Exploring the Perceptions of Self-Determination of Individuals With Intellectual Disability

Karrie A. Shogren and Ricky Broussard

Abstract

Interviews were conducted with 17 individuals who had intellectual disability to expand our understanding of the impact of self-determination in their life. Themes emerging from the interviews were grouped into three categories: meaning of self-determination, learning about self-determination, and dreams for the future. Participants described self-determination as being able to make choices and be in control of one’s life and setting as well as being able to work toward goals and engage in advocacy. Participants discussed the importance of supports for expressing self-determination and identified environmental characteristics that promoted and inhibited self-determination. Overall, their perceptions confirm the importance of promoting personal development of skills and attitudes associated with self-determination and systems change to create environmental opportunities for self-determination and causal agency. Implications for future research and practice are discussed.

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Self-determination has received significant attention in the disability field over the past 3 decades. Promoting self-determination has been identified as best practice in special education and transition services (Eisenman, 2007; Wehmeyer et al., 2007) as well as in the design and delivery of adult supports and services (Nerney, 2002; Powers et al., 2002). Self-determination has been identified as a key dimension of individual quality of life (Lachapelle et al., 2005; Schalock, 2000) and as a key predictor of valued life outcomes in the domains of independent living and employment (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997).

A vast array of research has been conducted to identify evidence-based practices to promote self-determination in educational settings (Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009; Fowler, Konrad, Walker, Test, & Wood, 2007), to identify environmental characteristics that impact the expression of self-determination by youth and adults with disabilities (Van Gelder, Slington, & Pugh, 2008; Zhang, 2001), and to explore the perceptions of self-determination held by special educators, families, and support staff (Carter, Lane, Pierson, & Stang, 2008; Zhang, 2005).

However, relatively little research has been done to explore the perceptions of self-determination held by individuals with disabilities. Of the research that has been conducted, most has been focused on the perspectives of individuals with learning disabilities on the role of self-determination in transitioning from school to adult life (Trainor, 2005) and in college success (Anctil, Ishikawa, & Scott, 2008; Getzel & Thoma, 2008). Researchers have not systematically explored the perspectives of individuals with intellectual disability, a group whose perspective is often underrepresented in social science research (Know, Mok, & Parmenter, 2000; McDonald, Keys, & Henry, 2008).

Exploring the perspectives held by individuals with intellectual disability on self-determination and its meaning in their life has the potential to expand our understanding of the relationship between self-determination and quality of life. Furthermore, the perspectives of individuals with intellectual disability can provide insight into important emphases for self-determination re-
search, policy, and practice to make initiatives in the field maximally relevant to these individuals. Further, understanding the perspectives of individuals with intellectual disability can provide insight into the diverse application of the self-determination construct in the disability field. For example, in the field of special education, self-determination is often associated with a set of skills and attitudes that can be taught (e.g., teaching choice-making and self-advocacy skills), whereas in adult supports/services, self-determination is often associated with a systems change initiative to promote consumer control of funding (Wehmeyer, Bersani, & Gagne, 2000). There is often confusion on the application of self-determination, given the diverse self-determination initiatives and underlying theoretical frameworks (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003). Understanding the meanings individuals with intellectual disability attach to self-determination and the impact of the construct on their life can facilitate the identification of common issues and priorities that cut across initiatives.

Given that the intended outcome of self-determination research, policy, and practice to support individuals with disabilities to be causal agents, people who make things happen in their life (Wehmeyer, 2005, p. 117), in this study we sought to promote causal agency by giving voice to the understandings of self-determination held by individuals with disabilities. Specifically, our aim was to explore the meanings attached to self-determination by such individuals to provide direction for future research, policy, and practice.

Method

The authors interviewed 17 individuals with intellectual disability during a statewide self-advocacy conference in Texas. The first author is a researcher who works in a university setting, and the second author is a self-advocate who lives in the community and owns his own business. Both authors collaborated on all phases of the research project.

Sample

We advertised the interview project in the program of a statewide self-advocacy conference. The advertisement contained information about the purpose of the project, and interested individuals at the conference were invited to come to an information table, which was manned by graduate students, outside of the room where the interviews took place. The authors also conducted a workshop entitled “Telling Your Story” during the first day of the conference, and an announcement was made about the project at that time. When potential participants came to get information about the project, a trained graduate assistant provided an introduction to the project, and interested individuals went through the informed consent process and signed up for 20-min interview time slots. We originally had 15 time slots, which we expanded to 17 based on interest and room availability. There were an additional 10 individuals who expressed an interest in participating, but we were unable to accommodate them based on time and room constraints.

Table 1 provides descriptive information on the 17 participants (9 women and 8 men). The majority of participants were Caucasian. They ranged in age from 26 to 56 years, with an average age of 42. All of them self-reported having an intellectual disability, and all received services from a provider organization in their region; however, the nature of these services varied. One individual lived in an institution (called state schools in Texas), 4 lived in group homes, 8 in apartments or their own homes, and 4 lived with family members. All of those who lived in apartments received some form of direct support for varying numbers of hours each day or week. Nine individuals were competitively employed. Two of the 9 worked full time. Two reported receiving ongoing support from a job coach, and 2 were employed by a local chapter of The Arc, where they received ongoing support from other employees. Three individuals worked at sheltered workshops, 1 attended a day habilitation program, and 1 worked on the grounds of the state school where he resided. One individual reported being a housewife. Two participants were unemployed. Two individuals were married, and 6 reported having a boyfriend or girlfriend. A majority reported ongoing, sustained community involvement, with a large proportion participating in organized religious activities and self-advocacy or volunteer activities.

Procedure

A graduate student met individually with each participant, explained the study, and obtained
<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Race/ethnicity</th>
<th>Living situation</th>
<th>Employment</th>
<th>Relationship status</th>
<th>Community involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dan</td>
<td>M</td>
<td>54</td>
<td>White</td>
<td>State school</td>
<td>Part-time housekeeping at state school</td>
<td>Single</td>
<td>Synagogue</td>
</tr>
<tr>
<td>Mark</td>
<td>M</td>
<td>26</td>
<td>White</td>
<td>Group home</td>
<td>Sheltered workshop</td>
<td>Girlfriend</td>
<td>Church, Special Olympics, self-advocacy group</td>
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<tr>
<td>Maria</td>
<td>F</td>
<td>39</td>
<td>Hispanic</td>
<td>Apartment</td>
<td>Unemployed</td>
<td>Single</td>
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</tr>
<tr>
<td>Steve</td>
<td>M</td>
<td>42</td>
<td>White</td>
<td>Apartment</td>
<td>Full-time advocacy</td>
<td>Single</td>
<td>Biking, hanging out with friends</td>
</tr>
<tr>
<td>George</td>
<td>M</td>
<td>37</td>
<td>White</td>
<td>Apartment</td>
<td>Sheltered workshop</td>
<td>Single</td>
<td>Sunday school, volunteer work</td>
</tr>
<tr>
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<td>F</td>
<td>47</td>
<td>White</td>
<td>House</td>
<td>Housewife</td>
<td>Married</td>
<td>Church; volunteer work</td>
</tr>
<tr>
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<td>F</td>
<td>52</td>
<td>Hispanic</td>
<td>Apartment</td>
<td>Part-time with job coach: clerical work</td>
<td>Boyfriend</td>
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</tr>
<tr>
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<td>Part-time receptionist</td>
<td>Single</td>
<td>Self-advocacy group</td>
</tr>
<tr>
<td>Brian</td>
<td>M</td>
<td>56</td>
<td>White</td>
<td>Group home</td>
<td>Full-time restaurant</td>
<td>Relationship</td>
<td>Special Olympics, church, self-advocacy group</td>
</tr>
<tr>
<td>Lisa</td>
<td>F</td>
<td>38</td>
<td>White</td>
<td>Apartment</td>
<td>Part-time restaurant</td>
<td>Single</td>
<td>College Buddies, self-advocacy group</td>
</tr>
<tr>
<td>Tony</td>
<td>M</td>
<td>56</td>
<td>White</td>
<td>Apartment</td>
<td>Sheltered workshop</td>
<td>Relationship</td>
<td>Church, self-advocacy group</td>
</tr>
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<td>48</td>
<td>White</td>
<td>Family home</td>
<td>Part-time with job coach: university dining hall</td>
<td>Girlfriend</td>
<td>Special Olympics</td>
</tr>
<tr>
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<td>43</td>
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<td>Group home</td>
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<td>Relationship</td>
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<tr>
<td>Sara</td>
<td>F</td>
<td>44</td>
<td>White</td>
<td>Family home</td>
<td>Day program</td>
<td>Single</td>
<td>N/A</td>
</tr>
<tr>
<td>Patty</td>
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<td>43</td>
<td>White</td>
<td>House</td>
<td>Housewife</td>
<td>Married</td>
<td>Church, Habitat for Humanity</td>
</tr>
<tr>
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<td>F</td>
<td>46</td>
<td>White</td>
<td>Group home</td>
<td>Part-time fast food restaurant</td>
<td>Single</td>
<td>Church, self-advocacy group</td>
</tr>
<tr>
<td>Gary</td>
<td>M</td>
<td>43</td>
<td>White</td>
<td>Family home</td>
<td>Unemployed</td>
<td>Single</td>
<td>Special Olympics, church, golfing, fishing</td>
</tr>
</tbody>
</table>

*aAll names are pseudonyms.*
informed consent from the participant (2 participants had legal guardians who provided consent, with assent provided by the individual participant). After consent was obtained, the graduate student collected basic demographic information from the participant, which was entered into a standardized form.

After meeting with the graduate student, the participant went into the interview room (a typical meeting room at the conference facility) and met the first and second author. We restated our purpose for conducting the study and confirmed the individual’s interest in participating. All participants were interviewed individually by the authors. We videotaped all interviews for later transcribing. The authors sat at a round table in the meeting room with the interviewee. There were two cameras in the room and a camera operator who ensured that the sound was working and that the authors and interviewee were on film at all times. The average interview lasted 10 min (range = 3 to 22 min).

The second author generated a list of questions he felt would enable his peers to describe their life and the meaning of self-determination in their life. We used these questions to create an interview guide that included open-ended “grand tour” questions (“Tell me about your life. Where do you live? Where do you work? What supports do you receive?) and four follow-up “probe” questions (What does self-determination mean to you? How did you learn about self-determination? What do you want for your future? What could keep you from achieving your dreams for the future?) The questions were reworded and re-phrased as necessary during each interview to ensure that the interviewee was clear about the meaning of the question and able to respond in a meaningful way.

The grand tour and follow-up probe questions were deliberately left open-ended to allow for expansive responses. In addition, when introducing himself, the second author provided background on his life (e.g., previously lived in an institution and now had a job and an apartment in the community) and, throughout the interview, in order to scaffold the questions for the participants, he provided examples from his life regarding what self-determination meant to him and what he wanted for the future. We individualized additional follow-up questions for each participant to facilitate the expansion of their ideas. The open-ended process was intended to gather unanticipated perspectives or other important information from the participants (Miles & Huberman, 1994; Patton, 2002).

Support persons were present in the room for three of the interviews. In two interviews, the support persons sat apart from the interviewee and provided clarifying information at the request of the interviewee about the supports they provided. For the third interview, a support person (the sister of the interviewee) brought along a photo album to enable the interviewee to tell his story. The interviewee’s sister provided elaborations on the nature of the pictures and what the participant was communicating, as needed.

Analysis

The interviews generated 61-single spaced pages of data. We used the constant comparative method (Patton, 2002) to analyze the transcripts. The first author reviewed all transcripts and coded the data for initial themes. During this process, she iteratively assigned working definitions to each code. The codes and working definitions were iteratively evaluated against the data and against one another to confirm they captured participants’ meanings. The first and second author then collaboratively reviewed the codes and working definitions generated by the first author, added additional codes, and refined the codes and working definitions until consensus was achieved. To enhance credibility, a graduate student not directly involved in the interviews but engaged in the transcription of the videos and familiar with qualitative methodology and self-determination research served as a peer-debriefee (Lincoln & Guba, 1985). The graduate student independently reviewed the transcripts and the coding framework and met with the first author to review and make refinements to the coding framework. The authors then reviewed and finalized the coding framework and organized the codes into the three categories presented below.

Results

All participants shared diverse stories about the meaning self-determination had in their life. The primary themes from the interviews were grouped into three categories: the meaning of self-determination, learning about self-determination, and dreams for the future. Despite the presentation
Participants talked about 'NUMBER 49, 2: 86–102' K. A. Shogren and R. Broussard

Participants

APRIL 2011

Perceptions of self-determination

of these categories as distinct and linear, it is important to note that there were significant relationships among the themes between and within the categories.

Meaning of Self-Determination

Participants described self-determination and its meaning in their life in diverse ways. Three key interrelated themes emerged: choice and control, setting and working toward goals, and advocacy. It is important to note that a small number of participants struggled to respond to the question of what self-determination meant to them. Three said that they had heard of self-determination but were not exactly sure what it meant. Two others said they had never heard the word self-determination. When participants were unsure about self-determination and what it was, the second author talked about what self-determination meant to him in his life. After he spoke about self-determination, each of the 5 participants was able to elaborate and relate self-determination to his or her personal experiences.

Choice and control. Participants talked about how being self-determined meant being able to make choices and being the person in control of his or her own life and the decisions made about their life. Participants described being able to engage in preferred activities when they chose to do so; one described being able to watch, and occasionally go to, WWE wrestling matches, one of his favorite pastimes. Another person described being able to go out and order a beer at a restaurant and make his favorite breakfast. Another individual discussed how she could go and do fun things and have a boyfriend.

Participants also talked about how being self-determined influenced how they lived their life (i.e., where they worked, where and with whom they lived, and even how they managed their finances). One individual said that self-determination was:

Freedom, not having to live in the house with my parents and being able to be married, and being able to live away from my family and together with him for 10 years. That was a big, big thing… I didn’t think we were going to make it this far, but we did (Patty).

Another participant emphasized enjoying what he did in his life:

I choose where to live. I like my job. I like what I do. I go to church on Sundays. I have a family. I go visit my family very often. My staffs take me to the store, they take me to Wal-Mart or wherever I need to go (Brian).

Participants also discussed the importance of being responsible and having self-control when living a self-determined life. One person said that self-determination meant he could “stand on my own feet. I am a man, I can find my own way” (Steve). Other participants described being responsible for household chores, like “cleaning [my house], fixing my TV dinners, and making my lunch every day” (George). Several people also mentioned some type of self-management strategy that enabled them to “stay on track,” like a calendar or schedule.

It’s like taking the bus… I need to know where I am going and I call the [local bus service] to do my evening activities. I call ahead of time and then call the day before to confirm my pick up and return… I always stick with my schedule so I know what I am doing at certain times… My schedule helps me do things (George).

The role of the environment and the opportunities it provided (or did not provide) for choice and control was also emphasized by many participants, who described the influence of where they lived on their ability to be self-determining.

Self-determination could help me get out in the community… be on my own. I’d rather not be in a state school… I’ve been there 38 years and I don’t like being there so long. I never go out to eat, I never go to movies, I never go anywhere else. Sometimes, a lot of times, I get bored. I don’t want that. I don’t want to get bored. I’d rather go to movie. I’d rather go get something to eat or go out to eat and shopping. I’d like to do that (Dan).

Other participants, especially those living in group homes, described wanting to have more choice and control over the activities they engaged in—such as where, when, and what types of activities they did in the community. Others expressed frustration about not being able to pick whom they lived with and shared their personal space with. “They pick ’em for us… My roommate does all these weird things like leave the lights on all the time and he blames me for it, but I have to live with him (Tony).

Setting and working toward goals. Participants also talked about how being self-determined meant identifying and setting personal goals. As Maria said, self-determination means “to make goals for myself to have my own house and my own business at my own house.” Participants also articulated the importance of having ways to follow through on
goals. One participant said that she had learned to write down her goals so that she could stay on track. Others emphasized the importance of having people that were supportive of your goals. Self-determination is being “able to talk about what you want in your life and set goals and dreams for yourself” (Isabel). Several participants stressed that you also have to go after your goals and that “no one will do it for you” (Mark). Others said that “you have to just go out and just go do it. … you have to set goals and go for those goals” (Patty) and “you have to do something or you won’t be nothing at all” (Kevin).

Advocacy. The relationship between self-determination and advocacy was emphasized by participants, who talked about how important it was to be able to stand up for your rights. As one individual said, “it’s important to me because it’s our life, it’s actually my life” (Nancy). A number of participants talked about confronting discrimination they encountered, particularly when looking for jobs. One individual described how she kept applying for an open job at her local library because she enjoyed books. She said that self-determination meant that she kept going after the job even though the library kept making excuses, like the budget was not in yet. She said she thought that they were “looking at my disability and not the person I am. If they really look at me as a person and not as a disability they would know me better and I can talk to them” (Nancy). So, she said she kept going back so she could achieve her dreams. Another person said that he was having a hard time scheduling a job interview at a local restaurant. He said they kept canceling or changing the time and that he has to “stand-up and speak-out so I can get a job interview” (Mark).

Participants talked about how advocacy could and should impact a number of different life domains; they discussed how advocacy was needed so that people with disabilities could get out of state schools (i.e., institutions) and so that employers would stop “just looking at the disability.” Several participants emphasized the importance of advocating for all people with disabilities. “It’s being able to advocate for myself and others too if they need it” (Nancy). Other participants emphasized that some people struggled to advocate for themselves, either because they had never been taught or because they did not have the opportunities to do so where they lived or worked. Janet talked about how her advocacy would enable her to “get out there and make it better for someone else that can’t yet speak up for themselves.” Participants also described how part of being a self-advocate was “helping others to believe in themselves and gain confidence to speak of the issues” (Steve). As Lisa said: “Everyone has self-determination. It’s not just me that counts, everybody has self-determination also. They have their rights and they have their own space. Their freedom. They have their rights to speak for themselves too.”

Learning About Self-Determination

Participants described multiple ways in which they learned about self-determination. Three primary themes emerged: conferences, trainings, and materials; established self-advocates and allies; and school-based experiences.

Conferences, trainings, and materials. Multiple participants discussed the self-advocacy conference where our interviews were conducted as a venue for learning about self-determination. They mentioned that they could attend multiple sessions in which speakers talked about self-determination and being in charge of their own life. They also talked about opportunities to socialize and learn informally from other self-advocates. Several people did mention that it took them time to get comfortable and understand what people were talking about. As one participant said, “When I first started coming to advocacy meetings, I was real shy and didn’t want to talk to nobody. … Then I started coming every year and that’s when I started getting involved” (Maria). Many participants made similar statements that, at first, they were not very involved, but after they attended the conference multiple years, they learned more and became more involved.

Other participants talked about local self-advocacy groups in their communities. Several attended weekly or monthly self-advocacy group meetings. They said that the meetings ranged from fun social events to learning opportunities about their rights, how to live the life they wanted, and how to advocate for policies that would give them more control over their life. Many people talked about the significant impact of these meetings on their life. As one person said, “I think I found my voice when I went to my first self-advocacy meeting and people were talking about dreams and hopes. I got to thinking about my dreams and hopes” (Steve).
Other participants mentioned self-advocacy and self-determination trainings that were offered in their communities, often through a local chapter of The Arc, or state trainings that they received funding to attend. Participants indicated that these trainings offered information that enabled them to go back and advocate in their communities and be self-determining in their life. Several participants talked about going through a multi-week training using the “My Voices, My Choices” curriculum. As one individual said, “I went through a training at The Arc called My Voices, My Choices. I think that is where I really heard about self-determination and really got into it really deep” (Janet). Other participants talked about Partners for Policymaking and how going through the Partners course enabled them to learn skills to serve on local boards and to contact their legislators on issues that were important to them. Several individuals also talked about participating in rallies at the state capital about waiting lists and other injustices they perceived in the system.

Established self-advocates and allies. Related to the previous theme, participants frequently discussed the importance of being “mentored” into self-advocacy by established self-advocates and by reliable allies (generally individuals without disabilities). Many individuals, as briefly highlighted in the previous sections, expressed that they were shy or initially uncertain of how they could be self-determining. Several also discussed how having a person or people who followed up with them, got them involved in activities and helped them overcome the barriers that they sometimes faced in environments that were not supportive of self-determination. As Steve described:

The local advisor of the [self-advocacy] group, we … humped into each other at the county fair. And she asked me why I wasn’t coming to any meetings and I said well the group home says they don’t want to support me to go to those meetings. And, she took her time to help me get there and help me learn. … She gave me a little nudge to be successful. … And, I come from working at a sheltered workshop for 50 cents an hour. Now I make great money, but I never before dream of myself doing the job I’m doing today. In the group home, it was a lot of rules and a lot of low expectations on me. I tried to ask for help and no one was listening to me. … Now I want to help others get the tools to be empowered.

School-based experiences. Given the range of ages represented in the study, the school-based experiences of the participants differed significantly. However, all participants expressed that they learned about self-determination as adults. We followed up with several participants to ask whether they had learned about self-determination in school, and, overwhelmingly, participants replied that there had been little support for self-determination in school, and they had not learned to be self-determined until they were adults. As one participant said, “I went all the way through school but I didn’t learn it in school” (Patty). Nancy elaborated:

Teachers don’t teach us that in high school because they don’t know what self-determination means to them. When I entered as a freshman they wanted me to be in a special class but I didn’t because my parents fought for me to be in a regular class. And that’s where I met my friends. They never taught us that [self-determination] because they just didn’t know it. They’re uneducated but we can educate them in different ways.

Dreams for the Future

Participants described a wide array of dreams for their future. Although the specifics of the dreams were diverse and personal, most expressed long-term goals related to living in the community in a location of their choosing, having a career that they enjoyed and that matched their interests and preferences, and building more community connections through friends, family, and meaningful contributions.

All of the participants, with the exception of those who were already living in their own apartment or home, indicated that they wanted to live in the community, in a place they chose, with people they chose. Several participants indicated that they wanted to live in locations that enabled them to use the bus system to get around so they could easily access work, favorite activities, and family and friends. Several participants mentioned that although they would still need support staff when living in their own home or apartment, they want to have more of a choice in where and how they lived their life. “I would like to get my own apartment in the city, because honestly, I bet I could do it with support” (Mary).

Another common theme was for participants to express a desire to have a “real” job in the community. Several people who worked in sheltered workshops or in other settings made statements like Tony’s: “I’d like to find a, you know, a regular job; like in a restaurant or movie theater.” Other participants, particularly those who had been
working in a similar job for a number of years that was not well matched to their interests, expressed a desire to start their own business. For example, one individual who worked at the local chapter of The Arc said that he enjoyed what he did, but he was really interested in establishing a party rental business. He talked about how his parents helped him get contacts, and he had received a small grant to purchase his first piece of equipment, a margarita machine. Several participants expressed similar, self-employment-related goals that were matched to their interests. One participant who was very interested in animals said that she wanted “to get some money together and find a place for my business. I want to have a boarding kennel for dogs” (Patty).

Some participants viewed getting a “real” job or starting a business as a gateway for a “real” life. As one individual who worked in a sheltered workshop said, “Well I would like to find a real job and make more money. I have to get a full-time job and make money if me and my girlfriend decide to get married and start a family” (Tony). Wanting a real life was something described directly and indirectly by the majority of participants, who defined a real life as living in a place of one’s own and working in a meaningful job as well as being close to family and friends and connected to the community through ongoing engagement in activities, volunteer work, and fun social activities. Several participants made statements like Steve’s, “I want to try to be more involved in my local community and have more friends.” Another common goal was to develop more meaningful close, personal relationships and, for a handful of participants, to start a family. About half of participants expressed a desire to have a girlfriend or boyfriend or to become engaged or married to their current girlfriend or boyfriend and have the opportunity to share a life together. “I want to marry my girlfriend and start a family. … I’d like to live in a house. A nice house, you know, with a garden” (Tony). Several participants described an interest in having kids or adopting kids or serving as a mentor to other youth with disabilities.

Finally, a number of participants reported goals related to their personal development. Multiple individuals discussed wanting to learn more about saving money or to start saving money in order to reach their goals related to living, working, and playing. Several people mentioned needing to manage money to be able to do fun things. One individual described a dream of going on vacation, “I might like to go to the Caribbean or someplace like that someday” (George). Others mentioned wanting to learn to drive and get a driver’s license. Participants also mentioned goals related to their health (e.g., eating better and exercising more). Kevin said that he wanted to work to “be healthy and eat better.” Individuals also expressed an interest in furthering their advocacy activities for people with disabilities. As Janet said, “I would like to see more people with disabilities on boards, like at The Arc.”

**Barriers to dreams.** When talking about their dreams, the participants mentioned many barriers to achieving their vision for the future. One of the most commonly cited barriers was the attitudes of others. For example, multiple participants mentioned that others did not believe that they could achieve their dreams—and told them that frequently. Maria described her biggest barrier as “people who are telling that I can’t have my own home or my own business because of my disabilities.” Nancy expanded on this saying,

People need to look at me as a person and not as a disability. … they should realize that we are just like them. We are normal, we are normal just like people. They need to realize what they are doing [when they just look at my disability], and they need to think.

Other participants mentioned that parents could sometimes be overprotective of children with disabilities and that this made it difficult for them to grow up and have their own life and advocate for their needs. Janet described struggling with what she wanted and what her family wanted: “Sometimes my family tells me not to do certain things. I wanted to move into my own apartment and my family was against it.” Participants also talked about how important it was that families understand that although individuals with disabilities might always need support, they could also be more independent. As Nancy said,

Parents can be overprotective of their child. My parents aren’t that way cause they don’t tell me what to do because I make my own decisions and I’m my own guardian. I can sign forms by myself without anyone asking me to. I can do things by myself but I do need a little help sometimes. … but parents have to realize we only need a little help.

Finally, participants talked about how some parents might not realize the negative consequences for people with disabilities when parents are overprotective. Steve described implications for all
people with disabilities, particularly in the policy arena:

I get frustrated by some people. ... Like one [parent group] who tells the legislature that their son and daughter have the mind of a 6 year old child or the mind of a 3 month old baby. That is very frustrating for me because if they do that, they look down on us and not value as a person and it's demeaning instead of a positive. ... We need to do education over and over and over again. ... I feel like it has to be a two way street because they need to learn from us and we need to learn from them.

Another oft-cited barrier was the lack of availability of systems of supports that were guided by the individual's preferences, interests, and abilities rather than the needs or structure of the service system. For example, the issue of the waiting list in Texas came up in almost all interviews (except for individuals who had already qualified for a Medicaid Home and Community-Based Services Waiver). As Mark described the situation, "Well I gotta wait and see what day I come up [on the waiting list]. I've been waiting like 7 or 8 years now…. I'm thinking I just want to be by myself in an apartment." Steve said that he did not feel like the system wanted to change:

I think the providers are scared of change and especially me being in charge of the money. They are afraid of losing beds. I think we have to convince the legislators and also that advocates that we need to have a voice about what services we really want.

Participants also described the difficulties they sometimes faced in accessing supports that enabled them to achieve their dream.

Well I used to have a job coach that would help me [fill out applications] because it's hard for me. ... I need help. ... My house manager is always so busy going in and out all the time, running errands so she can't help me fill them out. ... I need someone to help me get a real job, you know get away from [sheltered workshop] (Tony).

Other participants had dreams, but expressed uncertainty about how to go about achieving those dreams. Many individuals were able to articulate some of the steps that needed to happen for them to meet their goals, but they needed support (which was largely unavailable) to identify the more nuanced steps and to devise strategies to take concrete actions. One individual, who wanted to get his driver's license, knew the general requirements but not how to actually start the process.

I have to pass the test to get the permit…. But I don't know how to do that. ... I have to go down there to the office and they test me about what kind of kind of size is the roads, the streets, and school zones, all that (Mark).

Other participants knew some of the things that they would have to do when living in the community but articulated that they would need support to learn to do them and sustain them over time. Issues related to learning to manage your money and your banking and do grocery shopping and cooking came up repeatedly. Several participants indicated that they could learn to do those things, but they might always "need some staff to help get everything done" (Isabel). However, others, typically those living in more restricted settings, indicated that they needed to do all these things on their own prior to moving into an apartment or house.

I have to have good behavior. ... I have to learn to take responsibilities and learn to do things. ... [I have to] learn to do the right thing and not go around and bother other people and not go around not doing something wrong. Just doing something right and that way I can be out on my own, that way I can be on my own (Dan).

The last barrier identified by many people was fear. Several individuals indicated that they got scared sometimes, especially when they were experiencing major life changes. "I get scared. I was scared when I moved because I did not know anyone" (Steve). Other participants said that they did not always have confidence, and sometimes they were not sure they could do things—even after people had told them they might not be able to.

Self-determination as a facilitator of dreams. Although participants identified a number of barriers to achieving their dreams, they were also able to name a number of personal strengths and abilities that enabled them to make progress toward their goals. Several of these strengths and abilities were related to skills and attitudes they used to define self-determination.

One of the most frequent strengths mentioned by participants was their ability to try things in different ways—or to "roll with the punches." As Nancy summarized it, "Well if that job doesn't work out then I can find a different job that will meet my goals and my dreams." Participants also seemed to express an understanding that they might experience difficulties in trying to reach their goals, but that they needed to be persistent, trust in themselves, and not be afraid to try new things, even if they were scary. As Kevin said, "It takes time, you know it takes a lot of effort to go
out and achieve something. You have to be willing to go out and risk and you have to learn to do certain things.”

Participants also talked about how they would have to be able to advocate for themselves as they were working toward their dreams. “You have to be able to stand up for yourself and tell people how you are feeling” (Patty). They also discussed how they needed to keep advocating, even if some people did not support their advocacy or their goals. As Mary said, “I know it’s okay to get my own place and that nobody can tell me otherwise that I can’t.”

Participants also indicated that they had to be able to ask for help and support when they needed it. Several participants mentioned that it was okay to ask for help and that everyone needs help sometimes. Participants also said that they hoped that people with and without disabilities would feel like they could ask them for help if they ever needed it. It was a “two-way street.”

They also described several different people that they could ask for support. Some individuals talked about being able to ask friends or family for support; others talked about asking their staff to support them, especially with activities like cooking, cleaning, and shopping. Several participants also mentioned their “circles of support” (i.e., a group of people they saw regularly who helped them work toward goals). As Maria said, “I can get people in my circle [of support] to help me when I need it.”

Discussion

Individuals with intellectual disability in this study described a range of personal meanings associated with self-determination. These descriptions align with and extend the current literature on self-determination. The following sections describe the key implications of the findings and directions for research, policy, and practice.

Being Self-Determined

In the literature, self-determined behavior is defined 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, 2006, p. 17). The idea of causal agency, or being the person that makes or causes things to happen in one’s life, is central to being self-determined (Wehmeyer, 2004). Study participants described diverse ways that they acted as causal agents in their life, ranging from ordering a beer at a restaurant to having the freedom to choose to get married.

Participants described a continuum of choice-making, as has been discussed in the literature on choice-making (Shevin & Klein, 1984), ranging from relatively simple choices regarding what to do with one’s free time) to more complex choices related to where to live, where to work, and whom to spend time with. They also indicated the importance of having choice opportunities at each point along the continuum. None of them seemed to believe that only “simple” choices (e.g., what restaurant to eat at in the community) were enough to truly act as a causal agent in one’s life, although such choices were clearly important to them. Instead, in describing their dreams for the future, participants talked about making complex choices related to where they lived, learned, worked, and played that would enable them to be in situations and environments where they were able to make “simple” choices based on their interests and preferences. They linked being in environments of their choosing, where they were the person in charge, with being able to engage in the activities they preferred on a daily basis. This perspective is consistent with the literature suggesting that the characteristics of the environment can significantly impact the diversity of choice opportunities available to individuals with disabilities (Stancliffe, 1997, 2001; Stancliffe & Wehmeyer, 1995). Further, as other researchers have suggested, only providing simple choices does not necessarily avail individuals with opportunities to truly develop self-determination and causal agency (Cullen, 1999). Unfortunately, research in the disability field has consistently been focused on more simplistic choices (Shogren, Faggella-Luby, Bae, & Wehmeyer, 2004). Further research is needed on the continuum of choice, ways to increase the environmental opportunities available to individuals with intellectual disabilities for making complex choices and systems change that facilitates rather than limits choice opportunities along the continuum.

It is interesting that the primary themes that emerged from participants’ descriptions of the meaning of self-determination in their life were all skills commonly associated with self-determined behavior in the literature. The functional theory of self-determination (Wehmeyer, 2003, 2004, 2005)
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posit that self-determination emerges across the life span as children and adolescents learn skills and develop attitudes that enable them to be causal agents in their life. Making choices, setting goals, and engaging in self-advocacy—the three themes that emerged from self-advocates’ descriptions of self-determination—are all key skills believed to be associated with the development of self-determination. Participants’ descriptions of their applications of these skills were nuanced, however, and extend our understanding of the application of these skills by individuals with intellectual disability on a daily basis.

Participants connected making complex choices and working toward complex goals with responsibility and self-control. None of the participants suggested that self-determination meant having free choice all the time with no responsibilities. Instead, they seemed to indicate that living a self-determined life meant making choices and working towards goals, but that to do so effectively, one had to be responsible and use strategies to manage responsibilities. For example, several participants described self-management strategies, another skill associated with self-determined behavior, that they used to stay on task or manage their life. Logically, however, only the participants who had responsibility for specific aspects of their lives (e.g., maintaining a home or apartment, taking the bus, following a schedule) provided any description of the strategies they used to meet these responsibilities. All too often, assumptions are made that people with intellectual disability cannot use self-management skills or that these skills do not have meaning to their lives (Agran, Hong, & Blankenship, 2007; Wehmeyer, Agran, & Hughes, 2000); however, participants in this study clearly demonstrated they could use these skills (and had learned them at some point), but that having the opportunities to use the skills was also necessary. Further research is needed to document ways to transition from staff-direction to self-direction in natural environments.

Accessing Environmental Opportunities and Supports

Participants strongly emphasized the role of supports in their lives and in their self-determined behavior. Although all participants expressed beliefs in their abilities and strengths, they also mentioned that they would need support to achieve some of their goals. For example, several individuals who talked about wanting to move to their own apartment or house mentioned that they would still need supports to be successful. Other participants said that they needed support to complete job applications or to get to places in the community. Across the board, participants described being able to ask for help and support from friends, family, and staff as key to being able to achieve their dreams. Although participants may not have directly made this distinction, the results clearly suggest a difference between the personalized supports that they described as necessary to enable them to achieve their dreams and the program-driven services that many individuals received in their current, day-to-day life. Participants described major environmental limitations to their self-determination, resulting from program-driven services rather than individualized supports. For example, they talked about low expectations and limited opportunities and supports to engage in activities such as self-advocacy groups. Participants also discussed limited opportunities to access the community, particularly in more restrictive settings.

Further, although all participants had clear dreams for the future—living in the community, having close family and friends, getting a drivers license, engaging in personal development—many clearly needed personalized supports to develop and implement a plan for achieving those dreams. Participants knew what they wanted but were uncertain about how to go after it. However, they described several of their environments that they lived in and the services they received as seemingly being okay with the “status quo.” Instead of working with the individual to enable him or her to achieve individual dreams, many of the service systems seemed to introduce barriers that got in the way of individuals using their self-determination skills to go after what they wanted. Several participants also brought up environmental barriers, such as the presence of waiting lists for community services and the limited number of opportunities to truly self-direct one’s funding and supports. Participants were in a catch-22; they had the skills associated with self-determination, clear goals for the future, and an awareness of their support needs. However, the environment prevented the expres-
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Perceptions of self-determination build families of their own; however, several participants talked about how their families, or families of people with disabilities generally, could be overprotective. Participants described how some families internalized negative societal messages about disability, including the readiness model described above. Participants were clear that they might need a little help to be successful, but they emphasized that there was a difference between individualized supports and overprotection. More research is needed on perception of this distinction by individuals with intellectual disability, including their ideas for strategies to balance risk with the identification of needed supports.

Multiple participants also described societal attitudes, particularly those held by potential employers as a major barrier to their dreams for competitive community employment. Although such attitudes are documented by research (Bricout & Bentley, 2000; Irvine & Lupart, 2008), the awareness and insight that participants had into these attitudes were telling of the day-to-day impact. However, they also described creative, persistent ways that they advocated for themselves and for others to overcome these barriers. Participants also discussed the importance of advocating for all people with disabilities, viewing this as part of their responsibility as a self-advocate. More research is needed on perception of this distinction individuals with intellectual disability as well as the specific strategies used to contend with discrimination in the community.

Attitudes and Empowerment

As described in the functional theory, being self-determined is not just about having skills like choice-making, goal-setting, and self-advocacy. It is also about feeling empowered to use those skills and believing that if the skills are used, desired outcomes will result (Wehmeyer, 2001). Several participants identified the importance of persistence, flexibility, and believing in oneself and having others that believe in you. They also indicated, however, that they sometimes felt afraid or lacked confidence in their abilities, particularly after people had told them, repeatedly, that they could not achieve their dreams. Fear and insecurity are not uncommon, however, for all individuals, particularly as they face new and challenging tasks and transitions (Snyder & Lopez, 2002). The participants with disabilities, however, obviously...
found ways to overcome their fears and insecurities and showed great resilience (Keyes & Haidt, 2003; Masten & Reed, 2002) and hope (Snyder, 2002; Snyder, Feldman, Taylor, Schroeder, & Adams, 2000) as they navigated a world that was not always supportive of their dreams. Although psychological empowerment and self-realization are recognized as key to self-determined behavior, further research is needed on resilience in individuals with intellectual disability. Understanding the factors that enable some individuals with intellectual disability to persist in working toward their goals despite significant barriers and negative experiences could provide important information on resiliency and persistence.

Learning About Self-Determination

One of the unique contributions of this study is hearing directly from individuals with intellectual disability on how they learned about self-determination. Participants talked extensively about the importance of mentors and reliable allies in their journey toward self-determination. This supports the literature on the impact of effective mentoring generally and the limited literature on the effects of individuals with disabilities mentoring each other (Roberts, 2007). Interestingly, however, many participants described key mentoring roles played by people without disabilities; but these tended to be individuals described as being active in supporting self-advocacy and the empowerment of people with disabilities. Further research is needed to explore the characteristics of effective mentors without disabilities, particularly when supporting people with disabilities to become self-determining. Further research is also needed on mentoring relationships between established and developing self-advocates.

A primary vehicle identified by the participants for the formation of these mentoring relationships and for learning about self-determination was self-advocacy conferences, meetings, and trainings. Although the benefits of these vehicles are assumed, it is beneficial to have these benefits confirmed through research.

It is interesting that all participants indicated that they did not learn about self-determination until adulthood. Based on participant comments, this seemed to be related to educational supports and services adopting a more program-driven rather than individualized approach as well as a lack of teacher knowledge about self-determination. These perceptions are consistent with research that suggests special education teachers are underprepared to teach self-determination (Grigal, Neubert, Moon, & Graham, 2003; Wehmeyer, Agran, et al., 2000) and that school programs can create barriers to the development of skills associated with self-determination (Karvon, Test, Wood, Browder, & Algozzine, 2004; Martin et al., 2006). Although participants did most likely learn some skills in school that prepared them to be self-determining, even if the words self-determination were not used, it is important to note this finding. Further research that includes a larger sample of recent graduates is needed to explore the degree to which individuals perceive their education as supporting them to become self-determining.

Limitations

As with all research, there are limitations that must be considered in interpreting the results. First, the sample of individuals with intellectual disability was small. Further, it was confined to attendees at a statewide self-advocacy conference, and several individuals who volunteered to be interviewed were unable to be accommodated. However, the purpose of qualitative research is not to identify a sample that allows researchers to generalize information to the entire population of study. Instead, the purpose is to identify key themes that can be further studied and, in this study, used to aid in our understanding of self-determination as perceived by individuals with intellectual disability.

Second, issues in the validity of interviews with people who have intellectual disability have been described in the literature, including acquiescence, difficulty understanding questions, and problems with expressing one’s perceptions (Finlay & Lyons, 2001). We encountered these issues during the course of this study. Five participants initially indicated uncertainty with regard to their understanding of self-determination. However, after the second author described what self-determination meant to him, the participants were able to elaborate on what self-determination meant to them. In these elaborations they did not just repeat what the second author said, but instead expanded on what he said and made specific connections to their own life. This suggests that some participants did not, initially, feel confident with their under-
standing of self-determination and looked to the interviewers to support them in providing the answers. However, by the second author talking, personally and as a peer, about what self-determination meant to him, the participants may have become confident enough to discuss their understanding of self-determination and its meaning to them. Further research is needed to explore the degree to which individuals with intellectual disability are able to abstract from peer stories and make connections to their life in an interview situation.

Third, our sample was limited to individuals who could verbally express themselves in an interview situation. Although one participant did use pictures along with verbalizations and support from his sister to communicate his perspective, overall our primary mode of collecting information was through the verbal descriptions provided by participants. Clearly, this limited the inclusion of the perspectives of individuals who may need more support to communicate. In addition, even though our participants were able to verbally self-express, at times responses were not highly elaborative even with follow-up questioning. The majority of interviews lasted approximately 10 min, and one individual provided very brief responses and completed her interview in 3 min. We were cautious in our data analysis process, taking care not to draw conclusions or expand on less elaborative responses. However, this limitation must be considered when interpreting our results.

Conclusion

Despite the limitations of this study, the information shared confirms and extends our understanding of self-determination and its impact on individuals with intellectual disability. Overall, the participants emphasized the personal nature of self-determination and the role of learning skills and attitudes that enable one to be self-determining. However, they also clearly stated that personalized supports (not program-driven services) and an environment that facilitates self-determination are necessary to truly be a causal agent. Just as self-determination originally achieved recognition in the disability field both as a personal characteristic to be promoted through education and as a systems change initiative to reform how supports/services are organized and delivered, the participants highlighted the critical need to continue (and perhaps further) integrate research, policy, and practice initiatives to promote personal self-determination and to reform the disability service system. As the participants emphasized, they cannot be self-determining in an environment that is not supportive of self-determination; however, even if the environment is supportive, they cannot be self-determined unless they have the skills, attitudes, and supports to be a causal agent.

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