

# **SELF-DETERMINATION: HEARING THE VOICES OF ADULTS WITH PHYSICAL DISABILITIES**

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## **ABSTRACT**

*Most current self-determination research focuses on adults with developmental disabilities but neglects adults with physical disabilities who depend on caregivers for many or most aspects of daily living. This study investigated the perceptions of 12 adults with physical disabilities related to their self-reported abilities and opportunities to practice self-determination, the obstacles they encountered and strategies they used to attain self-determination, and suggestions they made for facilitating self-determination in other individuals with physical disabilities. Interview results indicated that participants' definitions of self-determination involved the importance of family, overcoming obstacles, and having the ability to persevere and attain goals. Facilitators of self-determination centered around four themes: (a) intrinsic factors; (b) support from families, individuals, and support networks; (c) opportunities; and (d) setting goals. Participants consistently recognized and identified the need to experience self-determination through various opportunities. Barriers to self-determination were grouped into two major categories: (a) internal barriers such as personal attributes and (b) external barriers such as financial issues, lack of accessibility to public facilities, and attitudinal and school-related hindrances. Discussion includes implications and*

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*recommendations for educators, adult care providers, direct care staff, personal care assistants, and family members as they strive to increase the self-determination skills of individuals with physical disabilities.*

The fundamental purpose of the educational system is to “produce responsible, self-sufficient citizens who possess the self-esteem, initiative, skills, and wisdom to continue growth and pursue knowledge” (Sarason, 1990, p. 4). Essentially, the goal of the educational process is to teach all students to become self-determined adults. However, educational systems often fail to educate students with disabilities in the area of self-determination (Wehmeyer & Schalock, 2001). Data from the National Longitudinal Transition Study (Cameto, Marder, Wagner, & Cardoso, 2003) indicate that too few people with disabilities become self-sufficient citizens and do not fare nearly as well as their nondisabled peers after schooling (Chadsey & Shelden, 2002; deFur, 1999; Nuehring & Sitlington, 2003).

Wehmeyer (1999) identified three important factors that influence the emergence of self-determination: (a) individual capacity or what a person is capable of doing, (b) the opportunities available to an individual, and (c) the supports and accommodations available to an individual. Individuals who possess control over their own lives seem to experience a greater quality of life. According to Thoma, Nathanson, Baker, and Tamura (2002), it is important to remember that the achievement of self-determination requires not only that people with disabilities develop their own inner resources, but that society support and respond to them as well.

Wehmeyer and Schwartz (1998) contended that adults with disabilities who are considered self-determined are more likely to be happy and have a better quality of life than those with similar disabilities who are not self-determined. In order to demonstrate this notion, Wehmeyer and Schwartz identified core dimensions to quality of life. These dimensions include emotional well-being, interpersonal relations, material well-being, personal devices, physical well-being, self-determination, social inclusion, and rights.

Despite the strides made in the area of self-determination, there still remain many obstacles in defining and assessing self-determination. Self-determination cannot be defined simply through a list of behaviors or non-behaviors, since essentially any behavior or action could be considered within the realm of self-determination. A list or set of self-determined behaviors does not account for cultural differences (Wehmeyer, 1999) and may also be limited by congregate living or work settings that limit opportunities for choice and decision-making (Wehmeyer & Bolding, 2001).

In addition to these difficulties, the ability to teach self-determination and support an individual's self-determined behavior may be confounded by the individual's negative past experiences. For example, learned helplessness that is characterized by passivity and negative self-attribution (Wehmeyer & Bolding, 2001) may interfere with an individual's ability to demonstrate self-determined behavior. Finally, self-determination cannot be measured as an outcome or process. What can be considered a successful outcome or self-determined behavior for one individual does not necessarily apply to another individual, and achieving a desired outcome does not ensure success. Halpern (1993) explained that neither education nor securing a job necessarily guarantees quality of life for young adults with disabilities and that accountability mechanisms that are in place in youth transition programs simply do not measure that particular outcome.

Research has demonstrated a correlation between self-determination and quality of life (e.g., Wehmeyer, 1999; Wehmeyer & Schalock, 2001; Wehmeyer & Schwartz, 1998). Living and working environments have also been shown to have an impact on both the quality of life and a person's self-determination (Stancliffe, Abery, & Smith, 2000; Wehmeyer & Bolding, 1999; Wehmeyer & Bolding, 2001). Stancliffe and colleagues' research in residential settings revealed that staff competence was related to residents' quality of life and the lower the staff presence in community residential settings, the more choice-making was demonstrated by residents with mental retardation. Wehmeyer and Bolding (2001) also found that self-determination was significantly positively related to a smaller unit size for residences.

Several factors have been determined to influence the development and continued support of self-determined behaviors in individuals with disabilities. One of the most influential but little studied factors is the role of family on an individual's self-determined behavior. Grigal, Neubert, Moon, and Graham (2003) examined the perceptions of parents and teachers on self-determination. They found that parents supported teaching self-determination skills, such as goal-setting and decision-making, and believed that students themselves should play a larger role in their IEP meetings as one way to practice their self-advocacy skills. Cunconan-Lahr and Brotherson (1996) asserted that the advocacy role taken by parents may be caused by either supports or barriers existing for their children with disabilities and that these children can learn self-advocacy through parents' modeling and support. Unfortunately, there are very few studies in the area of parents and self-determination, which is currently an untapped resource for understanding how children develop self-determination skills, what teaching strategies can foster self-determination skills, and how parents and teachers can support the

maintenance of self-determined behavior in their children and students. Additionally, investigation of the perspectives of adults with disabilities on their experiences in attaining self-determination is lacking. Listening to those individuals with physical disabilities who have encountered barriers to self-determination and have benefited from facilitators of self-determination is vital if we are to fully comprehend the process of self-determination.

### **PURPOSE OF THE STUDY**

Most current self-determination research focuses on adults with developmental disabilities but neglects adults with physical disabilities who depend on caregivers for many or most aspects of daily living. This study investigated the perspectives of adults with physical disabilities related to their self-reported abilities and opportunities to practice self-determination. The questions that guided this study are:

- 1) How do adults with physical disabilities define self-determination?
- 2) What do adults with physical disabilities identify as facilitators in attaining self-determination?
- 3) What barriers do adults with physical disabilities identify as impeding their self-determination?
- 4) What suggestions do adults with physical disabilities have for facilitating self-determination in other individuals with physical disabilities?

Results of this study should be useful to individuals with disabilities, educators, adult care providers, direct care staff, personal care assistants, and family members as they strive to increase the self-determination skills of individuals with physical disabilities.

### **METHOD**

#### **PARTICIPANTS**

Purposive sampling, which “maximizes opportunities for comparative analyses” (Strauss & Corbin, 1998, p. 211) was utilized to gather participants for this study. Participants were 12 adults with congenital physical disabilities (i.e., spina bifida or cerebral palsy). Special education undergraduate students recruited participants whom they knew from previous jobs, volunteer work, or public school interactions. The undergraduate students obtained informed consent and subsequently the primary researchers were introduced to the participants. This procedure was required by the university’s Institutional

Review Board to protect the participants' privacy. Participants had a wide range of physical involvement, speech intelligibility, and current living conditions; however, none of the participants had cognitive deficits. See Table 1 for participant characteristics.

#### RESEARCH DESIGN

Qualitative research was chosen as the methodology for this study due to the purpose of the study and the nature of the research questions. Several researchers have provided guidelines for selecting a qualitative methodology (e.g., Bogdan & Biklen, 1998; Leedy & Ormrod, 2001; McMillan & Wergin, 2002). Specifically, Creswell (2002) explained that qualitative research is utilized to study research problems that "require an exploration and understanding of a central phenomenon" (p. 30). Strauss and Corbin (1998) contended that "qualitative methods can be used to obtain the intricate details about phenomena such as feelings, thought processes, and emotions that are difficult to extract or learn about through more conventional methods" (p. 11). Thus, the study of perspectives of individuals with physical disabilities concerning self-determination lends itself to qualitative methodology precisely because it is an important phenomenon about which little is known.

Semi-structured interviews, lasting approximately an hour, were conducted with all participants. Interview questions were developed to address the research questions. Kvale (1996) stated that semi-structured questions consist of a sequence of themes and questions to be addressed while maintaining a feeling of openness to follow up on other themes of interest that may emerge during the interview process. Use of semi-structured interviews allowed the researchers to ask for clarification or additional information. (See Appendix A for a list of interview questions.) All interviews were audio-taped and transcribed verbatim to ensure accurate transcripts.

#### DATA ANALYSIS

This study employed collective case study methodology as described by Stake (2000). Collective case study involves the study of more than one case in order to "investigate a phenomenon, population, or general condition" (p. 437). This approach assumes that investigating a number of cases will lead to better comprehension and better theorizing. Cross-case analysis was used to analyze each individual case as a whole entity. A comparative analysis of all cases was then conducted. Miles and Huberman (1994) contended that studying multiple cases gives the researcher reassurance that the events in only one case are not "wholly idiosyncratic" (p. 172). Further, studying multiple cases allowed the researchers to see processes and outcomes across many

**TABLE I**  
**Participant demographics.**

Name*	Age	Gender	Physical Disability	Mobility	Speech	Living Arrangements	Education Level	Employment
Brian	21	M	Cerebral Palsy- Spastic Quadriplegia	Non- ambulatory	Moderately intelligible to the unfamiliar listener	Lived at home with family	High School diploma	Student at a community college
Susan	21	F	Cerebral Palsy- Spastic Quadriplegia	Non- ambulatory	Moderately intelligible to the unfamiliar listener	Lived at home with family	High school diploma	Student at a community college
Doug	22	M	Cerebral Palsy- Mild Hemiplegia	Ambulatory	Readily intelligible	Lived at home with family	Associate of Arts degree	Employed full- time as a teacher assis- tant and part- time student at a four year college
Opal	40	F	Cerebral Palsy- Spastic Hemiplegia	Non- ambulatory	Readily intelligible	Lived with husband	High school diploma	Employed part time at a not- for-profit agency

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**TABLE I  
(Continued)**

Name*	Age	Gender	Physical Disability	Mobility	Speech	Living Arrangements	Education Level	Employment
Naomi	23	F	Cerebral Palsy- Spastic Quadriplegia	Non-ambulatory	Readily intelligible	Lived in dorm	Attending a four year higher education institution	Currently a student
Ned	35	M	Cerebral Palsy- Athetoid Quadriplegia	Non-ambulatory	Unintelligible to the unfamiliar listener; used AAC to aid in intelligibility	Lived alone in an apartment; had personal attendant	High school diploma	Unemployed
Ken	41	M	Spina Bifida	Non-ambulatory	Readily intelligible	Lived alone in an apartment	College graduate	Unemployed
Veronica	36	F	Cerebral palsy- Spastic Quadriplegia	Ambulatory; used walker	Moderately intelligible to the unfamiliar listener	Lived alone in an apartment	Associate of Arts degree	Employed in private sector

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**TABLE I  
(Continued)**

Name*	Age	Gender	Physical Disability	Mobility	Speech	Living Arrangements	Education Level	Employment
Larry	34	M	Cerebral Palsy- Spastic Quadriplegia	Non-ambulatory	Unintelligible to the unfamiliar listener; used AAC to aid in intelligibility	Lived alone in an apartment; had personal attendant	High school diploma	Employed part time at a not-for-profit agency
Hank	48	M	Cerebral palsy- Spastic Hemiplegia	Ambulatory	Moderately intelligible to the unfamiliar listener	Lives with family	High school diploma	Employed on family farm
Frances	22	F	Cerebral palsy- Spastic Quadriplegia	Non-ambulatory	Unintelligible to the unfamiliar listener	Lives in a house; has a personal attendant	High school diploma	Unemployed
Alex	42	M	Cerebral palsy- Spastic Quadriplegia	Non-ambulatory	Unintelligible to the unfamiliar listener	Lives in an apartment attached to family home	Associate of Arts degree	Self-employed part time

\* Pseudonyms were assigned to protect participants' privacy.



cases and to develop a deeper understanding of the emerging phenomena through more powerful descriptions and explanations.

After completion of the interviews, the data were organized using a multiple coding approach (Barbour, 2001). Specifically, all researchers independently coded all interviews line-by-line. The researchers then met frequently as a group and developed categories based on their individual line-by-line coding. Disagreements about the categories were discussed, categories were refined, expanded, and/or deleted as needed, and concordance was reached (Barbour, 2001). The constant comparative method, by which researchers continually return to the data for analysis, was used as an overall methodological framework (Charmaz, 2000). Three members of the research team (i.e., two faculty members and a doctoral candidate in a Midwestern university's Department of Special Education) analyzed the data. *NVivo*, a data management software program, was used to manage the data (Richards, 2002).

#### CONFIRMABILITY

Confirmability of the findings was achieved through three approaches: triangulation, respondent validation, and member checking. Triangulation is the process of corroborating evidence from different individuals, different types of data, and different methods of data collection (Creswell, 2002). In this study, corroboration was achieved when incidences occurred across cases. Respondent validation is a process in which researchers ask participants to check the accuracy of the findings in the areas of descriptions, themes, and interpretations (Creswell, 2002). Once interview data in this study had been analyzed and described in narrative and graphic formats, all participants were asked to validate the accuracy of the conclusions. Once the researchers explained the findings of the study to the participants, they requested participant feedback. All participants confirmed the accuracy of the findings. One participant, Ned, summed up his confirmation saying, "It sounds right on from all the disabled people I've talked to. All we want is a chance to try and live our own life in the way we know how."

Confirmability of the findings was further assessed through member checking, the process of providing participants the opportunity to review material (Janesick, 2000). All participants were shown a transcript of their personal quotes that were included in the final report. All participants gave approval for use of each of their personal quotes.

## FINDINGS

Findings that emerged from this study of adults with physical disabilities are organized by the research questions and interview questions.

### HOW DO YOU DEFINE SELF-DETERMINATION?

Participants' responses to the question "How do you define self-determination?" were highly individualized, yet there were common elements in the definitions that involved the importance of family, overcoming obstacles, and having the ability to persevere and attain goals.

The goals you set and what you can accomplish and the way you go about doing it. (Veronica)

Self-determination, I don't know, I guess it would be the ability to achieve your goals. (Ken)

Self-determination means if there is something that you can't do, but you want to do it, you're determined. You're going to figure out a way to do it. (Opal)

Self-determination is the power, I would say, the power to do whatever the heck you want even if anyone says you can't. Without it I wouldn't have a life. I'd be stuck at home. (Larry)

Being able to push yourself to the limit. (Hank)

All participants said self-determination was important in their lives. They recognized the need for self-determination, recognized that they had not always achieved it, and knew self-determination was something for which they were continually striving.

### IDENTIFYING THE FACILITATORS OF SELF-DETERMINATION:

#### WHAT HELPS YOU ATTAIN SELF-DETERMINATION?

Data analysis indicated that while participants varied greatly in age and extent of physical disability, the facilitators of self-determination centered around four themes: (a) intrinsic factors; (b) support from families, individuals, and support networks; (c) opportunities; and (d) setting goals. The participants spoke of intrinsic factors such as motivation, determination, self-awareness, courage, and perseverance when they identified facilitators of

self-determination. These individuals recognized their own strength and fortitude and appeared to have an internal locus of control.

And I showed them that I could do it and they were like they were shocked. (Brian)

People say I can't do something and I say, 'Watch me' and show them I can do it. (Larry)

I never give up; I always try, and try, and try. (Naomi)

Support from family was a theme that emerged across all participants. Family support influenced the participants' self-determination primarily by providing them with role models for advocacy. Responses such as "I've grown up with it" and "My family . . . I come from a family, whatever you want, you go out and get it" underscored the significant impact family had on the participants' concept of self-determination. Family role models appeared to set the stage and provide an example of advocacy. These family role models were the initial contact the participants had with the concept of self-determination.

Self-determination to me is . . . and I think, honestly that it was laid out for me, it all started at home. I mean, with, there was a foundation that was laid for me. They've [his parents] allowed me to grow and to learn on my own. (Doug)

I think when I started in high school when I was still back at home; my parents made me do a lot more on my own. (Veronica)

Participants in their 30s and 40s identified support networks as facilitating self-determination. These included support from advocacy groups, programs that provided financial assistance (e.g., federal and state programs), and the community in the form of transportation assistance. It should also be noted that these individuals were living independently, perhaps with a personal assistant, but apart from their families.

Participants consistently recognized and identified the need to *experience* self-determination through various opportunities. For example, Ken said, "It's [self-determination] about being persistent and not giving up, staying focused." However, it is significant to note that it was the *opportunity* itself,

and not the end result that participants identified as vital to their growth in self-determination. Several participants spoke of opportunities where they failed to achieve self-determination. For example, Veronica spoke of her experience with a driver's education teacher in high school. The teacher initially refused to provide her with behind the wheel instruction.

Take driving for an example. In high school, normally you go through driver's ed., your mom writes a check and you get your permit . . . well, Mom wrote the check, and I never got my permit. My check ended up staying in my teacher's desk. All the other kids got their permits but me. I had to explain to the teacher that . . . for one . . . this shouldn't happen. The teacher shouldn't have done it that way, especially from the school that I came from, because it was a special lab school. And I convinced the teacher and she took me out the last day of school in the parking lot, and that's all I got to do. I was never behind the wheel before, I didn't know what to expect, and that was my very first time. The only thing I couldn't do was tight turns, and that's what we did, tight turns. So, that summer my mother found a teacher at [a nearby state university] that took me out like six times, and I learned to drive. I got my license, more or less. You tell me that I can't do something and I will prove you wrong. (Veronica)

Participants learned from opportunities to experience self-determination, regardless of their success with those opportunities. However, when an opportunity ended positively it gave them confidence, increased their willingness to try again, and provided them with an increased desire for self-determination.

I guess you can say that it's [self-determination] continued to increase. The more opportunities that I get and the more chances that I get to . . . (Doug)

Cause I know the first time I do something sometimes its harder to do it the first time. And then if I know that I'll have to do it again, I know it'll probably be easier to do it the second time. (Veronica)

Another facilitator of self-determination was setting goals, keeping the goals in the forefront, and working hard to attain them. These goals varied

across individuals but all participants spoke of their future goals and ones they had already attained.

And I was about to graduate and I started to read my roommate's philosophy books, I decided I wasn't very smart and that I wanted to study philosophy so I stayed in school (Ken)

One day I went to a [advocacy support group] meeting and I didn't want to go by myself.

And one day they moved over by me. They moved the meeting. Yeah, now I am up in [the advocacy group]. I am the president. And I want to be the president of the whole state [state advocacy group]. (Larry)

In summary, family advocacy for these adults began early, while they were still in elementary school. Family members were their initial role models and laid the foundation for the participants' own self-determination. Additionally, their personal intrinsic characteristics empowered and sustained them when they met with failure. The provision of opportunities to practice self-determination was vital; however, the value of these opportunities did not necessarily depend on successful outcomes. Indeed, some of the interviewees' responses indicated that when opportunities failed to foster self-determination, the experience of the opportunity led to increased resolve to attain self-determination.

#### IDENTIFYING THE BARRIERS OF SELF-DETERMINATION:

##### WHAT HAVE BEEN THE BARRIERS TO SELF-DETERMINATION FOR YOU?

The themes that emerged from the interviews as barriers to self-determination were grouped into two major categories: (a) internal barriers and (b) external barriers. Internal barriers were personal attributes that hindered self-determination. These barriers varied across participants, but all participants identified at least one internal barrier. Internal barriers included the physical disabilities themselves and the interviewees' intrinsic characteristics.

All participants identified their physical disability as the most obvious and compelling barrier to self-determination.

I can't and will never walk. (Alex)

It takes me hours to brush my teeth and I will never be able to tie my shoes. (Frances)

Yeah. I mean, obviously my main one being my disability. That's obviously my main barrier. (Doug)

Interestingly, for those 8 participants whose speech intelligibility was classified as either moderately intelligible or unintelligible to the unfamiliar listener, speech impairment was identified twice as often as physical limitations as the major barrier to self-determination. Only two participants, who were classified as either moderately unintelligible or unintelligible, used augmentative devices to supplement their verbal output. The other six participants who had poor intelligibility relied on repetition, pausing, affirmations of correct message reception by the communication partner, and shortened sentences to be understood.

Several of the participants mentioned personal attributes that hindered their self-determination. These included shyness, self-doubt, frustration, and depression.

I just remember when I was younger, through grade school, elementary school, junior high, and even high school because I was so shy . . . and they [her parents] felt they had to really advocate for me in my schooling. (Naomi)

Life gets everybody down and I guess it gets me down more than the average person. And little frustrations of daily living like tying your shoe or brushing your teeth are things that other people take for granted that I can't do. (Frances)

However, Frances noted the support she received from her family and friends and the concern she had for them helped her continue to battle the daily frustrations that are such an unavoidable part of having a significant physical disability.

Support is very important because there are a lot of times I don't want to keep going, but I know I have family and friends who love me and care about me. And [they] don't want to see me give up or get hurt and they want to see me succeed. I think it's hard living with a disability but it can be done. (Frances)

Barriers that were categorized as external were financial issues, accessibility to public facilities, attitudinal, and school related. Financial issues, particularly government programs, which provided financial assistance and

affected participants' ability to live independently were identified as a barrier. All non-ambulatory participants, except for Brian and Susan who live with their families and are only 21, identified finances as a barrier to self-determination. Non-ambulatory participants, those who had the most severe physical disabilities, were either unemployed or employed part-time and were reliant on government assistance to meet their basic needs.

I have X amount of dollars in my name each month. They [the government] pay for my aides. They pay for, if we go away, we get mileage. Until Governor . . . they would pay for camp. They would pay for special recreation. (Alex)

Physical accessibility barriers were mentioned as significantly affecting the lives of the participants. These individuals could not control these barriers, and even though public facilities have become more accessible, inaccessibility has had a profound effect on the older participants' lives. The issue came to the forefront in their educational settings.

It [her middle school] had stairs, no elevator. So all of my classes that were upstairs—my teachers came downstairs for those classes. Which is okay, but it made me feel like it was all because of me. It's not a good feeling, especially in junior high. I think my school years would be a lot different if I would've had friends. I hated high school . . . hated it. And I just don't think I would have if I had had friends. (Frances)

Every participant identified attitudinal barriers. These included the attitudes of individuals in their vocational settings and in their previous educational settings. At times, attitudinal barriers were more constraining than the physical barriers of inaccessible buildings.

And I'm not saying that this is the case always. People sometimes perceive people with disabilities with the fact that they're different, they can't do the same things as I can or whatever. (Doug)

One of the most disturbing attitudinal barriers was when the participants talked about teachers who had low expectations of them. These expectations manifested themselves in inadequate educational programming, a lack of accommodations, and a feeling of isolation. However, it should be noted that

several of the participants finished school before the IDEA amendments of 1997.

I thought she [his teacher] treated me completely unfair and you know I didn't know what to do. And she said, this exactly, "Aren't these kids in here normal?" [the special class Ken was placed in], she wanted to have some philosophical conversation, what it means to be normal. I wanted to know why I wasn't in the normal classes with the normal kids. (Ken)

Participants had no difficulty identifying barriers to self-determination. Yet, these barriers did not prohibit their development of self-determination. All participants responded with specific experiences of overcoming the barriers they faced.

#### THE PROCESS OF ATTAINING SELF-DETERMINATION: HOW DID YOU OVERCOME THE BARRIERS?

Analysis of the responses to this question from all participants yielded two major categories: (a) intrinsic factors and (b) action-oriented problem-solving behavior. The first category, intrinsic factors, is comprised of the personal attributes of each individual. While the participants identified factors similar to those they mentioned when they answered the first question, their responses to this question on how they overcome barriers to self-determination included an additional process component. Responses to this question consistently led to participants' explanation of the process of overcoming barriers. Specifically, this was an action-oriented process that involved recognizing that they had to persevere when confronting particular barriers, attempting to keep a positive attitude while trying to overcome these barriers, gaining a perspective on the barriers, and recognizing and accepting their own limitations.

The first step in the process of overcoming barriers was perseverance, which was frequently coupled with the participants' discussion of the importance of maintaining a positive attitude. For example, Ken described the process of overcoming barriers to self-determination as, "Well, first knowing what you want and just being persistent." Susan said, "Try to improvise and come up with different ways of doing things."

Gaining a perspective on the barrier and recognizing and accepting their own limitations comprised the second step in the process of overcoming barriers. At times this meant accepting their physical limitations, knowing when a barrier was insurmountable, and then devising a plan to navigate around it. Veronica met employee discrimination when applying for a job and recog-



nized that the employment situation was an obstacle she was not going to surmount.

And I just didn't want to give up . . . there's ways around things. . . so I had somebody call interested in the job. And they called asking if it was still open and if the job was open . . . the lady said come on in and pick up an application. But they [had] told me it was filled. It proved it to me that it wasn't a job that I really wanted. (Veronica)

Action strategies emerged as a theme used by all participants, no matter what their age. Action strategies developed from knowing when to ask for assistance, striving for independence, developing self-advocacy skills, and being determined to succeed. There were many facets to this action-oriented strategy, but it began with the desire to succeed and the development of an action plan. Veronica's encounter with a less than cooperating professor exemplifies an action strategy she used successfully.

I did have another experience just like that; I had an experience at a junior college about 5 or 6 years ago. This teacher did not want to have me in his class. He didn't want a note-taker in his class, he didn't want to accommodate anything. The trouble was the junior college only had one teacher in that area, computers. So he was stuck with me and I was stuck with him. And it got kinda bad. And I went in to the academic counselor's office, and told them that he didn't allow my note-taker in the classroom and all . . . The counselor got her to come back and from then on, he talked to and told my note-taker to tell me to do something, instead of him telling me. That was a mistake; you don't do that to me. And it got so bad, that he wouldn't even look at me. One day, the advisor, she set up a meeting, and the advisor purposely set him in a certain spot, so he sat across the table from me. So he had to face me, but the whole time they kept telling him to turn and talk to me, when he was talking to them instead of me. I kept all the paperwork, and documentation. I kept everyday on the same pad, I wrote things down. Then he starting calling me at home wanting to talk about the situation, and seeing what we could do about it and I was like . . . "You talk to me at school; you don't call me at home." (Veronica)

However, it should be noted that not all of the participants' actions were designed to overcome attitudinal barriers. Larry, who wanted to skydive, is a prime example of navigating around his physical disability (i.e., spastic quad-

riplegic cerebral palsy) to reach his goal. With the help of his friends, Larry was able to get information about skydiving, and find a skydiver willing to take him up and jump tandem with him. Larry proudly declares himself a “risk taker” and validates his claim through his actions, even though he must overcome his disability to do so.

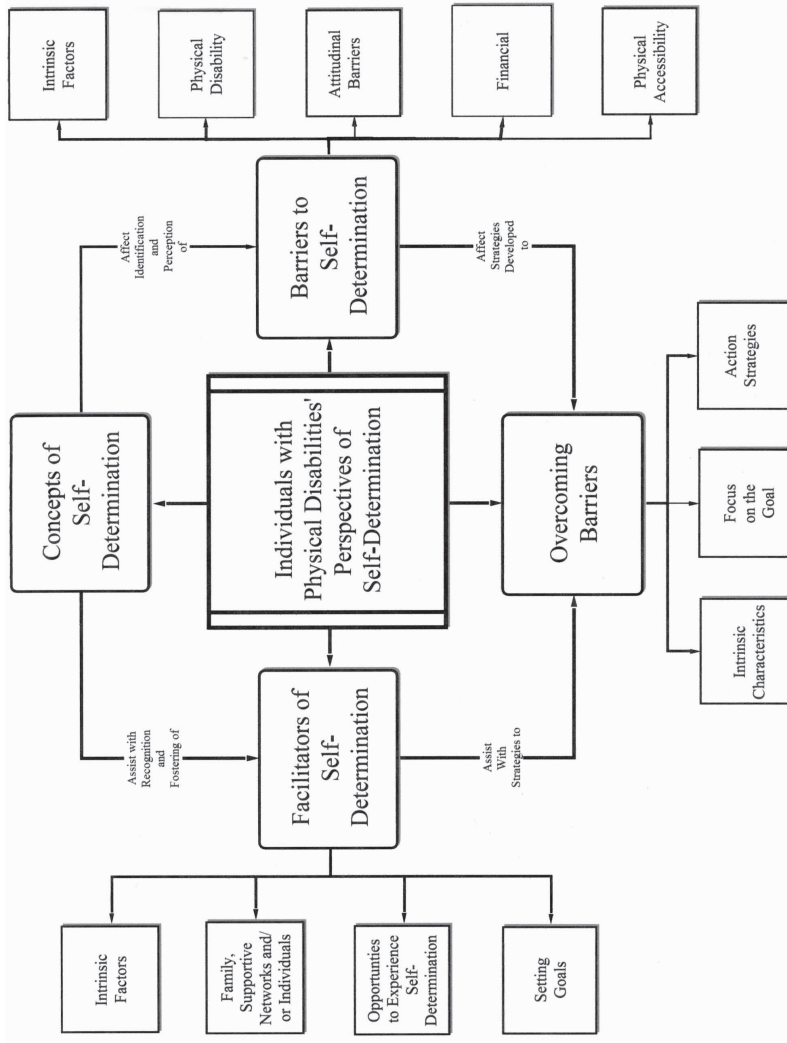
In summary, participants encountered numerous barriers to achieving self-determination. They overcame these barriers by persevering, gaining perspective on the barriers, identifying their own limitations, and developing strategies. At times, these strategies resulted in a conscious decision not to address the barrier, as exemplified by Veronica’s attempt to gain employment. At other times barriers were addressed with persistence and a strategy that succeeded, as exemplified by Veronica’s situation with her professor and Larry’s desire to skydive.

### **LIMITATIONS AND SCOPE OF THE RESEARCH**

The first limitation of this study is related to the ability to generalize the findings beyond the sample. This limitation is inherent to qualitative research. Use of purposive sampling yielded participants with physical disabilities who exhibited much variation in the nature and extent of their physical disabilities and life experiences. Additionally, the study was purposefully limited to 12 participants in an effort to provide a deep, rich description of the perceptions of individuals with physical disabilities. While implications may be made, caution must be exercised not to generalize the experiences, perceptions, and responses of participants included in this study to the larger population of adults with physical disabilities. However, even with that stated, we make recommendations for fostering self-determination of individuals with physical disabilities based on extant literature as well as professional experience.

### **DISCUSSION AND RECOMMENDATIONS**

This study’s findings indicate that several factors have served to facilitate or impede the development and continued support of self-determined behaviors in individuals with physical disabilities. Figure 1 serves as a guide to a discussion of our findings and depicts a summary of the participants’ voices as they described their experiences related to self-determination. The four major areas that emerged from the interviews are aligned with this study’s research questions.



**Figure 1.**

**Perspectives of Self-Determination of Adults with Physical Disabilities**

## PARTICIPANTS' DEFINITIONS OF SELF-DETERMINATION

The adults with physical disabilities who participated in the current study collectively defined self-determination using terminology similar to the terminology found in the existing literature. Consistent with classic definitions of self-determination, these adults' understanding of self-determination involved the importance of family, overcoming obstacles, and having the ability to set goals, persevere, and attain goals. Their ideas about the choice component of self-determination resonated with Martin and Marshall's (1995) belief that self-determined individuals know how to choose, know what they want, and know how to obtain what they want. Our interviewees' definitions also reflected previous researchers' notions that self-determined individuals act out of choice rather than obligation or coercion (e.g., Deci & Ryan, 1985; Reeve, Nix, & Hamm, 2003).

During the past few decades the definition of self-determination has expanded beyond choice-making to such constructs as self-awareness and self-knowledge (Polloway & Patton, 1997; Price, Wolensky, & Mulligan, 2002; Serna and Lau-Smith, 1995; Wehmeyer, 1998; Wehmeyer, Sands, Doll, & Palmer, 1997), psychological empowerment (Wehmeyer, 1996), action and active participation (Diaz-Greenberg et al., 2000), self-advocacy (Kling, 2000; Pennell, 2001), and goal setting (Field & Hoffman, 1994). Without naming them per se, these constructs were certainly discussed by our interviewees. Overall, these adults with physical disabilities embodied Field and Hoffman's explanation of self-determination as people's ability to define and achieve goals based on a foundation of knowing and valuing themselves and taking initiative to attain their goals (p. 164).

The participants' definitions of self-determination and their descriptions of their experiences were also reminiscent of Ward's (1988) view of self-determination as the attitudes, abilities, and skills that lead people to identify their goals for themselves and take the initiative to reach those goals (p. 2). Durlak, Rose, and Bursuck (1994) also saw the characteristics of assertiveness, self-advocacy, creativity, and independence in self-determined individuals. Our participants not only noted these components and characteristics in their definitions of self-determination; they also described incidences and events in their lives that vivified these attributes.

As we discuss the implications of this study's findings for individuals with physical disabilities in particular and for the field in general, we will incorporate other instances of the application of existing definitions of self-determination. For example, Wehmeyer, Field, Doren, Jones, and Mason (2004) have recently identified some of the components of self-determined behavior. As our participants described their experiences in the area of self-deter-

mination, the following components from Wehmeyer and colleagues' list emerged most strongly: (a) understanding one's strengths and limitations together with a belief in oneself as capable and effective; (b) awareness of personal preferences, interests, strengths, and limitations; (c) anticipating consequences for decisions; (d) initiating and taking action when needed; (e) setting and working toward goals; (f) using communication skills such as negotiation, compromise, and persuasion to reach goals; (g) striving for independence while recognizing interdependence with others; (h) persistence; (i) self-confidence; and (j) pride (p. 415). Our interview data showed these emerging factors as instrumental in helping our participants attain the levels of self-determination they reported to us: (a) intrinsic factors; (b) support from families, individuals, and advocacy networks; (c) opportunities; and (d) goal setting.

#### OVERCOMING THE BARRIERS:

##### INTRINSIC FACTORS THAT FACILITATE SELF-DETERMINATION

Internal barriers that some of our participants encountered as they developed self-determination included their physical disabilities, such as the inability to ambulate or limited speech intelligibility, and intrinsic characteristics or personal attributes such as shyness, self-doubt, frustration, and depression. Unlike the teachers, students, and parents studied by Eisenman and Chamberlin (2001) who were wary of acknowledging or discussing disabilities, our participants seemed quite willing to discuss their personal characteristics. Disabling conditions of students with disabilities may affect their belief about whether circumstances are obstacles or opportunities and their confidence in adjusting in order to gain from it. Adults with physical disabilities in our study seemed to use their personal strengths to their advantage.

Our participants' "I can" and "I'll show them I can" attitudes and their descriptions of the motivation, persistence, self-efficacy, or other personal qualities that facilitated their development and practice of self-determination skills are also consistent with explanations of self-determination found in the literature. For example, Johns, Crowley, and Guetzloe (2002) asserted that in order to self-advocate, students must have accurate perceptions of their strengths and weaknesses and must know the conditions that enhance their performance. Wehmeyer et al. (2004) also explained that people's understanding of their strengths and limitations together with belief in themselves as capable and effective are essential in self-determination. According to Wehmeyer and colleagues, when people act on the basis of these skills and

attitudes, they have greater ability to take control of their lives and assume the role of successful adults in our society (p. 415).

In their 1996 study of consumers with disabilities and their parents following advocacy training, Cunconan-Lahr and Brotherson found that their participants with disabilities' life experiences "left them in need of supports to enhance personal self-esteem, self-confidence, and self-determination" (p. 356). Because of this lack, the researchers contended that people's recognition of their positive personal qualities is essential for successful advocacy outcomes in disability-related matters. Participants in our study had physical disabilities. Further research on differences in levels and use of cognitive skills and internal locus of control across types of participants is warranted to understand the impact of self-awareness on the development of self-determination skills. For example, Gerber, Price, Mulligan, and Shessel (2004) indicated that individuals with learning disabilities rarely, if ever, request accommodations to assist in making their jobs easier (p. 288). Our adults with physical disabilities seemed to defy this finding, as they appeared to be quite successful as self-advocates. However, they cited communication deficits as their greatest personal challenge. We recommend that family members and education professionals provide individuals with disabilities with multi-faceted experiences in practicing self-determined behavior. Regardless of communication mode or level of participation, these opportunities, exercises in assertiveness, and application of personal strengths fostered self-determination in our participants with physical disabilities.

#### OVERCOMING THE BARRIERS:

##### SUPPORT FROM FAMILIES, INDIVIDUALS, AND ADVOCACY NETWORKS

Several researchers in the area of self-determination have pointed out the critical need to provide family, school, and community support systems that foster self-determination and, unfortunately, a lack of support by such systems (e.g., Field, Hoffman, & Posch, 1997; Fortini & Fitzpatrick, 2000; Grigal et al., 2003). Our interviewees identified financial barriers (e.g., their reliance on government assistance to meet their basic needs) and attitudinal barriers of school personnel as impediments to their practice of self-determination, but most of them positively described support they received from community support groups like People First and other advocacy agencies. These adults clearly cited their families as not only supportive, but as the foundation of their development of self-determination skills. They reported encouragement by their parents early in their lives to make choices, self-advocate, and participate as fully as possible in decision-making processes as Cunconan-Lahr and Brotherson (1996) and Wehmeyer and Schalock (2001) urged.

Admittedly, some parents overprotect their offspring, inhibiting growth in self-determination and preventing young people from cultivating self-advocacy and self-determination. Johns et al. (2002) and Kling (2000) suggested that while parents should advocate for their children and take initiative in modeling self-advocacy for their children, they should gradually transcend their protective role, relax control, and allow their children to develop self-advocacy and voice their own needs. We recommend that parents be trained in how to consistently foster self-determination skills in their children and that schools collaborate with families to address self-determination-related educational goals and objectives across both home and school environments.

#### OVERCOMING THE BARRIERS: OPPORTUNITIES TO PRACTICE SELF-DETERMINATION

Interviewees in the current study claimed to benefit from opportunities to practice self-determination, even if they did not derive or perceive any direct benefit from the end results of their participation in those opportunities and activities. In some instances, the successful outcome of an opportunity or activity boosted their self-confidence and in other situations the outcome increased their willingness to try again. Regardless of the actual outcomes, their participation in opportunities to practice self-determined behavior increased these individuals' desire to practice it more extensively.

In discussing barriers to and facilitators of their growth in self-determination, our participants with physical disabilities generally described their opportunities or lack of opportunities to practice self-determination, especially in their school environments. They also discussed disappointment in teachers who had low expectations of them. Previous researchers have found that although teachers support the provision of self-determination instruction, many educational programs do not include self-determination as a curricular area and many teachers do not teach self-determination (e.g., Agran, Blanchard, & Wehmeyer, 2000; Test et al., 2004).

While Wehmeyer, Agran, and Hughes (2000) did not draw clear conclusions about the effect of classroom settings and students' levels of disability on how teachers teach self-determination, they did note that the most common reason why special educators do not provide instruction to promote self-determination is that teachers believe that their students will not benefit from instruction in this area. Test and colleagues (2004) also cited three reasons for teachers' failure to provide self-determination instruction: (a) educators want and need more training in self-determination strategies, (b) educators are unaware of available curricula, and (c) educators and top level

administrators do not place a high priority on teaching self-determination skills (p. 8). We recommend more efficacy research on teacher training in self-determination curricula and strategies, especially as they relate to students with physical disabilities.

As Agran, Blanchard, and Wehmeyer (2000) pointed out, teacher-directed special education practices in which education professionals make major educational decisions for their students have traditionally done little to empower students with disabilities to be self-determined.

Based on our participants' experiences, we concur with Johnson and colleagues' (2002) recommendation that teachers employ student-directed, person-centered planning strategies, materials and instructional methods that help students set goals, make decisions and choices, solve problems, and self-advocate. All students need to be more actively involved in their educational decision making.

*Educational programs that foster self-determination.* Wehmeyer and Schalock (2001) recommended educational programs that include student-directed learning activities that foster growth in self-determination in students with disabilities. Participants with physical disabilities in our study noted inadequate educational programming, a lack of appropriate accommodations, school building inaccessibility, and attitudinal barriers as impediments to their full participation in their vocational and educational settings. Increasingly, educators are recognizing that students with disabilities' acquisition of self-determination skills in high school could be the basis for their future adult success. Field, Martin, Miller, Ward, and Wehmeyer (1998) noted that high school students often measure what they are learning by how useful they think the information or skills will be later in life. Based on our participants' experiences, we recommend that high school programs become more student-directed and that educators strive to make learning as comprehensive, relevant, and meaningful as possible for students with disabilities. We also endorse Malian and Nevin's (2002) belief that "teachers should allow students to participate, actively search for appropriate services, select from a menu, experience logical consequences of choices, reflect, and redesign" (p. 73).

*Transition programs that defy poor outcomes prognoses.* Substantial challenges and bleak outcomes data for adults with disabilities in the areas of gainful employment, independent living skills, or success in postsecondary education or community engagement have been reported in the literature to date (e.g., Kohler & Field, 2003; Lock & Layton, 2001; Modell & Valdez, 2002; Steere & Cavainolo, 2002). While most of our participants' school experiences predated IDEA legislation mandating transition services that



would help students with disabilities make smooth transitions to adult life (Johnson, et al., 2002), the successful adult self-determination-related outcomes they described almost defy the lack of systematic instruction in self-determination. We can only imagine how much more successful the participants would have been with improved educational and transition programs. We recommend that self-determination skills be included as an integral part of school curricula and that goals related to self-determination be specified on the IEPs of all students with disabilities across all grade levels, from pre-school through the secondary level. We also re-emphasize the recommendation of Carpenter, Bloom, and Boat (1999) that special education teachers implement practices that promote socially valid outcomes and result in increased levels of self-esteem, higher levels of self-determination and control, increased individual empowerment, and student behavior that indicates their desire to be engaged in meaningful learning activities.

#### OVERCOMING THE BARRIERS: SETTING GOALS

Steere and Cavainolo (2002) argued that the connection between students' outcomes and their annual goals and short term objectives is one of the critical factors in helping students achieve desired postschool outcomes but that, unfortunately, educators often fail to take specific action planning steps to ensure that the connection is made and positive outcomes are achieved. Our adult participants indicated that one of the strategies they used was keeping their goals as priorities and working hard to attain them. Again, we emphasize the inclusion of goal setting as an integral part of educational curricula at all levels. We concur with Wehmeyer and Schalock (2001) who exhorted education professionals to include students in their educational planning and decision-making across all grade levels and to focus on identifying and describing specific goals and objectives, implementing plans to achieve these targets, taking action to achieve desired outcomes, consistently monitoring progress toward objectives and goals, and making informed revisions of the plans as needed.

#### OVERCOMING THE BARRIERS: USING ACTION STRATEGIES

Researchers have cited awareness of personal skills, self-initiation of goals, self-regulation, decision-making, and problem solving as some of the skills and abilities required to achieve self-determination (e.g., Diaz-Greenberg, Thousand, Cardelle-Elawar, & Nevin, 2000; Polloway, Patton, & Serna, 2001). Our adult participants with physical disabilities described instances in which they exhibited action-oriented, problem-solving behavior, knowing that they had to persevere when confronting particular barriers, attempt to

keep a positive attitude when trying to overcome barriers, gain perspective on barriers, and recognize and accept their limitations. Interestingly, none of our participants referred to teachers as role models of action-oriented problem-solving. Based on our participants' experiences in school programs, we encourage teachers to provide students with consistent examples and instruction in problem-solving and ample opportunities to use action strategies (Wehmeyer & Schalock, 2001). Extended and consistent practice in these skills may not only promote self-determination, but facilitate more successful transitions to adult life and prepare individuals with disabilities to be more effective action-oriented risk takers.

### SUMMARY

Over the past few decades, researchers in the area of self-determination have recommended that students with disabilities be taught how to advocate for their own needs and interests, and to take actions to change circumstances that pose barriers to their pursuits (e.g., Agran, 1997; Agran & Wehmeyer, 1999; Browder, Wood, Test, Karvonen, & Algozzine, 2001; Martin & Marshall, 1996; Mithaug, 1996, 1998; Wehmeyer, 1996, 1997, 1998; Wehmeyer, Agran, & Hughes, 1998). Wehmeyer and Schwartz (1997) asserted that teaching self-determination skills should be the ultimate goal of education. Almost despite the fact that they received little or no formal instruction in self-determination skills, our participants exhibited a pleasantly surprising level of self-determination. Again, how much better prepared students with disabilities—indeed, all students—would be if they were exposed to educational programs that focused on the acquisition of self-determination skills that could be applied throughout their adult lives. According to Wehmeyer and Schwartz, if students with disabilities are to become more self-sufficient and better able to manage their own lives and if they are to succeed as adults, promoting self-determination skills must become a critical part of transition services (p. 245).

We recommend the strategies that Wall and Dattilo (1995) suggested over a decade ago for fostering self-determination. These strategies include: (a) incorporating self-determination goals into individualized programs; (b) providing transdisciplinary services in which each team member values self-determination as a worthy goal; (c) involving individuals in their planning and goal setting; (d) assessing individual preferences (of positive reinforcers, tasks, materials, companions, etc.); (e) designing responsive, supportive, informational environments through creative scheduling and physical, social, and material modifications; (f) providing opportunities for self-deter-

mined behavior by encouraging responsible choice making and active communicative participation; (g) responding to self-determined behavior by encouraging conversational reciprocity and providing informational feedback; and (h) teaching self-determination skills throughout the life span using systematic instructional procedures as naturalistic teaching and learning opportunities arise (p. 289).

Malian and Nevin (2002) described self-determined individuals as goal-oriented, self-motivated, self-advocating, empowered, and people who continually reevaluate their satisfaction with progress toward the goals they set (p. 72). As we elicited the voices of adults with physical disabilities, we realized that they embodied Wehmeyer's and Bolding's (1999) advice that

if individuals are supported to make choices, participate in decisions, set goals, experience control in their lives, and so forth, they will become more self-determined. As they become more self-determined, they will be more likely to assume greater control; make more choices; hone their skills in goal-setting, decision-making, and problem-solving; and have greater belief in their capacity to influence their lives (pp. 361–362).

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**APPENDIX A**

## INTERVIEW QUESTIONS

1. How would you define self-determination?
2. In your opinion, how important is self-determination in your life?
3. What helps you attain self-determination your life?
4. What barriers do you encounter in attaining self-determination?
5. Is there anything that you would have changed in your public school education that would have helped you in your adult life regarding self-determination?