determination							
	Questionnaire	22 care managers (social workers or nurses) within community ID teams	Knowledge of the role of Independent Mental Capacity Advocate	Less than half knew that the function of advocacy is to represent the client's views. Some incorrectly attributed decision-making functions to IMCA.	Mental Capacity Act, 2005	Implicit-supported	P=No R=No
Da Silva Martins ⁵⁰ UK, 2011	Structured interview	40 social workers and health professionals within community ID teams	Knowledge of mental capacity issues	Fourteen areas of significant gaps in knowledge were identified.	Mental Capacity Act, 2005	Supported - substituted	P=No R=No
Lane ⁴⁸ USA, 2012	Survey questionnaire	223 para-professionals from public schools	Para-professionals' involvement in promoting self-determination	Para-professionals attributed high importance to elements of self-determination (includes decision-making and self-advocacy), but provided instruction to address them to a moderate degree.	Individuals With Disabilities Education Act, 2004	Supported	P=No R=No

Transition to adulthood

Adulthood brings with it increased autonomy and the ability to be a causal agent in one's own life.⁸ In this review, only two qualitative studies focused on decision-making during the transition to adulthood. One of the articles⁹ was framed within UK's Mental Capacity Act 2005 (MCA)¹⁰ while the other did not regard a specific human-rights act.¹¹ The MCA makes a legal presumption in favor of capacity and increased autonomy of people with ID, aims to increase choice and recognizes that capacity can fluctuate over time and is decision-specific. When decision-making capacity is lacking, decisions, according to the MCA, must be made in the best interest of the individual. Both studies clearly highlighted the need to support self-determination and choice⁹ and regarded adults with ID as experts of their needs.¹¹ The first study implicitly supported the use of supported decision-making, while the second focused more on substituted decision-making.

The first showed that adults with mild ID differed in the extent to which they seek increased autonomy and the extent to which they perceived their parents to be supportive of their autonomy. The findings showed that young people with ID can indeed express their views by adopting a proactive approach, given the right environment and opportunity.⁹

The second study¹¹ focused on the transition from children to adult services and its implications for decision-making. Despite advocating for self-determination, parents pointed to their children's dependence, vulnerability, and limited capacity for understanding consequences. Some professionals also had their own idea of what was a "good choice," and thus not all choices made by individuals with ID were considered to be legitimate. Given these results, the authors suggested that professionals have a responsibility to engage both people with ID and their families in determining the best choices for them.

Self-advocacy

One way to increase decision-making is through advocacy groups which empower service-users to speak out, assert themselves, and make their needs and wants known. One study explored how decisions were made within a People First* self-advocacy group for individuals with ID. Findings showed that the participation of group members depended upon opportunities to share ideas and feelings, provide input, and be involved in meetings. Various levels of support were considered to be important for participation,

* <http://peoplefirstltd.com/> (accessed 28 September 2012).

including member support, advisor support, and system support.¹² Although the study did not clearly highlight a human-rights document, supported decision-making was clearly highlighted through the vision of self-advocacy and the participation of individuals with ID within the research team itself.

Residential settings

Six of the reviewed studies focused on decision-making in residential settings. Four of these studies acknowledged the importance of a human-rights framework via the CRPD^{13,14} or the MCA.^{15,16} While all four stressed supported decision-making, studies based on the MCA also supported substituted decision-making, by use of the ‘best-interest’ checklist, in those cases that individuals lack decision-making capacity.

One central issue in the residential field relates to opportunities provided to individuals to choose where and with whom they would like to live. One study, asserted that individuals should participate in living choices regardless of the severity of the ID.¹³ However, fewer than half of nearly 7000 adults with ID in the US have actually been given the opportunity to exercise a choice about where or with whom to live. Individuals with milder ID were found to have more choices, especially if they lived on their own or in a sheltered apartment, while they had fewer choices if they lived in an institution or in a group home. Individuals with more severe ID had the least amount of choice, regardless of residence type.¹³

Two studies focused on decision-making among ageing persons with ID¹⁴ or persons with ID and dementia.¹⁷ Findings from a study focusing on the transition into aged care showed that rather than respecting the rights of people with ID and viewing their needs and preferences as paramount, resource and organizational issues stemming from an ill-prepared system were responsible for shaping many of the decisions.¹⁴ Differently, a case study conducted within a unique group home for people with ID and dementia while not specifically citing a human-rights document, generated a theory of “supported empowerment” by which consumers can be empowered by practices of maintaining selfhood, freedom of choice, and active participation in the community.¹⁷

In Taiwan, improved decision-making was found among residents with ID who had moved away from their families, which suggests that residential services provided more autonomous living. However, many subsequently moved back to their families or institutions.¹⁸ Additionally, this study did not mention any human-rights nor supported decision-making approaches. This may be understood by the fact that Taiwan is not signed on the CRPD.

Two studies examined substitute decision-making within the residential context. In line with the MCA,¹⁰ ‘strategic decision-making’ was used for ‘life plan’ decisions and for health care interventions within a group home. However, ‘everyday’ personal and social interventions connected with the residents’ daily lives were based on ‘relational substitute decision-making’ within a framework of interpersonal care relationships.¹⁵ Likewise, interviews with 21 support workers showed that they used their personal lives as a starting point to make substitute decisions on behalf of their residents. This approach was found to be problematic because the workers gave primacy to their own values and life experiences rather than to the residents’ lives and needs.¹⁶

Employment decisions

As in the residential context, decision-making in the employment field is often driven by low expectations, funding restrictions, service delivery practices, and lack of information, rather than by individuals’ own choices.¹⁹ The only empirical study found for this review in the employment context²⁰ examined the factors that influence employment decisions for people with ID by interviewing adults with ID, their family members, and support staff. Although this study did not specifically mention a human rights document, the importance of supported decision-making was made clear through the conclusion that increased education and resources can improve self-determination. Additional recommendations included: family members’ engagement throughout the job search and planning process, building stronger links between schools and the employment system, changing negative assumptions about an individual’s readiness to work in the community, offering a selection of jobs and supporting individuals to make friendships in community workplaces. Finally, the value of self-determination was seen through the participation of individuals with ID in the research team.

Health care decisions

Four studies focused on decision-making within the health care field. Self-determination and the active involvement in and management of one’s own health is important to improving the health and wellness of people with ID.²¹ Unfortunately, studies showed that the involvement of people with ID in health care decisions was limited. Most of the studies did not mention a human-rights framework, although one made the case that choice agenda was part of the policy in Scotland.²² The other studies²³⁻²⁵ focused on substituted decision-making stressing that these decisions need to be made on behalf of the individual. For example, Ferguson, et al.²² showed that people with ID

demonstrated some understanding of choice and were involved in a number of everyday decisions. However, caregivers questioned their capacity to make health care decisions. Thus, the decisions to attend health care appointments were primarily made for, or in a few instances with, people with ID.²²

Similarly, the involvement of people with ID in end-of-life decisions was also found to be low. In a retrospective study of the medical files of deceased individuals, family members were found to be involved in end-of-life decision-making in about half of the cases, while no formal representative was involved in the other cases. The files examined did not include information about the views of the people with ID themselves or about their capacity to make an end-of-life decision. Furthermore, the decisions made were not discussed with the individual.²³ Nevertheless, it is important to acknowledge that, end-of-life decisions are difficult regardless of ID as seen by the finding that in the Netherlands (where the above study took place) communication between doctor and patient took place in only 38 percent of general end-of-life decisions. However, the situation in ID was worse as communication did not take place in any of the cases.²³

Although substituted decision-making was frequently used, studies also described the difficulties in this role. For example, in the previous study regarding end-of-life decisions, the authors pointed to a worrying possibility that parents' biased decisions may be discriminatory or lead to unethical practice.²³ Similarly, in the US, two studies^{24,25} highlighted the challenge in identifying the "best interests" of a person with ID, as they involve a value judgment about what matters most. Importantly, the choice process could be influenced by how the options are presented and reinforced, such that subtle or even coercive influences may be used to achieve the "right" choice as viewed by other interested parties.²⁶ Thus, the presentation of choices needs to be adapted to meet the needs of the individuals.²² Additionally, decisions should be carefully considered by a range of caregivers and professionals.²⁴

Sexuality and pregnancy

Individuals with ID have the same needs for intimate relationships and sexual expression as everyone else.²⁷ Adults are considered to have the capacity for sexual consent if the required rationality, knowledge, and voluntariness are present.²⁸ Only one of the three articles found in this life domain²⁹ made a specific regard to a human-rights document, the Adults with Incapacity (Scotland) Act 2000. This Act was used to make the case that capacity is not static and can be improved. Individually tailored sex education programs could improve supported decision-making by regarding sexuality,²⁹ pregnancy and parenting,³⁰ thus improving autonomous decision-making abilities.²⁹

Contrary to these studies, a recent review³¹ showed that individuals with ID encountered difficulties in exercising their full sexual autonomy due to social and environmental barriers. In cases of sterilization and hysterectomy, in Taiwan, the autonomy of women with ID was constrained by their families and professionals, with no consideration for the essential human rights of the women.³² Furthermore, it seems that decision-making among individuals with ID may also depend, at least to some extent, on the social status of the individual as most married women who were sterilized came from relatively low socio-economic background.³² However, it should be noted that in the traditional society of Taiwan, reproduction decisions, regardless of ID, are considered to be a familial issue involving the man's parents.³³ Furthermore, Taiwan has not signed and is therefore not bound to the CRPD.

Decisions on participation on research

Only one study focused on decision-making within the research field and examined the attitudes of Institutional Review Board members and ID researchers toward the research participation of adults with ID. This study was based on the guiding principles of the Belmont Report (1979) including respect for persons, beneficence and justice. Findings showed that participants who supported the general right of adults with ID to self-determination also endorsed their right to have opportunities to participate and make decisions in research settings. On the other hand, participants who advocated for the protection of adults with ID perceived a greater need for these individuals to receive support in making decisions about research participation.³⁴

CHALLENGES IN DECISION-MAKING AMONG INDIVIDUALS WITH ID

The reviewed manuscripts elicited various challenges with regard to decision-making which may be related to the individuals with ID, to their professional caregivers and to the service system.

Challenges related to the individual

Individuals with ID face several challenges that threaten their capacity to make decisions. In a study examining decision-making when coercive tactics were used,³⁷ the authors concluded that difficulties may arise in one or more of the following stages of the decision-making process: 1) framing

of the situation; 2) generating possible alternative solutions; 3) evaluating potential consequences associated with each alternative; and 4) selecting a decision response.³⁸

One of the barriers is severity of ID,²² with difficulties in verbal and memory deficits, difficulties with problem-solving, a tendency towards acquiescence and suggestibility, problems with abstract thinking, and an overly concrete thought process.³⁹ Although many individuals with ID have enough cognitive capacity in at least some components of the decision-making process,⁴⁰ individuals with severe ID may not be aware of their role in the decision-making process and the options available to them.²²

Additionally, for people with ID, it is especially difficult to make decisions that are based on information from two sources, such as magnitude (e.g., sum of money) and delay (e.g., immediate versus delayed reward).⁴¹ This relates to problems in executive functioning, rather than IQ, which may underlie reasoning abilities in people with ID. Executive functioning refers to the complex set of cognitive processes that regulate an individual's ability to organize thoughts and activities, prioritize tasks, manage time efficiently, and make decisions. It includes goal-setting and planning, organization of behavior over time, response initiation, response inhibition, attention, working memory, set shifting and fluency.⁴²

Communication difficulties pose an additional barrier to decision-making among individuals with ID by making it difficult for individuals to express their own needs.³⁵ The vocabulary which adults provide for children may be too restricted and insufficiently individualized for individuals with communication difficulties.³⁵

Dealing with decision-making challenges by use of visual aids and assistive communication

Three studies focused on how computerized visual aids may assist individuals with ID in making more advantageous decisions. As these studies focused on explaining and testing the utility of the aides; all but one⁴¹ did not mention any human-rights act. Further, most made no specific regard to the need for substituted or supported decision-making. In these studies, a symbol labeling intervention⁴³ and a visual aid⁴⁴ significantly improved advantageous decision-making among people with ID and enabled participants to 'weigh-up' evidence through a richer consideration of pros and cons in financial decisions and temporal discounting.⁴³ The authors asserted that after training, this visual aid may improve the ability to make choices in other daily tasks,^{41,44} which may point to the authors' awareness of the importance of supported decision-making.

Visual aids have also been found to be important for children with ID and communication difficulties. Two studies that examined this area were framed deeply within a human rights framework including the CRPD, the UN Convention of the Rights of the Child (1989), and other UK policy initiatives which assert the importance of listening to a child and allowing them to make their choices. These policies endorse supported decision-making by using appropriate methods for listening to children with ID and non-verbal communication.³⁵ For example, Mitchell, et al.⁴⁵ described the use of Talking Mats*, which allow for the expression of choice from a range of symbols. According to this study, professionals need to make children with ID aware of the range of potential choices available and allow them sufficient time to respond when making decisions.³⁵ These studies have emphasized the importance of individualized approaches based on a detailed understanding of children's needs.³⁵

Challenges related to professional caregivers

The literature shows that some challenges to decision-making among people with ID are attributable to professional caregivers. The main challenge is that individuals are not always provided with the information and support required to meet their needs⁴⁶ and may only be given restricted opportunities for decision-making. These difficulties can be understood in light of caregivers being wary about allowing too much choice, given the need to balance the rights of individuals to direct their own lives versus the personal, professional and ethical responsibility of the caregivers to make the "right" choice.⁴⁷

Knowledge, training, and attitudes of professionals have been found to be predictive of their ability to support decision-making. Based on the US Individuals with Disabilities Education Act 2004, Lane, et al.⁴⁸ found that more than 80 percent of paraprofessionals in the study rated decision-making as having a high instructional priority. Findings implicitly endorsed supported decision-making as the authors asserted the importance of providing meaningful opportunities to develop skills, attitudes and behaviors that enhance self-determination.

Two additional studies examined professionals' knowledge about the decision-making ability of individuals with ID based on the UK's MCA^{10,49,50} thus, referring to the importance of supported decision-making.

Based on this Act, Willner, et al.⁴⁹ found gaps in knowledge among health and social service professionals within community ID teams, including a lack of knowledge that it was the responsibility of all professionals to exercise

* <http://www.talkingmats.com/> (accessed 28 September 2012).

their own judgment about their clients' decision-making capacity. The second study⁵⁰ found that care managers did not have a clear understanding of the role of Independent Mental Capacity Advocates (IMCA), as only about half of them knew that their role was to represent the client's views. Furthermore, of nine decision-making scenarios presented, participants identified that an IMCA referral was called for in less than 50 percent of the cases.

Challenges within the service system

Many of the above challenges can also be understood as being rooted in the service system itself. For example, questions have been raised regarding the adequacy of training provided to professionals within services, such as MCA training⁵⁰ or provision of training and familiarity with self-determination.⁴⁸ Lack of training within services may also be related to large workloads and pressures which limit the ability of the service to commit to provision of training.⁴⁹ Additional challenges included: limited opportunities for choice-making, or lack of flexibility in services,³⁵ organizational difficulties, and an absence of relevant policies.¹⁴ Additionally, services may lack in resources including shortage in staffing¹⁴ and lack of availability of communication and visual aids to aid those individuals with ID and communication difficulties.³⁶ These may lead to limited use of supported decision-making approaches and limited time that staff members can provide to each individual.

DISCUSSION

The aim of this article was to map the current state of decision-making among people with ID by reviewing the available research, four years after the CRPD entered into force in 2008. Decision-making among people with ID was found to be complex. The vast majority of published knowledge was found in the fields of residential services, health care decisions, and sexuality-related decisions. Scant research has been conducted in other fields, such as employment, self-advocacy and research participation. Difficulties were related to the individuals with ID themselves, as well as to the caregivers in charge of supporting the decision-making process and service systems.

Since the CRPD entered into force relatively recently, it was not surprising that only three articles addressed it in their framework. These studies originated from the UK, US and Australia, and two of them focused on the field of residential care. As an international instrument, the CRPD does not replace domestic law, but rather serves as a supplement and an interpretive tool, depending on its status in each specific country. Local

legislation therefore often serves as the legal framework of the analysis. For example, studies originating from England and Wales utilized the MCA as their legal framework. Similarly to the CRPD, the MCA assumes that adults with disabilities have capacity to make decisions (Part 1, Principle 2). Adults are not treated as unable to make a decision unless all practicable steps and support to help them to do so have been taken without success (Part 1, Principle 3). Further, according to the MCA, any decisions made on an individual's behalf must be in the individual's best interests (Part 1, Principle 5),⁵¹ although criticisms on the application of the best interest standard have been raised.⁵² In line with this, in Scotland, the Adults with Incapacity Act 2000⁵³ regulates interventions in adults who may have impaired capacity. These interventions must be minimal and tailored to the individuals' needs using whatever aids, communication support or advocacy the individual may require. The references to these Acts in the above studies show that their authors appreciate the importance of protecting human rights in decision-making processes.

The findings of this review elicit several challenging questions such as: is supported decision-making among people with ID always possible? Is it possible to apply in all decision fields and also for people with more severe ID? The publications reviewed in our study showed that supported decision-making was more strongly endorsed in some fields (e.g., residential setting, employment and self-advocacy) and less in others (e.g., healthcare). One may conclude that in more complex and sensitive decisions, preference is given to caretakers' decisions. Another possibility is that in an acute stage of illness, an individual's capacity for decision-making may be hindered, regardless of ID. However, the second option most likely influenced only a minority of the cases.

While Article 12 of the CRPD places utmost value to supported decision-making, and places responsibility on caregivers, services, policy makers and researchers to find the way in which supported decision-making can be achieved for all individuals, it does not provide specific guidelines for achieving this and does not provide answers to situations in which individuals may be unable to take autonomous decisions. Consequently, the way of operationalizing and translating its recommendations is left blurred and undefined. Thus, it is not surprising that this review shows that, although some of the studies make recommendations on how to improve decision-making among this population, no study found presented comprehensive working models that can be used to guide and implement supported decision-making. This is one task at hand for the future. Without translating the recommendations of Article 12 into practical models that

will guide the stakeholders responsible for the well being of individuals with ID, their autonomy will remain only expressed in the legal article.

Finally, the reviewed studies showed that rarely did individuals with ID participate as research partners in a collaborative research design, as only two studies had individuals with ID take some role in the research itself. Both of these were studies conducted in the US, one in the field of employment²⁰ and the second in self-advocacy.²⁰ The lack of incorporation of people with ID in the research may be indicative of their general stereotype as less competent and unable to state their wishes. Future research should encourage such collaboration which may bring about enhanced community inclusion and participation of this population group.

LIMITATIONS OF THE REVIEW

The results of this review should be considered in light of several limitations. First, Despite making every attempt to unearth the relevant literature, we cannot disregard the possibility that some studies may not have been identified. This is an inherent limitation of systematic reviews, which in an effort to be specific are prone to miss papers of importance.⁵⁴ Second, the review is limited to published research and may not be exhaustive of the unpublished approaches utilized by ID services. Thus, I urge ID services to devote more time to evaluation research in order to examine the efficacy of the methods which they employ. This is highly important in order to enhance knowledge in the field and increase the use of effective decision-making models. Third, only four years have passed since the implementation of the CRPD. Thus, some of the studies cited may have actually been conducted prior to the CRPD. An additional review should be conducted in about five years in order to map the change during this time. This five year time-frame will allow researchers to examine if and how the CRPD has come to be employed within service system practice guidelines and curricula for professional care. Finally, most studies reviewed did not examine difference in choice-making as it relates to socio-economic status of the individual. It would be interesting for future studies to examine the possible existence of a social gradient to decision-making participation.

CONCLUSIONS AND IMPLICATIONS

In sum, this review shows that supported decision-making is still lacking in various decision-making fields for individuals with ID. Its findings have

conceptual and practical implications. Conceptually, this review blends two separate but interrelated perspectives—the public health and human rights perspectives. From the public health perspective, ID is a condition that should be investigated and monitored. From the human rights perspective, the focus is on dignity for all persons with disabilities and the need for policies to ensure the equal rights of these persons. The present review joins recent efforts to see these perspectives as complementary.⁵⁵

Practically, this review stresses the need to improve supported decision-making for individuals with ID. For example, in addition to the need to develop supported decision-making models for use in the health, social welfare and education sectors, this review highlights several recommendations. First, training and education must be provided to persons with ID in order to help them develop better decision-making skills.⁵⁶ This process includes teaching them elements of goal planning and self-regulation so as to encourage greater self-determination and actualization of their values.¹⁹ One-to-one educational interventions need to take into account the impact of cognitive disabilities and should be matched to the learning style, skills and abilities of the individual learner.²⁹

Second, services must be tailored to allow for true choice and self-determination. A larger workforce is needed as well as some flexibility in daily routine to fit with individuals' choices. This can be achieved through person-centered planning, which involves understanding individuals' specific dreams and aspirations and creating the conditions that will promote them.⁵⁷ Additionally, policies and practices, such as consumer direction in services, the support of self-advocacy movements and inclusion in decision-making, should be encouraged to help facilitate greater expression of self-determination.¹⁹

Third, caregivers (both family and professional) should be provided with the appropriate knowledge, skills and training in communicating with persons with ID in order to provide the needed support that will facilitate supported decision-making. Visual aids may be used in order to enhance the understanding of choices that will allow individuals with ID to make decisions. The main elements of true choice should be taught to caregivers, such as the need to focus less on the outcome and more on the process of decision-making.²² Furthermore, caregivers need to examine the individuals' ability to make a decision in each specific case, rather than as a general rule, and to accept that people with ID should be allowed to make mistakes as learning opportunities.⁵⁵ Finally, caregivers must undergo adequate preparation to learn how to discuss certain topics which may cause them discomfort.

Acronyms List:

CRPD = UN Convention on the Rights of People with Disabilities

ID = Intellectual disabilities

IMCA = Independent Mental Capacity Advocates

MCA = UK Mental Capacity Act 2005

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