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Adults With Intellectual and Developmental Disabilities and Participation in Decision Making: Ethical Considerations for Professional–Client Practice

Gurit Lotan and Carolyn Ells

Abstract

In this article, the authors challenge professionals to re-examine assumptions about basic concepts and their implications in supporting adults with intellectual and developmental disabilities. The authors focus on decisions with significant implications, such as planning transition from school to adult life, changing living environments, and managing health issues. The analysis highlights important concepts that are less often addressed: autonomy, empowerment, participation in decision making, asymmetrical power, outer-directedness, and respect for persons. The authors suggest that professionals adopt a moral principle of respect for persons as an overarching guiding principle in their work with adults with intellectual and developmental disabilities. The value of self-determination and person-centered planning processes are placed in the larger scope of ethical practice. The authors offer a set of practical considerations that encourage respect for these individuals by involving them in the decision-making process in situations that have a large impact on them.

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Ensuring that persons with intellectual and developmental disabilities are active in planning the course of their life is considered pivotal when planning lifelong support systems and developing educational programs. This concept, of what professionals ought to strive for, is anchored in the construct of self-determination and the view of what person-centered planning should be. Wehmeyer (2002, 2003a, 2003b, 2005) has discussed the construct of self-determination extensively and reflected on how its meaning is applied in professional practice. He posited that “self-determined behavior refers to volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (2005, p. 117). He clarified that self-determination is not simply control. It contributes to the extent of the person’s capacity toward the achievements of his/her goals (Wehmeyer, 2005).

Person-centered planning is a philosophy and a set of strategies aimed at promoting self-determination on the part of persons with intellectual and

developmental disabilities. It involves understanding each person’s specific context, dreams, and aspirations and responding by creating the conditions that will promote and support the person’s own view of a positive future (Holburn & Cea, 2007).

The practices that devolve from self-determination and person-centered planning have important ethical implications for professionals. In this article, we re-examine assumptions about basic concepts relevant to supporting persons with intellectual and developmental disabilities. In doing so, we focus on decisions with momentous implications, such as planning transition from school to adult life, changing living environments, and managing health issues.

To create a fresh vantage point from which professionals can reflect on their assumptions and practice, we begin with an analysis of the ethical principle of respect for autonomy. This is one of a number of ethical principles found in the “helping” professions but is often misunderstood as giving priority to whatever an individual chooses for him-/

herself. We develop our analysis by drawing attention to additional important concepts that are less often addressed: empowerment, participation in decision making, asymmetrical power, outer-directedness, and respect for persons. Ultimately, we propose that professionals adopt a moral principle of respect for persons as an overarching guiding principle in their work with adults with intellectual and developmental disabilities. The values of the construct of self-determination and person-centered planning processes are not diminished by our analysis but are explicitly placed in a larger scope of ethical practice. We discuss the relationships among the moral principle of respect for persons, self-determination, and person-centered planning. To help apply our results, we offer a set of practical considerations that encourage respect for these individuals by involving them in the decision-making process in situations that have a large impact on them.

Autonomy

The concept of *autonomy* originated in Greek political philosophy to refer to a state's capacity to govern itself: An autonomous state could act independently of governments or powers from outside its borders. The concept was later applied to individual persons, recognizing that persons have a certain capacity to govern themselves, to make and follow moral rules that they personally commit to. For some, the concept merged in meaning with the concept of self-determinism found in the philosophy–psychology literature in a distinction between free-will and determinism. At least in this early use, *self-determinism* referred more simply to making choices that influence an outcome. Where most actions in the world have external causes (e.g., gravity causes the apple to fall from the tree to the ground), many human actions originate, or are caused by, the human will. In other words, we have the capacity to choose which action to take. Rather than being determined from the outside, we are self-determined (see Wehmeyer, 2003b). Therefore, in this context, self-determinism does not necessarily have an ethical or moral dimension.

The specific meaning of autonomy depends largely on which theory of autonomy one is considering. Yet, at the present time, most theories involve personal authority and control over one's thoughts, goals, and actions. The ability to reason and to think or act purposefully, the capacity to value, the presence of preferences, and the absence

of undue influence or manipulation (that control the outcome of an action) are considered vital for autonomy. Embedded in this concept is the assumption that, to exercise personal autonomy, persons must have the information that is vital in order to make informed choices. In fact, the elements of mental capacity, voluntariness, and having enough information on which to base choices have been entrenched by law as prerequisites for evaluating the quality of consent of all persons, including persons with intellectual and developmental disabilities (Dinerstein, 1999; Picard & Robertson, 2007).

Theories of autonomy tend to assume a rational decision-making ability and a fairly consistent set of values, desires, and goals. The person must be able to reflect on their values, desires, and goals; affirm or disaffirm them; and make intentional judgments and choices based on them. Thus, their mental capacity must allow for self-reflection and critical scrutiny. It is important that these theorists and commentators acknowledge that autonomy admits of degrees, including a degree of understanding, degree of voluntariness, and degree of rationality, and other factors in decision-making capacity (Beauchamp, 2005; Christman, 2005). For these reasons, what is expected is not an ideal of maximal autonomy but a substantial satisfaction of the elements of autonomy, which varies according to the objectives of the choice situation (Beauchamp, 2005). Accordingly, whereas intellectual and developmental disabilities entail effects on mental capacity that cast doubt on an individual's potential for autonomy, their degree of capacity, understanding, and voluntariness should be assessed on a decision-specific basis.

In some views that we support, autonomy also explicitly involves the shaping and enacting of one's identity—of who one is as a person—in ways that take into account one's moral concerns and values (Bergsma & Thomasma, 2000; Donchin, 2000; Friedman, 2003).

The emerging cultural ideal of personal autonomy is now entrenched through public policy, the courts, and professional practice as the right to make decisions on one's own behalf without being compelled by others (Arnold & Lidz, 1995). Yet, the importance placed on personal autonomy in American and Canadian societies is a relatively recent phenomenon of the past 45 years or so, spurred on by numerous factors, including civil and women's rights' movements, disability rights' movements, public attention to discrimination and its

effects, and patients' rejection of paternalistic practices by physicians. In the field of intellectual and developmental disabilities, the focus has been on challenging the practice of professionals who were making unilateral decisions for clients about residential options, daily activities, and so forth.

With this history, it is not surprising that in our society independence and individualism are strongly linked to understandings of autonomy. However, categorical application of these concepts is incongruous with notions of disability. First, by definition, *disability–impairment* suggests a predicament less than an ideal or accepted standard. Impairment in functioning, cognitive or physical, implies one's need to depend on human, technical, or mechanical supports to bring oneself as close as possible to the coveted standard. That means the inevitability of varying degrees of dependency. Second, the ability of persons with cognitive and/or physical impairment to self-govern is dependent in a large measure on the society of which they are members. Societies that value self-governance by all will create conditions that promote the development and acquisition of skills and capacities for self-reliance. Such societies will encourage and facilitate the expression of those skills and support people's desires for self-expression. These dependencies are more apparent for those with intellectual and developmental disabilities, even though they also exist for people not considered to have cognitive or physical impairments.

It is important to note that, as opposed to freedom from others, a relationship with others is a precondition for autonomy. That is, it is through our interactions with others in a supportive and encouraging environment that we learn the skills and gain the confidence necessary for autonomy. Furthermore, the expression of autonomy is more complex than an independent and individualistic perspective allows. As Ells (2001) noted, "Because selves are not isolated from their situation, and their situation includes the complexities of every day reality, individual people are not and cannot be self-contained choosers" (pp. 609–610). Consequently, "autonomy...cannot be a discrete thing that an autonomous person has" (p. 611; see also Jennings, Callahan, & Caplan, 1988).

To foster autonomy in others, we must create the right conditions. For persons with intellectual and developmental disabilities, these include, whenever possible, helping them to recognize and organize their values, their sense of identity, and how they want their values enacted. It requires skill-

building to improve reasoning and communication, encouragement to think outside the box (Bowman, 1999), building trust, and fostering mutual relationships. It also involves consciousness-raising initiatives for people without intellectual and developmental disabilities to reorganize their own value systems and expectations. This places the onus on professionals and the general public to seek modifications to their own communication and interaction styles to enhance understanding of daily challenges by persons with intellectual and developmental disabilities (see, e.g., Wong et al., 2000). It requires that professionals attend to environmental conditions that enhance opportunities for increased autonomy (Duvdevany, Ben-Zur, & Ambar, 2002). Most important, we must remember that there is no single formula to foster autonomy.

Empowerment

The concept of *empowerment* emerged in sociology to refer to a process where members of specific sociological (often disadvantaged) groups gradually assume increasing social and political power over decisions that significantly affect their lives, both as individuals and as a group. Consequently, the verb *to empower* means both a legal right to do something (e.g., a law that invests specific powers in certain individuals to exercise some action that affects others in some way) and a psychological process whereby an individual acts in ways that encourage others to advocate for their own needs and preferences, sometimes at the risk of contradicting views of significant others such as caregivers or professionals. To empower, in this latter sense, involves creating conditions that increase others' self-confidence in asserting their points of view and providing learning opportunities to develop skills and capacities for autonomy. Such personal development can only occur in the context of certain types of relationships.

Participation in Decision Making

For momentous and complex decisions, although some of us prefer to act primarily on our own, most of us tend to rely on some form of assistance. We may invite others to participate in our decision-making process by asking them to provide us with information, emotional support, a sounding board, or advice. In some cases, we may choose to formally delegate our decision-making

authority to others who we trust to act in our best interests. The same care and flexibility should be present when adults with intellectual and developmental disabilities are involved in decisions with momentous implications.

Consider for example decisions to be made about transitioning from school to adult life. Because these decisions are momentous and complex and there is much at stake, others who are uniquely suited to contribute important knowledge, experience, and support to the individual are customarily invited to assist in this decision-making process. It is important to emphasize that in transition planning more people have a role in the process of decision making than have the authority to make final decisions. Family input about the relative benefits of various options and practical considerations of resource availability or accessibility are examples of the contributions of others that constrain the ultimate choices made. Even so, the decision-making authority itself rests with each adult with intellectual and developmental disabilities, or their legal representative.

Like all of us in making decisions, adults with intellectual and developmental disabilities will assign different weights to the information and advice they receive and will base their decisions on many factors. Some of these factors may include personal sensitivities, cognitive and emotional biases, perceptions about the impact of their decisions on others, the confidence they have in those who offer advice, their perceived dependence on the people who are involved in the decision-making process, and the extent to which others' approval is important to them.

Our understanding of factors that affect complex decision-making at critical junctions can be informed by medical research that helps unravel the intricate process of decision making by patients, including patients with intellectual and developmental disabilities. Many studies have broadened our understanding of patients' desires for information and participation in decision making as they interact with the medical system; these same studies have shed light on factors that impact professional-patient encounters (see Arora & McHorney, 2000; Beisecker & Beisecker, 1990; Blanchard et al., 1988; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Charles et al., 1994; Deber, 1994a, 1994b; Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Maly et al., 2004; Salkeld et al., 2004).

There are important similarities for both the patient facing a health crisis and the person with

intellectual and developmental disabilities dealing with important decision making that make this research relevant to consider. Adults with intellectual and developmental disabilities confront critical junctures in their lives, as do patients who are about to make significant decisions about their health care. They must face decisions that may have wide-reaching implications and ones that may not be easily reversible after a certain process has been put into place. They must make choices among options, the nuances and impact of which professionals may better understand. Accordingly, as is true for patients, it is true for adults with intellectual and developmental disabilities that the element of trust in professionals has a unique place in the ultimate decisions that are made. Furthermore, these adults must rely on professionals to create the conditions that promote a decision-making process that suits their needs.

The most salient findings from the medical studies are as follows: (a) A majority of adults who present for medical consultations want information, good and bad, about all aspects of their conditions and options for interventions (Beisecker & Beisecker, 1990; Blanchard et al., 1988; Cassileth et al., 1980; Charles et al., 1994; Gerteis et al., 1993). (b) The type and amount of information people wish to have varies at different times in their interactions with the medical system (Cassileth et al., 1980). (c) Patients' desire for information is not correlated with active information-seeking behaviors during their interactions with physicians (Beisecker & Beisecker, 1990; Charles et al., 1994; Gerteis et al., 1993). Therefore, it would be erroneous to conclude that those persons who want information will actually seek it or that those who are not vocal during their visits with physicians simply are not interested in the information. (d) The most striking finding from medical studies relates to the gap found between the desire for both information and participation on the one hand and the wish to actually make medical decisions on the other (Charles et al., 1994). Notwithstanding the majority's desire to be informed and to take part in the process of decision making, when reviewed together, these studies (Arora & McHorney, 2000; Charles et al., 1994; Deber, 1994a, 1994b; Gerteis et al., 1993) support the conclusion that over 50% of patients want their physicians to make decisions for them.

These findings point to a complex application of the ethical value of autonomy. To have a satisfactory experience of autonomy and participation in planning the course of one's life means

different things to different people. It appears that one's sense of being autonomous is not necessarily equated with making all decisions, not even ones that may be critical to one's future. Note for example the empirical findings by Duvdevany, Ben-Zur, and Ambar (2002) that cautioned us to (a) not assume which formal structures result in more autonomous decision making among persons with intellectual and developmental disabilities and (b) not equate the number of independent choices one can make with a global sense of life satisfaction. Instead, they suggested, that exercising one's autonomy in decision making includes being able to decide how and how much one wants or needs to be involved in actually making the decisions, what information one needs to make certain decisions, and who will make those decisions.

In addition, these findings raise some troubling questions about factors that may impede people's ability to exercise their autonomy in some situations. For example, how do we explain that many patients who want to be better informed do not pursue this desire by approaching their physicians for information and clarification? Why is it that even though patients express that it is important for their physicians to learn about their goals, preferences, values, and emotions, they do not initiate such discussions? Instead, they express a clear preference that physicians take the lead in this regard.

Gerteis et al. (1996), who surveyed over 6,000 patients across the United States, suggested that at least three factors may help explain these patterns: (a) Some patients are afraid of annoying health care providers and making a nuisance of themselves by asking too many questions; (b) some feel intimidated by the possibility of asking questions that would make them appear ignorant; and (c) some feel that they do not know enough to know what to ask (see also Maly et al., 2004). This introduces another concept that greatly affects people's ability to make autonomous decisions, that of asymmetrical power. As we explain, for people with intellectual and developmental disabilities, the effect of asymmetrical power relationships on decision making can be compounded by a behavioral tendency toward outer-directedness.

Asymmetrical Power and Outer-Directedness

According to Waltzlawick, Beavin, and Jacksons (1967), two persons, A and B, are in a

relationship of asymmetrical power when the following two conditions occur simultaneously:

1. A possesses, or is believed by B to possess, something that is of significance to B; and
2. B has no independent access to this something other than obtaining it from A.

For example, information, expertise, and access to key persons and to material objects (e.g., money) are goods that A may possess and that B may only obtain through A.

The kernel of the asymmetrical power relationship between A and B is a very specific message that A sends to B. Explicit or implicit, the message is one of predictability of future outcome. In a professional–client relationship, A's message to B is essentially as follows: "I am inviting you to believe me when I say (a) that I have the expertise to assist you and (b) that I shall, indeed, deliver the goods."

In this situation, B is at a disadvantage relative to A. B must choose to accept or reject A's assertion regarding the accuracy, value, and completeness of the information received or counsel offered. Most important, B must make a leap of faith, an "act of trust" (Pellegrino, 1991, p. 72), to believe in the predictability of A's assertion, that is, that A will deliver as promised.

Such acts of trust are routinely made by most of us as we seek out professional advice and care. One might ask, what gives us the confidence to go out on a limb and expect that our trust will not be disappointed? Our acts of trust are made possible by the privileges that our society accords certain individuals by virtue of their training and experience. Essentially, by imposing educational and training criteria as prerequisites for admission to professional groups, which in turn obligate members to adhere to articulated codes of conduct, society sends a message to the population that these professionals, whom we have licensed, can be trusted to act with appropriate expertise and good faith on our behalf. The message continues: We acknowledge that there is an asymmetrical power relationship between professionals and those seeking professional advice and care, but we have a structure in place that is meant to ensure that this trust will be accorded its proper weight in professional–client interactions (Sokolowski, 1991).

Adults with intellectual and developmental disabilities generally experience more asymmetrical power relationships in their daily lives than the population at large. In most cases, these individuals

must depend on others for living arrangements, for facilitating work and leisure activities, managing their money, and so on. Parents–guardians and professionals (e.g., from educational or service agencies) have a significant impact on, and ultimate discretionary power over, the future plans and lives of persons with intellectual and developmental disabilities. Administrative procedures and structural options further impact what may be possible for them (see, e.g., Heller, Miller, & Factor, 1999; Robertson et al., 2001). This dependency on others in so many domains is likely to affect how persons with intellectual and developmental disabilities interact with those on whom they rely for assistance and support and illuminate the decisions made.

In *A Guide to Consent* (published by what is now the American Association on Intellectual Disabilities [then, the American Association on Mental Retardation], 1999), professionals are encouraged to “carefully assess voluntariness” when they ask persons with intellectual and developmental disabilities to give consent to proposed actions (Hurley & O’Sullivan, 1999, p. 45). When discussing health care decisions, Hurley and O’Sullivan (1999) stated: “The influence and opinions of support staff and family may be unduly strong....[P]ersons with mental retardation may feel disempowered, eager to please, and unable to refuse treatment offered by a health care provider” (p. 45). Professionals are cautioned to be mindful of the “subtle forms” that psychological pressure may take, albeit unintended (Dinerstein, 1999, p. 3). This includes being mindful of the impact of our own values and belief systems as we interact with persons with intellectual and developmental disabilities. We are thus warned that, given the vulnerability and gullibility of persons with intellectual and developmental disabilities, “those seeking consent are obligated to make sure that the person’s consent is given freely and under non-coercive circumstances. Acting in accordance with this obligation can be particularly challenging when the consent seeker directs a program or otherwise exercises power over the person with mental retardation” (Dinerstein, 1999, p. 3). These cautionary observations alert us to consider the value of beneficence and nonmaleficence in our involvement in decision making with adults with intellectual and developmental disabilities and weigh our interventions accordingly.

Research from group-home settings is instructive about the impact that asymmetrical power can

have on interactions between professionals and adults with intellectual and developmental disabilities and the significant implications for outcomes in decision making. Analyzing video recordings of residents’ meetings held with staff in a group home, Jingree, Finlay, and Antaki (2006) found that despite institutional policies that asserted the promotion of choice and independence, and staff’s stated intent to facilitate these objectives, the patterns of their own verbal interactions with residents did not reinforce these objectives. The authors identified how residents’ responses and directions of conversations were “shepherded” (p. 224) by staff. These patterns included using leading questions and clues, providing the answers themselves to the questions they had asked, ignoring and neutralizing concerns, and using differential reinforcement of residents’ statements where positive ones met with approval and dissatisfaction was responded to negatively. Finlay, Antaki, and Walton (2007) studied communication patterns between group-home staff and residents with “limited spoken language” (p. 227). Their analysis showed that in many cases, nonverbal gestures with clear communicative intent by residents were not acknowledged by staff and that this, in turn, affected what ultimate decisions were “agreed on” between residents and staff. When staff did attend to nonverbal interjections by residents, the decisions made were inclusive of the residents’ preferences.

Further compounding the effect of asymmetrical power is the phenomenon of outer-directedness. As Bybee and Zigler (1999) explained, *outer-directedness* is observed when all the following conditions are met: (a) “an individual is presented with an ambiguous or novel task to be solved or dealt with” (p. 168), (b) “cues that may be used in problem solving must be available” (p. 168), and (c) the individual has a “choice in whether to utilize cues or rely on internal cognitive resources” (p. 169).

Research (Bybee & Zigler, 1999) has demonstrated that children without developmental disabilities typically use external cues “in a strategic and beneficial manner” (p. 168) and their dependence on such cues diminishes with increasing age as they learn to rely increasingly on their own internal problem-solving strategies. In contrast, children with intellectual and developmental disabilities tend to use external cues in a “harmful and indiscriminate manner” (p. 168). Furthermore, and more worrisome, this tendency appears to become entrenched as a general approach to problem solving for

individuals with intellectual and developmental disabilities. Thus, Bybee and Zigler warned that, “With development, outerdirectedness becomes more strongly correlated with maladaptive behaviors in the classroom and in daily life” (p. 200).

When including persons with intellectual and developmental disabilities in decision making, it is imperative that professionals appreciate the enormous impact on the person of the complex interaction between these asymmetrical power relationships with professionals and family members, compounded by the phenomenon of outer-directedness. It behooves us to be cognizant of each person’s vulnerability throughout this process as they attempt to define their own thoughts and preferences.

Respect for Persons

Our discussion brings to light some of the challenges that professionals face in daily interactions with persons with intellectual and developmental disabilities. Without diminishing or excluding the value of autonomy or current trends in self-determination and person-centered planning, and recognizing that the clients’ participation must have a pivotal role in promoting their own future (i.e., becoming causal agents in their lives), we propose a different framework that we believe can provide better guidance to professionals who work with persons with intellectual and developmental disabilities. We propose that professionals adopt the ethical principle of “respect for persons” as their guiding value in their work. “Respect for persons” can take into consideration, in processes and practice, all the equally important values that have been discussed above.

According to Downie and Telfer (1969), *respect* indicates that something is valuable in itself and worthy of cherishing. They explain that

To cherish a thing is to care about its essential features—those which, as we say, “make it what it is”—and to consider important not only that it should continue to exist but also that it should flourish. (p. 15)

Accordingly, *respect for persons* is an attitude toward persons that is based on the premise that “they are a thing which is valuable in itself” (Downie & Telfer, 1969, p. 14). An attitude of respect for persons is also a principle of action in that it dictates certain modes of conduct toward persons. These actions must reflect an acceptance of individual differences and an appreciation of others’ potential in shaping their own lives (Downie & Telfer, 1969, p. 37). Respect

obligates people to act in a manner that is consistent with “valuing” and “cherishing” (Downie & Telfer, 1969, p. 29) persons for those characteristics that make them who they are. It mandates professionals to make this possible—to enable them to live their lives well.

We propose respect for persons as a guiding value for several reasons. Respect for persons is a more fundamental philosophical value. Other values such as autonomy, empowerment, participatory decision making, beneficence, and nonmaleficence are explained in part by their contribution to an overarching value of respect for persons. That is, these other values also imply a moral commitment to cherish others for who they are and enable them to live well. The obligation to act in a manner that is consistent with respect for persons, in fact, imposes a duty to consider values other than autonomy, such as beneficence and nonmaleficence.

Professionals’ actions must consider important contextual features, including the role of the person’s dependence and interdependence with others, the potential desire of some persons to delegate decision making to others on their behalf, and the numerous contributors to a global sense of life satisfaction.

Because respect for persons is an overarching value, we accept that different actions give greater weight to certain subsets of values over others, depending on the context. We are led to evaluate every procedure, structure, and action against each of these subsets of values. For example, of a certain situation, we might ask: “How does X fit with each of the following: autonomy, empowerment, beneficence, research about the preferences these individuals tend to have and the variables that may affect the expression of these preferences, other professional values and knowledge, and so forth. Instead of autonomy versus beneficence, respect for persons mandates us to think in terms of autonomy and beneficence, in addition to other professional duties or values. Attention to respect for persons enables professionals to consider or evaluate all our actions and ask whether each action moves us further toward the goal of respecting someone as a person. Other values are more limiting in scope.

Link With Self-Determination and Person-Centered Planning

Note that respect for persons (and the multiple ways to enact that respect) resonates with promo-

tion of self-determination, understandings of person-centered planning, and considerations of quality of life that are already highly valued in the field of intellectual and developmental disabilities. Moreover it may be why they are valued.

Definitions of and elaborations on the concept of self-determination have been offered by authors from various disciplines emanating from different theoretical frameworks (Wehmeyer, 2003b). A common thread in these meanings is that humans have at least some degree of ability to set and act on goals and that doing so is integral to what is special, or to be appreciated, in human life. More recently, Sprague and Hayes (2000) discussed self-determination from a feminist perspective, centering their analysis on the concept of the self in the context of interdependence with others. Wehmeyer, Abery, Mithaug, and Stancliffe (2003) presented ecological, functional, and self-regulation theories of self-determination, each of which has its own implications to daily professional practice. Recognizing the complexity of self-determination as a construct, Wehmeyer (2002) cautioned against the risk of misinterpreting self-determination too narrowly: "Being self-determined does not mean that one does everything for oneself" (p. 59), nor does it mean that one must "independently make complex decisions or solve difficult problems" (p. 58). Equating self-determination with control is likewise a misunderstanding of the construct (Wehmeyer, 2005). Such misconceptions could lead to practices that are counter to its fundamental intent. Wehmeyer (2005) argued that it is the concepts of volition and causal agency that are the cornerstones of self-determination.

In essence, all of the evolving formulations of self-determination are attempts at articulating what seems to most of us to be instinctively morally correct: Our job is to assist our clients to achieve a sense of well being as they continuously negotiate life, as we all do, with the purpose of maximizing potential goods and minimizing potential harms to ourselves and those about whom we care.

Person-centered planning starts from the reality of the particular person—including their sense of self, negotiation with life, and particular context—and is specifically guided by that reality. It takes into account the needs of others and one's interdependence with others. Accordingly, as Mount (2002) explained, "Person-centered work has been a complex, interactive, dynamic, long term process of personal, organizational, and social

change—a process that can never authentically be reduced to or measured by its smallest parts" (p. xxi).

In writing about the implications of person-centered planning for self-determination, Wehmeyer (2002) described specific person-centered planning processes that can promote and enhance self-determination for persons with intellectual and developmental disabilities. These include skills-building of various forms and opportunities for experiences and meaningful choices.

We believe that by adopting respect for persons as a governing principle, promotion of self-determination and person-centered planning can be enhanced by further expanding the scope of considerations that professionals and clients are able to draw on, resulting in a more satisfactory quality of life for persons with intellectual and developmental disabilities.

Conclusion

In Table 1, we offer a set of practical considerations to operationalize the principle of respect of persons. To customize the support process when assisting individual persons with intellectual and developmental disabilities with decision making, a step-wise approach can be useful: (a) identify the objectives, (b) assess factors that contribute to meaningful participation of the client in the decision process, (c) prepare for conversations with the client, (d) plan any decision-making meetings, and after decisions are made (e) follow up with the client, and (f) follow up with the team.

Beginning with the specific objectives relevant to the situation at hand can help to focus the process. This can be done by considering what specific questions must be answered or what specific outcomes must be achieved. Many factors will affect clients' ability to participate meaningfully in their own decision-making process and the team's in-depth understanding of their clients, including their clients' profiles, psychological and emotional factors, and abilities to process information. Because clients' wishes must remain paramount (and, with the specific objectives, orient the decision-making process), particular emphasis must be placed on understanding how best to encourage clients to express their thoughts and wishes. For example, with whom does the client feel most comfortable sharing personal information? How can professionals facilitate the sharing of the client's

Table 1 Customizing the Support Process When Assisting Persons With Intellectual and Developmental Disabilities With Decision Making

Identify objectives	<ul style="list-style-type: none"> • What are objectives of the proposed discussion with the client? • What are specific questions to be answered?
Assess factors that contribute to meaningful participation of the client in the decision process	
Understanding client's personal characteristics	<p>Intellectual profile and adaptive skills</p> <p>Competencies related to receptive and expressive language</p> <p>Attention span</p> <p>Other psychological and emotional aspects (e.g., concern about anxiety, capacity to manage change and stress)</p> <p>Ability to process information necessary to make informed decisions (e.g., ability to appreciate the risks and benefits involved, short- and long-term implications)</p>
Client's wishes	<p>Has client already expressed her wishes? To whom?</p> <p>How to better understand client's wishes?</p> <p>With whom would client be most comfortable to share her genuine wishes?</p> <p>Would client like to state her wishes in a meeting? If so, in what format (e.g., verbally, a prepared written list, a prepared picture list)? Who should be there?</p> <p>Would client prefer to delegate someone else to represent her views?</p>
Other factors likely to impact client's decision making	<p>What is client's relationship with significant persons in her life?</p> <p>What is nature of the interdependence between client and significant others?</p> <p>How might these relationships affect client's perceptions of her real options?</p> <p>Is client comfortable sharing her preferences with significant others? Does she require and/or want assistance in doing so?</p> <p>How can you support the client and significant others work through challenges?</p> <p>What is client's comfort level with various people who may be involved in explaining and discussing issues related to the decision that needs to be made?</p>
Establish consensus among staff about the real options available to the client	<p>In the domain under consideration, what options are realistic to offer to client?</p> <p>Which of client's wishes, if any, can be realistically facilitated?</p>
Prepare for conversations with client	
Decide the format for discussions with client	<p>Prepare for a series of conversations with client:</p> <p>Who should be having these conversations with client?</p> <p>Where should these conversations take place?</p> <p>How should these discussions be paced? If necessary, establish a graduated process, breaking down decision-making process into smaller steps over an extended period of time, allowing for reflection, further questioning, and discussion by client.</p> <p>Plan how to present options in most neutral manner possible</p> <p>Consider multimodal presentation of information to increase comprehension of variables involved in decision (e.g., use of pictures, videos, stories, discussion with friends, or visits)</p>

Table 1 Continued

Plan to reinforce client's expression of independent ideas	<p>Emphasize to client your desire to hear her wishes, thoughts, and feelings</p> <p>Encourage client to express hesitations and reasons</p> <p>Throughout the exchanges, send a clear message to client to take her time making decisions, that she may ask for clarification and have further discussions at a later time, and set some dates for further discussions</p> <p>Send a clear message to client that she is welcome to talk to others about these decisions. It may be helpful to list persons that client may want to consult with (e.g., certain family members, certain staff).</p>
Prepare for the possibility that the client:	<p>Asks for opportunities that are not available</p> <p>Expresses wishes that parents, guardians, and/or professionals consider unacceptable (e.g., due to variables such as parents' values/preferences; learning objectives that professionals consider inappropriate for client at this time; practical issues such as transportation)</p> <p>Wishes to make a final decision, which she is thought not competent to make</p>
Take into account limitations of the client's understanding	<p>Establish how team will be satisfied that client has understood options and has made informed and meaningful choices</p> <p>Establish plan to follow if team views client's understanding as too limited to allow for meaningful decisions</p>
If a meeting is considered for the purpose of decision making...	
Prepare client	<p>What benefits would be derived from client's presence at meeting?</p> <p>Can client imagine what the experience would be like to participate in such a meeting?</p> <p>How best to prepare the client for such a meeting (e.g., review purpose of meeting, who will be there, and what will be discussed)? Plan what she wants to say/express, coping strategies, and exit strategy.</p>
Prepare other attendees	<p>Reinforce need to use language and terms that client understands</p> <p>Agree not to discuss issues that client does not understand in her presence (e.g., administrative details)</p> <p>Agree that subjects too sensitive to address at meeting will not be raised</p> <p>Agree to discuss varied professional perspectives on decision in question prior to a meeting with the client</p> <p>Agree that if unforeseen issues arise during meeting that require further consideration by client/team/family, these will be addressed at a different time</p>
Prepare a statement for the beginning of the meeting to convey client's role at meeting	<p>Examples:</p> <p>"Claire, I know that you wanted to listen today to what we say. We will not ask you any questions."</p> <p>"Claire, I know that you prepared a list of things that you would like to tell us/do. Shall we go over them now?"</p> <p>"Claire, you don't have to make any decisions today. You will have time to think about what you want and talk about it with..."</p>

Table 1 Continued

Plan how to support client during meeting	Facilitate client's expression of her preferences Be vigilant about, and responsive to, client's verbal and nonverbal reactions throughout the meeting Ensure that client understands what is being discussed Reassure client of opportunities after the meeting to ask questions and review what was said
Follow up with client	
Review conversations and meetings with client	Help client talk about her comfort level (e.g., what worked for her about a meeting/conversation; what did not, what would have been easier) Review content of conversation/meeting and assess client's understanding Review time frame for the action plan if one was established Follow up with team
Review the process, decisions, and plan	Did the process support and assist client's involvement with decision making? Is the team satisfied that client has understood options and has made informed and meaningful choices (to extent she is able)? Is there a need to return to client for further clarification of statements she made or emotions expressed at earlier points in process?

wishes (e.g., a prepared picture list, a prepared written list, preparing a venue for the client to explain wishes verbally)? Given the contextual nature of every decision, other factors that are likely to impact on the client's decision must be explored. Particularly important for persons with intellectual and developmental disabilities is their interdependence with others and the preferences of their significant others. Before approaching clients for further discussion, the team should establish which of the client's wishes can be facilitated.

Preparing for conversations with clients about their desires and the manner in which the decision-making process can be enhanced require special attention. Table 1 provides details on how to decide the format for discussion with the client and the plan to reinforce the client's expression of independent ideas. It is important to anticipate how to respond to situations where clients may ask for opportunities that may not be available or express wishes that others may consider unacceptable.

If a meeting is considered for the purpose of decision making, this too needs to be customized. Taking the time to prepare the client and other attendees for the meeting is critical because of the constellation of factors that impact the process and

outcome of such a meeting. Asymmetrical power, outer-directedness, and the variability in individual preferences regarding participatory decision making affect the comfort level of clients and their ability to benefit from such a meeting.

A good decision-making process does not end with the decision made. Debriefing with the client is important to assess the client's understanding of the decision, what actions will be taken and the time frame, and the client's experience of the steps that led to the decision. Likewise, follow up with the team is also important. This includes reviewing the process and its effect on the client and the team and developing a plan to implement and evaluate decisions that are made.

Throughout this article, we have tried to demonstrate that to assist persons with intellectual and developmental disabilities (and to understand and respond respectfully to all persons), the conceptual framework needs to be broadened to include many other factors, only some of which we have discussed here. For example, among the factors that we have not discussed, yet must consider in the context of autonomy, are the roles of developmental stages (Wehmeyer, 2003a), the impact of personality traits (Jenkinson, 1999; Zigler, Bennet-Gates, Ho-

dapp, & Henrich, 2002), and effects of motivational orientation (Reiss & Havercamp, 1996; Switzky, 1997). Deeper reflection about the concepts of autonomy, empowerment, participatory decision making, asymmetrical power relationships, outerdirectedness, and respect for persons provide professionals with insight and confidence that we can do better. We can develop frameworks and procedures that enhance our expression of the respect that we already have for adults with intellectual and developmental disabilities.

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