

## “I’m Supposed to Be In Charge”: Self-Advocates’ Perspectives on Their Self-Determination Support Needs

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### Abstract

In this qualitative interview study, we explored the perceptions of adults with intellectual disability regarding interpersonal or social supports needed to express their own self-determination. Specifically, 10 adults, all members of a self-advocacy group, were asked to discuss their understanding of the term *self-determination* and ways in which support staff have either supported or inhibited their self-determination. Ten themes characterizing supportive and impeding staff actions were identified. The need for greater exploration of environmental and social influences on self-determination is emphasized.

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Supporting adults with intellectual disability to lead self-determined lives has been a salient focus of both research and disability services for over two decades (e.g., Policy Research Brief, 2009; Wehmeyer, 2001). The construct of self-determination carries multiple meanings. When defined from a personal and a psychological perspective, *self-determination* is characterized as “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” (Wehmeyer, 2005, p. 117). From this perspective, self-determination is viewed as a drive, motivation, or trait. When the construct is applied to service systems, self-determination is viewed as a right, referring to the freedom, authority, support, and responsibility needed for individuals to direct and control their own services and budgets (Nerney, 2007). Despite the variation in meanings, a consistent thread is that self-determination is about people self-directing their lives in positive ways.

Arguably, self-determination is the hallmark of adulthood and an essential attribute needed for achieving a good, quality life (Lachapelle et al., 2005; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1998); but how does one come to express self-determination? This is a salient question given a strong consensus in the research literature that many adults with intellectual disability do not live very self-determined lives (Stancliffe, 2001; Wehmeyer, 2001).

In theory, individuals’ expression of self-determination is influenced positively or negatively by the interaction between one’s personal characteristics and environmental conditions (Abery, 1994; Field & Hoffman, 1994; Wehmeyer & Garner, 2003). Specifically, in describing the functional theory of self-determination, Wehmeyer and Garner (2003) proposed that (a) personal capacity, influenced by learning history and personal development; (b) opportunity, influenced by environment and experience; and (c) supports or accommodations that enable people to exercise self-direction all impact the expression of self-determination. Although it may be tempting to focus on personal limitations, environmental influences, including related supports, may be the most relevant for adults with intellectual disability. Research supports this supposition. Several studies have shown that adults with intellectual disability who live or work in more congregate settings display lower levels of self-determination than those who live or work in more independent or nonsegregated environments (e.g., Stancliffe, Abery, & Smith, 2000; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1998). Further, when researchers controlled for personal characteristics, the environment, and not intelligence, was found to be the significant contributor to self-determination, confirming the relative importance and impact of this variable on the lives of adults with intellectual disability (Wehmeyer & Bolding, 2001; Wehmeyer & Garner, 2003).

Research on the environmental influences on self-determination is emerging. Beyond understanding the broad impact of congregate settings, very little is known about specific environmental factors that occur within and across settings that either promote or hinder individuals' expression of self-determination. The setting itself may not be the most influential variable, but, rather, the conditions within settings that foster self-direction may be the most relevant (Wehmeyer & Bolding, 2001). The provision of choice is one variable that has received considerable research attention, but a myriad of other environmental factors, physical and social, are likely to be influential (Stancliffe, 2001).

One potential environmental influence that has received little research attention in relation to self-determination is the quality and type of interpersonal supports provided to individuals with intellectual disability by their family, friends, or support staff. Given certain cognitive and physical limitations, many individuals with intellectual disability are not likely to act completely autonomously but, rather, require the on-going assistance of others to participate in daily decision-making and to advocate for their own preferences and needs (Thompson et al., 2009). The extent to which supporters through their daily personal interactions can help foster or hinder individuals' expression of self-determination is especially critical to our understanding as theoretically supporters create the conditions for self-determination. Several authors have speculated about the characteristics of interpersonal supports that may enhance self-determination. These include establishing trusting relationships (e.g., Kennedy, 1996), interpreting and responding to nonverbal communication (e.g., Brown, Gothelf, Guess, & Lehr, 1998), and providing on-going encouragement for and assistance with decision-making and other acts of self-direction (e.g., Bambara, Cole, & Koger, 1998; Lotan & Ellis, 2010); however, these and other forms of interpersonal supports on the expression of self-determination by adults with intellectual disability have yet to be systematically documented by researchers.

Central to this discussion on interpersonal supports is the attending to the voices of adults with intellectual disability regarding the types of supports they need or want. Rarely are the perspectives of individuals with disability included in the research literature in general (e.g., Robledo & Donnellan, 2008; Ruef & Turnbull, 2002; Stoner, Angell, House, & Goins, 2006). With regard to published research on self-determination, the involvement of

adults with intellectual disability has been largely limited to measuring their level of self-determination, quality of life, or opportunities for choice and control (e.g., Lachapelle et al., 2005; Stancliffe & Wehmeyer, 1995; Wehmeyer & Palmer, 2003) rather than assessing their perceived support needs. By contrast, national initiatives, such as Self Advocates Becoming Empowered (SABE: <http://www.sabeusa.org>) and the Robert Wood Johnson Foundation self-determination projects (Robert Wood Johnson Foundation, 2007), have actively sought and encouraged adults with intellectual disability to speak-out about the services and supports needed to enhance self-determination. The resulting outcomes have broadened our understanding of self-determination from the perspectives of self-advocates (e.g., Bradley et al., 2001); however, these initiatives have been focused on broad systems and policy changes needed for consumers to direct and control services rather than to understand the influences of self-determination from a personal perspective.

In a study related to the current investigation, Stoner et al. (2006) interviewed adults with physical disabilities regarding their perceptions about factors that facilitated and impeded their self-determination. The participants described specific intrinsic (e.g., personal fortitude, self-doubt) as well as extrinsic or environmental variables (e.g., support networks, physical accessibility) that influenced their ability to be self-determined. Family support and other social networks were identified as facilitators, bringing into the spot light the importance of more thoroughly investigating the nature of interpersonal supports and their influence on self-determination.

Our purpose in this study, therefore, was to explore the perspectives of adults with intellectual disability regarding the interpersonal or social supports needed to express their own self-determination. Understanding the perspectives of adults with intellectual disability regarding how to best encourage their expression of self-determination is imperative not only to develop meaningful supports that are important to them, but also to target potential environmental influences not previously explored by researchers that may result in improved outcomes for adults. Because support staff through community disability services plays a major role in the support of adults with intellectual disability, our focus was on understanding staff actions that were perceived to support or impede self-determination. Using a qualitative approach to inquiry, we interviewed well-informed adults to talk about their self-determination

and experiences with support staff. All participants were members of a self-advocacy group and were knowledgeable and conversant about the topic of self-determination. In addition, at the time of the study, the participants received staff supports in community settings. Specifically, we sought to answer the following questions. How do the self-advocates with intellectual disability define self-determination? What staff actions do they perceive as supporting their self-determination? Conversely, what staff actions do they perceive as inhibiting their self-determination?

## Method

### *Self-Advocate Selection and Recruitment Procedures*

Ten adult self-advocates with intellectual disability who were members of one of two self-advocacy groups located in northeast Pennsylvania participated. To recruit participants, we asked mentors of the self-advocacy groups who co-facilitated meetings with group members to nominate individuals based on the following inclusion criteria: (a) diagnosis of intellectual disability as evidenced by the receipt of disability services (e.g., Medicaid Waiver), (b) a minimum of 10 hours of staff support per week from a community, residential, and/or employment service provider, (c) conversational skills necessary to participate in interviews, (d) conceptual understanding of the construct of self-determination observed through group discussions, (e) ability to articulate concerns about events that affect them, and (f) an expressed willingness to participate in the interviews.

All self-advocates nominated by the mentors participated. To establish a relationship with the nominees and confirm that they understood the concept of self-determination and had sufficient language skills to respond to interview questions, the first author attended monthly meetings with each group for 3 to 4 months prior to conducting individual interviews. Attendance at meetings continued for an additional 3 months during and after the interviews to maintain relationships.

### *Self-Advocates*

Table 1 provides descriptive information for each of the 10 self-advocates, including their age, gender, and ethnicity and the participants' present (during the time of the interviews) and past (within past 10 years) living and employment situations for which they received staff support

through a disability service provider. As shown, the self-advocates were 6 women and 4 men, ranging in age from 24 to 56. With regard to present services, 7 self-advocates received staff support for residential living only; 1 received support for employment only; and 2 received staff support for both residential living and employment. With regard to present living situations most self-advocates lived in a 24-hour group home or in a semi-independent living situation that provided less than 30 hours of staff support per week. One self-advocate lived in a family living situation where the host family was paid to provide care. With regard to present staff support provided for employment, 2 self-advocates worked in a sheltered workshop. Outside of paid support, 1 self-advocate, Marie, lived with her family and 7 self-advocates were either competitively employed, self-employed, or unemployed at the time of the interviews.

Past living and employment situations also varied. Some participants lived and worked in multiple situations within the past 10 years. Past living situations that provided 10 hours or more of staff support included family, semi-independent, and group home living as well as institutional placement in an Intermediate Care Facility. Past employment situations providing paid staff support included sheltered work and competitive community employment.

### *Data Sources and Procedures*

We used one-on-one, in-depth semi-structured interviews to explore the self-advocates' experiences and perspectives concerning their self-determination. Interviewing individuals with intellectual disability may pose a number of challenges associated with the interviewees: (a) recalling experiences, (b) understanding and responding appropriately to open-ended questions (particularly when questions exceed their linguistic abilities), and (c) pleasing the interviewer with responses that they believe the interviewer or others want to hear (Biklen & Moseley, 1988; Finlay & Lyons, 2002). Interview procedures were designed to address these challenges.

Following Seidman's (1991) recommendations for conducting a multiple interview series, we interviewed each self-advocate twice. The first interview encouraged free recall to open-ended questions and general discussion about self-determination. In the second interview we asked the self-advocates to clarify their responses made in the first interview and to detail their experiences by providing specific

**Table 1** Demographic Information

Name	Age	Present staff support	Residential experiences		Employment experiences	
			Present	Past	Present	Past
Jerry	49	Residential	Semi-independent	Personal family, semi-independent with roommate	Competitive	Competitive
Mickey	56	Residential	Group home	Personal family	Competitive, volunteer	Workshop, competitive
Bob	29	Residential	Semi-independent	Personal family, group home	Competitive	Competitive
Phil	53	Residential	Group home	Personal family, institution	None	Workshop
Joni	44	Residential	Family living	Personal family	None	Competitive
Carolyn	49	Residential	Group home	Family living, semi-independent	None	Workshop
Dina	49	Residential/ employment	Group home	Personal family, institution	Workshop	Competitive
Marie	24	Employment	Personal family	Personal family	Competitive, volunteer	Competitive, volunteer
Carly	46	Residential/ employment	Group home	Personal family, semi-independent with roommate	Workshop	Competitive

*Note.* All participants were Caucasian.

examples. The two interviews were spaced less than one month apart. Following a topical interview guide, the first author conducted all interviews, which ranged from 60 to 90 min.

The interview guide consisted of open-ended questions, examples of alternatively worded questions that were used in instances when a self-advocate appeared to have difficulty comprehending a question, and sample follow-up probes that encouraged them to detail their responses. Before using the interview guide, we asked members at one self-advocacy group meeting to provide feedback on the clarity of the questions and interview format outlined in the guide. Their feedback was used to shape the final protocol.

We organized the interview guide around four broad categories. First, the self-advocates were oriented to the purpose of the study and asked to talk generally about themselves in an effort to build rapport and reduce any uneasiness about participating in the interviews. To discourage interviewer-pleasing statements, the interviewer stressed the importance of speaking honestly. Self-advocates

were reminded periodically throughout each interview that what they say would not be shared with others (especially staff members) and that "I don't know" was an option for every question.

Second, we asked self-advocates to define the meaning of the term *self-determination* (e.g., "What is self-determination?" "Why is important?" "What things do you do to be more self-determined?"). Third, we requested that they discuss their experiences in which staff actions were viewed as interfering with their ability to express their self-determination (e.g., "Can you tell me a story of when a staff person did something that got in your way of being self-determined?" "What things have you seen with other people with disabilities?"). Fourth, we asked self-advocates to describe their perspectives about how staff members can help support their self-determination (e.g., "Can you tell me a story of when a staff person did something that helped you be self-determined?"). In addition to rephrasing questions to ensure comprehension, the interviewer frequently summarized and paraphrased the self-advocates' responses to ensure that she

correctly understood their words and intended meaning.

All self-advocates chose to be interviewed in their homes in a private location. When given the option of having a trusted person present for support during the interviews, 3 elected to have their mentor present. To reduce the possible influence of the mentor's presence on participant responses (Biklen & Moseley, 1988), we asked the mentor not to participate in the interviews but, rather, to interpret hard-to-understand communication between the interviewer and the self-advocate only when asked. If the mentor offered an interpretation, the interviewer asked the self-advocate to verify its accuracy (e.g., "Judy said you were afraid. Is this true?").

### Data Analysis

A research team, consisting of the two authors and a doctoral student in special education, conducted the data analysis. All interviews were audio-taped and transcribed verbatim by a professional transcriptionist. The first author, responsible for the interviews and the primary analysis, listened to the tapes and corrected any inaccuracies in the transcripts. Data analysis of the transcribed interviews progressed in four stages, following a modified version of the Consensual Qualitative Research procedure developed by Hill, Thompson, and Williams (1997).

First, we developed a set of domain codes to categorize the participant responses into related topic areas. The process involved two team members reading through the first three sets of interview transcripts, generating an initial start list of domain codes based on participant responses, independently applying the codes to the first set of transcripts, and then coming to consensus on the categorization of text, modifying or creating new codes as needed to categorize all the data. This resulted in a start list of 20 domain codes that were then used to code the remaining sets of transcripts.

Second, the primary coder applied the domain codes across all the remaining transcripts, resulting in the categorization of all text within the transcripts; however, we maintained and used original transcripts throughout all stages of data analysis to prevent decontextualizing the self-advocates' responses. Once all transcripts were coded, a second team member audited the categorized text; any disagreements with the primary coder were resolved through consensual

agreement. As needed, we continuously modified domain codes or created novel ones as new concepts emerged from the interviews.

Third, we abstracted the content of each domain by preparing a succinct summary of each self-advocate's core ideas. The goal here was to reduce the data in preparation for the cross analysis. A second team member audited the abstracts and met with the primary coder to come to consensus, making sure that the wording of the abstracts was representative of the participant's words and ideas.

Fourth, we conducted a cross analysis by comparing all abstracted domains across participants. All cases within abstracted domains were analyzed to determine similarities across participants and whether or not abstracted ideas could be further coded into smaller subcategories. A final comprehensive analysis linking domains and subcategories into themes is reported below in the *Findings*. The research team reviewed the final themes to achieve consensus and to confirm that the themes were grounded in the data.

### Member Check

To verify that themes reflected self-advocates' experiences, we presented a summary of the findings at two self-advocacy group meetings that were held in different locations to elicit comments. At least 3 self-advocate participants were present at each meeting. Specifically, we asked the group members to comment on whether the themes and illustrative examples were typical to their experiences and those of others with intellectual disability. Both groups indicated strong endorsement of the themes. Several members responded by providing additional examples and telling their own personal stories. These accounts were recorded in fieldnotes by the self-advocacy mentor and were integrated into the findings.

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## Findings

Here we describe how the self-advocates (a) defined the meaning of self-determination and (b) perceived staff actions to either impede or support their ability to express their self-determination.

### Definition of Self-Determination

Two themes seemed to capture the self-advocates' understanding of the construct self-determination: speaking out and being in charge.

### 1. "I'm my own advocate": Speaking out

When the self-advocates were asked, "How do you describe self-determination," they expressed a common view that self-determination was about speaking out on their own behalf about what they wanted or did not want, and it was about making their intentions heard. Jerry said that being able "to talk about what I want" with others defined self-determination for him. Similarly, Bob and Dina described self-determination as knowing "your rights" and talking about "what you want." Bob defined self-determination by stating, "Self-determination to me is how I moved out of a group home." He explained that when he learned from his caseworker that he had the right to "not to live in a group home," he spoke out by making his desire to move known to his support staff. Jerry stated that if he did not speak out on his own behalf, "nobody else would do it for me."

### 2. "Being my own boss": Being in charge

In addition to speaking out, being "in charge," or making and acting on decisions, also defined self-determination for the self-advocates. Phil said that when "the ball is in my court, I decide how things should be done." In particular, the self-advocates shared many examples of being in charge through daily choice-making, such as deciding what to do during free time, choosing where to live or work, determining what to do with personal spending money, and choosing to have intimate relationships with others. Joni said that choosing to have a boyfriend and choosing what to do when she had free time were ways that she was self-determined, while Jerry stated that self-determination means, "Doing what I want." Another self-advocate participating in one of the focus group meetings said that self-determination "means doing things for myself and reaching my goals."

Although the self-advocates emphasized being in charge, 3 participants explicitly acknowledged their need for support or assistance from others to do so. Bob voiced that being self-determined meant being "independent," but if he needed, he knew whom he could go to seek assistance "to be more independent." Jerry seemed to echo this sentiment of being in charge while also securing help when needed. He stated:

I want somebody to help me, yes, I ain't saying that [I don't want someone to help me]. Everyone needs help. I need help, you need help, everybody needs help. The point is, if I am going to be a self-advocate, the first thing I could do is speak up for myself—to know what's going on in my life.

### Staff Actions

Ten themes characterized the self-advocates' perceptions about staff actions that influenced their ability to express their self-determination. These themes are organized by staff actions that either impeded or supported their acts of self-determination.

#### *Actions Impeding Self-Determination:*

#### 1. "They'd boss me around": Usurping decision-making and control

All but one self-advocate relayed numerous instances in which their opportunities to express self-determination were impeded when support staff made decisions for them. Based on the self-advocates' examples, congregate and family living settings posed the most restrictions. For instance, Bob stated that when he lived in a group home, he and his roommates "[had] to do whatever staff says." He explained, "They'd tell me what time to go to bed, what time to eat, and wherever the staff go, we'd have to go." Dina, who lived in an institution, reported being upset by having to eat dinner at three thirty in the afternoon, expressing that it was "so early for supper" and that "people would be getting hungry" later in the evening. Cass, who lived in a family living situation, also spoke about the limited control she had over her daily activities.

Staff control over decision-making extended beyond daily choices and often pre-empted opportunities for self-advocates to decide where to work and live and with whom. After sharing an apartment with a roommate without disabilities for years, Carly explained that one day she was informed by a program supervisor that her roommate no longer wanted to live with her and that she would be placed in a group home. Similarly, Phil reported that he moved from an institution to his group home without being presented with any options. Concerned about their personal welfare, Carly and Marie angrily explained that they and their friends were not given the choice of selecting their own roommates and support staff. Speaking about her friends, Marie said,

They have a right to choose who they want in their group home. They weren't able to sit and say yes, will you like this person to come in there? "NO," we don't want him working in the group home, because he's mean.

Two self-advocates also expressed dismay about their support staff changing their employment without consulting them. When Dina was asked what she would have said if her caseworker had asked her whether she wanted to change jobs, Dina stated, "I

would have said to her, no, I want to keep the job." In summary, in sharp contrast to the self-advocates' characterization of self-determination (i.e., speaking out and being in charge), staff control over decision-making was perceived as a major impediment to the self-advocates' expression of their self-determination.

2. *"He used to hold my money": Controlling personal spending*

Staff control over personal spending money, resulting in the self-advocates either not having direct access their money or having to ask support staff for daily spending money, was a significant barrier to self-determination for 5 self-advocates. They seemed to equate lack of control over their money with lack of power or general control over their lives. Phil reported that when he lived in an institution, his money was locked in an office. Mickey reported wanting to watch a truck pull contest at a local fair, but when he asked his support worker for money, the staff person refused by stating, "That's not nice, that's not for you." Three other self-advocates who lived in group homes had to ask for their money when they wanted to buy something and were not permitted to keep their money in their personal possession.

3. *"I can't tell her I don't like my job": Being unapproachable or inaccessible*

Although not a staff action per se, self-advocates perceived unapproachable or at times inaccessible staff persons as another impediment to self-determination. Four self-advocates described situations in which they simply did not feel comfortable confiding in their support staff or seeking their assistance when needed. Dina explained that when she lived in the institution, she was pressured by another resident to have sex. Although frightened by his advances, she was afraid to speak out because it seemed as if "the staff didn't care at all." She also feared that if she reported the situation, her support staff would tell the resident's sister, whom Dina perceived as being mean. Similarly, Mickey reported that although he did not like the hard work and little money he made at the sheltered workshop, he did not feel comfortable telling the workshop staff that he wanted another job. One self-advocate who participated in one of the focus groups seemed to offer a partial explanation. He bluntly stated that he stopped going to one support worker for help because the worker failed to follow through with his requests. Overall, discomfort or hesitancy with approaching support staff for fear of staff not doing anything or

for fear of undesired repercussions seemed to have inhibited the self-advocates' drive to speak out.

The lack of accessible or available support staff also posed a barrier. Marie and Joni reported that when support staff were inaccessible or unavailable, it was difficult for them to speak out about what they wanted and carry out their intentions. When Marie's job coach abdicated his responsibility of doing weekly follow-up checks, she expressed dismay that she did not know whom she could turn to and discuss this issue. Joni expressed that when her group home is understaffed, and only one staff person is available, she is unable to leave the group home and do the things that she wants to do without her roommates.

4. *"I told her I wanted a job, but I haven't seemed to get one yet": Failing to follow through*

Based on their accounts, there were times when the self-advocates clearly spoke out by making their intentions and decisions known; however, staff failed to follow through by providing timely and needed supports to help the self-advocates carry out their intentions, which posed another barrier to their self-determination. Specifically, 6 self-advocates discussed situations in which support staff either procrastinated or did nothing at all to assist them.

Several self-advocates reported instances in which they informed support staff of their preference for a new job or living situation, but had to wait before staff took any noticeable action to assist them. Mickey explained that his support staff did not listen to him at first after he declared that he wanted another job. Upset and unsure of why they did not listen, Mickey reported that it took a long time before his support staff finally helped him. Similarly, Joni also reported that she told her staff she wanted a job at Wal-Mart. She finally got the job she wanted, but emphasized that "it took a while." Jerry declared that it took his support staff a long time to "hear" that he wanted a new place to live. When a new apartment was found, he said, "It was like a hurricane, like one, two, three and I'm in there. I didn't know what really hit me. I still got a lot of stuff missing."

Other self-advocates wondered whether some staff persons listened to them at all. Phil recounted a time when he approached his staff about getting a job. When asked if he thought his support staff listened to him, he stated sarcastically, "I haven't seemed to get one yet." Carolyn stated that the reason that she was no longer interested in pursuing

a job was that her support staff did nothing to help her, despite the fact that she clearly made her desires known.

Four self-advocates talked about the lack of staff support around transportation. Living in rural areas with limited public transportation, Joni, Cass, Dina, and Carly relied on their support staff to take them to work or to desired community places and activities, yet the lack of staff assistance posed problems for them. Cass said that her family living provider declared that he was "too busy" to take her to self-advocacy meetings. Joni mentioned that she liked her job at Wal Mart "till there was no buses; then I could not do the job." One self-advocate who participated in a focus group explained that her desire to do something was constantly dictated by the availability and willingness of her staff to provide transportation, not when she wanted or needed to do something. These self-advocates viewed transportation as means to their self-determination, and if staff could or did not provide transportation, the self-advocates were either left to find alternative methods or were left being unable to pursue their interests.

5. *"She said if I moved out she wasn't going to talk to me anymore": Obstructing and coercing*

Six self-advocates spoke candidly about another way that support staff impeded their self-determination. This came in the form of obstructing or vetoing the self-advocates' decisions, sometimes through acts of coercion or manipulation. Mickey explained that he told both his mother and his staff worker that he no longer wanted to work in a workshop, but was informed by both that he "had to stay," totally disregarding his choice.

Four self-advocates spoke about staff manipulating the self-advocates' view of a situation in an effort to persuade them to do what staff members thought was best. Jerry talked to his caseworker about wanting to move to his own apartment, but reported that, "they told me to wait until the end of July; now they're trying to talk me out of it." Bob explained that when he told his group home staff that he was "ready" to move out, they responded, "no, you're not." Similarly, when he told his boss and job coach that he "doesn't want to be doing dishes the rest of life," Bob's boss responded that he was "the best dish washer ever."

Carolyn said that her family living provider threatened her to change her mind about moving out. Carolyn reported that when she told the woman about wanting to move, the woman responded by

saying "if you move out [she] wasn't going to talk to [Carolyn] anymore." Taken together, these examples of coercion (purposeful or not) suggest that support staff, or others in position of authority, may at times distort facts, make false statements, or use their position of power to impose their views or persuade self-advocates to change their decisions.

*Actions Supporting Self-Determination:*

By contrast, five themes emerged that characterized the self-advocates' descriptions of staff actions that supported their self-determination.

1. *"They point me in the right direction when I need it": Expanding options and experiences to encourage choice*

Nine self-advocates spoke positively about support staff who encouraged them to initiate choice-making by presenting options and exposing them to new experiences. Phil, for example, reported that his support staff helped him to find a new job, by describing to him "what's out there" and asking him if he would like to learn more about available jobs in his community. Three self-advocates spoke fondly about a support program that provided a monthly recreation calendar in which activities and events in their area were listed. Joni talked about how the calendar made her think about new activities that she wanted to try. Dina revealed how experiencing an option helped her to make a decision to move from a large congregate care facility. Although she admitted that she did not like living there, she explained that she would have never considered moving out until her caseworker suggested she try living in a group home on a trial basis.

Three self-advocates described specific examples of staff providing them with opportunities to make frequent, daily choices in their homes, speaking at length about support staff providing them with options for meals. They expressed that even though support staff took primary responsibility for cooking meals, they welcomed opportunities to make meal selections or choose something else to eat when they did not like what was being served. Although these choice opportunities seemed minor in comparison to making decisions about employment and living situations, they were nonetheless important to these self-advocates.

2. *"I could go to somebody higher up": Supporting access to people of authority*

Eight self-advocates expressed that their self-determination was supported when they were able

to access people of authority above their direct support staff who could make things happen for them. Based on the self-advocates' accounts, the role of support staff was to either educate the self-advocates about whom to go to for help or to assist the self-advocates to make connections with people in power. At least, supportive staff members did not appear to stand in their way. For example, Dina stated that if she had an issue with a staff person telling her when she should go to bed, she knew she could "go to somebody higher up" to express that she "should" be able to stay up later. Similarly Carly, who was required to have 24 hours of staff support because of balance problems, planned to talk to the "big bosses" (i.e., residential program directors) at her annual planning meeting about her desire to have time alone with her boyfriend. She stated emphatically, "We'll talk about it at my meeting." Cass posed this question to one of her support workers, "What can I do if I had a problem with somebody [staff person] and I didn't know who to go to? Or, can I come to you to talk? Being supported to have access to people of authority seemed to have provided the self-advocates with a way to resolve issues that either involved their support staff or issues that their support staff could not address themselves.

3. *"I feel comfortable with her": Being approachable and accessible*

Ways in which support staff fostered the self-advocates' expression of self-determination seemed rooted in the relationships formed between support staff and the self-advocates. An overarching premise expressed by 8 self-advocates was feeling comfortable enough with their support staff in order to approach them for help and accept their guidance when needed. Both Carly and Dina talked about liking certain staff persons and being able to tell them anything. Carly explained, "It's important to me if you like your staff. You could talk to her about more, you could open up to them." Dina indicated that staff persons who are "nice and don't boss her around" are the ones that she goes to if she needs help in making decisions.

In addition to being liked, approachable staff persons were the ones the self-advocates trusted. Dina made specific mention of trusting a staff person to the point of accepting her recommendations; she explained that she took her staff person's advice to change her job without trying it first because she "trusted her." Similarly, Carly explained that

because of her relationship with her support staff (one with whom "she is able to kid around with"), she is "fine" when her support staff makes suggestions for buying new clothes. Positive relationships built on trust and comfort seemed to foster the self-advocates willingness to accept guidance and foster their initiative to speak out.

4. *"I will have the staff sit down ... and I will sort out the choices": Listening without judgment*

Five self-advocates reported that their self-determination was supported when support staff "really listened" to them when they spoke out, rather than dismissing or ignoring their assertions. Implicit in their discussions, listening seemed to mean that support staff took the time to understand the self-advocates' point of view, offered assistance when they could, and refrained from imposing judgment or their own position on the self-advocates' decisions.

Carolyn, for instance, shared many examples about the choices she made, which included wanting to live in town, not wanting to work (especially not in a workshop), going to bed early, and not wanting to be part of a community club hosted by her residential provider. Through these stories, Carolyn conveyed that support staff respected her recreational, employment, and residential decisions because they did not attempt to change her mind. Phil was appreciative that when he and his friend approached his group home staff and the residential director about wanting to change group homes, his staff and program director did not question his decision or "give their two cents" trying to persuade him differently. Rather, he explained, they all sat down together to devise a plan to move.

Three self-advocates acknowledged that there were times when support staff could not honor their requests or help them to act on their decisions. Rather than doing nothing or ignoring their requests, the self-advocates appreciated support staff who explained honestly why they could not help. Phil explained that he usually talks to the program director if he has an issue because she listens; but, he also understands that she "tells [him] what she can and can't do."

5. *"Have staff in my corner, whatever I want to do, they will help me": Providing support for follow through*

Lastly, and perhaps in the most obvious way, the self-advocates indicated that their self-determination was upheld when support staff provided needed assistance to help them carry out or refine their decisions

once they had spoken out. Based on the self-advocates' accounts, support for follow through took on various forms. First, 7 self-advocates spoke about support staff sitting down with them to problem solve and plan a course of action. The key was not for staff to impose their views but, rather, to provide information in the form of options and advice for the self-advocates to consider in their decision-making. For instance, 4 self-advocates spoke about telling their support staff that they wanted a new job, and how they felt supported when staff assisted them by looking through job ads and describing available options. Similarly, Bob explained that when he declared that he wanted to move to a place of his own, his support staff helped him make decisions by explaining his financial situation, looking at the classifieds together, and providing him with several apartment options to consider.

A second form of support for follow through was when staff members encouraged or motivated the self-advocates to pursue their decisions and goals, Jerry spoke appreciatively about staff members motivating him on "days when he didn't want to do things." When asked what motivating meant to him, Jerry replied, "To have them in my corner. Like whatever I want to do they could support me. Motivate me, [get me] moving and get another job; encourage."

Phil and Dina spoke about staff members encouraging them to lose weight after they declared their interest by reminding them to practice portion control and motivating them to exercise. In another example, Carly talked appreciatively about her support worker who encouraged her to make decisions for herself. When shopping for clothing, her support worker said, "don't buy it to make me happy, what do you like?"

A third form of support for follow through consisted of support staff assisting the self-advocates to carry out tasks of daily living. When asked specifically, "what do staff do to help you be self-determined?" several self-advocates talked about the many ways that staff provided daily assistance, including assistance with taking medications, going to the bank, doing laundry, going to the grocery store, cooking, and going to doctor appointments. Carolyn, for example, talked about how support staff taught her to manage her diabetes and give herself insulin shots. Support to participate in daily activities was viewed by the self-advocates as being relevant to their self-determination because these activities were important to them; staff assistance helped the self-advocates exert control and pursue the things they wanted to do. This form of support was extended to transportation and spending

as well. Several self-advocates gave examples of their self-determination being supported when staff made alternative arrangements for transportation or helped them manage, as opposed to controlling, their budgets and spending.

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## Discussion

In this study we explored the perceptions of self-advocates with intellectual disability regarding their understanding of the construct of self-determination and the ways in which support staff have either facilitated or hindered their self-determination. Consistent with the views of other self-advocates described in national reports (e.g., Bradley et al., 2001), the participants described self-determination in terms of speaking out for themselves, being in charge, making decisions, and having control over the things they want. Yet, at the same time, they seemed keenly aware of their personal limitations and restrictions imposed on them by their living and work situations and, as such, turned to support staff or others for assistance. The ways in which support staff created opportunities for self-determination and responded to the self-advocates' self-determined acts seemed to have a strong influence on the self-advocates' ability to carry out their will and their future expression of self-determination. The findings are discussed within the context of four overarching themes that summarize potential key influences of self-determination identified by the self-advocates.

Perhaps, one of the most important key influences on self-determination identified by the participants was the quality of their interpersonal relationships formed with support staff. Good relationships seemed to create the context for all other supportive actions to follow. Self-advocates spoke fondly about staff members whom they trusted and liked. Implicit in their discussion, liking and trust was facilitated by support staff consistently acting on the self-advocate's behalf and interests. If self-advocates viewed their relationship with support staff as positive, they seemed open to staff support by initiating requests for assistance, sharing sensitive information, and being receptive to staff members' guidance. Indeed, in some instances, the self-advocates seemed to relinquish control and accept staff actions that can be construed as controlling (e.g., portion control) perhaps because of the trust that had been established. By contrast, self-advocates reported avoiding staff members whom they did not trust, sometimes at the expense of not pursuing their

own interests or protecting their personal welfare. In other words, the extent to which self-advocates could express their self-determination and seek assistance when needed seemed mediated by the quality of the interpersonal relationships formed with their supporters. This conclusion is consistent with the findings of a small, but growing number of studies that point to the quality of relationships as a key mediator in establishing effective supports for individuals with developmental disabilities (e.g., Bambara, Gomez, Koger, Lohrmann-O'Rourke, & Ping Xin, 2001; McLaughlin & Carr, 2005; Robledo & Donnellan, 2008). It is also consistent with Ryan and Deci's (2000) self-determination theory positing that self-determined behaviors are more likely to flourish in social contexts characterized by a "sense of security and relatedness" (p. 71) imparted by others.

The second key influence identified by the participants was the specific support strategies implemented by staff to encourage and respond to their self-determination. As indicated by the self-advocates, supportive staff actions came in several forms, such as encouraging them to try new things or to pursue their goals and interests, listening to their wants and ideas without imposing judgment, providing support for decision-making by sharing information and problem-solving with them, and providing whatever assistance was needed (e.g., arranging transportation, helping with grocery shopping) in order for the self-advocates to carry out their intentions and engage in activities that were important to them. According to self-determination theory as advanced by Deci and Ryan (1985), these staff actions can be classified as informational, those that support autonomy and promote competence, rather than controlling, those actions that force one to act or think differently. In their review of research conducted with nondisabled populations, Deci, Connell, and Ryan (1989) concluded that informational actions support self-determination, whereas controlling actions diminish it.

The contribution of the findings in the present study is that self-advocates provided specific examples of how support staff can facilitate their self-determination in noncontrolling or informational ways during daily interactions. As suggested by many professionals, promoting self-determination requires that supporters understand the target person's frame of reference and willingly follow the person's lead and interests (Bambara et al., 1998;

Brown et al., 1998; Turnbull & Turnbull, 2001; Wetherow & Wetherow, 2003). Clearly, speaking out or making choices is not enough. For individuals with intellectual or other developmental disabilities who need assistance, self-determination cannot be fully realized without the on-going support of others.

It is interesting that, although making choices is considered only one facet of self-determination (Wehmeyer, 2005), the self-advocates viewed having frequent opportunities for daily choice-making as an important source of support. Although, their emphasis on daily choice may have been fueled by their limited experiences with having control in their lives, it is possible that choice served an important function in their relationship with support staff. That is, choice may have allowed self-advocates to establish and maintain self-direction as they relinquished some control for certain activities (e.g., finding a job or apartment) to support staff. Choice provided a vehicle for shared decision-making between self-advocates and their supporters.

The third key influence of self-determination relates to how support staff exerted their power. Due to personal limitations, people with intellectual disability are vulnerable to the control of others who do not share the same limitations. In a positive vein, self-advocates described numerous ways in which staff used their power to support their self-determination, such as sharing information or helping them to gain access to people in positions of authority. On the other hand, supporters were described as abusing their power sometimes through acts of coercion. Specifically, self-advocates talked frankly about staff members who manipulated a situation or a self-advocate's view of a situation in an effort to persuade self-advocates toward what staff thought was best.

Van Knippenberg, Van Knippenberg, and De Cremer (2007) identified two driving forces behind the use of coercive tactics by powerholders: competence and reward structures. With regard to competence, the use of coercive tactics by support staff may reflect traditionally held beliefs that people with intellectual disability are incapable of making competent decisions (e.g., Bannerman, Sheldon, Sherman, & Harchik, 1990). With regard to reward structures, staff workers may use coercive tactics to manipulate situations for their own benefit, such as making their jobs easier in some way. The primary implication is that in order for staff to fully adopt a noncontrolling posture of support, they may need to

become aware of their own motivations for their actions.

The fourth key influence relates to the settings in which the self-advocates lived and worked. Consistent with previous research (e.g., Stancliffe, 2001; Wehmeyer & Palmer, 2003), the self-advocates' strongest voiced concerns about staff control (e.g., controlling money, usurping decision-making, failing to follow through) seemed largely associated with congregate living or work settings. Staff actions perceived as interfering with the self-advocates' self-determination may be partly explained by the policies and organizational structure of congregate settings that are imposed on staff (e.g., locking up money), including the inherent conflict of balancing individual support needs with group care. However, unsupportive staff actions were not limited to congregate settings. Self-advocates reported numerous instances in which support staff, and sometimes family members and in one case an employer, usurped their decision-making, failed to follow through on requests, or pressured them into changing their minds in noncongregate environments. At the same time, they gave positive examples of staff support occurring in group settings as well. These findings suggest that the influences on self-determination are complex and cannot be explained by a single variable (i.e., setting alone). In order to fully understand the influences of self-determination, greater consideration must be given to multiple factors (e.g., setting, interpersonal, attitudinal) and the interaction among them.

The findings of this study should be interpreted in light of two primary limitations. First, similar to all qualitative studies, the findings are uniquely tied to the participants' experiences and should not be generally applied to other individuals. For instance, all participants were members of one of two self-advocacy groups run by the same organization; therefore, their perspectives about the meaning of self-determination were likely shaped by their group discussions. Similarly, the self-advocates' perspectives about staff actions that supported or impeded their self-determination were likely influenced by their present and past living and work situations and the contrast among them. Most self-advocates experienced congregate living or work situations, or they lived with a host family paid to provide support. Thus, it is unclear whether other adults with intellectual disability who receive supported living services in their own home would share similar views. In addition, because the self-advocates had

such varied living and work experiences, tracing their perspectives about staff support to specific contexts with any certainty is impossible.

A second limitation is that in this study we focused only on perceptions. Although understanding the perspectives of adults with intellectual disability is vital to our understanding of meaningful supports, perceptions alone do not reveal whether reported staff actions actually influenced self-determination. Direct observations of self-advocate and support staff interactions could have provided more corroborating evidence and yielded richer descriptions of what supporters say and do to promote or hinder self-determination.

In conclusion, by focusing in this study on the perspectives of adults with intellectual disability regarding the interpersonal or social supports needed to facilitate their self-determination, we provide a unique contribution to the literature. This study clearly documents that self-determination cannot be viewed outside of social contexts, especially for individuals with intellectual disability who must rely on the assistance of others to carry out their will. Future researchers should continue to explore how all supporters, paid and unpaid, can best create interpersonal contexts supportive of self-determination and how to change their orientation toward greater support of self-determination through training and development.

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# Résumés en Français

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## **Identité liée au handicap de dirigeants du mouvement de promotion et de défense des droits**

**J. Caldwell**

Les récits de vie et les perspectives de dirigeants du mouvement de promotion et de défense des droits ont été explorés afin d'augmenter les connaissances sur le développement de l'identité en ce qui concerne leur handicap. Des entrevues qualitatives approfondies ont été menées auprès de 13 dirigeants du mouvement de promotion et de défense des droits. Cinq thèmes principaux sont ressortis: (a) la résistance, soit affirmer son identité en tant qu'individu et avoir l'occasion de s'exprimer, (b) la relation avec la communauté composée de personnes handicapées, (c) le fait de reprendre en main son handicap et assumer sa transformation personnelle, (d) l'échange avec des mouvements plus larges des droits des personnes handicapées, et (e) le lien avec la justice sociale et l'interdépendance.

## **«Je suis censé être en charge»: la perspective des personnes qui défendent leurs droits sur les besoins de soutien à l'autodétermination**

**S. L. Nonnemacher et L. M. Bambara**

Dans cette étude qualitative, nous explorons la perception des adultes présentant une déficience intellectuelle concernant le soutien interpersonnel ou social nécessaire pour exprimer leur propre autodétermination. Plus précisément, 10 adultes, tous membres d'un groupe de défense et de promotion des droits, ont été consultés afin de discuter de leur compréhension du terme *autodétermination* et de quelles façons les intervenants peuvent soutenir ou inhiber leur autodétermination. Dix thèmes décrivant des actions des intervenants qui soutiennent ou empêchent l'autodétermination ont été identifiées. La nécessité d'une

plus grande exploration des influences environnementales et sociales sur l'autodétermination est renforcée.

## **Prestation de services selon le genre: une perspective masculine et féminine sur le genre du personnel**

**N. J. Wilson, R. J. Stancliffe, T. R. Parmenter et R. P. Shuttleworth**

Malgré la reconnaissance que les intervenants rémunérés ont un impact significatif sur la vie des personnes présentant une déficience intellectuelle, l'expérience subjective du genre de l'intervenant est rarement considérée dans la recherche. Les données qualitatives provenant d'une étude sur les besoins de santé sexuelle des hommes et des garçons ayant une déficience intellectuelle sont présentées. Nous avons conçu cette étude pour déterminer l'impact du genre de l'intervenant sur les besoins de santé sexuelle des hommes et des garçons ayant une déficience intellectuelle. Les résultats suggèrent que bien que les intervenants utilisent les mêmes techniques de soin, ils le font de façons uniques à leur genre. Le genre du personnel est important à considérer lorsqu'il s'agit de questions de santé sexuelle et il peut améliorer le type et la qualité des relations entre les personnes ayant une déficience intellectuelle.

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