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"YOU HAVE TO CARE' PERCEPTIONS OF SUPPORTING AUTONOMY IN SUPPORT SETTINGS FOR ADULTS WITH INTELLECTUAL DISABILITY.

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Abstract

This study investigated the perceptions of persons with intellectual disability (ID) receiving support and the persons providing support regarding the autonomy of people with ID and how they perceive that it is either supported or denied within daily interactions between direct support professionals (DSPs) and people with disabilities. The participants included 10 people with ID receiving various support services and 10 DSPs. This qualitative investigation used interviews to examine issues related to the support role, the support relationship, the decision-making process of DSPs and the lives of people with ID. Analysis of participant interviews revealed that although participants with ID were capable of demonstrating their autonomy, DSPs faced several challenges that contributed to their difficulty in supporting autonomy of people with ID. Both groups of participants noted that DSPs had to demonstrate care towards people with ID to effectively support their autonomy. Some additional findings were that challenging behavior of individuals with ID may be caused by the lack of choices provided; that DSPs' concentration on the safety, health, and protection of persons with ID often limited the expression the autonomy of persons with ID. I found that DSPs often exerted subtle,

pervasive, obvious, or overt control over the individuals they supported and often

prioritized institutional goals over the goals of individuals with ID. In summary, paid

caregiving presents problems in supporting the autonomy of those receiving support,

despite the often well-intentioned efforts of the DSPs.

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CHAPTER 1

Introduction

People with Intellectual Disability (ID) have historically had limited access to express their autonomy (Jenkinson, 1993). People with disabilities have been labeled, often not through their own designation, with the label of disability (Snyder & Mitchell, 2006). These labels may have been cause to restrict their autonomous actions, labels that most of us might reject (Murugami, 2009). Recently, people with intellectual disability have been active in advocating for their own needs, desires, hopes, dreams, and feelings (Stroman, 2003). They, and people who care about them have also advocated for improved supports (Stroman), as well as autonomy. Promoting autonomy is the ultimate endeavor in respecting human dignity (Stainton, 1994), as well as increasing participation in support services (Cardol, De Jong, & Ward, 2002)

Many people with disabilities receive services meant to support them to achieve life goals and to lead a better life (Schalock et al., 2010; Soriesi et al., 2011). These services may be used to create empowerment that was often missing in the kinds of support that people with disabilities historically received (Kosciulek, 2000), and Direct Support Professionals (DSPs) can be the key to supporting dignity of people with disabilities (Kittay, 2011). The support can provide "a sort of prosthesis that permits one to be independent" (Kittay, 2011). Support services are often provided in the name of rehabilitation and protection (Zola, 1982), and should improve individual functioning in people with ID (Schalock et al., 2010). The purpose of this support may be to improve autonomy (Bell, Henthone, Hill, Turnbull-Humpries, & Zito, 2009; Dunn, Clare, & Holland, 2010), dignity, and liberation for those to whom it is provided, though this is not

always the case (Ellis, 1992). DSPs may be in the best position to promote autonomy

(Grimby, 2002).   The concept of disability is not one that is easily understood and

may have many harmful implications for the people so designated (Bell et al., 2009;

Davis, 2002; Oliver, 1990). Frequently the support services that people receive based on

the label of disability may actually lead to compromised autonomy and less opportunity

to fulfill self-designated goals (Barron, 2001; Stainton, 1994).

Definitions

The following definitions will clarify the discussed topics in this paper. I use the

phrase "people with intellectual disability" (ID) to describe a disability "characterized by

significant limitations both in intellectual functioning and in adaptive behavior as

expressed in conceptual, social, and practical adaptive skills" (Schalock et al., 2010, p. 1).

This definition includes the following assumptions:

- The limitations must consider the context that is typical for the individual's age
  and culture.

- The assessment must take into account culture and customs.

- All people have limitations and strengths.

- Limitations are described so that support needs can be determined.

- Appropriate supports will lead to better functioning of the individual (Schalock et
  al., 2010).

Intellectual disability is a label that takes into account various issues and provides for

support.

Another term I use is Direct Support Professional (DSP). Larson, Hewitt, and

Anderson (1999) provide a definition of Direct Support Professionals as "people whose

primary job responsibility (50% or more of their hours) is to provide support, training, supervision, and personal assistance to people with disabilities" (p. 38). The AAIDD (Schalock et al., 2010) further defined supports as "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person that enhance individual functioning" (p. 18).

DSPs are typically employed by provider agencies that provide many different kinds of support, however, all of the DSPs in this study worked for residential provider agencies. I refer to these as agencies, support providers, or provider agencies. Larson et al. (1999) defined residential agencies as

> Agencies supporting people with intellectual disability in ICFs/MR [intermediate care facilities for the Mentally Retarded], other 24-hour group residential settings specifically for people with MR/DD [mental retardation/developmental disabilities], such as group homes or supported living arrangements, semi-independent living services, and in home support settings. (p. 38)

Although seven of the participants with ID in this study received residential services, all ten of them received various other types of support services that are described in chapter 4.

Autonomy, a primary concept of this study (also discussed in a later section) is defined by Stainton (1994) as "the agent's freedom from both internal and external constraints, to formulate and pursue self-determined plans and purposes" (p. 21). I also explain many concepts related to autonomy and support services. I discuss self-determination, a component of autonomy throughout this paper (and in detail further). Wehmeyer (2005) stated that "self-determined behavior refers to volitional actions that

enable one to act as the primary causal agent in one's life and to maintain or improve

one's quality of life" (p. 117). There are many concepts and issues related to people with

ID and their autonomy that I discuss in detail in this chapter and the following chapter.

Disability, Disability Support Systems, and Disabled Identities

Disability has historically and continues to be thought of as the opposite of how

people are supposed to be (McRuer, 2006). McRuer alleged that there is a compulsory

able-bodiedness and that all normal people are able-bodied, and able-minded. According

to McRuer "a system of compulsory able-bodiedness repeatedly demands that people

with disabilities embody for others an affirmative answer to the unspoken question, 'yes,

but in the end, wouldn't you rather be more like me'" (p. 9). "There is (literally) no way

of articulating the very word 'disability' in the absence of 'ability'" (McRuer, p. 141).

Disability may be used as the primary means that people without disabilities establish

ability (Snyder & Mitchell, 2006). Normalcy would not even exist if not for the idea of

disability (Davis, 1995). In other words, normality is the absence of abnormality. In this

way normal is defined by not having disability. Snyder and Mitchell posited that "the

categorization of disability as a pathological deviance was not an excursion from

normalcy but rather its ultimate product" (p. x). Snyder and Mitchell stated that

"disability is a difference that exists only to be undone" (p. 190). People with disabilities

go through assimilation to become more like people without disabilities (Murugami, 2009,

p. 3). The entire purpose of the designation of disability is to attempt to rectify the

disability, a purpose that I believe disenfranchises the people to whom the concept

applies.

DSPs may act in the role of the oppressors of people with disabilities because they are often directly responsible for rectifying some of the symptoms of disability (i.e., inability to live alone and without support). Because society wants to make people identical without making them equal, rehabilitation demands compliance (McRuer, 2006). I argue that both the oppressors (DSPs) and the oppressed (People with ID) are disenfranchised. DSPs have little power and are in the position of providing support that often leads them to become the oppressors of people with intellectual disability, just as powerless people who have been given power become the oppressors over other powerless people (Freire, 1970). Because DSPs are often in such intimate relationships with people with disabilities, they may have the power to support or deny their autonomy (Grimby, 2002).

Identity may be a complex concept to people with ID because of the disability label attached to them. Murugami (2009) argued that people with disabilities often have an identity separate from the impairments that they face, and that stereotyping is abusive because people with disability are lumped into a group identity rather than getting to define themselves. It is through the construction of a reinvention of identity that people with intellectual disability stand even the remotest chance for equality. It is my contention that autonomy may serve the most important function for people with intellectual disability, guiding them to equality by reconstructing the way that others perceive them as capable and contributing to their own lives. Lotan and Ells (2010) stated that "humans have at least some degree of ability to set and act on goals and that doing so is integral to what is special, or to be appreciated, in human life" (p. 119). In other words, autonomy may be what makes the human condition so facilitating. Everyone has inherent

dignity even when it is unrecognizable to others (McRuer, 2006). Rehabilitation, as currently constructed, or the making of identical people, teaches depreciation of people with disabilities' own unique lives, and is counterproductive to identity development (McRuer). In the U.S. the label of "disability" is often required for people with intellectual disability to receive support services that they may require for their very livelihood. The use of this label demonstrates how eugenics was not a short horrible history, but a lasting phenomenon that informs our political, cultural, and intellectual discourse about what it means to be different (Snyder & Mitchell, 2006).

Different is not the same as deficient. It is natural for people to be different and the difference in people with ID is that they may need support to access the opportunities that people without disabilities have (Schalock et al., 2010). Attempting to define disability by a set of characteristics makes disability seem odd, even though most people are affected in some way by disability (Zola, 1982). Disability is a flexible category that is not easily defined. People can be a little disabled or extremely disabled (Davis, 1996). Many people who do not identify themselves as a person with a disability (i.e., people who are deaf), would indeed be categorized as such by society (Davis, 1996). I contend that disability is part of reality, a normal natural part of reality that has existed since reality, itself, has been recorded. I argue that the expectations of and for autonomy are affected by the mere labeling of disability.

It is necessary to consider that people with intellectual disability have rarely been involved in defining the label of disability, though they certainly could be considered experts in the experience of it. Disability has usually been defined socially, and people with disabilities have had to conform to whatever the definition of the day was, and live

by that definition though they had no part in its construction (Snyder & Mitchell, 2006).

Not only does this severely compromise their identity and indeed force upon them a

fractured or spoiled identity, but it also severely compromises their ability to be

autonomous because people in society, and often those people that directly provide

support to them, do not think that they are worthy of or able to make their own decisions

(Owen et al., 2003). Snyder and Mitchell (2006) defined the "cultural locations of

disability (p. x)" as "sites of violence, restriction, confinement, and absence of liberty for

people with disabilities" (p. x). I believe that because of these cultural locations of

disability people with disabilities have often been prevented from participating in

defining and projecting what disability is. People with disabilities and people who

support them are trying to carve out a new advocacy movement and redefine disability,

but are often confronted by a society, that it seems has already decided for them what

disability is.

People with disabilities live such regimented and structured lives that it prevents

them from being autonomous (Snyder & Mitchell, 2006). Worse, people with disabilities

may have internalized historical perceptions about disability, making emancipation (and

emancipatory research) difficult (Snyder & Mitchell). According to Snyder and Mitchell,

most of what we know about people with disabilities is what people other than those with

disabilities have said to be true. Davis (2002) argued that any time society attempts to

define someone, it compromises that person's identity. People with disabilities need to be

able to reinvent themselves (McRuer, 2006). Because disability has already been defined,

any further conceptualization of disability will emanate from the current concept. People

with disabilities should, as McRuer stated, embrace disability as better than non-disability.

I believe that this perception not only has the power to emancipate the sometimes oppressive world that people with disabilities live in, but may also lead them to be more assertive in expressing their autonomy. Conversely, when autonomy is respected and expected from people with disabilities, they may be able to embrace their disability as a matter of pride.

Disability and Support Politics

I affirm that disability is political, it is social, it is cultural, it is flexible, it is sincerely felt by those who have it, and how it is conceptualized constantly informs how society perceives it. The label of disability in research needs to be carefully weighed as it has the potential to maintain oppression and limit autonomy. Goodley (2001) stated that people with disabilities demand "that we start asking how we see people with the label of 'learning difficulties', while alerting us to the contexts (real or imagined) in which we do the seeing" (p. 221). It is necessary that researchers understand the implications of disability in society. Because people with disabilities live such regimented and controlled lives their very lives are political (Davis, 2002). This is especially true of people with intellectual disability who often receive support services that may minimize their involvement in their own lives. Davis suggested that the categories of disability, though socially defined (for *treatment* under the pretense of support and protection), can perpetuate continued oppression. He claimed that maintaining the category of disability is demeaning to all people. Davis stated that any research using identities inherently marginalizes some group. Further, politics using assumed identities inherently marginalizes certain groups of people (Davis, 2002). I believe that this is especially true

of the politics surrounding intellectual disability support systems that use the label of disability as a cornerstone to their provision.

Disability has historically been constructed as a problem to be dealt with, a difference to be undone (Snyder & Mitchell, 2006). Often society dealt with the problem by attempting to rid itself of the problem (Black, 2003). People with intellectual disability are often thought of as visitors of the outside world (Zola, 1982)—"the ones who are a reminder of man's failure, are somehow made invisible and kept isolated from the rest of the world" (p. 95). Society looked to institutionalization as a means to deal with the problem. Slater (1970) stated:

> Our ideas about institutionalizing the aged, psychotic, retarded and infirm are based on a pattern of thought that we might call The Toilet Assumption—the notion that unwanted matter, unwanted difficulties, unwanted complexities and obstacles will disappear if they are removed from our immediate field of vision….Our approach to social problems is to decrease their visibility: out of sight, out of mind….The result of our social efforts has been to remove the underlying problems of our society farther and farther from daily experience and daily consciousness, and hence to decrease in the mass of the population, the knowledge, skill, resources, and motivation necessary to deal with them. (p. 198)

Institutionalization was used as a means to deal with the problem of disability. I assert that institutionalization also removed the visibility of disability and led people to perceive disability as a difference removed from their lives, a perception that still exists.

There are many issues involved in using the label of disability and its necessity in the first place. Davis (2002) stated that "'them' is actually 'us'" (p. 4), highlighting that

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we all have the potential to be disabled. I believe that acting in the best interests of people with disabilities is in the best interest of everyone. I argue that labels should not be necessary to provide certain groups protection; all people who require support deserve it, and everyone deserves protection. Nor should the label of disability prevent people from expressing autonomy. Disability is not static (Davis). People can have degrees of disability, people can acquire disabilities at any time in their lives, and people can sometimes be "cured" of a disability (e.g., traumatic brain injury that becomes less noticeable as the person regains skills). Even when people have been labeled with a disability, they can reject social identities, and therefore, the intrusion of social identities into their lives (Murugami, 2009). Powerful or empowered people can define their own true identities. I believe that people who are powerful or empowered can express their autonomy by defining what disability is and how it is experienced. The concept of disability has changed throughout history and simplistic definitions can have much broader implications than providing for support. Definitions can alter the conception of disability and the perpetuation, creation, or rejection of disabled identities. Treatment of disability has also changed throughout history. Davis stated that "it is too easy to say, 'We're all disabled.' But it is possible to say that we are all disabled by injustice and oppression of various kinds. We are all nonstandard" (p. 32).

Disability Assumptions

It is important in qualitative research to outline the assumptions that I, as a researcher have about disability, especially considering the oppressive history of disability, and the power that research may have over the conceptualization of disability. These assumptions not only affect the kind of research that I conducted, but also my

actions as a researcher. For the purposes of this research, I hold the following

assumptions about intellectual disability:

1. Intellectual disability is socially constructed.

2. The intellectual disability label is harmful to people who are labeled, and

   perpetuates oppression.

3. Intellectual disability and the current approach to treatment of disability are a

   result of medicalization of society.

4. Intellectual disability is defined by people without disabilities and imposed

   upon people with disabilities who, because of compromised autonomy, maybe

   limited in defining disability themselves.

5. Many of the problems that people with disabilities experience are due to

   negative perceptions about disability. There is no need to fix people with

   intellectual disability; however, there is a need to fix the perception and

   treatment of people with disabilities.

6. The label of intellectual disability leads to compromised autonomy of the

   labeled person, wherein people who have been labeled with ID do not express

   their autonomy in the same way that people without ID express their

   autonomy.

7. Intellectual disability and other disabilities are a natural and normal part of life.

8. Every individual regardless of intellectual ability has a right to be autonomous

   and have opportunities to lead a meaningful life.

9. Support services, though necessary at this point in history can restrict the autonomy of people with disabilities or can liberate people with intellectual disability in the ultimate support of autonomy.

10. The label of intellectual disability, though it may be harmful, is necessary at this point in history to provide for the collective identity for advocacy for equality, but may not be necessary in the future as perceptions continually change.

11. The situation of people with intellectual disability is getting continually better. As a researcher, it is my responsibility to ensure that I am informing positive changes that influence autonomy rather than negative changes that perpetuate segregation and powerlessness.

12. People with intellectual disability are the best equipped to discuss their situation, and are in fact experts on the experience of disability.

Autonomy in People with Intellectual disability

Autonomy as a concept is difficult to define. It is difficult to generate a readymade definition of autonomy, and even harder to form a definition that is applicable to everyone (Saadah, 2002). Lotan and Ells (2010) determined that autonomy has gained importance in recent years due to disability rights movements, discrimination of people with disabilities, and paternalistic attitudes towards people with disabilities, and that it is used in ID services to challenge professional control. They also stated that there is no perfect way to support autonomy. Due to the difficulty in defining autonomy there are many different components that are subsumed into the concept of autonomy that improve its understanding (discussed in detail later in this chapter). Some components of

autonomy (such as choice and self-determination) are vital, while others position the concept of autonomy as a right not to be infringed upon (such as freedom, rights, power, control, and coercion). Berlin (as cited in Stainton, 1994), defined freedom as:

> the wish on the part of the individual to be his own master….I wish to be the instrument of my own, not of other men's, acts of will….to be moved by reasons, by conscious purposes, which are my own, not by causes which affect me, as it were from outside….conceiving goals and policies of my own and realizing them. (p.10)

Stainton (1994) stated that freedom and autonomy are inextricably linked and that understanding the value of freedom is essential to understanding autonomy. Indeed freedom is a quintessential American value, and is pivotal to American ideals. The Declaration of Independence was founded on freedom (United States, 1776). Further, Stainton argued that autonomy is more important than freedom because it provides for freedom. Yet to have freedom, one must first obtain autonomy (Stainton).

According to Stainton (1994) the word autonomy comes from the Greek words autos and nomos. The word autos, meaning "self", and nomos, meaning "rule" (p. 23). Saadah (2002) defined autonomy as "what makes a life one's own (p. 979). Lotan and Ells (2010) stated that the concept of autonomy when applied to an individual person means the capacity to be self-governing, and that "most theories involve personal authority and control over one's thoughts, goals, and actions" (p. 113). Wehmeyer (1999) described behavioral autonomy as "the outcome of the process of individuation and encompasses, fundamentally, actions in which people act (a) according to their own preferences, interests and/or abilities, and (b) independently, free from undue external

influence or interferences" (p. 57) (independence in this sense meaning independent from coercion, not independent in that one is entirely capable by themselves). Lotan and Ells further stated that these theories "assume a rational decision-making ability and a fairly consistent set of values, desires, and goals" (p. 113). Clapton and Kendall (2002) defined autonomy as having some level of control over actions and decisions. Bell et al. (2009) suggested that it is implied that people have to be independent to execute autonomy, but that this is not true. Wolfensberger and Glen (1975, as cited in Peter, 1999) defined autonomy for people with disabilities as having "the same amount of control over their [sic] actions, decision-making, wishes and desires as any other person of comparable age" (p. 809).This is important to consider because even though it subjects them to normalized standards, it also affords them the opportunities to become autonomous and fully access their human rights. Sigafoos, Feinstein, Damond, and Reiss (1988) further determined categories of autonomy including self-/family-care, management activities (independence in handling affairs), recreational/leisure, and social/vocational activities. Autonomy for people with intellectual disability is based on control (or self-rule, Stainton, 1994), power (Jenkinson, 1993, as cited in Finaly, Walton, & Antaki, 2008), choice (Stainton), and self-determination (Stainton).

Although all of these definitions of autonomy assist in understanding the construct of autonomy, in this paper I focus on Stainton's (1994) definition of autonomy as "the agent's freedom from both internal and external constraints, to formulate and pursue self-determined plans and purposes" (p. 21). In addition Stainton also added that autonomy must consider the individual, the capacity for planning, the capacity to act on plans, and self-determination (situating self-determination as a necessary component of

autonomy). He stated that plans are made apparent through the choices that individuals make (situating choice as a necessary component of autonomy). Some additional elements of autonomy he defined are: making choices based on options, initiating action towards plans, and identifying values and beliefs. In addressing definitions of autonomy that have reason as a primary component, Stainton stated that "autonomy requires us to have a reason, it does not require us to have a good reason in any objective sense" (p. 40). Though people with disabilities may make choices that may seem bad, so do many people without disabilities. Therefore making poor choices should not be used as a reason to restrict autonomy.

According to Cardol et al. (2002) there are two different kinds of autonomy. These are decisional autonomy or the ability to make decisions, and executional autonomy or the ability for people to act on decisions. Decisional and executional autonomy may be affected by disability or the environment, so that a lack of accommodations prevents control, or the disability is such that it prevents control over the environment (Cardol et al.). For example, a person who needs a wheelchair but does not have one is severely restricted in controlling his or her environment, just as a person with a significant cognitive disability may be unable to control his or her environment when he or she does not possess the skills necessary to be in control.

Information plays a vital role in autonomy. "Ignorance restricts decisional autonomy just as information facilitates it" (Cardol et al., 2002, p. 972). Even when choices are provided many alternatives are not mentioned, thus facilitating ignorance rather than autonomy (Cardol et al.). The authors further state that "autonomy is central to client-centered rehabilitation since it is a pre-requisite for effective participation.

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Cardol et al. suggested that autonomy, conceived as a basis for participation, is the ultimate aim of rehabilitation" (p. 970). In other words, autonomy for people with intellectual disability is contingent upon the support that they receive, especially when they do not possess the skills necessary to control their environment, and the support that they receive should contribute to their expression of autonomy. The support that is provided may assist them in developing skills needed to manage their environment or assist them in managing their environment even though they may never acquire the skills to do so independently (Cardol et al.).

Stainton (1994) also defined two different kinds of autonomy. Occurrent autonomy is the autonomy that is present in a given act, and dispositional autonomy is the autonomy that develops over time (Stainton). In other words, autonomy is necessary to meet short term goals and to express long-term interests. Stainton claimed that people do not need to actually carry out every plan that they make, so long as they initiate the process of carrying out their plans (e.g., a person who wants to get his or her car fixed and brings it to the mechanic, or a person with a significant physical disability who decides that he or she wants to grow a garden and has a DSP do the bulk of the heavy work). He also recognized that many times people who lack information about a decision may defer the decision to someone who is more knowledgeable (e.g., a person who takes the advice of a contractor as to how to fix his or her home). Cardol, et al. (2002) stated that "autonomy is not a state of being, but rather something individuals develop in the course of their lives. Autonomy can be viewed as a continuous and personally unique variable which exists in different degrees depending on a person's circumstances" (p. 972). As such, autonomy is dependent upon the circumstances in which a person lives.

Issues Affecting the Experience of Autonomy by People with ID

Stainton (1994) stated that autonomy is lost with coercion, and that influence limits autonomy. I argue that coercion and influence both occur within support services, and are the primary ways that autonomy is denied in interactions between people with disabilities and DSPs. Further when influence happens throughout a person's life, he or she may even adopt a value system that is not truly his or her own, and therefore become incapable of being autonomous (Stainton). Support systems may foster a lifetime of coercion and influence, hindering the autonomy of people with disabilities.

"People with mental retardation [ID] are individuals. This central truth is sometimes lost in our attempts to classify them and categorize their abilities, needs, and behaviors" (Ellis, 1992, p. 1782). For many people the concept of autonomy is fostered by the idea that people should get to choose who they want to be or engage in managing their lives. This becomes paramount for people with intellectual disability who may (a) have been prevented from making choices altogether (Owen et al., 2003) or have had all of their major life choices made for them (Agran, Storey, & Krupp, 2010), (b) not be aware of their rights to make choices and decisions (Sobsey, 1994), (c) need to be explicitly taught to make choices and decisions (Sobsey, 1994), or (d) have internalized negative perceptions that prevent them from emancipating themselves (Snyder & Mitchell, 2006).

Ellis (2005) suggested that human rights for people with intellectual disability are more about autonomy and having control over one's life, than developing independence. In other words people with disabilities need not be entirely independent, but need to have

autonomy to experience their human rights. They need power. Jekinson (1993) said that power is about:

> …what happens between people moment by moment, in the mundane details of everyday interaction. Power permeates everyday life—it is exercised in the way people talk to each other, in what utterances are taken up and what are ignored, in how and what options are offered, in how information is presented, how spaces are opened up for people to express preferences and how spaces are shut down.

Autonomy is executed or denied in this very way. People with intellectual disability either forcefully exert themselves when prevented from making choices (Peter, 1999), make limited choices based on the severity of the disability or the kind of environment in which they are supported (Lakin, Dolijanac, Byun, Stancliffe, Taub, & Chiri, 2008), or may not make choices at all (Ellis, 1992). Choices are embedded in everyday existence and autonomy is not about just deciding where to live or who to have as a partner. Autonomy is also about choosing how to wear your hair, choosing what to eat for dinner, getting to be spontaneous, and immeasurable other daily choices that many people take for granted. It is also about having power to express desire, having the skills to make choices, and understanding the implications of choices.

"The task in a life involving disability is necessarily one of dealing with control and being controlled" (Ellis, 2001, p. 607). Stainton (1994) acknowledged that paternalism often gets in the way of autonomy. He defined paternalism as "the idea of interference with someone's liberty/autonomy for their own good" (p. 81). I believe that this is true for people with intellectual disability whose support often involves paternalism because of the need to provide protection. Stainton discussed public

paternalism, whereby the government sanctions paternalism. This is the case of support services where the autonomy of people with disabilities is restricted so that they can obtain a higher degree of autonomy (e.g., a person with a disability may be coerced to make a choice to not engage in a criminal act, so that he or she is not imprisoned and can exercise autonomy in other areas). Another way to think about this is protecting people with disabilities from themselves, or at least from their own poor decisions.

Ellis (1992) suggested that people with disabilities are often subject to abuses based on protection that limited their autonomy. Perske (1972) stated that denying people with ID "exposure to normal risks commensurate with their functioning tends to have a deleterious effect on both their sense of human dignity and their personal development… the removal of all risk diminishes the retarded in the eyes of others" (para. 1). By acting in paternalistic ways, DSPs may be preventing people with ID from expressing their autonomy by limiting their opportunities to express it in the first place, or denying their dignity of risk. When this happens it might lead to the incompetence of people with ID. "True autonomy is not promoted by pretending that an individual is competent to make choices that he or she cannot in fact understand" (Ellis, 1992, p. 1809). Ellis suggested that despite the many barriers to assisting people with intellectual disability in making decisions (e.g., communication difficulties, difficulty in understanding information, denial of disability), people with disabilities have been prevented from making decisions, in such a way and for such a length of time that it has compromised their ability to make decisions. This lack of decision-making capacity may be a result of support provided in an overprotective manner (Jenkinson, 1993). Further, for certain decisions, an ability to provide legal consent may be required of the individual based on the label of the

disability itself (Ellis). An individual's placement in a residential setting automatically raises questions about their ability to provide consent, even for the provision of services in the residential setting (Ellis). Ellis further implied that placing people with disabilities into support settings is often done without their consent, since legally many of them would be unable to provide consent for such "treatment". "Decisions about where a person will live, and with whom, involve a degree of coercion and intrusiveness that have no parallels in the lives of non-disabled individuals who are not incarcerated" (Ellis, 1992, p. 1793). This implies that people with disabilities automatically have restrictions on their autonomy by their placement in residential support settings.

Lotan and Ells (2010) stated that most people rely on assistance from others to make decisions. They stated that often people who have no decision-making authority are involved in making decisions for people with intellectual disability. Ellis (1992) suggested that decisions by people with intellectual disability often involve excessive coercion by others. Ellis discussed the various levels of coercion that can occur for people with intellectual disability. One example provided by Ellis is "authorized official coercion" or coercion that is applied by the courts (e.g., guardianship, representative payee). Unauthorized coercion can also occur on many levels for people with disabilities receiving support (Ellis, 1992).

> …The reality of the lives of people with mental retardation involved a more pervasive coerciveness. A wide variety of nondisabled individuals, including social workers, therapists, operators of sheltered workshops and group homes, and others will often assume and exercise decisionmaking [sic] authority over people

with mental retardation in ways that are not described in or authorized by the law

(Ellis, 1992, p. 1802).

Ellis (1992) argued that people with disabilities often feel like they have to ask for

permission for things they want to do, and DSPs perceive this as business as usual. Ellis

(1992) argued that people with disabilities should be involved in all decisions, regardless

of their capacity. He also cautioned that they should not be subject to an all or nothing

approach of determining capacity for decision-making. "It is important to realize that

achieving complete control over one's destiny is not required for autonomy" (Ellis, 2001,

p. 608).

"It is then, the potential capacity to be autonomous which we value, the ability to

be the architect of our own world, to struggle and perhaps fail, which brings us dignity as

persons" (Stainton, 1994, p. 48). I contend that autonomy is about people getting to

actually become who they decided that they want to be, or at least having the opportunity

to try to be who they want to be. Autonomy is not about being given an identity, directed

how to behave, forced to act *normal*, or being so protected that it is difficult to experience

real life. Although people with disabilities may require support for their continued

livelihood, people with disabilities do not need to be held to normalized standards.

It is a natural part of human existence for people to be different. There is nothing

wrong or abnormal about being different, and I believe that attempting to correct

difference through control and restrictions on autonomy is neither *support* nor productive

in assisting people with disabilities to access human rights. According to Stainton

"autonomy can only be infringed for the sake of autonomy" (p.104). For people with

intellectual disability this means that the only time their autonomy should be restricted is

when the infringement actually acts to support their autonomy. For example if a person

with an intellectual disability is unable to manage their money and doing so would mean

that they would become homeless (restricting in many ways their autonomy), then they

should be given support to manage their money. It does not meant that they should be

restricted from choosing how to spend their money, even if they want to buy frivolous

things that others do not see value in. I contend that there is a fine line between DSPs

restricting autonomy to allow for more freedom, and restricting autonomy because DSPs

have unofficial authorized coercion to restrict autonomy.

Self-Determination as a Component of Autonomy

Autonomy is very much about the self-determination that a person exhibits over

his or her life. According to Wehmeyer (1999), autonomy and self-determination have

been linked since the concepts emerged. Self-determination plays a major role in the

definition of autonomy and how the construct of autonomy is applied to the lives of

people with intellectual disability. It is also an important construct in the disability rights

movement. Lotan and Ells (2010) defined self-determinism as "choices that influence an

outcome" (p. 113). Wehmeyer (2003a) defined self-determination as a personal construct

that is based on the amount of control that people have in their lives. Deci and Ryan

(1985) determined that self-determination is based on an innate need to manage one's life.

Soriesi et al. (2011) stated that "self-caused action is, by definition, set in opposition to

other-caused action" (p. 23). Wehmeyer (1999) suggested that autonomy is basically

individuation, and that functional or behavioral autonomy is independence.

Definitions of self-determination can assist in understanding the construct of

autonomy. Martina and Marshall (1995) stated that people who are self-determined

know how to choose—they know what they want and how to get it. From an

awareness of personal needs, self-determined individuals choose goals, then

doggedly pursue them. This involves asserting an individual's presence, making

his or her needs known, evaluating progress toward meeting goals, adjusting

performance and creating unique approaches to solve problems. (p. 176).

Wehmeyer (2003b) determined that this definition is problematic because people with

disabilities also demonstrate self-determination when they do not act, and that all

behaviors may be used to enact self-determination. In other words autonomy can also be

expressed by choosing to not make a choice when appropriate. Wehmeyer (2003a)

defined self-determination as "acting as the primary causal agent in one's life and making

choices and decisions regarding one's quality of life free from undue external influence

or interference" (1996a; 1998; 1999; & 2001, as cited in Wehmeyer, 2003a, p. 26). This

definition of self-determination is contingent on the following elements: autonomy, self-

regulation, psychological empowerment, and self-realization (Wehmeyer, 2003a).

Bandura (1997, as cited in Wehmeyer, 2003a) added that human behavior is contingent

upon multiple factors; therefore people contribute to rather than exactly determine the

course of their lives. As such, all people make choices and decisions based on conditions

in their lives, and all people have external influences that guide their choices. Being self-

determined does not mean that everything happens exactly as someone desires, but that

people are constantly involved in negotiating and evaluating external factors to guide the

courses of their lives. Further, people with disabilities do not need to be in complete

control to be self-determined, and being in control does not necessarily imply that a

person is self-determined (Wehmeyer, 2005). I believe that self-determination is having

the opportunities to determine and affect outcomes in life. Though we are all included and affected by things going on around us, people who are self-determined are not so influenced that they incapable of determining the outcomes that they desire, nor are they so influenced that they are not given opportunities to affect life outcomes.

Self-determination is composed of a hierarchical decision-making process. Choice-making includes indicating preferences, using choices to facilitate decision-making, and expressing autonomy (Guess, Benson, & Siegel-Causey, 1985). Decision-making includes multiple steps, such as listing alternatives, identifying consequences and the probability of consequences occurring, understanding the value of consequences, and using information to evaluate the best decision (Beyth-Marom, Fischhoff, Jacobs, Quadrel, & Furby, 1991, as cited in Wehmeyer, 2003b). Problem solving involves situations where solutions are not immediately apparent or there are multiple solutions (Wehmeyer, 2003b). Additionally, Wehmeyer includes the components of goal setting and attainment, self-monitoring, self-evaluation, self-instruction, self-reinforcement, self-advocacy and leadership skills, internal locus of control, perceptions of self-efficacy, self-awareness, and self-knowledge. Although there is a difference in choices and decision-making, it is difficult to always make the distinction between where one ends and the other begins, as small daily choices may lead to life altering decisions (i.e., the choice to participate in helping a friend fix a car, may result in the decision to become a mechanic). In the remainder of this dissertation I use the terms provided by specific authors, or use the terms interchangeably as I deem necessary.

Self-determination develops from a life-long process (Sands & Wehmeyer, 1996). All people can potentially be self-determined. Wehmeyer (2003b) stressed the

importance of opportunity for people with intellectual disability. Because they are often

so dependent on others for their livelihoods and care, people with intellectual disability

need opportunities to be self-determined and therefore autonomous. According to

Wehmeyer (2005) a person does not have to be successful to be self-determined, just as a

person does not have to have good reason to make choices. He further stated that self-

determination is not doing everything for oneself by oneself. In addition, self-

determination is a characteristic, not a program or curriculum. So even though people

with ID may need to acquire skills to become self-determined, they will not automatically

gain self-determination from being enrolled in a program. Wehmeyer (2005) also stated

that though making choices is central to being self-determined, choices aren't the only

important part of self-determination. Self-determination also involves developing values

over time (Wehmeyer, 2005). Wehmeyer (2005) stressed the importance of intention in

self-determination and that "self-determined behavior refers to volitional actions that

enable one to act as the primary causal agent in one's life and to maintain or improve

one's quality of life" (p. 117). In other words, people with disabilities who are self-

determined are continuously determining the kind of life they want to lead, acting to

make that life possible, and having opportunities to do so. It is a difficult balance between

supporting self-determination and protecting people with disabilities (Wullink,

Widdershoven, van Schrojenstein Lantman-de Valk, Metsemakers, & Dinant, 2009).

People with Disabilities as Advocates

Though historically people with disabilities have often been construed as less then

desirable members of society (Black, 2003; Davis, 1995), they certainly have the

experiences and understanding to be the best advocates for their own situation. People

with various disabilities and some of their advocates have carved out a new advocacy

movement, wherein they are the bearers of knowledge and expertise, and they directly

impact the kinds of services and support that they receive. If people with disabilities self

identify as having a disability then the group identity can be used to further their causes

(Murugami, 2009). Even though the disability label has many negative implications, it

can support them to gather collectively (Goodley, 2001). Davis (2002) stated that the

instability of the disability category could transcend identity politics, and that difference

is what we all have in common. Although people with disabilities have been influential in

changing their circumstances, it is a continued necessity for people with disabilities to

make things happen for themselves through their advocacy efforts (Bell et al., 2009).

Disability rights organizations began as early as the late 1800s (Stroman, 2003).

In 1950 the Arc organization began (Stroman). The Arc's purpose was to advocate for

deinstitutionalization, education, research, social supports, prevention, and other services

for people with cognitive disabilities (Stroman). The 1970s, however, brought about

significant changes in disability services, as a result of the efforts of people with

disabilities and advocates on their behalf (Stroman). Spearheaded by Ed Roberts in 1972,

the first Center for Independent Living opened in Berkley, California (Longmore, 2003).

The independent movement followed shortly after (Longmore). The Disabled in Action

(DIA) and ADAPT were both successful advocacy groups for people with many

disabilities to receive needed supports and have a political voice in matters important to

them (Barnartt & Scotch, 2001). Disability activists were essential to the passage of the

Rehabilitation Act, the Americans with Disabilities Act (ADA), and Section 504

(Longmore). Barnartt and Scotch found that more than 80% of the people with involved

in disability protests were people with disabilities themselves. These advocacy efforts

paved the way for deinstitutionalization and the supports that people with ID currently

receive in the community, without which a greater restriction of their autonomy may

occur.

People with ID have been active in speaking on their own behalf as well. Soriesi

et al. (2011) asserted that there is actually a self-determination movement in the US. This

seems evident by some of the advocacy organizations that are in existence. People First

(a self-advocacy group for people with ID) began in 1974 in Oregon (Stroman, 2003).

Today there are over 500 People First chapters in the US, as well as some in other

countries (Stroman). There are more than 17,000 people involved in the People First

organization (Stroman). It is clear that people with ID are capable of speaking for

themselves and speaking about the services that they receive. People with ID will need to

continue to speak up for the changes that they believe are necessary within the support

system. They should also speak about what autonomy means to them, and how support

services can better promote their autonomy.

A Political Case for Autonomy

Autonomy and its relevant components are supported by many international,

inter-American, and federal foundational documents. I contend that autonomy has a

political basis, and because of these precedents autonomy is constructed as a right that

should be made available to people with disabilities, even those whom it is difficult to

support. Many international documents support autonomy and some of the relevant

components of autonomy. In 1948, the UN passed the Declaration of Human Rights

(United Nations, 1948) so that inherent dignity and inalienable rights in every person

would create the foundation for a world of freedom, justice, and peace, as well as stipulating that people with disabilities should have choices (albeit in relation to vocational choice). The International Covenant on Civil and Political Rights went into force in 1976 (United Nations, 1966). It recognized the inherent dignity in all human beings, and stated that all people have a right to self-determination. It also maintained equality under the law, and stated that no-one should be denied the right to enjoy their own culture, religion, or language. The Protection of Persons with Mental Illness and the Improvement of Mental Health Care (United Nations, 1991) specifically stated that the purpose of treatment is to enhance and promote autonomy. The World Programme of Action Concerning Disabled Persons (WPA) adopted by the UN in 1982 stressed creating opportunities for people with disabilities, full participation of people with disabilities, and the importance of decision-making, even for people with cognitive disabilities (United Nations, 1982). It also discussed the importance of advocacy and self-advocacy. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1993) stressed the need for providing equal opportunities to people with disabilities. It also encouraged people with disabilities, parents, guardians, advocates, and organizations to be active participants in advocacy. In 2006 the UN approved the Convention on the Rights of Persons with Disabilities (CRPD) and Optional Protocol (United Nations, 2006) that recognized the inherent dignity and rights of all people, including autonomy. It specifically stated that people with disabilities should participate in any efforts to change their current situation through policies and program planning. It also called for increased choice opportunities for people with disabilities (such as the right to choose a living arrangement).

Several documents emerged in North and South America. The Inter-American
Convention on the Elimination of All Forms of Discrimination Against Persons with
Disabilities, adopted in 1999 (Organization of American States, 1999), called for
respecting rights without distinction and integration of people with disabilities in social
life. The Montreal Declaration on Intellectual Disabilities of 2004 (Montreal Declaration,
2004), recognized that people with disabilities should be afforded all of the rights in
existing human rights frameworks. It specifically called for full social inclusion and
recognized that people with disabilities need to make choices regardless of their ability. It
further stipulated that surrogate decision-makers must make choices that are
commensurate with the preferences of the individual for whom they are deciding. In the
United States, the Declaration of Independence created in 1776 stated that "all men are
created equal, that they are endowed by their creator with certain unalienable rights, that
among these are life, liberty, and the pursuit of happiness" (United States, 1776). The
Civil Rights Act of 1964 (United States, 1964) protected from discrimination and called
for desegregation of schools. The Developmental Disabilities Assistance and Bill of
Rights Act of 2000 stated that people who have a disability should not have their
participation or control impeded upon (United States, 2000). It also called on state
councils to make changes that promote self-determination, states to strengthen advocacy
networks, and people with disabilities to be involved in advocacy efforts. Voting, an
important way to express and support autonomy in the US is supported by two acts, the
Voting Accessibility for the Elderly and Handicapped Act of 1984 (United States
Department of Justice, 2005) and the Voter Registration Act of 1993 (United States
Department of Justice, 2005). The ADA signed into law in 1990, cautioned that

overprotective policies have isolated people with disabilities and made many inclusive practices federal law.

This legislation supports the need for choice, advocacy, self-advocacy, freedom, and personal expression. Ultimately it seems that what is really supported by these foundational documents is the right of everyone, and in many cases specifically people with disabilities, to be autonomous.

Autonomy as a Human Right

Labels of disability are challenging (as discussed above). Though all people must be deemed incompetent before they can legally lose basic rights to choice and autonomy, I contend that the reality for many people with disabilities is that they have a compromised autonomy. People with disabilities, especially intellectual disability, are often reliant on the assistance of others, and this reliance can compromise their basic right to autonomy. Because people with intellectual disability often need support in many areas of their daily lives, they often require support services. In these support services, there may be a lack of understanding about how to support people with intellectual disability to act autonomously, and people with disabilities may lack both the education (Sobsey, 1994) and empowerment (Snyder & Mitchell, 2006) required for an autonomous life.

Although I have provided a political case for autonomy, there are still problems in supporting human rights, including autonomy, in people with disabilities. Ward and Steward (2008) asserted that the group most often denied access to their human rights and autonomy has been people with intellectual disability. Ward and Steward also determined that "human rights create a protective zone around persons and allow them the

opportunity to further their own valued projects" (p. 298). In Doe v. Bolton, 1973, Justice William O. Douglas called personal liberties not only the rights guaranteed by the constitution, but also the right to be left alone, to manage one's own affairs and life, and to move around or be lazy (Bannerman, Sheldon, Sherman, & Harchik, 1990). Ward and Steward defined human rights as personal freedom, material subsistence, personal security, elemental equality, and social recognition, or the idea that people should be in control of their own lives. They asserted that the state is obligated to provide people with disabilities the capabilities to promote their own human rights. Ward and Steward determined that the denial of human rights is essentially the denial of dignity. Dignity is respected by supporting autonomy (Stainton, 1994), and autonomy leads to access to human rights (Ellis, 2005). Ward and Steward claimed that people with disabilities are often thought of as not being able to understand and promote their own human rights. This faulty assumption, based on societal perspectives about people with disabilities, may prevent them from participating fully in their own lives. The authors further contended that the denial of rights can lead to the disempowerment of people with intellectual disability. This in turn, can lead to internalized beliefs about their ability to control the direction of their own lives, causing them to be less involved in making choices and decisions (Snyder & Mitchell, 2006). Much of the treatment that is directed at people with intellectual disability is provided as support for protection from danger (Ellis, 1992). Using protection as an excuse for abuses of power is unreasonable because humans have the right to take risks (Zola, 1982, p. 70). Protection should not prevent autonomy. Support services should not interfere with autonomy, unless the interference is to support the autonomy (Stainton, 1994).

Bell et al. (2009) argued that autonomy is a human right. The right to autonomy, Megret (2008) stated, cannot be granted to an individual, but can only be achieved by changing the social situation that the person experiences. People will have greater access to human rights when they have autonomy (Ellis, 2005), but cannot be granted autonomy. Therefore, people with disabilities would need to be accepted as capable and self-determined, before they will be able to be autonomous. Autonomy, Megret posited, is what allows someone to experience their rights and is the reason for human rights. "Autonomy is effectively a form of human rights that takes its meaning in relation to the specific vulnerabilities of a particular group" (Megret, p. 514). Megret stressed that it may be necessary for people with disabilities to carve out a new specific right to autonomy. Autonomy should be constructed as a right because people with intellectual disability will not have access to autonomy if it is not constructed in this way. It is my belief that not constructing autonomy as a right for people with intellectual disability perpetuates the idea that the rights of anyone in society can be restricted. Stainton (1994) specifically defined a "disability right" because civic rights for everyone are diminished if the rights of people with disabilities are ignored or neglected. By respecting the right of people with intellectual disability to be autonomous, people would essentially be supporting the right of all persons in society to be autonomous. Especially considering the flexibility of the disability category (Davis, 1995). Bell et al., discussed the dire consequences of not acknowledging autonomy as a human right, and challenged people to think of a world where autonomy is not considered a human right. I argue that even though people cannot be granted autonomy, acknowledging that they should have it may

change the social situation that causes them to have compromised autonomy in the first place.

Autonomy in Support Provision

Thompson et al. (2009) suggested that not providing supports to people with disabilities, would negatively affect their ability to function. Thompson et al. defined services as "organized means for delivering supports, instruction, therapies, or other forms of assistance" (p. 143). The AAIDD (Schalock et al., 2010) stated that support should be based on the needs of the individual, but that it should also take into account personal competence and environmental demands. This implies that support should be about the individual, their needs, and their circumstances. The AAIDD also stipulated that support should be based on person-centered planning. Thompson et al. listed some of the components of support. The first is to identify the goals of the individual who is being supported. The second component is to determine how to use support to effectively meet the goals that the individual has set forth. Other components are completing a support plan and monitoring its progress, as well as evaluating whether the goals are being met. As such services should act to support the goals of the individual, and should center on the person and their needs. Services often have the power to do just the opposite by isolating people with disabilities and jeopardizing their human rights (Nerney, Crowley, & Kappel, 2002).

Ethical support provision is comprised of people making decisions, having opinions, and participating in their lives (or in other words, acting autonomously) (Morris, 2001). Support provision should enable people who would otherwise have difficulty accessing their human and civil rights to access them, rather than act as restricting force

(Morris, 2004). People with disabilities become more impaired when neglect of human rights occurs in day-to-day interactions (Morris, 2004). This scenario seems likely considering that DSPs have to balance protecting people with intellectual disability and supporting their autonomy. I believe that neglecting human rights may be utterly devastating for people who may have only minimal capacity to influence their lives in the first place. Restricting choice-making leads to powerlessness in individuals with intellectual disability (Salmento & Bambara, 2000). All individuals, including individuals with severe disabilities have the ability to make choices in their lives (Salmento & Bambara, 2000). I believed that autonomy can be supported when ethical support is provided to people with intellectual disability, and when DSPs value people with ID as competent, capable, and self-determined. Finlay, Walton, and Antaki (2008) stressed the importance of DSPs paying attention to the small things. Antaki, Finlay, and Walton (2009) asserted that people with ID are being denied the rights to choice, and that DSPs need to consider all of the minute choices to be made in a day. This implies that one of the best ways to support the inherent rights and the right to autonomy of individuals with intellectual disability is to ensure that they are able to make choices about all of the seemingly unimportant things and the long term and fundamental decisions of life. In this sense it is also vital that they are perceived as capable of participating in choice-making. Autonomy can be supported by DSPs by supporting people with disabilities to understand options, develop strategies, provide information, allow time for making choices, and respecting and encouraging autonomy (Cardol et al., 2002). Bell et al. (2009) add that support staff must not merely provide choices, but also think through the choices that people with disabilities make to help them understand the consequences of those choices.

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Supporting autonomy occurs when an individual in a position of authority listen's to another person's perspective, acknowledges that person's feelings, and provides pressure-free information and opportunity for choice (Deci & Ryan, 1985). I believe that supporting people with intellectual disability to make choices and decisions about their lives will transform them from participants in their lives, to directors of their lives.

Problem Statement

People with intellectual disability are often perceived as being incapable of directing their own lives (Karlsson & Nilholm, 2006). Many people with disabilities receive support services that are intended to increase their autonomy (Cardol et al., 2002). Yet, these support services may actually act to restrict the right to autonomy of people with intellectual disability (Stainton, 1994; Barron, 200; Nerney, Crowley, & Kappel, 2001). This may be because of societal perceptions that do not value people with disabilities' rights to autonomous expression (Snyder & Mitchell, 2006), overprotection that prevents them from being autonomous (Davis, 2002; Ellis, 1992; Stainton, 1994; Zola, 1982) and normalized standards that are forced upon them. DSPs, however, have the greatest potential to promote the human right to autonomy for people with intellectual disability (Grimby, 2002). The problem addressed in this investigation is that people with intellectual disability receiving support are involved in numerous daily interactions with DSPs that act to promote or restrict their autonomy.

Purpose of the Study

The purpose of this study is to investigate the perceptions of persons receiving support and the persons providing support regarding the autonomy of people with intellectual disability and how they believe that it is either supported or denied within

daily interactions between DSPs and people with disabilities. The research questions of this study are:

1. How do people with intellectual disability and DSPs perceive the role of the direct support provider?

2. What are the understandings and experiences of DSPs and people with disabilities in regard to the autonomy of people with intellectual disability?

Reflexivity

I am interested in this topic because I have previously worked as a DSP with people with ID. In this experience, I was appalled by the treatment (by myself and others) of people with intellectual disability and the lack of opportunity for them to be autonomous. As a DSP, I was often confronted with ethically challenging situations that I was grossly unprepared for. I had low expectations about the capabilities of people with intellectual disability. I did not understand that they had the same rights that I did. My inaccurate perceptions limited their opportunities to be autonomous.

Looking back, I have guilt about my own interactions (and certainly many that I was witness to, and did not intervene in) with people with ID in which I did not support their autonomy. Due to my experiences as a DSP and the ability to reflect years later, I am certain that there are systemic and social barriers that prevent the realization of autonomy by people with intellectual disability that need to be rectified in service provision and the world at large. I personally witnessed extreme oppression due to low expectations and negative perceptions of service providers and DSPs that limited daily opportunities of people with disabilities. I witnessed that people with disabilities were regarded as not capable of making choices and decisions in their lives, people with

disabilities were blatantly and subtly controlled in many ways by DSPs, DSPs were not prepared to address all of the ethically challenging issues that came up within support provision, DSPs were often forced to make decisions for people with disabilities without understanding how it limited the autonomy of the people that they supported, and institutional barriers prevented people with ID from accessing their rights. As a result of these experiences, I may have unreasonably negative opinions of support services.

Reflecting on my experiences, I am acutely aware that negative perceptions about the capabilities of people with disabilities and their value to the world affected the kind of support that I provided and the kinds of interactions that I had with the people that I supported. Those perceptions were in large part formed by the negative social perceptions held about people with intellectual disability and my lack of direct contact with people with disabilities themselves. When I was learning about the place of people in the world, people with disabilities were people that you didn't look at, that you felt sorry for, and that you provided charity for. They were not people that you invited to your house or hung out with on Saturday nights. I experienced a segregated schooling system that prevented many individuals with disabilities from even eating lunch at the same time. I saw them leaving as I was walking in. Though I did have contact with two people with disabilities, I felt that they reflected on me. Because I had negative perceptions about them, I thought others would have negative perceptions about me and it severely impacted the relationships that I had with them. When others joked about my *boyfriend* with ID, I was offended. I grew to have a strong curiosity about *those* people and have concluded that they should have never been *those* people in the first place, they should have been us. As an adult hoping to have a fulfilling lifelong career in this field, I remain

appalled at the conditions that people with disabilities are served in. I am sorry that my relationships with people with ID seem strained and at times artificial. I witness people with disabilities who are constantly held to normalized standards and whose daily lives are literally controlled so much that they are instructed how to sit properly… of all things!

There are many personal motives for conducting this research, the major one being rectifying my own past—escaping it by replacing it with something more admirable. In addition, however, I hope that by conducting this research I can generate information that will inform future planning initiatives for people with intellectual disability in such a way as to provide necessary support services, while allowing for a greater degree of autonomy by people with intellectual disability themselves. I hope that within my lifetime support services for people with disabilities become obsolete because people with disabilities will be our family members, friends, neighbors, co-works, and employers, not our jobs. I believe that the only way this will occur is if social perceptions about people with ID change and people in society begin to see people with disabilities as more like themselves than different. I further believe that starting within the current system and working towards this more idealistic vision is the only way that the U.S. will be able to change perceptions. Though I disagree with the current system of supports, at this time in history there is no viable alternative and working to correct this system and perceptions about people with disabilities will be a way to move towards better outcomes. I hope that this investigation will assist people to understand how autonomy can be supported within our current system, so that persons with intellectual disability can attain a degree of autonomy that allows them to work to change the system themselves in the ways that they see fit.

CHAPTER 2

Literature Review

For the purposes of this literature review, I reviewed literature that focused on many different variables related to autonomy. First I reviewed literature examining the role that self-determination and self-advocacy play in facilitating the autonomy of people with intellectual disability, and what issues are involved in these areas. Next I reviewed literature that investigated some of the components of self-determination and self-advocacy, such as choice and decision-making which also influence autonomy. I paid attention to these specific research articles because they reveal the opportunities that are provided to people with disabilities to be autonomous, and how their abilities and opportunities allow them to act in self-determined and self-advocating ways. They also illustrate interactions between people with disabilities and people without that support or deny autonomy. Next I reviewed literature pertaining to Direct Support Professionals (DSPs): the challenges that they face in their jobs, their perceptions of the people for whom they provide support, and institutional barriers that prevent DSPs from supporting the autonomy of people with disabilities. Finally, I reviewed literature that directly explored autonomy issues of people with disabilities. I then analyzed the findings of these studies in terms of barriers that prevent people with disabilities from acting in autonomous ways.

Inclusion Criteria

To find the studies included in this literature review, I searched through the relevant data bases with the search terms "disability", "mental retardation", "intellectual disability", "learning disability", and "developmental disability" in conjunction with the

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terms "autonomy", "self-determination", "self-advocacy", "choice-making", "decision-making", "control", and "power". To gather literature on DSPs, I used the terms "support staff", "direct support staff", and "caregivers" alone and in conjunction with the disability terms provided above. Searching through the term "autonomy" yielded few results applicable to the aims of this investigation. The most fruitful searches used the terms "self-advocacy", "self-determination", "choice-making", and "decision-making." Of the results that I acquired from using these terms, I skimmed the information, and kept only studies pertinent to this investigation. I also looked within the text and in the bibliographies of the research articles that I used for this literature review for other relevant reports. Lastly, I searched specifically for authors who had completed numerous studies within these areas.

I included articles that discussed either the perspectives of people with disabilities or the perspectives of DSPs regarding service provision. I included articles that discussed the capabilities of people with disabilities in the areas of self-determination and self-advocacy, as well as articles that discussed the opportunities to be autonomous. I included many articles because they investigated barriers to exercising autonomy and exercising other elements of autonomy (e.g. choice, self-determination, self-advocacy). I excluded articles if they did not directly address elements that promote the attainment of autonomy or barriers that prevent autonomy.

The Role of Self-Advocacy/Self-Determination in Facilitating Autonomy

Self-advocacy and self-determination are necessary components of autonomy for all people, though they are often specifically conceptualized for people with disabilities

within the disability literature. People first defined self-advocacy as "people with learning difficulties speaking up for ourselves" (People First, n.d.). According to Pennell (2001):

> self-advocacy focuses on the ability to stand up for oneself and to help other people with disabilities stand up for themselves by speaking up, speaking out, and speaking loud. It means having the opportunity to know your rights and responsibilities, to stand up for them, and to make choices about your own life…. it means taking risks and going after your own dreams. It means making mistakes and learning from them" (p. 223).

Another definition concluded that

> …A self advocate never ignores a wrong when the opportunity exists to correct it. Self-advocates are not afraid to reject conventional wisdom and advice when they know it is the wrong path. They are confident, take charge individuals….Self-advocacy allows all who choose it, to navigate life under their own terms (Turner, 2007, p. 70).

Self-advocacy, as defined above, means that individuals speak up about things that are important to them in an attempt to improve their lives and the lives of other people with disabilities. According to Goodley, Armstrong, Sutherland, and Laurie (2003), "self-advocacy is an important development in terms of the opportunities it offers for developing the confidence of individuals and groups to enable them to speak out for human rights and challenge oppression in a disabling society" (p. 149). Self-advocacy not only acts to support people with disabilities, by allowing them to speak up for themselves, but also works to change societal perceptions about people with disabilities.

Pennell (2001) defined self-determination as the social movement to shift power from institutions that support people with disabilities to people with disabilities themselves, including choosing how they live and how they are supported. Wehmeyer (2005) stated that "self-determined behavior refers to volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (p. 117). Kennedy (1996, in Sands & Wehmeyer) stated that "self-determination is what life is all about" (p. 91). I contend that self-determination plays a major role in most peoples' lives, even though people seldom realize the role that it plays. Most people that I know have at least rudimentary plans for their lives and consciously work to make their lives match their plans.

Nota, Ferrari, Soresi, and Wehmeyer (2007) conducted a study to determine the correlations between quality of life, social abilities, self-determination, and IQ. They found that people with the most severe intellectual disability had the lowest levels of self-determination, quality of life, and social abilities. They also found the converse to be true, that people with less significant disabilities were more self-determined, had a greater quality of life, and more social abilities. Hatton, Emerson, Robertson, Gregory, Kessissoglou, and Walsh (2004) conducted a study to assess opportunities for self-determination. They found that individuals who had more choice and ability and also fewer challenging behaviors. McDougall, Evans, and Baldwin (2010) conducted a study to determine the importance of self-determination for quality of life for personal development and personal fulfillment. They found that self-determination predicted perceived quality of life. In a meta-analysis of the literature on self-determination, Chambers, Wehmeyer, Saito, Lida, Youngsun, and Singh (2007) found that self-

determination led to positive desired outcomes in autonomy, correlated with higher

quality of life, and predicted positive outcomes in employment and independent living.

They also found that self-determination is affected by the places where people live and

that living in more restrictive placements led to fewer choices and lower self-

determination. Wehmeyer and Metzler (1995) found that people living in large

congregate settings were less likely to be self-determined, while people living

independently were the most self-determined. In summary, self-determination is affected

by the situations that people live in and has positive impacts on quality of life.

Chambers et al. (2007) suggested that factors like the opportunities for choice-

making are more important than functional ability or IQ scores. Wehmeyer and Garner

(2003) examined the self-determination and autonomy in people with intellectual

disability. They found that IQ scores had less importance than opportunities to make

choices. They found that the opportunities to make choice had positive effects on the self-

determination and autonomy of people with disabilities. They also found that people with

more severe disabilities tended to live in more restrictive settings and they suggested that

it is due to societal expectations rather than characteristics related to the person.

Stancliffe (2001) in a review of the research on choice and self-determination concluded

that all people have preferences and can demonstrate them no matter how severe their

disability and that though certain interventions may improve some self-determination

competencies, interventions may not be necessary to increase personal control of adults

with disabilities. Wehmeyer and Garner stated that IQ scores should not be the deciding

factor of whether or not to promote autonomy. This implies that all people can act in self-

determined ways.

All people can be self-determined, regardless of their level of ability. Ippoliti, Peppey, and Depoy (1994) in a review of the self-determination literature, found that even poorly educated oppressed groups of people could articulate sophisticated observations about their culture and lives, and that people with disabilities could articulate what high quality support services looked like. Ippoliti et al. concluded that people with intellectual disability understood their needs and wanted to have options in their support services. People with all different levels of disability can act in self-determined ways to support their needs, make choices, and make decisions. Certain factors, such as where they live, the level of their disability, and the kinds of interventions that they receive can contribute to their self-determination and thus facilitate autonomy.

Self-determination opportunities. Even when people with disabilities have voice, the interactions they have with DSPs may limit their choice opportunities. Finlay et al. (2008) conducted an ethnographic study of residential services, and found that staff members often spoke to people with disabilities in a way that countered any chance for them to exhibit choice and control in their lives. Finlay et al. (2008) suggested that DSPs overlooked little things that could support choice-making within daily interactions, such as choosing how much coffee to drink. Another barrier noted by the authors was that staff members were not sensitive to the communication needs of the clients that they served and often made choices more difficult to understand due to the way they presented them. To the DSPs in this study, being competent in their jobs focused on ensuring that they met certain objectives on the shift rather than supporting the choices and decisions of people with disabilities (i.e., making sure that the person lived in a clean home and ate all of their dinner). The DSPs in this study also supported the choices of family members

rather than the people that they directly supported. Lastly, the researchers discovered that the constant focus on teaching is an obstacle because it prevented DSPs from accepting people with disabilities as they were, and supporting the choices that they made in their current capacity.

Barriers affecting self-determination/self-advocacy in the facilitation of autonomy. Negative perceptions about the abilities of people with disabilities can affect the self-determination of these individuals. Karlsson and Nilholm (2006) in a Swedish study examining how self-determination is facilitated in support meetings for people with disabilities found that there were often situations in which DSPs and family members acted paternalistically toward the people receiving support. These situations occurred when the DSPs had difficulty interpreting the communication of the client, when the client's were unaware or hesitant to participate in the discussion, when DSPs were insincere in their attempts to elicit information from the people with disabilities, and when the clients had desires that were difficult to support. The authors stated that "voice rather than choice is often the means whereby services can be influenced" (p. 204). This seems frightening considering the communication difficulties that many people with ID experience.

There are often considerable problems in supporting self-advocacy, even when attempting to specifically promote self-advocacy. In an analysis of the discourse used in residents' meetings meant to promote self-advocacy, Antaki, Finlay, Sheridan, Jingree, and Walton (2006) found that DSPs routinely controlled the topics and flow of the conversation. Often the agenda had been established, a staff member lead the meetings, and the people with disabilities discussed predetermined topics rather than identifying

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what is important to them. Not only did the DSPs control the discussion in the residents'

meetings, they often used "directive guidance" to lead the conversation into the assigned

topics, shaped yes/no questions, ignored information irrelevant to the predetermined topic

being discussed, and lead the participants to specific answers to the questions posed.

They also hurried the residents through choices and ignored people who dissented to the

decisions posed. According to the authors, DSPs made light of potentially important

topics. Antaki et al. stated that DSPs actions in these meetings seemed to be more aligned

to the goals of the institution than the goals of the residents and that "although the

institution administrators might be able to point to the existence of residents' meetings as

an example of service-user empowerment, in practice the forum can become a further

tool in the disempowerment of the residents" (p. 341).

     Jingree, Finaly, and Antaki (2006) conducted research to examine the interactions

between people with disabilities and DSPs in meetings to discuss the quality of services

people with disabilities received. They found that even in residents' meetings meant to

provide people with disabilities a voice in their services, DSPs guided the discussion so

rigidly that it produced desired statements, rather than the actual concerns of the clients,

even to the point of reframing concerns as positive affirmations. The authors found that

DSPs often tried to control the meetings by ignoring communication attempts by people

with intellectual disability, leading people to certain choices, and controlling the

conversations. Further, they often ignored the statements made by people with disabilities

that indicated concerns or preferences. Jingree et al. also found that staff members

ignored statements of dissatisfaction, reframed negative statements as positive statements,

used yes/no questions, prompted individuals to produce affirmations of the service

philosophy, and hinted or provided clues for desired answers. They affirmed that the subtle exercising of this power impeded the autonomy of people with intellectual disability.

Antaki, Finlay, and Walton (2007) in an analysis of the discourse in residents' meetings in Great Britain found that DSPs coached people with disabilities about who they should consider friends. They discussed the identity development negotiations that occur between people with disabilities and DSPs, and the problems associated with DSPs applying limitations beyond the limitations related to their diagnosis within these meetings (i.e., assuming that people with disabilities are incapable of choosing who their friends are). They suggested that talk between DSPs and people with disabilities might restrict their lives more than necessary on the basis of their disability alone. The DSPs in this study also directed people with disabilities to talk about their relationship with support staff as opposed to other friend relationships. Antaki et al. suggested that in these interactions DSPs negotiated the identities of people with disabilities so that they had "defective social rights" (e.g. the right to decide who they considered friends). They implied that these kinds of interactions imposed a flawed identity on people with disabilities in an extremely subtle and pervasive way. They argued that in interactions such as this people with disabilities are treated "as not being able to form their own sense about who their friends are, and whose feelings (natural in anyone else) have to be explicitly coached" (p. 5), and that they had to consider DSPs as friends, regardless of the fact that it might be highly problematic. Antaki et al. argued that the service philosophies and what happened in actual practice often conflicted. Clearly the choices of people with disabilities are not the most important in these situations.

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Antaki et al. (2009) conducted a conversation analysis on the interactions between support staff and people with ID. They found that DSPs often offered choices that were not important to the individual, were not commensurate with a choice that would be offered to an adult, and were in the interests of the institution as opposed to the interests of the residents. DSPs used choices as a way to offer alternatives to a preference indicated by the people that they supported that they did not agree with. DSPs used choices as a means to solicit a certain answer, so that they could proceed with what they wanted to do with agreement from the person that they supported. In this study, DSPs also used choice in such a routine and familiar way that it allowed for only common choices to be made, and led to confusing explanations of what the choices entailed. The researchers concluded that the staff used choices as a means for the staff to set the agenda. This study is a good example of the in-authenticity of choices provided to people with ID.

The studies described above illustrate how some interactions in support services can actually diminish the autonomy of people with intellectual disability in particular ways. In summary, not providing choice opportunities, paternalistic attitudes, controlling the conversations, ignoring concerns, and prioritizing institutional philosophies over individual choices can all act to impede their autonomy. Zola (1982) listed some common reasons for people with intellectual disability to allow the status quo to remain the same. Among them are that people with disabilities aren't good at making decisions because they haven't had a lot of experience doing so, they think that things are getting better and that they'll just have to live with them as they are in the meantime, they feel that they are receiving the maximum amount of service, and they fear retaliation if they complain. Further, people with disabilities may be perceived as being ungrateful and unworthy of

services if they complain about the services that they get (Zola). These studies highlight the complexities in supporting self-determination.

The Role Choice and Decision-Making in the Facilitation of Autonomy

Choice and decision-making are vital components of self-determination, self-advocacy, and autonomy. I argue that living the life one desires necessarily includes deciding what that is, and making choices on a daily basis that support that ideal. Stancliffe (2001) defined choice as an active selection between two alternatives that is not forced or coerced. Bell et al. (2009) defined choice as "a decision-making process [sic. that] involves the expression of needs, desires, and preferences, as well as implies the ability to select among options" (p.19). Brown and Brown (2009) stated that the prerequisite for making a choice is an entitlement and right to make choices. They call choice "the outward manifestation of an individual's personal wishes and the life direction he or she wishes to take" (p.12). They discussed opportunities and choice-making as the two major components of choice-making. They further contended that opportunity had to do with the range of choices and the familiarity of options. Choice-making, they asserted, has to do with freedom, initiative, and skill. Guess, Benson, and Siegel-Causey (2008) determined that there are three categories of choice: choices to indicate preferences, choices as part of the decision-making process, and choices for autonomy. In conceptualizing the role that choice plays in autonomy Guess et al. (2008) stated that

> Each choice we make is an expression of our personal autonomy—our freedom to define who we are and what we value. The opportunity to make choices provides us with power to determine, to a great extent, what happens to us on a moment-

by-moment basis as well as over the span of our lives. To have the power to make

choices taken away would for many of us, be devastating if not unbearable. (p. 78)

This speaks volumes about the role that choice play in most of our lives.

Choice opportunities. The way that DSPs define choice for the individuals that

they support has profound effects on the kinds of support that they then provide. Wareing

and Newell (2002) studied the concept of choice within Australian support services using

membership category analysis to analyze the way that DSPs discussed choice. They

found that the DSPs constructed choice for people with disabilities in a limited and

repressive way. The DSPs constructed choice as what happens when there has been no

support, no information, and no choice assistance provided (e.g.., sitting in the same spot

for an extended period of time was constructed as a choice because the person had not

moved). This study demonstrates the need for support for choices, as well as pointing out

how problematic choices can be without proper supports. It also demonstrates how

inauthentic choices are constructed.

The types of choices and decisions that people with disabilities are *allowed* to

make can be revealing. Lakin, Dolijanc, Byun, Stancliffe, Taub, and Chiri (2008)

conducted a study using the National Core Indicators to determine the level of choice

experienced by people living in community based settings and Intermediate Care

Facilities for the Mentally Retarded (ICFMR). They found that people living in settings

with greater numbers of residents made fewer daily choices. They also found that people

who had more severe disabilities made fewer daily choices. Lakin et al. found that people

with milder disabilities had more choice in support related matters. All individuals

involved in the study had fewer opportunities to make choices about the kind of support

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that they received (how they wanted to be assisted) than daily choices (what to eat, what to wear, etc.). About a fifth of the people surveyed had other people set their daily schedules. Only about a half of the participants had choices about where they lived. This information sheds light on the painful truth that people with disabilities have very few opportunities to make choices, especially people with more significant disabilities. It also demonstrates that people with disabilities have very little input into the support that they receive, even though they ought to have a directing role.

Smith, Morgan, and Davidson (2005) stated that all people have less control over major life decisions such as where to live and what job to have than they do over daily choices. They advocated that most people should have absolute control over daily choices. They conducted a study to determine whether the normalization principle could be applied to the choices that people with disabilities living in Australia made. They found that choice availability corresponded to disability level rather than age. They also found that choice availability is lower for people with more severe disabilities.

I argue that it is necessary for people with ID to make choices and to have experiences that provide for making choices. Guess et al. stressed that especially for people with severe disabilities, every opportunity to make choices needs to be utilized, and these individuals need to have contingent experiences, where they get to control the situation. This provides opportunities to acquire skills in choice-making. Based on a review of the choice literature, Bannerman et al. (1990) concluded that having the ability to make choices increased participation in activities where choices were provided, resulted in better performance, and decreased problematic behaviors. They further found that people prefer situations where they have choices. Due to these findings, the authors

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recommended providing services that more appropriately balance service constraints with choice-making. They advised that choice-making training be a requirement for DSPs.

Owen et al. (2003) stated that people with disabilities are often prevented from making the choices that the rest of society takes for granted because DSPs do not perceive that these individuals are capable of making their own choices. Guess et al. (2008) discussed some of the barriers to providing choices to people with intellectual disability. They stated that often providers are focused on the "worst case scenario", that when people with disabilities are allowed to make choices, they will make the worst possible choices. Guess et al. also stated that often people with disabilities are overprotected and prevented from having valuable life experiences that might contribute to their ability to make choices or understand and options and outcomes. Sobsey (1994) stated that people with disabilities may not know about their rights, not because of their disability, but because they have not had the actual experiences to learn about them. I contend that people with ID are also at a disadvantage because of the inauthentic way that choice is constructed for them.

Real and perceived choice abilities. In a study by Bigby, Clement, Mansell, and Beadle-Brown (2009), the authors stated that provider agencies now invest large amounts of money in funding a value system for their employees. The researchers observed service providers in Australia, and followed up with group discussion. They found that DSPs expressed that it is unrealistic to support people with significant disabilities to make choices. They also expressed that the people that they supported were too different to support their choices. The DSPs articulated that they did not see the importance in offering choices to people with significant disabilities and that they knew what choices

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the person would make anyway. In this study, the DSPs provided narrow choice opportunities and often referred to the people with significant disabilities as childlike. The DSPs sometimes did not provide choices because of their concern about how it would reflect on them. This study is another example of how perceptions inform the choice opportunities of people with ID.

Robertson, Emerson, Hatton, Gregory, Kessissoglou, and Hallam (2001) conducted a study on self-determination using questionnaires and interviews, and found that in the more significant decisions (e.g., where to live, who to live with, reviewing staff performance, firing unsuitable staff) DSPs rated people with disabilities as being primarily unable to decide. For most components of leisure and relationships (especially involvement with intimate partners) DSPs reported that people with disabilities decided for themselves, but did not have the final say, especially if it posed a safety risk. In most areas covered in the questionnaire (major home decisions, staffing, employment, daily activities, personal appearance, leisure, relationships, household appearance and possessions, meals, and household routines), people with disabilities had few opportunities to exercise self-determination. This study highlights how negative perceptions can be an obstacle to choice-making. If people are perceived as incapable of making decisions, they will not be provided with choices.

In a review of the literature on choice assessment of people with severe disabilities, Cannella, O'Reilly, and Lancioni (2005) found that choice-making by this group of people led to better behavioral outcomes, and the effectiveness of using various strategies in assessing choice, even with individuals with severe disabilities. They found that increasing choice interventions led to decreased inappropriate behavior and increased

positive behavior. It should not be surprising that when people have more autonomy and control in their lives, they may be more satisfied and have less need to resort to negative behavior. Lancioni, O'Reilly, and Emerson (1996) in a review of the literature about choice-making in people with severe disabilities, found that people with severe disabilities could make purposeful choices. The authors also stated that providing choice opportunities for people with severe disabilities may have other potentially positive benefits such as increased attention and social acceptance from DSPs. As such, increased social acceptance from DSPs may result in increased choice opportunities as DSPs perceive people with disabilities as being capable. This study points to the fact that and people are capable of making choices and that when choice opportunities are increased people with significant disabilities can be successful. In summary first people with ID need to be seen as capable of making choices, then choice opportunities may increase leading to better outcomes.

Choice problems. Bannerman et al. (1990), in a review of the choice-making literature, discussed many problems with choice opportunities for individuals with intellectual disability. One issue they listed is inappropriate goals on support plans because input is not gathered from the person for whom the support plan was developed. Another issue they discussed is that DSPs did not gain input from people with ID about how they wanted to learn something. Another area where staff exerted control over personal liberties is through the lack of choice-making training provided to the persons that they supported—moreover, many staff reported that choice-making was something that they "allowed" the person to do. Further, the author pointed out that often DSPs did not even present the choices and that many people with disabilities were required to

follow inflexible schedules. Martin, Woods, Sylvester, and Gardner (2005) conducted a study where they reviewed the vocational choices that DSPs made and the vocational choices that people with cognitive disabilities made for the people with cognitive disabilities. They found that the choices indicated by the participants with disabilities and the choices indicated by support staff were often different. Pilnicek, Clegg, Murphy, and Almack (2010) conducted a study where they observed transition meetings in England to look at the interactions in choice contexts. They found that in the interactions the decisions that people with disabilities made were often considered inadequate. They stressed that it would be difficult for people to support people with disabilities to make choices when their choices are sometimes unrealistic or impossible to support. These studies reveal the control that DSPs exert over people with ID and how inadequate their decisions on behalf of people with disabilities may be. They also demonstrate how difficult it can be to support choices.

DSPs are crucial to the choice and decision-making abilities and opportunities of people with disabilities who receive support. Kjellberg (2002) conducted interviews with people with disabilities in Sweden to determine their perceptions about what facilitated or prevented them from making decisions. Kjellberg found that perceptions of DSPs about the decisions made, legislation supporting choice for people with disabilities, types of activities, changes in activities, and access to education could both support and prevent people with disabilities from making decisions. The author also found that control over finances supported people to make decisions, while lack of control in this area prevented them from making decisions. Kjellberg found that people living in their own apartments, having their own personal items, having developed routines, and regular meetings all

worked to support their opportunities to make decisions. They found that not getting to choose where to live and not having continuity of support staff prevented these individuals from making decisions. DSPs play a vital role in whether or not people with disabilities make choices and decisions. Therefore, it is important that they act in ways most likely to support the autonomy of people with disabilities.

The Role of Provider Agencies in the Facilitation of Autonomy

Support providers or provider agencies are the institutions and agencies that hire DSPs to support people with disabilities. These providers have great influence over the choice-making opportunities of the people with disabilities whom they serve. They are in charge of defining the role of DSPs and meeting federal and state mandates for the people that are served by the provider agency. They are also responsible for instituting agency, state-wide, or federal goals for the people they support, such as autonomy. There are many issues that might affect people with disabilities at the provider or agency level, most notably because problems at the agency level may influence how DSPs provide support to people with disabilities.

Provider agency problems. In a study by Gardner and Carran (2005) that reviewed interviews from accreditation procedures, the authors found that certain decisions (i.e., where to live, roommate selection, where to work, and interacting with community members) presented difficulty for one agency to control, because often multiple providers worked together to support different needs of individual clients. These provider agencies are very strictly regulated. Gaventa (2008) in reviewing regulations for service provision, literature on compliance and person centered planning, and reviewing his personal experience in service provision, suggested that attempts to fix the system by

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imposing regulations often make it so that services are more impersonal. He further

suggested that support systems are founded on fear of liability, disciplinary actions,

negative publicity, mistakes, and ultimately a fear of loss of money, instead of positive

improvements in the lives of people with disabilities. "Herein lies the paradox: In order to

meet the regulations, a setting or a home must become more impersonal, hierarchical, and

bureaucratic, and these are some of the features that made institutions dehumanizing and

abusive in the first place" (Taylor, 1992, as cited in Gaventa). One study reviewed by

Gaventa found that a woman with a disability had more than 500 DSPs while she was

supported in just one agency (Demar, 2005). Systems so stringently based on regulations

and running in constant fear of reprimand can be harmful to people with disabilities,

especially because those concerns may be relayed to DSPs and impact their direct support.

Finlay et al. (2008) discussed many of the issues that encroach on the autonomy

of people with disabilities. One of the barriers discussed is conflicting agendas between

supporting choice for people with disabilities and institutional practices. Another issue

listed is inspection regimes (scheduled inspection routines) that caused DSPs to overlook

needs of individuals with disabilities in order to be competent employees. An example of

this is when a DSP would force individuals into regimes such as cleaning or eating in

ways inconsistent with the individual's choice because DSPs worried about the

ramifications of inspection by the institution. It also meant preventing people from

participating in their lives as fully as they would like. The authors further suggested that

inspections encouraged staff members to adopt defensive practices thought to be in the

best interest of the clients, even though they did not allow for personal expression or

understanding of human rights. These examples illustrate the lack of power that DSPs

have, even though they face complex ethical challenges on a daily basis. Just as people

with disabilities lack ability to make choices, providers and agencies limit the autonomy

of DSPs to manage their work situation. Though regulations are necessary to prevent

abuses, they also act to limit autonomy. These examples also highlight how institutional

goals are given greater importance than goals of people with ID.

Levinson (2010) completed a study to determine what work is done in group

homes. He found that in the group home staff often used "psychological knowledge"

wherein they regard everything that occurs within the daily lives of people with ID as

clinical matters and govern people with ID as such. In doing this they also were also

constantly monitoring and diagnosing the interactions that they had with people with ID.

Levinson found that both people with ID and DSPs work in a group home. He found that

work was never-ending for DSPs, that they constantly had to intervene in the problems of

the people they supported, and that they had to constantly use surveillance to manage the

group home. He stated that there was a conflict between limited resources and unlimited

work. Levinson characterized this as "the climate of accountability" being at odds with

the providing care and that there was a conflict between "professional ideals and

organizational demands" (p. 93). In this study DSPs had limited authority, and used plans

inappropriately to control the people that they supported. These examples highlight how

the practice of providing support within an agency can be difficult, and how DSPs

enforce undue control over people with ID.

Batavia (2002) called for support service choices that maximize the autonomy of

people with disabilities by allowing them to control the kinds of services that they receive

and the hiring their own DSPs. He further stipulated that in other countries this has been

done effectively and without abuse to the system. Under the current system of supports in the U.S. there is little opportunity for people with disabilities to manage their own programs of support and to therefore be provided with more effective services. Zola (1982) was correct when he stated that "society has created many avenues for some people to determine what other people need, but few channels for those in need to easily ask for what they need" (p. 229). Attempts are being made to allow individuals with disabilities to have more autonomy over the services that they are provided. For example, in this state the self-directed waiver allows people with disabilities flexibility in the kinds of services that they receive; however, the overwhelming majority of people with disabilities in the state are served on the existing Developmental Disabilities or DD Waiver. It is my contention that when people with ID have more decisions over the kinds of support that they receive, their goals will be supported and they will obtain a higher degree of autonomy.

The Role of Direct Support Professionals in the Facilitation of Autonomy

DSPs may be in the greatest position to restrict autonomy, as Kittay stated:

The person in need of care is in their [DSP's] power with respect to intimate details of

life… This is an imposition and intrusion which can be oppressive and, when it turns the disabled person into a supplicant, is experienced as being at odds with dignity. (p. 50).

They may also be in the greatest position to support and promote autonomy (Grimby, 2002) for precisely because of the intimacy noted by Kittay. DSPs have an important role in how people with disabilities experience autonomy. It is important to know who DSPs

are because they are often blamed when things go wrong, though they have limited

control, and are often put into situations for which no amount of training could prepare

them. Providing support to people with intellectual disability can be a very difficult and

ethically challenging job, especially when confronting negative assumptions about the

abilities of people with intellectual disability and dealing with how those reflect on DSPs.

According to the Direct Service Workforce Resource Center (Hewitt et al., 2008) most

people who work as DSPs are over the age of 35 and the overwhelming majority of them

are female. They are among the lowest paid workers in the health industry. They also

spend the most time with people with disabilities, and have the greatest potential to

support people with disabilities to be autonomous, or to prevent people with disabilities

from acting autonomously (Grimby, 2002).

DSP competencies The Community Support Skill Standards (Hewitt et al., 2008)

identified competencies for DSPs. According to these competencies DSPs have multiple

responsibilities in supporting people with intellectual disability to make choices, self-

advocate, and promote empowerment. These competencies state that DSPs are

responsible for not only understanding the rights of people with intellectual disability, but

providing information that enables them to understand and access their rights, as well as

helping them overcome barriers to their rights. DSPs are also required, according to these

standards, to act as advocates for people with disabilities when they are not able to act as

self-advocates. They are called upon to be aware of how their own values affect their

practice of supporting people with disabilities to recognize and access their rights.

There also is a code of ethics for Direct Support Professionals developed by the

National Alliance of Direct Support Professionals (NADSP) that can guide DSPs to

become competent employees. The NADSP Code of Ethics strongly emphasizes the need for DSPs to empower people with disabilities, and calls for person-centered planning as best practice. Additionally, it encourages DSPs to challenge professionals to respect the rights of individuals with disabilities, and to teach others to respect the human rights of all people. Providing support is evidently a complicated profession. DSPs are not only responsible for carrying out the immediate duties of their jobs, but also for educating the entire rest of the population about people with disabilities. I posit that the responsibilities in support provision can be overbearing, and DSPs often lack the training to be able to effectively carry out their jobs. They could perhaps never have enough training to do their jobs effectively, but the little that they do get leaves them grossly unprepared to fulfill such intricate duties. Also because they have so little power themselves, it seems unlikely that they would be able to engage in such broad undertakings.

DSP relationships. The relationship between DSPs and people with intellectual disability is an important one for both groups. DSPs need people with disabilities to earn a living, and people with disabilities often need the support provided by DSPs to enable them to exercise their autonomy. Clarkson, Murphy, Coldwell, and Dawson, (2009) conducted a study in the UK to determine how people with intellectual disability regarded their DSPs. They found that people with disabilities had mixed perceptions about their DSPs but that they appreciated consistent support staff with whom they could form relationships based on honesty, trust, and caring. The people with disabilities expressed that they felt protected by their DSPs, and that immature or inexperienced DSPs made them feel frustrated and vulnerable. In this study people with disabilities also reported that they felt that some of the older DSPs were unmotivated. The authors

implied that this may have been because of staff burnout and low job satisfaction. People

with disabilities seem to have positive feelings toward DSPs, and these feelings could

lead to increased autonomy when DSPs are better equipped to provide support that

maximizes autonomy. Alternately, Hastings and Horne (2004) conducted a study to

determine the perceptions of DSPs about the people that they supported in the UK. In

their attempt to pilot a questionnaire involving positive associations of working with

people with disabilities, they found that on the overwhelming majority of questions most

DSPs agreed that a positive statement applied to them. These finding indicate that DSPs

also enjoy the relationships that they have in supporting people with disabilities.

Problems Affecting Direct Support Professionals Performance in Facilitating

Autonomy

There are multiple issues that affect DSPs' ability to promote self-determination

and autonomy in residential supports. Some of the problems are involved in the way that

they provide support services in the day to day services. It can be difficult to define what

their role in supporting people with disabilities actually is. They may lack adequate

training to be able to support people with disabilities. There are multiple issues in

retention and recruitment of DSPs. They may experience negative personal effects as a

result of providing support. Finally, there are immense ethical issues in supporting people

with disabilities that are not accounted for in training and that are difficult to mitigate on

a day to day basis.

Problems in day to day services. Borbasi, Bottroff, Williams, Jones, and

Douglas (2008) interviewed individuals with disabilities, DSPs, and family members in

Australia to learn about how support services assisted individuals with disabilities after a

move away from institutionalization. In this study DSPs expressed concerns about the number of staff members coming in and out of the house to work without regard for the fact that people lived there, making it more of a workplace than a home. They stated that often staff had more power because of their sheer number when they outnumbered clients. The DSPs also expressed fears about allowing people to experience autonomy while preventing abuse. Further many of the DSPs had actually worked in institutions and maintained beliefs about how they should provide support consistent with impersonal institutional practices. DSPs stated that when new staff began they had to be taught that they worked in a home, not an institution. DSPs also discussed the tension between allowing for dignity of risk and protecting the individual from abuse. A family member expressed concern that the DSPs did everything for the individuals with disabilities and did not let them live their own lives. Clearly it is difficult to determine when people need support, when they don't, and how to provide support in a manner that maximizes autonomy. Borbasi et al. suggested that training for DSPs may be the answer.

Training DSPs for supporting autonomy. Walker (2004) stated that the traditional training model for DSPs teaches them to manage people with disabilities rather than act to liberate them, and that training is not often a priority for DSPs. Test, Flowers, Hewitt, and Solow (2004) conducted a study on the training needs of DSPs using surveys and focus groups. They determined that staff burnout is often related to a lack of training. They cautioned the ability of unprepared DSPs to support people with disabilities to be self-determined. They stated that most providers only focused on mandatory training, and did not take initiative to provide additional training that might be beneficial for people with disabilities (such as training that facilitates autonomy). Test et

al. found that DSPs in their study actually wanted additional training. More than half of the respondents wanted additional training in client empowerment, supporting informed decision-making, helping clients to provide more input into service design, providing opportunities for self-advocacy, and providing support to clients about human and civil rights. More than 75% wanted additional training on educating and training clients for self-development and nearly as many wanted support to educate clients and community members about current issues in the disability field. It is clear that DSPs want more training than they are getting in these areas. Additional training would perhaps help them maneuver some of the more challenging aspects of their profession.

The training provided to DSPs has an effect on outcomes for the people with disabilities served by the DSPs. Owen et.al. (2003), in a study to determine the effectiveness of training DSPs on human rights, found that when DSPs received training on human rights, they identified human rights violations better. Salmento and Bambara (2000) examined how effective choice training is for DSPs and found that by explicitly training staff to provide choices to adults with profound mental retardation, they provided more choices to these adults and the individuals themselves made more choices. Wong and Wong (2008) conducted a study to determine whether residential staff in Hong Kong could learn skills to support self-determination of people with disabilities. They found that the group that had gone through the training program better supported self-determination than the group that had not gone through the training program. The training program that they used had DSPs working to adjust their own negative perceptions about the self-determination of people with disabilities and adjust practices that prevented self-determination. Chambers et al. (2007) in a literature review of self-determination found

that many of the researchers who attempted to implement interventions for self-determination experienced success in doing so. There may be no amount of training that can prepare DSPs for some of the complex situations that they face, but training may have positive implications for people with disabilities when its focus is to improve the autonomy of people with disabilities.

Recruitment and retention of DSPs. In conjunction with the lack of training necessary to facilitate support that maximizes autonomy, Hewitt and Lakin (2001) characterized the current state of direct support as a crisis. Persons providing direct support often experience many problems outside of the dilemmas that they may face in providing direct care. Perhaps these problems contribute to the kind of support that they provide.

Hewitt and Larson (2007) stated that DSPs do much more than just provide support to people with intellectual disability; often they are responsible for integrating people with disabilities into the community as well. They stated that one of the problems with recruitment of DSPs is that many people are not even aware that such jobs exist. Hewitt and Larson suggest that turnover rate of DSPs can have monumental effects as the costs of providing training to replace DSPs may average about two thousand dollars. Further they state that the turnover rate is as high as 52%. This creates costs in excess of seven million dollars every year to replace DSPs who have left the job (Hewitt & Larson). According to Hewitt and Larson DSPs also have a very limited career path, with little opportunity for advancement. They also implied that training provided to DSPs is outdated and is based on training models used in the institutions. They suggested that many DSPs work overtime to account for the vacancies within their organizations, and

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the overtime often leads to burnout, job dissatisfaction, poor performance, and increased

abuse and neglect of the persons they support. Hewitt and Larson also suggested that

turnover rates led to problems for people with disabilities. They stated that turnover

hinders the development of trusting relationships between DSPs and people with

disabilities, hinders the development of new support techniques based on long-term

understanding of the needs of people with disabilities, and hinders continuity of care.

Larson et al. (1999) conducted a study on provider agencies to determine what

issues they experienced with staff recruitment. They found that most agencies had trouble

finding qualified applicants to fill positions. They also found that vacancy rates averaged

at 6% for DSPs and 4% for their direct supervisors. They estimated that it cost the state of

Minnesota in excess of six million dollars annually to pay for advertising and to cover

overtime incurred by DSPs to fill vacancies. Larson and Lakin (1999) conducted a

longitudinal study to determine what factors led to staff turnover rates. They found that

higher staff turnover rates correlated with lower pay, high resident to staff ratio, location,

length of time the home existed, low unemployment rates within the community, length

of time that direct supervisor of the DSPs had been employed, age of staff members, less

experience, supporting people who had low adaptive behavior skills, and supporting

people who had higher IQ scores. They reported that for the agencies surveyed,

recruitment is more problematic than staff turnover rates.

High turnover rates and recruitment issues do not only affect providers. Test,

Flowers, Hewitt, and Solow (2003a) in a statewide survey of the direct support workforce

in conjunction with focus groups, found that harm resulted to people with disabilities as a

result of the difficulties in recruitment. New DSPs were often uncomfortable working

with people with disabilities, qualified applicants did not apply because of the low salary, and many support staff left DSP positions to get more money. They also found that DSPs and administrative staff expressed that turnover harmed people with disabilities. People with disabilities indicated that turnover led to sadness, different expectations, disrupted routines, wasted time in developing relationships, self blame, uncomfortable and nervous feelings, and hurt feelings. Further they often had no warning that DSPs would no longer be supporting them. In their study they found that DSPs provided support to up to 17 different individuals at one time and that classifying their jobs would be complicated because of the many various duties that they had. Problems in support provision are not unique to DSPs. Hewitt, Larson, Lakin, Sauer, O'nell and Sedlezky (2004) conducted a study with frontline supervisors of DSPs and found that they also experienced numerous problems within their professions. They experienced inadequate training, lack of contact with DSPs they supervised and, turnover rate of DSPs. These problems are rampant through providers and agencies, and ultimately affect the kind of services that people with disabilities receive.

According to the National Direct Service Workforce Resource Center (Hewitt et al., 2008) people who provide services to people with intellectual disability often experience some of the stigma that people with disabilities experience. They stated that "together, relatively low wages and benefits, minimal training, the absence of status, clear role definition, and career pathways often create the sense that DSW [direct support work] positions are low skill, dead end jobs" (p. 9). They suggested that much of the recognition that DSPs get is in the form of vilification, where they are portrayed to be abusive. This is often done in the media where DSPs are only brought up when something goes wrong.

DSPs not only have to endure this vilification, but also have to engage in challenging situations that may pose risks to them.

Risks to DSPs. Daynes, Wills, and Baker (2011), in a study investigating aggression towards DSPs, found out that about a third of DSPs had experienced some degree of aggression by the people that they worked with. They found that often these situations could have been avoided. They also found that nearly a third changed their interactions with people with disabilities to control the reactions of the people that they supported. Respondents did not see this as a reason to quit their jobs, but demonstrated commitment and wanted to learn how to deal with the behaviors so that they could do their jobs. This would obviously present risks to DSPs

Gray-Stanley, Muramatsu, Heller, Hughes, Johnson, and Ramirez-Valles (2011) conducted a study where they measured stress and depression in DSPs. They found depression was more likely to occur when workers experienced more stress in their jobs. They found that heavy workloads, lack of decision-making capacity, client disabilities, and client care contributed to the stress. They found that heavy workloads related to administrative issues. Leyin and Wakerly (2007) studied work stress in DSPs. They found that although about two thirds reported high job satisfaction, a third of DSPs reported experiencing stress from their jobs that affected their lives outside of work. They also found that the staff with the most frequent contact with DSPs provided the most support to them, and that people with ID rated experiences with agency employees who held positions higher than the line manager, negative about a third of the time. On top of the extensive list of problems that DSPs experience (or perhaps because of it) they also have their own mental health to contend with.

Ethical issues in supporting people with disabilities. Wilson, Clegg, and Hardy (2008) discussed many ethical and human rights issues that come up in providing daily care to people with intellectual disability. Some of the issues they encountered in their research are about the acceptability of giving psychotropic drugs to someone who is phobic of medication, the appropriateness of purchasing a sex toy for a person who masturbates in public, the appropriateness of using mobility aids in different ways than intended for, and so forth. In their study, though the DSPs worked under specific guidelines, they articulated that these guidelines neglected the human aspect and often led to punitive services. The participants expressed that guidelines were too loose to provide direction in any given situation. The participants cited the discrepancies between laws and the realities of service provision and the divergence in perception of DSPs and the community (especially in terms of specific issues, like sexuality). The DSPs expressed concern that if they did not exert control over the lives of people with disabilities, they would be seen as being irresponsible. Wilson et al. suggested that DSPs often acted more accountable to parents, the agency, the public, and legal ramifications than to the people with intellectual disability. All of the participants experienced anxiety and extreme vulnerability in providing ethically challenging services. The participants also experienced an extreme duty to act as advocates for the people that they supported and experienced distress when they were not able to. Even after the ethical situations had been resolved some of the participants continued to experience discomfort about the issue. Some of the participants also took on the feelings of the people that they supported, so that they experienced difficulty in supporting people in despair, and more difficulty in realizing that the despair did not end when their shift did. They also expressed that the

workplace did not support discussing the difficult emotions that they frequently

experienced in performing their jobs. Finally, in this study DSPs often expressed

powerlessness to make positive changes in the lives of people with disabilities. For these

reasons, working as a DSP can be regarded as a very difficult undertaking, one that

requires substantial skills and knowledge about people with disabilities.

According to Walker (2004) one of the major barriers in ensuring that human

rights are being met within service provision are the perceptions held by staff. Despite all

of the issues that they face… "at the same time it tends to deny the equally important fact

that what men do in the face of even the most constraining social conditions is indeed

something that they choose to do" (Abrams, 1982, in Oliver, 1990, p. 38). Though DSPs

may have difficult jobs, ultimately (most often) they are the ones who have the greatest

ability to support autonomy in people with ID. It is necessary that they become aware of

how their perceptions and actions influence the support that they provide in the

expression of autonomy.

Autonomy

The struggle for autonomy is significant for people with intellectual disability

who receive support in their daily lives. Part of the reason for this significance is related

to the social perceptions about people with disabilities. It is also linked to the

opportunities that people with disabilities have to make choices and decisions, to act in a

self-determined manner, and to act autonomously. It is imperative to look at what people

with disabilities value within their lives. In Swedish a study conducted by Wadensten and

Ahlstrom (2009a) the authors interviewed clients who received services in their homes.

They found that it was important for the people served to maintain dignity in personal

relationships, to have privacy, to communicate the support provided to them, to enjoy the parts of their lives they had control over, to get information about their disability and their rights, and to use their personal characteristics to deal with problems. The participants in this study stated that their personal assistants threatened their integrity, but stated that they appreciated the assistants' ability to assist them to become autonomous.

In another study, Wadensten and Ahlstrom (2009b) conducted interviews with adults with disabilities living in Sweden who received support services. Participants in this study brought up many issues that they experienced within the provision of care. The participants talked about how they had no privacy, the people supporting them tried to control them, and they recognized the necessity of working with compatible people. They further expressed feeling secure because of their support staff and being able to maintain some control over their lives because they received support. For people with disabilities DSPs can be both a barrier and a vehicle to assert their autonomy.

Barriers to autonomy. The relationship between DSPs and people with disabilities can be a troubling one. The autonomy of people with ID sometimes depends on that relationship. Barron (2001) conducted a study in Sweden to determine the impact that legislation for autonomy had on the exercise autonomy of people with disabilities. She found that DSPs refused to assist clients when they did not approve of their actions. Clients talked about what they were "allowed" to do, instead of what they would or wanted to do. Barron stated that support services acted to impede autonomy. This can be the case in support services where, as discussed above, DSPs have very complex, ethically challenging jobs and cannot figure out how to support the autonomy of people with disabilities when they are constrained by regimes of provider agencies.

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McConkey, Sowney, Milligan, and Barr (2004) conducted a study to determine how people with intellectual disabilities living in Ireland felt about their varying residential placements. Most of the participants expressed happiness with their current living situations (though the author cautioned that they may be withholding information due to fear about expressing criticism). The participants stated that they often had disagreements with roommates. People living with many roommates and family members expressed that they felt restricted. Participants recognized that they had less independence in placements with a greater number of residents. These findings indicate that people with disabilities prefer the least restrictive settings to support their autonomy. Wiltz (2007) suggested that an area where self-determination rarely comes into play is in roommate selection, even though it is very common for people with disabilities to have roommates. He listed some barriers for supporting autonomy in roommate selection such as waiting lists for residential services and scarcity of information regarding roommate compatibility and relationships. In addition to choosing services, people with disabilities should be supported in their autonomy to choose roommates and residential placements.

In a study conducted by Bond and Hurst (2010) about the perceptions that people with ID had about living independently, the authors directly interviewed adults with disabilities. They found that people preferred living independently to living in residential centers, even though they expressed the difficulty and loneliness of doing so. People with disabilities expressed that they didn't have control over who supported them or when they came. Even though they lived independently they still expressed discontent about the amount of control in their lives by others. They also spoke of positive experiences that they had in choosing whether or not to take advice. The participants spoke of feeling

vulnerable. They talked about health issues and the difficulty in managing them. The participants also talked anxiously about losing the freedoms that they currently experienced if they did not do things right. In summary though DSPs have difficulty determining how to support people with ID, people with ID have difficulty being supported without losing additional freedoms.

Petry, Maes, and Vlaskamp (2007) conducted a study using proxies and questionnaires to determine the perceptions of DSPs and family members of how to support the quality of life of people with intellectual and multiple disabilities. They found the physical environment, staffing ratio, group composition, staff turnover, and group size to be important structural factors in supporting quality of life or people with disabilities. They found partnership between people with ID and their families, teamwork, and support planning to be organizational factors in supporting quality of life. They further found that experience with people with ID, sensitivity to communication, physical strength, knowledge and skills, commitment and motivation, and self-reflection were DSP characteristics that supported quality of life. This study provides a glimpse of some of the perceptions that DSPs hold about how to properly support people with ID.

Dunn et al. (2010) conducted a study in England on substitute decision-making for people with ID with interviews and observations. They found that DSPs used their own lives as a guide to make decisions for people with disabilities and contemplated what they would do in different situations that the people that they supported experienced. This kind of thinking enabled them to expand the opportunities that they provided to the people with disabilities. They also expressed that the people that they supported lacked the ability to make spontaneous decisions and that the regimented planning involved in

their lives limited their opportunities for ordinary experiences. The DSPs also stated that person centered planning limited opportunities because people with disabilities' lives cannot be summed up in a matter of pages, and basing all decisions on what is included in the plan restricts the kinds of opportunities that people with disabilities have. The DSPs spoke about taking risks and doing things spontaneously with the clients that constituted living a ordinary life. The DSPs wanted to support the people with ID to have extraordinary experiences, and to socialize with others, even if only just their roommates. The authors did not find that the DSPs considered the experiences in terms of what the people with disabilities wanted, but rather what the DSPs saw as a fulfilling life, and often provided opportunities that the people with disabilities could not or would not experience in the same way. Though they expanded the opportunities of people with disabilities because they related their experiences to the lives that the DSPs led, they also restricted their experiences by not determining what the people themselves really wanted. I surmise that it is complex to determine what other people want, especially then they are unable to express it easily (either due to lack of skills or lack of power). When people are faced with such situations it seems reasonable that they would resort to considering their own lives and experiences. The decision-making aspect is just another area where the complexities of supporting another person come to light. Even so decisions should reflect what people with disabilities want rather than what seems normal to the people that support them.

Schelly (2008) wrote an ethnographic reflection of his experiences as a DSP and discussed the complexities of his position supporting people with ID. He stated that his client's social elevation would lower his (as a DSP). He further stated "my unconscious

fear is that SW [client] really can become normal (or is normal!), make unnecessary my position of authority over him (p. 722). Schelly talked frankly about the concerns that he experienced in trying to support the person that he supported to lead a normal life, and how difficult it is to support choices when people with disabilities have limited understanding of so many of the components of making a choice. He questioned whether forcing social inclusion, a full schedule, and discouraging cussing and drinking actually supported him to lead a normal life. These seem to be institutional goals forced on people with ID. In regard to the presumed lack of ability to make decisions that Schelly believed the person that he supported had, he said that it "makes me feel like I am engineering a life for him" (p. 725). He stated that it is necessary to influence his client's decisions so that he could contribute to their happiness. He stated that his client's dependency actually led to a higher quality of life. Schelly highlights some of the subtle ways that DSPs have overbearing effects on the autonomy of people with disabilities and some of the complexities of the job.

Healy, McGuire, Evans, and Carley (2009) conducted a study to understand the experiences, understanding, and sexual choices of people with ID. They found that the service providers influenced people with ID, both in the kinds of choices that they would make and what they believed they were allowed to do. In this study people with disabilities sometimes did not share information about their choices with support staff out of fear that they would prevent them from getting what they wanted. People with disabilities expressed concerns that support staff prevented them from having relationships and that support staff treated them unfairly, in that they did not allow them to make choices that others could make about their sexuality. This study draws light to

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the complexity of the relationship and the difficulty that people with ID experience in trying to have their choices supported. Sexuality choices can pose risks that may be extremely difficult for DSPs to support, especially when they are supposed to protect people with ID. Because people with ID participated in this study it offers a good contrast to the studies that included DSP problems with supporting choice. Though DSPs may find it difficult to support choice, people with ID may find it difficult to have their choices supported.

A study conducted by Bernert (2011) involved directly talking to women with ID about their sexual autonomy. Bernert found that the women primarily associated with people supported by the same agency, often were only involved in solitary activities due to inadequate transportation, were most often grouped with females, and had little choice in what activities they wanted to participant in. They were, however, allowed to choose whether or not to participate. The women in this study listed disadvantages to their limited social associations, such as privacy (in that everyone knew everything about them). The women did not identify themselves as having a disability, though they recognized that others did. Their level of independence did not necessarily relate to the degree of autonomy that they asserted, however the assistance that they received was likely to contribute their expression of autonomy. They experienced conflict with staff and family when they did not support their sexual choices. The women discussed some of the restrictions that they experienced in their socialization with others such as supervision, dependency on DSPs to arrange meetings, and need to gain approval from guardians. Further because of the conflicts that they experienced, they often engaged in risky sexual expression. Bernert determined that the protectiveness is a result of the assumptions

about people with disabilities that the agencies had and their liability to support the

women with ID. This study is another example of the difficulties that people with ID

experience in being supported. This study also illustrates how not supporting choices, can

lead to risky decisions that may result in less autonomy for people with ID (e.g. risky

sexual decisions could lead to diseases that would limit autonomy).

The following case study presents numerous examples of the kinds of interactions

between people with intellectual disability and DSPs that can limit autonomy. Peter

(1999) conducted a case study of a young man with intellectual disability living with the

assistance of DSPs. Peter found that though the man, Barry, wanted to have more things

to keep him busy and expressed boredom, the house supervisor believed that Barry

needed more relaxation time and therefore did not support him to stay busy. In this case,

though the DSPs would not support Barry to do things that he wanted to do, they

provided much more support than necessary for things that he could do by himself. As a

result of this over-assistance, Barry couldn't do things that he would've been able to do

by himself with some teaching. In an example provided, at the bank, he expected the

person with him to complete his transaction, even though he could do it himself. The

DSPs in this study expressed that Barry had no responsibilities for anything and often

intervened in situations that could have provided learning opportunities (i.e., staff gave

Barry money when he did not have enough money for something that he wanted to buy,

instead of letting him learn that he would have to wait to purchase it until he had more

money). Barry also resorted to self-harm behaviors when he lacked control of his life in

other ways. In conversations, Barry did not seem to know how to communicate about the

things going on in other people's lives. It was as though everyone that he interacted with

was a helper, and so only the events in his life had importance (Peter). Peter implied that

Barry's involvement as a "client" actually produced the behaviors considered abnormal

or deviant that Barry engaged in. Peter stated that even though the label of mental

retardation is stigmatizing because it implies incompetence, DSPs missed out on many

opportunities to facilitate Barry becoming more competent. Though Barry did not need

support in many situations, he still maintained that he needed it. Peter stated that this may

have been to limit his isolation and loneliness. He suggested that the goal of support

services is not to change the individual, but to change the role of the support so that it is

more applicable to the person.

       Barry's situation highlights some of the complexities in the relationship between

the support provider and the person with an intellectual disability that over time may

contribute to compromised autonomy. Barry may not have been able to get to the bank

without the support of the DSP, but he also may have been able to be more independent

without the over-assistance provided at the bank. Interpreting this in light of many of the

problems that DSPs face, this interaction may have occurred in this way because DSPs

are fearful that they will be held liable for the mistakes that people with disabilities make.

It may also be because this was a new DSP supporting Barry who was not aware that

Barry could complete the bank transaction by himself. It further might have occurred

because the DSP was supporting three other people at the same time, who did not want to

go to the bank. Maybe he was trying to hurry the interaction to support the autonomy of

the other clients in the only way that he was capable of managing the situation. Another

potential reason that this may have occurred is because the DSP had negative perceptions

about people with disabilities. Or perhaps Barry had asked for the assistance in the

transactions so that he could not worry about the bank and express his autonomy in other more significant matters, and the DSP supported his autonomy by helping. Regardless of why this happened, Barry provides the perfect example of how autonomy is supported or denied within everyday interactions between DSPs and people with disabilities.

Summary and Discussion

As discussed above many people with ID have often been judged incompetent by society and by the very people whose job it is to support them to lead autonomous lives. Very often the issue of control is not that people with intellectual disability have too much control over their lives, but rather that people who are there to "support" people with intellectual disability, have too much control over the lives of those they support. Oliver (1990) contended that services that are supposed to provide choice and control to people with disabilities, fail at doing so. This, as Oliver points out, is at least partially due to the fact that people with disabilities are not autonomous in regard to the kinds of services they receive. People with disabilities have very limited input into the service delivery system (Lakin et al., 2008). How services are provided is primarily decided by people without disabilities for the primary use of people with disabilities. Therefore from the onset their choice is regarded as unnecessary and unimportant. If they do not even provide input into the overarching kind of support that they receive, it becomes easy to understand why DSPs do not take more of an initiative to garner their input in how to provide support.

This review of literature finds that people with disabilities are capable of being self-determined and acting as self-advocates (Ippoliti, et al., 1994; Stancliffe, 2001). It also finds that many interventions meant to provide choice and decision-making

opportunities are conducted in a paternalistic way, and therefore do not support the autonomy, self-determination, and self-advocacy of people with disabilities (Antaki et al., 2006; Jingree et al. 2006; Karlsson & Nilholm, 2006;). In the areas of choice and decision-making, there are limited opportunities provided by DSPs (Finlay et al., 2008), a poor construction of what choice means to people with disabilities (Antaki et al., 2006; Wareing & Newell, 2002), and the more severe the disability, the less autonomy exercised by the person (Lakin et al., 2008). There are numerous issues in the provision of care that currently exist, such as high turnover rates, lack of DSPs for hire, wage issues, inadequate training, depression and stress in DSPs, and so forth (Gray-Stanley et al., 2010; Hewitt & Larson, 2007; Larson et al., 1999; Larson & Lakin, 1999; Leyin & Wakerly, 2007; Test et al., 2003a; Test et al, 2003b; Test et al., 2004). These issues further contribute to diminishing the experience of autonomy by people with intellectual disability because DSPs can be the primary force in supporting the right to autonomy of people with disabilities, or they can be the restrictive force that prevents people from being autonomous (Grimby, 2002). Ultimately the crisis affecting DSPs is a crisis affecting people with disabilities because they experience the brunt of the negative effects.

"All people have the right to eat too many doughnuts and take a nap" (Bannerman et al., 1990, p. 88), and having the choice to do those things is the best proof that human rights and autonomy are valued and promoted in people with intellectual disability. Bannerman et al. asserted that it is every professional's duty to protect the rights of individuals with disabilities by providing them choices to the maximum extent. Allowing people with intellectual disability to manage their life through supported choice in thousands of miniscule daily interactions will be the ultimate support of autonomy.

The only studies found in this literature review that examined how interactions between

DSPs and people with ID contributed to or hindered autonomy were those of Peter (1999)

and Bernert (2011). Most of the studies discussed perspectives about the interactions that

impeded components of autonomy. It yielded only two studies that directly examined

autonomy from the perspectives of people with disabilities (Berner, 2011; Healy et al.,

2009), and both of those studies investigated sexual autonomy. Although this literature

review found two studies that directly viewed the interactions between DSPs and people

with ID that promoted or denied autonomy (Levinson, 2010; Peter, 1999) it did not

uncover any studies that looked at both the perceptions of DSPs and people with

disabilities in terms of interactions that support or deny autonomy. Though many of the

studies examined the concepts of self-determination, self-advocacy, and choice and

decision-making, none of the reviewed studies investigated autonomy in terms of

interactions that support or deny right to autonomy from the perspectives of both DSPs

and people with ID.

Reason for Study

The study that I conducted was designed to address these gaps in our

understanding of the exercise of autonomy in the lives of persons with disabilities. Also it

is hoped that this study will contribute to the training needs of DSPs working with people

with intellectual disability by determining which kinds of interaction in daily care support

autonomy. It is also hoped that this study will contribute to the development of policies

that support the right to autonomy of persons with disabilities, without additional

burdensome regulations. This study will contribute to understanding that will enable

providers or agencies to facilitate interactions between DSPs and people with disabilities

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that support autonomy. This study will also expand on the work done in self-determination, self-advocacy, choice and decision-making, and the direct support workforce by providing insight into how to develop relationships between people with disabilities and DSPs that provide meaningful benefits to both parties and that are respectful of the perceptions of support by both parties. Lastly it is hoped that this study will have positive effects on the perceptions of people with ID as being thoughtful, contributing, valuable members of society, who are worthy of expressing their autonomy.

CHAPTER 3

Methodology

"We are prisoners of a grammar invented at an early stage of human evolution, and it

seems that, since we can think only by using language, our reason too is conditioned by

the most primitive notions of reality" (Nietzche, 1901, in Davis, 1995).

The purpose of this study was to investigate the perceptions of persons receiving

support and the persons providing support regarding the autonomy of people with

intellectual disability and how they believe that it is either supported or denied within

daily interactions between DSPs and people with disabilities. The research questions of

this study are:

1. How do people with intellectual disability and DSPs perceive the role of the

direct support provider?

2. What are the understandings and experiences of DSPs and people with

disabilities in regard to the autonomy of people with intellectual disability?

Theoretical Framework

The theoretical framework that I used for this research study is one that takes in to

account the social model, dependence, ableism, and medicalization. It is my intent in this

section to describe how social perceptions lead to a stigmatized view of disability. Then I

discuss how systems of support contribute to dependency, rather than fostering

interdependence. I argue how rampant ableism in society influences beliefs about people

with disabilities. Lastly I discuss how the medicalization of intellectual disability is

harmful to people with this disability, and how it influences the support systems on which

people with ID depend. The framework that I used for this research not only influenced

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the research questions and how I conducted my research, but also highly influences my

advocacy efforts. I argue that barriers, such as historical perceptions of disability, ableism,

dependence, and medical treatment of intellectual disability, prevent people with

disabilities from becoming autonomous to the degree that people without disabilities are.

For these reasons, the framework that I layout below is relevant to this research study.

The social model. The social model is essential to any discussion about disability.

According to Oliver (1990) the social model is a political movement about redefining

disability, creating services that provide for self-defined needs, and promoting the model

of social construction to conceptualize disability. The social model uses the idea of social

construction to force people to confront their perceptions about disability while

recognizing the needs of people who have disabilities. Campbell (2002) relayed the

importance of using the social model in disability discourse. She suggested that the social

model emphasizes the inadequacies of the typical ways of handling the disability

"problem" through rehabilitation, cure, institutionalization, and death. The author

emphasized that in the social model, problems are viewed as residing in the social

practices that work to exclude people with disabilities, rather than in the individuals

themselves. The social model, Campbell asserted, imparts control to people with

disabilities. Conversely, many traditional treatment programs have acted to restrict

control through segregation and denial of human rights (e.g., institutionalization).

Oliver (1990) posited that disability is socially constructed and the meaning of

disability is determined by the social meanings attached to it. He also contended that

disability is constructed for social policy purposes. Accordingly, with disability being

founded upon social policy, action to compensate or ameliorate the disability becomes

necessary (Oliver). The idea of disability as a tragedy results in actions taken to compensate or ameliorate the disability that are done on or for people with disabilities, rather than done to allow people with disabilities to do things by themselves (Oliver). The social model, however, permits people with intellectual disability to engage in political actions to make changes that are self-directed or more autonomous.

Disability, interdependence, and dependence. I argue that the needs of people with disabilities sometimes inform unrealistic or misguided beliefs about their abilities and opportunities to be independent. Independence is commonly cited in disability literature, but may not be the appropriate lens from which to view the autonomy of people with intellectual disability (Reindal, 1999). People with disabilities may view their independence differently than people without disabilities. According to Oliver (1990) professionals define independence as being able to complete daily care rituals without assistance, whereas people with disabilities consider independence in terms of being able to control their lives. Because independence is unattainable for many people with disabilities (according to the standards that people without disabilities have for independence), interdependence is a more appropriate lens through which to view the needs of people with intellectual disability (as well as people without disabilities).

Roman (2010) asserted the importance of dignifying dependence for people with ID. I assert that it is important to dignify not only their dependence, but our dependence on them. Interdependence is a necessary component of everyone's lives (Barron, 2001), but may be especially important for people with disabilities. Though they may require support in multiple areas of their lives, they can rely on this interdependence to support their autonomy, rather than prevent them from attaining it. Condeluci (1995 as cited in

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Gooden-Ledbetter, Cole, Maher, and Condeluci, 2007) defined interdependence as "the interconnection or interrelationship between two or more entities that suggests a connection or a partnership in an effort to maximize one's potential" (p. 154). I would, however, add to this definition that interdependence actually works to maximize both parties' potential. For example, the shopper who purchases from a store helps to support the store owner's family and the people who work at the store and does not have to produce her own food. Likewise the DSP who provides support to people with disabilities is actually supporting him or herself and their family by doing so, in both examples, maximizing both parties' potential. Gooden-Ledbetter et al. suggested that interdependence rather than dependence ought to be the goal of support services. In a study about self-efficacy, these authors determined that interdependence is a better predictor of life satisfaction. Bell et al. (2009) asserted that recognizing interdependence as a natural part of human existence would lead to understanding that people with disabilities are also a natural part of our society. Recognizing interdependence as opposed to dependency for people with disabilities is a necessary step in promoting autonomy of people with disabilities.

Interdependence applies to everyone because everyone is dependent on others for the so-called independence. Cardol et al. (2002) determined that recognizing and understanding interdependence is pivotal in gaining or regaining autonomy. I assert that people with ID may actually be able to use DSPs and support services interpedently as a means to acquire autonomy (through interdependent means), and recognizing the role that interdependence plays in the lives of people with disabilities (and people without disabilities) may be pivotal to this acquisition. "We are all dependent on others to varying

degrees. The Western societal notion of a self-made individual is false. Just as autonomy

need not necessitate total independence, dependence on other people need not be

oppressive" (Clapton & Kendall, 2002, p. 989). I argue that dependence is just part of life

(an interdependent part of life), but that the way that is constructed for people with ID is

problematic.

  The creation of dependency. Aside from the issues looming around

interdependence for people with disabilities, the issues surrounding dependency are

problematic. Support systems may actually decrease independence and increase

dependence. Davis (2002) stated that "dependence is the reality, and independence

grandiose thinking" (p. 31). People with disabilities are made dependant (Oliver, 1990).

Oliver asserted that the welfare system developed to create dependence undermines the

ability of people to manage their own lives and will ultimately "corrupt the human spirit",

so that people believe that they cannot function without the dependence inducing welfare

(p. 81). Oliver further contended that:

  There are a number of ways in which dependency is created through the delivery

  of professionalized services. The kinds of services that are available, notably

  residential and day care facilities with the institutionalised [sic] regimes, their

  failure to involve disabled people meaningfully in the running of such facilities,

  the transportation of users in specialized transport and the rigidity of the routine

  activities which take place therein, all serve to institutionalise [sic] disabled

  people and create dependency… it remains unfortunately true that the power and

  control continue to remain with professional staff (p. 90).

"Infantilization and invalidation" are what face people with permanent disabilities to cause "a state of dependency most characteristic of children" (Zola, p. 234). Zola concluded that the only model for supporting the needs of people with disabilities is the model of the parent and the child. I argue that this perspective demonstrates society's expectations for the autonomy of people with intellectual disability. According to Zola, the dependency created by such a model acts as a "leash" for people with disabilities, preventing them from making any changes to better their lives.

Dependency of DSPs. Dependency is demeaning to people with disabilities as well as those who provide support to them (Kittay, 2011). Oliver (1990) stated that dependence is also applied to professionals in the field of disability who are dependent on people with disabilities for their livelihoods. "This dependency is created… because their lives are shaped by a variety of economic, political and social forces which produce it" (p. 94). Therefore people who are served in the support system and people who serve in the support system are co-dependent on each other. DSPs require people with disabilities as much for their livelihoods and autonomy as people with disabilities require DSPs. I contend that if this relationship is made more apparent (DSPs' dependency on people with ID) it might promote DSPs' support for the autonomy of people with disabilities, just as people with disabilities support DSPs' autonomy (by supporting their livelihood). I contend that dependency of people with ID is socially constructed, is enforced and maintained by societal structures, and is problematic to both people with ID and people without. I further contend that we are all interdependent (as evident in the relationship between DSPs and people with ID), interdependency is not as problematic as independence, and therefore is an appropriate aim of support service.

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Ableism. I argue that ableism, because it maintains negative perceptions of people with ID, is at least partially responsible for the dependency of people with disabilities. Ableism is the perception that people with disabilities have limited value in their lives, aren't entitled to any "special" treatment, and infringe upon the needs of other people (Johnson, 2003). I believe that the issue of ableism is pertinent to any discussion about human rights for people with intellectual disability. Because there are many parallels to racism, the issue of ableism is best understood by examining those parallels. Ableism is much like racism though not acknowledged in even remotely the same scope (Johnson). According to Johnson, for example, disability rights are rarely regarded with the same fervor that civil rights are. In many ways they are not the same. People did not have to do anything extra when enacting civil rights (like add ramps) to apply them as they often do for disability rights (Johnson). Yet in many ways civil and disability rights are the same. Johnson stated that when African Americans were sent to the back of the bus there was often great national debate, but when people couldn't even get on the bus because the bus did not accommodate them there wasn't even minimal recognition, much less national media attention. According to the author, minority groups tend to think that disability truly denotes inferiority, as opposed to just being labeled as inferior (though labels for both groups came about through similar circumstances and similar ideas about inferiority). People who are openly against people from other racial groups are defined as racists (Johnson). People who are openly against the needs of people with disabilities do not understand that this same type of hatred prevented minority groups from recognizing their rights (Johnson). I contend that ableism is just as real and damaging as racism and should be treated with the same fervor and passion.

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Ableism is complicated by the fact that people think that the only way to treat disability is through cure, charity, and benefits, rather than inclusion into society, and is evidenced in the way that society perceives disability issues (Johnson, 2003). According to Johnson, while race has been defined by white privilege, disability has been defined by difference, rather than able privilege. People with disabilities fighting for their rights are seen as selfish while people advocating for minority rights are heroic (Johnson). People with disabilities are not perceived as a true minority (Johnson), even though their experiences are similar and often much worse than other labeled minorities. This is evidenced by the fact that language that is offensive to minority groups is widely recognized by society to be deplorable, but language that is offensive to people with disabilities often goes unnoticed (Johnson). Ableism is evident in the fact that the disability issue to gain the most national attention is the right to die—obviously problematic for people with disabilities (Johnson). As Davis (2002) pointed out "the 'hate' against people with disabilities is a much more subtle and ingrained hatred. It is a hatred of difference" (p.156)

I argue that ableism is so ingrained in our beings, so subtly pervasive, that we do not even realize it ourselves. Ableism is defended wholeheartedly because as Davis (2002) pointed out, people do not understand that upholding normality is oppressive. Though we may openly refer to society as racist, few people would ever even know that it is ableist or have an understanding of what that entails for people with disabilities (Johnson, 2003). Further, I assert that people in society often do not understand that upholding the oppression of anyone is oppressive to everyone. "Anything that separates and negates those with a chronic condition will ultimately invalidate not only them but everyone else"

(Zola, p. 238). Put simply, because everyone is subject to acquiring a disability, rejecting people with intellectual disability and their right to autonomy ultimately means that, as individuals, we may be setting ourselves up for rejection at some point in the future if, and when we become disabled. Not only does this mean that everyone can potentially become a person with a disability without autonomy, but it may also prevent individuals who support people with intellectual disability from providing support in a manner that promotes basic rights, such as the right to autonomy, because they may not believe that people with disabilities are entitled to it. They may not understand how their ableistic attitudes affect the kind of support that they provide.

I contend that ableism is perhaps the most accurate lens through which to view the type of research I conducted. I argue that societal perceptions about people are what form our interactions with them, especially when people have not had significant interaction with people with ID. I believe that people have limited interactions with people with ID because they have historically been, and continue to be segregated so that many people do not regularly associate with people with intellectual disability. When this is the case people may rely on attitudes of others, spread through discourse and the media, to inform their opinions about what people with disabilities are like and what they are capable of doing. I contend that because society has ableistic attitudes, people with ID are subjected to discrimination that prevents them from accessing their human rights and expressing their autonomy. It seems that society is just beginning to address the notion that ableism occurs within language and actions toward people with ID. It seems that if the parallels between racism and ableism were made apparent they would have profound impacts on the expression of autonomy in people with ID.

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I believe that disability is complicated to define, even by people with disabilities themselves. Though people with disabilities are certainly the ones who should define themselves, the issue of ableism may be made worse by the reluctance of people with disabilities to identify themselves as disabled (Davis, 2002). By self-identifying, they may be rejecting the assumption that there is something wrong or different about them. More ominously, when they do not self-identify, they may be implying that they, themselves, believe that there is something wrong with disability (possibly due to the message that is conveyed by an ableistic society, or because of their desire to have overcome their disability). Further, the fascination with overcoming disability is counteractive to the efforts of people with disabilities who cannot overcome their disability (Zola, 1982). If people fail to overcome their disability, it is blamed on their failure in being human and not their disability (Zola). The pressure to overcome disability spreads the message to people with disabilities that there is something wrong in being who they are (Zola). Regardless of whether they self-identify or not, it seems that ableism is something that people with ID, themselves, confront.

Kumari Campbell (2008) cautioned on the internalization of ableism by people with disabilities. It seems that when people with disabilities internalize ableism it may contribute to the difficulties that they experience in expressing their autonomy because people with disabilities, themselves, may have conflicting disabled and ableistic identities. Campbell stated that:

> Internalized ableism means that to assimilate into the norm the referentially disabled individual is required to embrace, indeed to assume, an 'identity' other than one's own—and this subject is repeatedly reminded of this by

epistemological formations and individuals with hegemonic subjectifications of

their provisional and (real) identity. (p. 157)

In other words, people with disabilities are forced to adopt identities that others assign for

them because they, themselves, have internalized ableism. I contend that because ableism

exists, and may be internalized, it neither requires nor forbids people with disabilities to

claim their disability, rather people with disabilities should decide for themselves what it

means to be disabled (while recognizing the possible internalized ableistic attitudes they

might have). Because people with disabilities live in an ableist society, however, it may

be impossible for them to completely reject their disabled identities (Kumari Campbell).

Kumari Campbell asserted that people with disabilities cannot refrain from incorporating

some internalization of disability and that disability "cannot be detached from its negative

association" (p. 159). For these reasons, I believe that it is not only an ableist society that

needs to change, but people with disabilities need to participate in defining the social

structures that apply to them.

Ableism is a problem that I believe affects the autonomous expression of people

with ID because if their very existence is seen as a mistake, their interests will not be

valued, and they may take on identities that are not their own because they perceive they

perceive that there is something wrong in their degree of human variance. People are

socialized into a society where it widely believed that "normal" exists, and they

experience discomfort in confronting the idea of disability (Zola). I contend that ableism

is so rampant because of the notion of a normal human being. I further contend that

ableism is harmful to everyone in society. According to Zola (1982) "both those with

physical handicaps and those without –all—are deprived of the knowledge, skills,

resources, and motivation necessary to promote change" (p. 211). I believe that this is a

sad situation for people with disabilities, those without, and the world at large. To not be

allowed to experience the full range of human ability because a portion of our society is

restricted and silenced by ableistic attitudes (and internalized ableism) is bad for people

with disabilities, people without disabilities, and society. Davis (1995) stated that the

category of disability, created by repulsion, not only affected disabled people to whom

the category applied, but also everyone else. I posit that this is so because our interactions

are disabled, so that people with disabilities are prevented from having authentic

experiences, and people without disabilities are prevented from having genuine

relationships with people with ID. I argue that the experiences seem almost artificial

because people without disabilities see people with ID as different (not relatable, not like

them). The repulsion is an act of society (Davis). "The 'problem' is not the person with

disabilities; the problem is the way that normalcy is constructed to create the 'problem' of

the disabled person" (Davis, p. 25). Everyone is simply human (Zola). I contend that

people should have access to all kinds of people, and that supporting the autonomy of

everyone ensures that this access is granted. I assert that supporting and promoting the

right to autonomy of people with intellectual disability ensures that they remain a valued

part of society; a part that all people can interact with and learn from.

   Medicalization of disability. I argue that ableistic attitudes can be attributed to

the medicalization of disability, and that as a society we are inundated with medical

knowledge that is not entirely helpful nor warranted in all situations. People with

disabilities are relics of the inability of man to entirely control his existence (Zola, 1982).

Medicalization, it seems is an attempt to control human existence by treating and fixing

the problems that it defines in society. In a medicalized society it seems that people with

disabilities are thought to be suffering, worthy of pity, worthy of anything but respect and

dignity, and ultimately autonomy. According to Murphy (1987, as cited in Oliver, 1990)

"The disabled spend a lifetime in a similar suspended state. They are neither fish nor fowl;

they exist in partial isolation from society as undefined, ambiguous people" (p. 20). I

have discussed extensively the conceptualization of disability, but it is still important to

understand the gravity and implications that such a definition holds when it is based on a

medical model, as intellectual disability is. Oliver (1990) put it this way:

> The disabled individual is an ideological construction related to the core ideology
>
> of individualism and the peripheral ideologies related to medicalisation [sic] and
>
> normality. And the individual experience of disability is structured by the
>
> discursive practices which stem from these ideologies. (p. 58)

In other words, a medicalized notion of disability has profound impacts on the experience

of disability. The current system of support in the U.S. is based on the medical model. I

believe that this is particularly damaging to people with intellectual disability because

this system attempts to make what is defined as abnormal, normal. It seems to uphold the

grandiose idea of independence while it may actually cause dependency and ableism in

the first place.

     Special treatment. I argue that people with disabilities are given special treatment

that is not all that special. Johnson (2003) stated that the major difference between people

with disabilities and those without are that people with disabilities experience

discrimination. Johnson implied that the medicalization of disabilities prevents others

from seeing that people with disabilities are discriminated against because their needs are

often categorized as medical needs to be cured, rather than social needs to be accepted. This problem is paramount for people with disabilities where "special" is seen as something extra that takes away from everyone else (Johnson). This implies that their needs hurt the rest of us. Johnson asserted that there is nothing "special" about special services, except that they are used to segregate people from society. I believe that this segregation will never lead to wider promotion of rights or expression of autonomy.

Treatment and regulations directed at people with disabilities are not consistent with what is applied to everyone else because people with disabilities are rarely considered in the original planning processes (Johnson). This is evidenced in the numerous regulations that list oppressed groups, but give no consideration to the plight of people with ID (such as the civil rights act of 1964). Because of this medicalization, Johnson stipulated that a "no-one is against the handicapped" mentality (i.e., it would seem wrong to openly admit opposition to the needs of people with disabilities) leads to negative perceptions about their needs (p. 24). In other words, because people assume that everyone is charitable to people with disabilities (demonstrated in the constant care that is provided to them), arguments to deny them necessary supports seem more logical, perpetuating the notion that their support is a detriment to everyone else. "The 'special solution was a logical one for a society which saw things in terms of us and them, which acted as though it believed that anything given to them necessitated something being taken from us" (Johnson, p. 84). Special treatment assumes that their care is provided by taking a wealth of resources from the general population. These social perceptions seem to perpetuate continued fear and separation of people with disabilities, and denial of their

rights. Further, special, segregated services do not seem to be the ideal way to support autonomy of people with ID.

There has historically been and continues to be a strong influence on curing and ameliorating disabilities, as in the medical model (the model still used by our current support system) (Johnson, 2003). Johnson stressed that the constant attention on cures detracts from the lives that people with disabilities lead because they are not thought of as being fully able to enjoy their lives just as they are. Zola (1982) stated that "we must free ourselves from the… dominance of our life by the medical world" (p. 243). He further stated that people are made to think that they are dependent on medical services and public money so that they feel that they have no rights (a point that I assert leads to greater dependency). I believe that society must confront its medicalized notions of intellectual disability that create dependency, while at the same time denying the supports that people with ID are dependent on.

Power of medicine. I argue that the medicalization of ID has profound implications for the practice of providing support, and because medical science holds so much value in society, it acts as a privileged form of information. "There has been expansion of the influence of science and in particular medical science until medicine has in some ways replaced religion and law" (Zola, 1982, p. 244). Oliver (1990) contended that doctors not only have the power to cure disabilities, but also to decide whether someone is capable of driving, who should and should not get assistive devices, who should receive financial assistance, who is capable of working, who should be educated, and how they should be educated. "The problem comes when they determine not only the form of treatment (if treatment is appropriate), but also the form of life for the person

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who happens to be disabled" (Briseden, 1986). Put simply, medical knowledge may have control over the life experience of people with ID. Oliver identified this kind of medical favoritism as "medical imperialism". "We are experiencing a medicalization of society and with it the growth of medicine as an institution and instrument of social control" (Zola, 1972, as cited in Zola, 1982, p. 245). Oliver further contended that the "aim of returning the individual to normality is the central foundation stone upon which the whole rehabilitation machine is constructed" (p. 54). I believe that trying to make people with ID like everyone else, overshadows their unique contributions to society, as well as demeans their very existence and further compromises their identity and autonomy. Oliver stated that working at being "normal" is painfully emotionally draining. I contend that medicalization, meant to help people with disabilities to become more like people without, does just the opposite because it is the very thing that makes them different and separate from "normal" people in the first place.

> ***Equality.*** I argue that medicalization is the major obstacle in supporting the
>
> equality of

people with ID. Lukes (1973) stated that treating equality seriously can only be done:

> on the basis of a view of un-abstracted individuals in their concrete, social
>
> specificity, who in virtue of being persons, all require to be treated and to live in a
>
> social order which treats them as possessing dignity, as capable of exercising and
>
> increasing their autonomy, of engaging in valued activities within a private space,
>
> and of developing their several potentialities (p. 59).

Put simply, all people have the right to be treated with respect, dignity, and to express their autonomy. Morris (2004) stated that "the civil rights movement of disabled people

has learned—as have other civil rights movements—that all forms of prejudice have at their heart a refusal to acknowledge the common humanity shared by the oppressor and the oppressed" (p. 6). It seems that this refusal maintains the ableism experienced by people with ID. Further, people without disabilities may have difficulty confronting that they are like people with disabilities because disability, it seems is what truly denotes inferiority. I believe that under the guise of medicalized care, it is difficult for society to recognize that ableism exists and that it prevents people with ID from being treated with equality. Further dependency, ableism, and medicalization profoundly impact the relationship between DSPs and people with ID. The DSP it seems is knowledgeable, powerful, and normal. The person with a disability is ignorant, needy, and abnormal, much like the doctor and patient relationship.

Reconceptualization of disability. I argue that people with disabilities need to claim and reframe their disabled identities. McRuer (2006) stated that they need to "come out crip". He asserted the importance of reframing medical needs as social needs (e.g., that support will enable them to become part of society rather than enabling them to get dressed in the morning). Part of coming out crip, as he defines it, is that people with disabilities must embrace who they are. They must identify with disability and disability identity politics, and claim their history. They should focus on the possibility of an accessible world that is accessible not only physically, but also socially for people with disabilities (McRuer). I would also add that the world should be cognitively accessible. People with disabilities need to point out that not only is such a world possible, but desirable (e.g., they may desire to be disabled, it may be a source of pride for them) (McRuer). McRuer further stipulated that they need to not just come out as disabled, but

need to come out within the cultural movement of disability, and continually reshape and reform what disability is. He suggested that it is possible for people with disabilities to reinvent themselves in their own image (rather than images that are projected on them. "Probing or testing the limits of rehabilitation and compliance may at times be as vital as, or more vital than, acquiescing to them" (p. 131). Oliver (1990) further contended that people with disabilities could be a viable political force, because of the sheer number of people affected by disability. These perceptions and actions are vital to confronting the medical monopoly over intellectual disability.

I argue that the problem is not that people with disabilities are seen as a different group, among many different groups, but that people with disabilities are a clearly definable group that is different from the rest of the population. If society conceptualized disability as a minority group among many, their treatment would cause uproar. Davis (1995) contended that disability is used as a means to create rigid and inflexible categories of people, and that though people with disabilities have claimed the category for themselves, it "still serves at least two masters" (p. xv). Davis further stated that such an absolute word (disability) can only act to exert control over the people so defined while neglecting the continuum of people who fall into the category; over emphasizing the needs of some and entirely neglecting the needs of others (because of the assumption that some people are clearly disabled or not).

Davis (1995) warned against a totalizing view of disability wherein disability becomes the defining element of a person. Though identifying oneself as disabled may perpetuate negative perceptions and the segregation of people with disabilities, claiming disability may be the best way within the current system to advocate for equality. In the

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future, such categories may be unnecessary, as people may be provided with support just because they need it, not because they have been labeled in some way. I contend that for these reasons disability should be stated in terms of a minority classification, such as a physical or cognitive minority. I hope that, in the future, as Davis stated that the notion of disability denoting inferiority and difference will be perceived as antiquated and barbaric, just as the notion of inferiority based on race and gender is perceived as insensitive. I also hope that in some small way this research will contribute to such a change in perception.

Disability in Research

People with intellectual disability are a group as widely varied as the human population. This is because intellectual disability occurs in every racial, ethnic, and gender group. Intellectual disability does not discriminate. I argue, however, that research with this population does have the potential to discriminate and reinforce discriminatory and oppressive practices. Some research of the past justified socially oppressive practices (Yan & Munir, 2004) and contributed to the perception of people with disabilities as mistakes to be fixed (Snyder & Mitchell, 2006). A forgotten and invisible history of eugenics camouflaged the justification of abhorrent "treatments" for disability (Black, 2003). Prominent authors of the past not only advocated inhumane treatment, but continually questioned whether people with intellectual disability could even be classified as human (Black, 2003). I contend that research, literature, and discourse have pegged people with disabilities as burdening, deficit ridden, inferior, subhuman creatures in need of fixing. Ableist attitudes perpetuate not only history, but also can influence how the modern researcher engages in the research act.

This disabling history of research is still a part of disability research, as Olkin (2004) noted when she found that recent research continued to label children with disabilities as burdens to their parents. I argue that the history of disablement is so pertinent to disability studies, that disability research cannot really be conducted without a thorough review of it. As Iacono (2006) implied in reference to a study where children with disabilities were injected with viral hepatitis, when she stated, "knowingly or not, every researcher submitting a proposal to a research ethics committee does so in the shadow of the Willowbrook study," (p. 173). Put simply, researchers in the disability field will be held accountable to the research of the past. Research practices such as this form a collective memory for people with disabilities (Olkin). Yan and Munir (2004) declared that historically, research in the field of intellectual disability has utterly violated human rights. The discourse about people with disabilities has lead directly to their marginalization (Snyder & Mitchell, 2006). Researchers currently working in the field of ID will be held liable to this past, as we should.

Snyder and Mitchell (2006) stated that "disability has been routinely represented as the site of undesirability; one that only provides recourse to a battery of interventions involved in the alleviation, diminishment, normalization, oversight, and invasive management of disabled persons' lives" (p. 21), and further, that this is done under the guise of objective science. Accordingly, often disability research is about how to fix the problem of disability (Snyder & Mitchell). Davis (2002) stated that research on people with disabilities is typically undertaken to situate normalcy. Snyder and Mitchell suggested that eugenics still has its stamp on disability studies in the U.S. They contended that support and care (often the aims of research) are merely veils for attempts

to extinguish disability and by extension people who have disabilities. They asserted that disability research is riddled with unquestioned assumptions about its potential, and that without the insight of researchers, research can perpetuate oppression. Harry (1996) cautioned against "othering" people with research. Magana (2000) addressed the issues of being able to perform culturally competent research within different cultural groups. Magana suggested that imposing cultural beliefs onto others or perceiving other cultures as dysfunctional is possible when researchers and participants do not share culture. I argue that it is necessary to refrain from imposing normalizing standards on the culture and experience of disability. This is especially important, since as a researcher conducting disability research, I do not identify as a person with a disability

I contend that research is political; recognizing that what we, as researchers, do to socially and politically construct someone's identity is paramount. I argue that published research can act as the primary enforcer, and in the case of oppression, reinforcer, of knowledge about disability. Shakespear (in Barnes & Mercer, 1997) stated that it is ultimately the researcher who will have to live with whatever they have done, but this is not so. Research will live on in whomever reads it and uses it to rationalize anything, potentially forever. I posit that recognizing the power of research, ethical researchers will do everything they can to provide participants with the means to be powerful.

Ferguson and Ferguson (2000) listed some common factors of quality in qualitative research. They determined that truth is not so much about getting it exactly right as it is about not missing it entirely. This is an essential consideration when investigating with people who may have difficulty communicating and expressing their thoughts and ideas. Gilbert (2004) discussed the implications of creating difference

through research. He suggested that people with intellectual disability might be seen as different leading to deviance, social exclusion, and ultimately stigma. I assert that researchers need to use great caution in both understanding people with ID within research and what their research implies about difference in people with ID.

In this investigation the category of disability is employed because it is used in support systems and the aim of this investigation is to provide potentially valuable information to those systems. It is, therefore, necessary to delineate the people who are served by that system. As a researcher and a human being, I do not believe that disability denotes that something is wrong. I feel that it is a perfectly normal part of the human experience. I contend that the only problem with disability is that the category of disability leads to marginalizing people who have it. Though I have been raised and continue to live in an ableistic society, I have attempted to refrain from using abelisitc and demeaning language and actions within my research, my writing, and my interactions with people with disabilities. As a researcher, I recognize that the goal of improving the autonomy of people with disabilities, subjects them to normalizing standards. I support the need for improved autonomy not because it is what typical people do, but because I feel that it is an unquestionable and undeniable human right, that everyone should have access to, and that people with ID currently may not have meaningful access to.

Campbell and Oliver (1996) discussed three things that would need to happen before people with disabilities are able to carve out a movement. These are that people with disabilities need to be (a) empowered to raise consciousness, (b) get attention to their cause, and (c) maintain a civil and human rights focus. Longmore (2003) stated that the links between disability rights movements were that they reframed disability as a

social and political construct rather than a medical and rehabilitative construct. They also shifted priorities from individual correction to social reform, asserted participation and integration as being civil rights rather than charity, asserted their power over professionals and politicians, and sought for individual and group empowerment and self-determination. Longmore contended that the first phase of the disability rights movement was for civil rights and that now it should explore and create a disability culture. According to the author, people with disabilities need to affirm their value, not self-sufficiency, but self determination; not independence, but interdependence. I hope that this investigation meets the aims of the disability rights movement.

Qualitative Research Methods

Mmatli (2009) stated that "research on disadvantaged people, including people with disabilities, is justifiable only if it leads to practice that improves the quality of services and outcomes for these individuals and their families" (p. 14). Mmalti declared that qualitative research "allows people to speak for themselves, enabling researchers to hear stories that have been suppressed" (p. 15), and suggested that quantitative research has consistently reinforced the oppression of people with disabilities. The author suggested that the wealth of disability research has rarely led to political or social change for people with disabilities. He stressed the need to meaningfully involving people with disabilities in research. "As a matter of human rights, social justice, and respect for human dignity, people with disabilities ought to participate in processes that shape their lives" (p. 17). Duckett and Fryer (1998) determined that people with intellectual disability have rarely had a voice in research and that that qualitative methods would be a welcomed departure from past research initiatives and methods. For the purposes of

providing insight into the research questions examined in this study, it was necessary to use qualitative methods and include people with ID.

Barnes and Mercer (1997) stressed that participants with disabilities should be involved in every step of the research process. They stressed that the emancipatory research model would best meet the needs of people with disabilities and that research should be about "changing the world, not describing it" (p. 5). The emancipatory research model is about changing the social relations in research and contributing to emancipation (Oliver, in Barnes & Mercer). Barnes and Mercer stated that "the emancipatory paradigm rejects this notion of researcher-experts moving between projects like 'academic tourists', and using disability as a commodity to exchange for advancing their own status and interests" (p. 6). They repeatedly surmised that the way to do emancipatory research is through reflexive self-critical means because researchers are either oppressors or emancipators. Reflexivity "means that, however painful, we must ensure that we examine our own research practice in the context of the current oppressive social and material relations of research production" (Oliver, in Barnes & Mercer, p. 28). Oliver also suggested that researchers continually reflect on the aims of the research. He stated that it would be difficult to determine whether research is emancipatory until it is completed and cautioned that intent to engage in emancipatory research does not guarantee that the research will serve that function. I am aware that the methods of this research project are not truly emancipatory methods. I hope, however, that in valuing the perspectives of people with disabilities about matters that significantly impact their lives, this research can ultimately contribute to the emancipation of these individuals.

Priestley (in Barnes & Mercer, 1997) provided recommendations for emancipatory research including the use of the social model of disability. The author suggested that researchers (a) support people with disabilities to be self-emancipatory while denying so-called objective notions about disability, (b) conduct research that benefits people with disabilities, (c) reorganize control over research, (d) personalize disability while tying it into the larger context of disability experience, and (e) create flexible methods to suit the needs of people with disabilities. Though emancipatory research, it seems, offers the possibility of emancipation, it will not be able to redeem insurmountable issues or deny abhorrent historical practices in research with, on, or for people with disabilities. I am aware that the history of disability is overwhelming and that practice will change painstakingly slowly over time as people with disabilities become the primary creators of knowledge in the field. I hope that this research has allowed people with ID to be the creators of knowledge.

Newell (1997) stated that "people with disability (known in the jargon as research subjects—a wonderful way of categorizing and depersonalizing people), and their stories and concerns are dismissed as a hindrance" (p. 809). Shakespear (in Barnes & Mercer, 1997) stated that, in the case of disability research and the accounts it produces, "the personal is political" (p. 179). The political knowledge that research produces, should lead to more positive outcomes (i.e., improved autonomy), rather than stigmatizing and marginalizing people with disabilities. The primary ethical question is "how do we rethink the ethics of research to allow disabled persons to speak for themselves concerning their social predicament, rather than harnessing their lives to the research machinery of others?" (Snyder and Mitchell, 2006, p. xi). As a researcher, I need to value

the stories told by people with ID and be cognizant of the magnitude of their contribution to the research act.

People with Disabilities as Research Participants

I argue that although there may be difficulties in including people with ID as research participants, there can be many benefits, and it is imperative to consider whether including participants with ID in research outweighs the negative aspects of their involvement. Becker, Roberts, Morrison, and Silver (2004) found that not using representatives to speak for people with disabilities compromised the research findings as much as using representatives when the researcher is unable to communicate with the group. For this investigation I directly interviewed people with disabilities. Yan and Munir (2004) argued that inclusion is a "matter of ethical obligation" (p. 44). They stated that without participation of people with disabilities in research, it would be unlikely to benefit them. McVilly and Dalton (2006) cautioned that excluding people who lack decisional capacity is harmful because it suggests that vulnerable populations have nothing to offer the researcher. The exclusion of people with disabilities in research can be incredibly damaging and for these reasons I included people with disabilities in this investigation, even though it presented additional problems (accounting for alternative communication needs, making information accessible, and interpreting data). Mactavish, Mahon, and Lutifyya (2000) offered some suggestions for including people with disabilities in research. The first is the presumption of credibility. In this research, I held the assumption that people with disabilities are the best suited to speak about their situation. Oliver (in Barnes & Mercer, 1997) listed some more recommendations including describing the experience of people with disabilities within the collective

experience of disability, redefining disability, challenging dominant research paradigms, and developing emancipatory methodological techniques to support emancipation. It is my hope that by including people with disabilities, this investigation has fulfilled those aims.

Method

Participants. In this investigation participants consisted of both adults with disabilities receiving support services and DSPs working with adults with disabilities. I recruited ten individuals to participate in each of two interview groups. I conducted the interviews individually. I conducted follow up individual interviews with three participants with disabilities and follow up individual interviews with three DSPs for the purposes of clarifying questions and eliciting additional and valuable narrative information.

Criteria for inclusion as participants with disabilities were that they:

- Had an identified intellectual disability (i.e., mental retardation) that they self-identified.

- Were 18 years of age or older.

- Had, at any point in their lives, received residential or other support from a provider agency.

- Provided consent or assent to the research.

- Had consent provided by a guardian when applicable.

- Were able to communicate in an understandable manner either by speaking, writing, or using an augmentative or alternative communication device.

The inclusion criteria for DSP participants were that they:

- Worked or had recently worked with people with identified intellectual disability (i.e., mental retardation) within a residential setting.

- Were 18 years of age or older.

- Provided consent to the research.

Participant recruitment. To recruit participants for this investigation, I used a variety of methods. I enrolled ten participants in each group, and conducted interviews with ten participants with intellectual disability and ten DSP participants. I asked the first three individuals from each group to consent to individual follow up interviews, and they agreed. After these six people agreed, I did not ask anyone else to participate in a second interview.

To recruit individuals with disabilities, I placed calls to major service providers and community organizations in a large city in the southwestern region of the U.S. and provided them with additional information about the study. I provided contact information and was available to answer questions about the study. I asked them to identify individuals who might want to participate in this study, and to pass the recruitment materials on to potential participants and their guardians when appropriate. I contacted agencies listed on the freedom of choice list (a list containing all of the service providers in a large city in the southwestern region of the U.S.) and some of the following community agencies and organizations: The Center for Self-Advocacy, The Special Olympics, The Center for Development and Disabilities, People First, The Intellectual Disability Planning Council, and the Metro Regional Office of the Developmental Disability Waiver supports, The ARC, Parents Reaching Out, and so forth. I also provided recruitment materials to parents of people with intellectual disability or people

who were likely to know people with intellectual disability (such as related service providers, case managers, etc.). I asked that people who were given recruitment materials pass them on to interested individuals. After potential participants contacted me, I scheduled a time to meet with them to present them with informational materials and answer questions they had about the study. I then provided them with contact information or scheduled another time to meet with them to confirm their participation in the study. At this second meeting, I collected consent forms and scheduled a meeting time that was convenient the participants.

To recruit DSPs, I placed calls to some of the major service providers in a large city in the southwestern region of the U.S. and requested a time to meet with them to provide additional information about the study. I also provided contact information and was available to answer questions about the study. I asked them to identify any DSPs that might want to participate in this study, and to pass the recruitment materials on to potential participants. I contacted agencies listed on the freedom of choice list and some of the following community agencies and organizations: Direct Support Staff Coalition, The Special Olympics, the Metro Regional Office of the DD Waiver, National Alliance of Direct Support Professionals (NADSP), and so forth. I provided recruitment materials to people who were likely to know DSPs (such as related service providers, case managers, etc.). I asked that people who were given recruitment materials pass them on to interested individuals. After participants contacted me, I scheduled a time to meet with them to present them with informational materials and answer questions that they had about the study. I then provided them with contact information or scheduled another time to meet with them to confirm their participation in the study. At this second meeting, I

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collected consent forms and scheduled a meeting time that was convenient for the participants.

Participant information. For this study I interviewed ten individuals with intellectual disability and ten DSPs. The participants were from both urban and rural locations in the Southwestern United States. Although I did not collect self-identified ethnic or racial demographic information, both participant groups seemed to be ethnically diverse. The participants with ID received services from at least five different provider agencies. The DSP participants provided support services in at least three different provider agencies. I initially assumed that I would have difficulty gaining participation from individuals with disabilities, but within the first two months of eliciting participation, I completed all ten interviews with persons with disabilities. I had more difficulty garnering participation from DSPs. I contacted a previous employer who assisted me to find additional DSP participants for the study.

I did not collect information about participants' diagnosed disabilities, or specific services, other than those self-identified by the participants. Of the individuals with disabilities, seven participants were male and three were female. Of the individuals with disabilities, six lived in a supported living situation, where they received support from DSPs 24 hours per day through a residential agency. This meant that they lived in a home with up to four other individuals supported by the same residential agency and had DSPs who came into their homes to provide assistance. An additional participant received assisted living services, wherein she lived alone in her own home and DSPs came to her home to provide support. These seven participants listed multiple services that they received, such as day habilitation (a service provided during the day to advance daily

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living skills, vocational skills, and educational skills), vocational support (on-the-job

support for people who are employed), community membership (support for

individualized integration into the community to develop natural supports), speech

therapy (support to maintain or improve communication), physical therapy (support to

maintain or improve physical health), and transportation (special transportation).

Three of the participants with ID lived with family members and received support

in other supported settings. Of those, one received self-directed waiver services (self-

directed services) and two received services other than residential under the DD waiver.

The person on the self-directed waiver reported that she received help with budgeting and

money for transportation. She also reported that she received speech therapy services and

money for massages. She also reported that she received job coaching (which is a typical

DD waiver service). One person receiving DD wavier services (other than residential)

reported that he was provided day habilitation services and had received employment

services in the past. The other person receiving DD waiver services (other than residential)

reported receiving respite services on the DD waiver. He often spoke about his high

school transition program, so I only used for data analysis statements he made that related

to the respite services he received. Because these three participants did not receive

residential services, they were asked to relate the questions to the services that they did

receive.

I further only collected self-identified demographic information on the DSPs

interviewed. Of the DSP participants, seven were female and three were male. All of the

DSPs currently worked or had worked as a DSP within the previous 5 years providing

direct support in residential services. One of the DSPs had advanced from a DSP to a

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service coordinator (a person who coordinates multiple services received by the individual within the agency and ensures cooperation among other service providers who provide support to the individual) at the provider agency. Another DSP was no longer employed as a DSP, and had moved on to another career pathway. The DSP with the least experience had 1 year of experience. The DSP with the most experience had worked as a DSP for 20 years. The average length of experience for the DSPs interviewed was 6.85 years. All of the DSPs had participated in mandated training programs through the agencies that employed them. The mandated training consisted of forty hours of training that was completed at various times. Some of the mandated trainings taken by DSPs included: pre-service (what must be taken prior to providing any support to individuals with ID), health, individual specific training, person-centered planning, first aid, CPR, assisting with medication delivery, participatory communication and choice-making, rights and advocacy, positive behavior supports, and teaching and support strategies (Developmental Disabilities Supports Division, 2009).

     Method. For the purposes of addressing the research questions of this study, I used individual interviews. In the interviews, I encouraged conversation to flow naturally; however, I used several structured questions to elicit dialogue (see appendices A and B). For the interviews, I generated a list of questions and used follow up questions as needed. As well as providing insight and valuable narrative about autonomy, additional interviews presented an opportunity to clarify previous information garnered from initial interviews, so that I restated and asked some of the questions asked previously.

     Interviews. I began the initial interview with each participant by collecting self-identified demographic information. The demographic information that I collected from

participants with disabilities (included in questions in Appendix A) included information about living and support situations, advocacy experiences, work experiences, school experiences, friendships, hobbies, and interests. The demographic information (included in the questions in Appendix B) that I collected from DSP participants included self-identified information about the capacity in which they supported people with disabilities and how they came to work in the field. Interviews were used to elicit information about what the role of the support provider is. I also used interviews to elicit insight into the notion of autonomy; how it is conceived and how it can be facilitated by support. I conducted interviews with ten participants in each group to elicit this information.

In the second interview conducted with three participants with ID and three DSPs, I asked follow-up questions to complete member checking. I used member checking interviews to verify the accuracy of the data that I collected. I did a rough analysis of the transcriptions from the first interviews and scheduled a second interview with three participants in each group within roughly one month of the initial interview. I generated questions based on the rough analysis and asked questions that would help to clarify my understanding of the data. I asked for additional explanation when I wanted to understand the reasoning behind a statement that was made by the participants.

I held the interviews in places selected by the participants to be respectful of their time and their comfort level. When they did not choose a place to meet, I offered suggestions (e.g., in their home, at a public place, at a park). When DSPs accompanied individuals with ID, I asked the DSPs for privacy or asked the participant with ID if we could meet in a more private setting. Seven of the interviews occurred in the homes of the participants with ID, that were also support settings (i.e., they received support within

their home). Six of the participants with ID were interviewed in their homes while they were receiving support (i.e., a DSP was present), one interview took place in a home where the participant's parent was present, and another interview took place in a day habilitation support setting. In each of these interviews, I asked DSPs for privacy. Sometimes this meant that I was alone in a room with the participant with the door closed (and often support staff came in periodically to fulfill support roles); other times it meant that I was in a living room that was within earshot of a kitchen where a support staff was located. In these situations, I tried to speak quietly, sit in close proximity, and reminded participants that they did not have to answer any questions that they were not comfortable answering.

In addition, I included some information at the beginning of each interview that was pertinent for the participants to know. Specifically, I told the participants with ID that they could stop the interview at any time, that they did not have to answer any questions that they were uncomfortable answering, and informed them that I would be writing and recording throughout the interview. For the DSP participants, I told them I would have to report any reportable issues that they discussed with me (i.e., abuse, neglect, exploitation), that they could stop the interview at any time, they did not have to answer any questions that they were uncomfortable answering, they could think about questions and come back to them later when needed, and informed them that I would be writing and recording throughout the interview.

Data collection. The average interview length was 58 minutes. The shortest interview lasted 28 minutes. The longest interview lasted 1 hour and 32 minutes. All of the participants chose the location of the interview, as I described above. I conducted all

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but two of the interviews with participants with ID in their homes. I conducted only one of the interviews with DSPs in the participant's home while the rest took place in public places (mostly restaurants). None of the DSP interviews took place within the support setting.

With participants' permission, I recorded all audible data with a digital audio recorder. I also took additional notes during interviews to ensure accuracy and include opinions and insights that from the interviews. Audio recording was necessary to verify the accuracy of the data as well as allow for more through note-taking. I then transcribed all recordings in Microsoft Word for analysis. For confidentiality, I assigned pseudonyms based on the participant type and interview number to conceal the participants' identities. Initially I used the pseudonyms in all the written data and analysis. I stored the documents tying the participants to the pseudonyms, original notes, and digital data in a lock box in my home.

Data Analysis

I completed the data analysis in accordance with LeCompte (2000). First I transcribed the interviews in a Microsoft Word document. I read through the interviews several times and commented on different quotes that were provided by the participants using the new comment feature in Microsoft word. For example, I read a quote about caring, and using the new comment feature, I added my personal thoughts about what I believed this participant was saying. In this case, I believed that this participant was indicating that competent staff members are people that care.I reviewed the transcripts several times and selected quotes based on frequency and declaration as they related to the research questions (LeCompte). For example, Juan said "He's cool because he cares

about me," a quote I selected because the issue of caring came up several times with participants with and without disabilities. In another example Karen said, "you have to care about the people" which I selected because Karen told me this when I asked her if there was anything else important that she thought she should share. This was a declaration that related to the research questions of supporting autonomy. Throughout the process of reading and rereading the transcripts, I reflected on the research questions and selected quotes that seemed to address components of the research questions.

All of the selected quotes were placed into a single Microsoft Word document that I referred to as the analysis document. As the quotes were copied and pasted into the analysis document, the subcategories evolved, and quotes were placed into whichever subcategory seemed to address the quote. I read the quotes in context and individually copied and pasted each quote into the analysis document. After all of the quotes had been placed into this document, I reviewed this document several times and adjusted the quotes and subcategories as necessary. If a quote seemed to be important, but I had difficulty in determining where it belonged, or there didn't seem to be a category that it fit in, I placed it in an "other" category. I continually reviewed the "other" category throughout the analysis process to build new subcategories. At this point in the analysis, all of the quotes were still attached to the comments that I had written using the new comment feature of Microsoft Word. For example Karen's quote (see above) was initially organized by labeling it "caring about them". I organized the quotes based on their similarities, reviewed them for appropriateness, and adjusted the subcategories to reflect the changes (LeCompte, 2000). From this process I generated 51 subcategories.

Still working in the same analysis document, I grouped the quotes into larger categories based on the relationships that they had with each other (LeCompte, 2000). I looked for patterns in what people said and what specific words were frequently used by the participants. I grouped data together that seemed to belong together or that seemed to help define what the concept was. Initially I placed Karen's quote into a category called "doing a good job" that included participant quotes that were about listening, getting to know people with disabilities, supporting their choices, really caring about them, and so forth. All of these seemed to fit into a category of doing a good job because some of them were responses to questions about what DSPs did well. In other quotes placed in this category, participants mentioned that this is what competent DSPs did or their tone indicated that they believed this is what competent DSPs did. At different points in this process I generated six to nine different categories. I also removed the personal comments that I had included earlier in the analysis. Lastly I placed all of the subcategories, with their proper headings, under the headings for the categories.

I then reviewed the categories for patterns with interconnected elements that became themes (LeCompte, 2000). I strived to think about what the participants meant by what they said, instead of taking what they said at face value. The interview questions were meant to elicit information about how DSPs could support autonomy, so I continually reflected on the research questions and the tone of the participants in the interviews. For example, Karen's quote became the inspiration for the theme "caring in support of autonomy" because participants' responses indicated that they believed that if DSPs really cared about the people that they supported then they would want to listen to people with disabilities, want to get the know people with disabilities, and want to help

people with disabilities to make informed choices that DSPs could support. It seemed that if DSPs did these things, then they would act in support of the autonomy of the people that they worked for by demonstrating that they cared about them.

In this part of the analysis, I also deleted categories that did not seem to fit. For example, I had a category called "passing the buck" that included stories about when DSPs chose not to address a problem that occurred for a person with ID, and instead made up an excuse. I deleted this category because it was not well defined, and it seemed that the category of "listening" sufficiently addressed this issue within the "caring in support of autonomy" theme. At the end of this process I had three themes, one that had three additional subthemes. At this point in the analysis, I began selecting quotes that exemplified the themes. I checked the quotes for accuracy within the analysis document, and within the original transcripts. I highlighted these quotes within the analysis document.

During this phase of the analysis I started building the graphic. I used the themes and categories to create a graphic (or structure) that depicted the key themes emerging from the data (LeCompte, 2000). Throughout the analysis the graphic changed, as I moved categories around to find the best fit. The graphic allowed me to move around categories within themes to find the best fit. The graphic went through several revisions throughout the process (see the final graphic in Appendix C). The final graphic depicted the three themes and three subthemes that were the result of the entire analysis process.

To ensure the accuracy of the findings, I also used a critical friend. The critical friend reviewed excerpts of data (with all indentifying information removed) to determine categories and subcategories. Specifically, she was provided with quotes from each of the

51 subcategories that were identified at the time that I met with her. Each subcategory was given an identifier number (instead of the name that I used in the analysis) and contained roughly three quotes. The critical friend was asked to name the subcategory based on what she believed the quotes were about. She was also instructed to move any quotes that she did not believe were consistent with the subcategory. She was also asked to group any subcategories that she believed belonged together. I met with the critical friend one time to discuss her findings for approximately one hour. Most of the subcategories determined by the critical friend were consistent with the subcategories that I defined. Some of the categories, however, were more consistent with categories that I identified at an earlier stage in the analysis. For example, she reviewed several sections and named them "role of DSP", a category that I initially labeled "support logistics," "support relationship," and "programs" to identify different struggles that DSPs faced within their jobs. In a later stage of analysis, I determined that all of those categories related to a larger theme of "Challenges for DSPs are challenges to supporting autonomy" because the issues that the participants brought out seemed to be obstacles to supporting autonomy for people with ID. I used the information from the critical friend to change category names to names that more appropriately reflected the intent of the category. For instance, I initially called a subcategory in which people with disabilities and DSPs talked about labeling people with disabilities "label", however after conferring with the critical friend, I renamed the subcategory "stigma." I felt that stigma more appropriately illustrated the intent of the subcategory because these participants seemed to be more concerned about the effects of the label or the stigma associated with the label. This seemed to more appropriately relate to the interconnected theme of "caring in

support of autonomy" about people with ID because if DSP participants demonstrated concern about how labels affect people with ID that they support or their interactions with people with ID, then he or she might refrain from using labels to define people with ID.

Summary

In summary, the purpose of this study was to investigate the perceptions of persons receiving support and the persons providing support regarding the autonomy of people with intellectual disability and how they believe that it is either supported or denied within daily interactions between DSPs and people with disabilities. By listening to perspectives of both individuals receiving and providing support this study respected their voices. Though many studies have investigated the perceptions of DSPs about their feelings about their jobs (i.e., Borbasi et al., 2008; Daynes et al., 2011; Gray-Stanley et al., 2011; Hastings & Horne, 2004; Leyin & Wakerly, 2007; Schelly, 2008; Test et al., 2003a; Test et al., 2003b; Test et al., 2004) or how they provide services (e.g., Bigby, et al., 2009; Dunn et al., 2010; Robertson et al., 2001; Wareing & Newell, 2001; Wilson et al., 2008), fewer have investigated the perceptions of people with disabilities regarding their support (Borbasi et al., 2008; Clarkson et al., 2009; Healy et al., 2009; Kjellberg, 2002; McConkey et al., 2004; Wadensten & Ahlstrom 2009a; Wadensten & Ahlstrom 2009b). Bernert's (2011) study and the study by Healy et al. were the only studies I was able to find that investigated the perspectives of people with ID about their autonomy. The current study that I conducted enabled people with disabilities to speak about how to best support their own autonomy.

Chapter 4

Results

Themes

Analysis of participant interviews yielded three primary themes. The first theme was "being an autonomous person" and included advocacy, benefiting others, quest for knowledge, authentic relationships, ideals, and values. The second theme that emerged was "challenges for DSPs are challenges to supporting autonomy" and it included three subthemes. The first, "walking a fine line" included drawing a professional line, defining support boundaries, institutional control, informed choices, repression, natural consequences, safety/protection, and buffers to the real world. The second subtheme, "institutional barriers" included inflexible services, inappropriate services, Individual Support Plan (ISP) process problems, administrative issues, and typical DSP problems. The third subtheme, "a challenging role" included dealing with challenging behavior, restrictions, and making difficult decisions (factors in decision-making and using compromise, concession, and repression). The third theme that emerged was "caring in supporting autonomy," which included, good feelings, trust-building, teamwork, having a good attitude, getting to know them, acknowledgement and encouragement, offering and supporting choices, difficult conversations, advocacy, DSP compromise, stigma, teaching, treating with dignity and respect, and caring.

Being an autonomous person. The first theme identified was being an autonomous person. Only participants with ID contributed to this theme. Being an autonomous person meant that participants with ID demonstrated that they were capable of speaking about the goals and plans that they had for their lives that they could

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autonomously pursue. They were also capable of talking about what constituted good

support, and that could promote their autonomy. These participants did not identify

autonomy directly, or respond to any questions that specifically referenced autonomy,

rather this theme captured how people with ID in this study perceived their capabilities

and contributions to the world, and how they saw themselves as autonomous beings. I

asked the participants with ID questions about their lives (refer to Appendix A), and their

answers indicated that they see themselves as acting autonomously in many ways.

Specifically, they saw themselves as capable of advocating for themselves, they want to

be of benefit to others (especially to other people with disabilities), they have a quest for

knowledge, they have authentic relationships with other people that are important to them,

and they have ideals about how they believe that they should live their lives and values

that guide them. These participants with ID want what it seems most of us want—the

good life, however they define it. This theme came about because within the questions

that I asked people with ID, they capably spoke about their lives and how they wanted to

lead them. The participants in this study demonstrated that they are, in fact, autonomous

people. In the following sections, I provide information on the specific ways that

participants with ID demonstrated their autonomy.

　　　　The participants with ID indicated that with the right support, they could lead

more autonomous lives. For example, several participants with ID expressed that living in

a supported living situation was better than living with their family members and offered

more opportunities for autonomy. Tito said "it's better for me [living in supported living

rather than at home with family]… I have more stressing… Not that much stressed."

Alex made a similar statement when he said "I can do a lot more stuff than I did living

with my family. Now I get to go to (day habilitation) five days a week and when I was living with them I was only getting to go three," indicating that day habilitation was something he was interested in and more support (adding residential support to the existing support services he received) allowed him to do it more, further supporting his autonomy.

Most of the participants with disabilities identified the importance of advocating for themselves as an aspect of their autonomy. Stainton (1994) stated that a necessary component of autonomy is initiating actions toward plans. In advocating, these participants were initiating actions towards plans. All but one participant spoke about advocating for themselves, either by telling stories of times when they advocated or talking about what it meant to be an advocate. In doing so they clearly established their capability in speaking about what was important to them (in addition to their participation in this study). In advocating, the participants with ID solved their problems and enacted their autonomy. Pastor bluntly said "I stand up for myself." Katrina stated "I was advocating for, advocating to get on the waiver… when I came back there they knew exactly what I was going there for at that point, and then not long after that it happened." Tomas said "Uh I've had some good experiences. I talk up for myself and my other roommates. I got a staff, one that wasn't quite right for this home switched to another home." These quotes demonstrate that they are capable of speaking for themselves and more importantly using advocacy to solve their problems. These statements further indicate that the participants with ID are capable of enacting their autonomy. One participant, had very specific ideas about what advocacy meant to her, and described how formal self-advocacy programs did not support her autonomy. She said "you know I have

a certain way of advocating for myself and that just wasn't it." This statement indicated a deeper understanding of advocacy, that advocacy meant she could advocate in support of her identity (even if it was against participating in formal self-advocacy programs).

In addition to advocating for themselves, the participants with disabilities expressed a strong desire to advocate for and help others. This was especially true in regard to advocating for other people with disabilities. Advocating in any sense is a way to enact autonomy because it is an initiation of actions toward a plan (Stainton, 1994), and advocating for others indicated that these participants were capable of understanding when others required advocacy. They also indicate that people with ID can and do support the autonomy of other people with ID. Alejandra reported "I have a lot of opportunities to do uhm advocacy, and uhm kind of trying to help people that want to better their lives, uhm do that, accomplish that." Similarly, Alex stated "yeah I've tried to advocate for people with disabilities on the Internet, and I said in order to have true world peace we have to include the people with disabilities in it." Pastor simply stated "I go out in the community and and help."

More than half of the participants with disabilities expressed their desire to advance their education. The participants, in speaking of their educational plans, demonstrated their autonomy because autonomy involves initiating and pursing plans (Stainton, 1994). The following quotes demonstrate that the participants with ID have a quest for knowledge and perceive themselves as capable of learning and using education to better their lives. Katrina said "I took some continuing ed. classes… and that uhm was pretty good that seemed to work out." Jesus stated "and and that's… one of my goals to get to, is… going to (names university), and having theater, other teachers, stuff like

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that." Participants with ID expressed that they didn't just want to attend school because it was something that they thought they should do, but also because doing so would contribute to living a better life. They recognized that acquiring additional knowledge and skills would increase their opportunities. For instance, David reported "I wish I could be able to read some more." Tomas said "I'm just going to go to the adult learning center and mess around with the computer and work on my math."

Relationships with others are important to people with and without disabilities. Authentic relationships (other than paid support relationships) with others may contribute to the autonomy that these participants with ID experience. The participants with ID clearly discussed how others contributed to their lives. All of the participants with disabilities spoke fondly of friends, family, and partners. Jesus reported "I got lots of friends. I got tons of friends." Juan stated "I get a lot of like friends that care about me and look out for me." Tomas said "My family gives me support." Alex, in talking about companionship said "Yeah I probably need that [companionship] more than anything."

I directly asked the participants with ID what a good day would be like for them (See Appendix A). Their responses to these questions indicated that they had an idea about what makes a good life and could attempt to pursue those things in an autonomous way. Stainton (1994) and Lotan and Ellis (2010) situated identifying values and beliefs as necessary components of autonomy. These participants spoke of their ideals (e.g., the idealistic plans that they had for their lives). Their answers indicated that they had varied interests, but appreciated being productive and getting things done. Katrina stated that a good day is "when everything is working out." Alejandra asserted that a good day is the "kind of a day where I feel somewhat productive and somewhat able to be myself, you

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know." Other people talked about a good day as being one that made them feel good, like Carmen who said that a good day made her feel "just really good inside, like just really good about myself," or Jesus who stated that a good day is "well being happy."

The participants with disabilities indicated some significant values that they held. Speaking of their ideals and values indicates that these participants had a belief system that they could use to guide autonomous decision-making (Stainton, 1994). Alex said "I uh I read the Bible a lot and I pray too." Juan said "I wanna do a good l- good things in my life. I wanna get a job. I wanna make money, and when I go to a group home, I wanna be independent."

Challenges for DSPs are challenges to supporting autonomy. This second primary theme emerged from comments from both participant groups that indicated that the challenges that DSPs faced within their jobs often presented challenges that prevented DSPs from supporting autonomy in people with ID. In the following sections I will describe the fine line that DSPs walk in balancing supporting autonomy of people with ID and meeting other demands of their challenging positions; the often insurmountable institutional issues they face supporting the autonomy of people with ID; and the challenges of the DSP role that can make it difficult to support people with ID. Each of these areas contributes to the challenges that DSPs face in supporting the autonomy of those they provide services to. This theme included three subthemes: walking a fine line, institutional barriers, and a challenging role.

Walking a fine line. The first subtheme identified as a challenge to supporting autonomy related to the difficulties DSPs often face in providing support to people with disabilities. Both participants with ID and DSPs contributed to this subtheme. The DSP

participants in this study often walked a fine line in balancing many varied and

conflicting objectives of their jobs and supporting the people they worked for to be

autonomous. The DSPs seemed to have to navigate through uncertain boundaries where it

was difficult to know how to provide support, how much or how little support to provide

(e.g., how much was too much), and when they should just back off all together. They

seemed to walk a fine line between subtle influence and blatant control that may have

stemmed from the institutional support that they provided to people with ID. For example

several DSPs discussed eating restrictions they placed on the people that they supported

because these individuals did not make healthy eating choices. In restricting them, the

DSPs acted on institutional (i.e., agency) objectives to support health, but in doing so also

exerted blatant control over people with ID. These participants seemed to support agency

objectives over the individual objectives that people with ID had.

DSP participants also seemed to walk a fine line in understanding how to help

people with ID in ways that support the goals of the person receiving services. DSPs may

not always support people with ID in ways that people with ID see as meaningful. It may

be challenging for DSPs to determine when and how they should intervene and for what

reasons. In discussing the kinds of assistance that they needed, the participants with

disabilities talked about needing assistance with more difficult tasks such as using the

computer, managing money, paying bills, taking medicine, and so forth. Katrina said

"well I need them to help me with finances and help me with computer stuff. I definitely

need them to help me with those things." Tito stated that they way his staff provided

assistance was to "go over the books [agency record keeping books, including

information on daily living, health and safety, and behavior], see our books, update stuff,

medical forms done." These quotes indicate that they need help with some of the difficult aspects of managing life that people without ID often require assistance in. Katrina said that "my feeling is that they [DSPs] want to do the easy stuff not the hard stuff, and I need them to do the hard stuff more than the easy stuff." Alejandra, in speaking of a DSP that she considered to be helpful said "she was just a very observant person, uhm, and I think you need someone who's observant. You need someone to pick up on things, even if I don't know that I'm struggling with this or that."

None of the participants with ID stated that they received or needed help with everything, but the DSPs interviewed in this study often emphasized the help that they provided. This illustrates that DSPs may have difficulty in determining how best to provide support, and understanding the boundaries of the support that they provide, possibly because they perceive the people that they support as lacking competence. Matthew stated:

> No we do everything… give them their meds, we feed them, we clo-, we help clothe them, we make sure they're safe, if there's health issues, we make sure we contact the nurse. Uhm we offer friendship, we offer companionship with them… if they have behavior problems, we try to alter it as best we can.

Jennifer, another DSP, said "when I worked at the house, I did everything." Sophia, in response to a question about what support she provided, stated "oh man, like everything." The variance between the responses of DSPs and people with ID on this topic seems to indicate that DSPs also walk a fine line in defining the boundaries of their role. It seems unreasonable that any DSP does everything for any person with ID. The things that seem to make up most of a typical person's life usually require minimal assistance even for

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people who have extensive support needs (e.g., sleeping, relaxing, watching TV, etc.). It seems that the DSPs emphasized their role because they did not perceive that people with ID are capable of managing their own lives.

Some of the DSP participants were cognizant of the influence that they or others had over the people that they supported. These DSPs walked a fine line in balancing influence and autonomy because this influence might impede the autonomy of the people they supported. Several discussed situations in which guardians' values impacted the support that DSPs provided to individuals with disabilities. Sandra said:

> Well one of the guys I had worked with at one of the houses, his mother was Mormon, and so he couldn't drink caffeine, or couldn't do any of that stuff, even though he went to a Catholic church and it didn't matter to him. Still, she was his guardian and so her values were legally important to him, and he could care less about caffeine or anything like that.

Matthew said:

> I think sometimes the team and guardians kind of force their beliefs on our consumers… 'someone will say 'I hate smoking. So I don't want him smoking.' 'Who the hell are you to say that he can't smoke? Maybe he likes smoking. Maybe it is unhealthy, but that's his choice."

Some of the DSPs interviewed also recognized that DSPs may impose their own values on the people that they support. DSPs walk a fine line in supporting people with ID to be autonomous and influencing their values. Christian further explained how DSPs subtly influence the people that they support. In the way that Christian described it, it seems subtle and pervasive, so that DSPs and people with ID may not even be aware of it

occurring. In discussing her and her co-workers' influence on the people that she

supported she stated:

> You know like the world view of the staff… their [people with ID] behaviors are
>
> controlled in this particular way that has been established over such a long period
>
> of time, that it really feels that the staff's world view… is kind of taught to the
>
> individuals… The world is filtered through what the staff thinks… they have so
>
> many staff too that they get a lot of world views.

Participants with ID discussed the importance of DSPs knowing what their jobs

are and knowing where to draw the professional line. Knowing where to draw the

professional line meant that DSPs understood that they were professionals, not friends or

family of the people that they supported. It also meant that they knew what their job was

and they did it. In doing so, they supported the autonomy of the people that they worked

for. The comments of the participants with ID indicate that it may be difficult for DSPs to

judge where to draw the professional line and what exactly they need to do to support the

people that they worked for. Katrina said "well I want them to do their jobs we- I want

them to do what they're being paid for. That doesn't quite always happen like it should."

Tomas, in response to a question about the kind of support he receives, stated that DSPs

help him "in living, and where I could have a better life," indicating that he understood

that the support could improve his life. Alejandra said that "I feel like I can live my life

when everyone around me knows what they're supposed to be doing." Some of the

participants with ID discussed, specifically, the importance of drawing a professional line.

Alejandra said that "in order to keep the professional line, you know there's a certain

amount of relating that I cannot do with my staff just because we want to keep things professional."

In contrast, the DSP participants sometimes regarded themselves as being like friends or family of people with disabilities indicating that they had difficulty determining the professional line that Alejandra spoke of. Their statements also seem to emphasize their role in the lives of people with ID in ways that did not seem to value their competence in being autonomous human beings. The DSP participants had difficulty balancing the intimacy of the support relationship with acting in a professional manner. Christian said "I kinda end up taking a parental role about it, even though they're like 50." Matthew stated

Uhm you know how parents their, they take care of them, they make sure every their needs are met. We're also there a lot, The people that take care of them are the people that they see most often. We're kind of like their families.

Karen, another DSP, went a little farther in her explanation of why she perceived her role as important to the people she supported when she said:

Uhm, I am really key to their world, whereas they may not be as centered in mine. So they see me every, I see them every day, but I also see other people. They see their home staff, they see their dayhab people uhm, I'm not saying that they don't have friends that are peers, but a lot of times they're closer to their home staff than they are to what would be considered a more normal balanced friendship or relationship… when I'm with them I'm in their world, and then I leave and I go to my world. They don't have a world that's separate from me. I have a world that's separate from them.

The participants with ID when asked directly were unlikely to say anything

negative about their support staff (this may have been related to their fear of saying

anything negative about the DSPs, especially because I held most of the interviews in the

homes of the participants with ID while DSPs were present). When asked what the

support staff could do better, most participants struggled to think of something, or

answered "nothing", even when prompted further. Over the course of the interviews,

however, participants with ID told stories that brought out some of the issues that the

DSPs supporting them faced in balancing support and autonomy. The problems they

described often related to the difficulty DSPs face in defining boundaries and

understanding when they should intervene with support and when they should back off.

The following examples demonstrate that participants with ID perceived that the DSPs

did not provide enough support. Katrina, for example, spoke about experiencing a lack of

support when she said "let's see what support I get. It's not. It doesn't always feel like

it's a lot." Tomas told a story about when he wanted a DSP to intervene and advocate for

him in a medical situation that he experienced. He said:

> Nobody didn't even care about me. They didn't wanna give me no support. They
>
> didn't even wan-, nobody wanted to back me up. They want me just leave, be
>
> uhm all by myself, and that isn't fair. That makes me very angry!

The following comments demonstrate how participants with ID perceived their

staff as overstepping their boundaries by being controlling. Alejandra said "I think there's

a way to take charge of of stuff that needs to happen in a house without taking charge of a

person." In talking about a specific support staff, she also said "it almost felt like when

she came into my house that I worked for her instead of her working for me." Tomas also

addressed issue of control when he said

> I just get mad about when people tell me you can have st- so much stuff in your
>
> room, and I tell them it's my life, nobody can tell me how to live it, and I choose
>
> what I wanna do, and that really makes me mad when they, people tell me "no
>
> you can't your room is like a like a mess", I don't care if they wanna say it about
>
> me I'll take off, and I feel like I'm being insulted.

David also addressed this issue when he talked about being prevented from going on

walks in the following discussion.

> David: Oh well when I had, I get to go walking, when I have Sandra, they don't
>
> let me walk anymore.
>
> Jami: Do you ask them?
>
> David: I try to.
>
> Jami: And what, what do they say?
>
> David: They say let's go in the car.

The DSPs in this study walked a fine line in setting the boundaries of their role in

supporting people with ID. Both participants with and without ID, discussed the fine line

in supporting both independence and autonomy. Some of the DSPs discussed the

assumptions they had about supporting people with ID to be independent, but in

providing support they may be inadvertently controlling them. For example, they may be

supporting them to do things that people with ID are not interested in doing in the first

place in a subtly pervasive controlling manner. Maria, a DSP, in telling the following

story, indicated that her values in keeping her house clean and tidy should also apply to

the people that she supported. She stated:

> I tend to tell em "I'm here to assist you, and you know, now this is your home.
>
> This is your home and everything, and I have my home, and I keep mines up to
>
> par-tay [clean and orderly], and this is yalls'. And I'm here to assist you in
>
> whatever way I can, in helping you to keep, you know to keep you house, and to
>
> you know cook or… That's that's me.

Although she wanted them to be independent, it seemed that she enforced her value on

their independence. Jennifer, another DSP, discussed how her co-workers provided

support in ways that were not needed or desired and that may be controlling of people

with ID. She said:

> I still see uhm some staff uhm automatically doing stuff for people with
>
> disabilities, as opposed, and and it might be, well that might be, it is a natural
>
> human behavior to try to do something for someone with disability, as opposed to
>
> maybe waiting for them to ask for help.

Some of the participants with ID also discussed how their support staff made

assumptions about people with ID based on what the DSPs believed was important. By

making assumptions these DSPs may have inadvertently exerted control over participants

with ID. When these DSPs exerted control over the people that they supported, they

usually did not seem to be supporting their autonomy (though there were exceptions in

dealing with challenging behavior discussed later). Alejandra, a participant with ID,

provided an example of this when she stated that:

that's part of some people's personalities. They like to be organized. They like things clean and tidy. I don't give a rat's butt about stuff like that sometimes. I realized that I don't want cockroaches all over my house, but uh beyond that I don't really care. So if I have piles of laundry all over my room, that's okay. And I'm perfectly capable of changing that when I choose.

DSP participants walked a fine line in determining how much support is enough and how much is too much. Though it seemed that they sometimes inadvertently acted in controlling ways, DSP participants sometimes seemed to choose to exert what seemed to be blatant unwarranted control over the people that they supported. The following illustration provided by Anthony implied that the person Anthony supported was not competent to make minor decisions, and that the person needed to be controlled. In this story Anthony talked about institutional control (observation) coming into conflict with personal objectives (eating ketchup), and demonstrated how institutional control might prevail. Anthony said:

> If I, we go out to eat with one of the guys he loves like his condiments on his food, and he knows you know that he's only supposed to have you know 2 or 3 ketchup packets, you know for his French fries, but if you weren't there observing him, he would probably be taking you know, 10 or 20 ketchup packets and he would end up eating it all.

Many of the DSPs actions discussed by both groups of participants demonstrate how DSPs frequently err of the side of institutional control. Institutional control seems to be built into the system of providing support, requiring the DSP participants to walk a fine line in supporting autonomy and enacting institutional control expected of them by

the agencies they worked for. Matthew expressed this when he said "I never worked at an agency where they [people with disabilities] could go wherever they want. But [if] they can do whatever they want whenever they wanted, they wouldn't need the agency, right?" Control, it seems, is just part of the programming and was perceived by DSP participants to be part of their job. These interviews indicate that DSPs may frequently enact control instead of providing support.

Participants with ID, in contrast, discussed the need for DSPs to back off, or be less controlling. Their comments illustrate that it may be a fine line for DSPs to determine what constitutes appropriate support and what constitutes control. When these participants' support staff acted in controlling rather than supportive ways they impinged upon the autonomy of these participants with ID. Tito stated "need it, my time alone." Carmen said "You know I'd like to be treated like an adult, and I need my my personal space and they give me my personal space." Tomas, in talking about a DSP who had difficulty determining boundaries of support and control, stated "he could have not got on our cases, not yelled at us, not butt into our lives."

Participants with ID who lived in supported and assisted living (which included seven of the ten participants with ID involved in this study) also discussed issues that made their homes seem almost institution-like. They discussed how some of their homes seemed to have institutional characteristics and told stories that highlighted how agency objectives were given priority over their individual goals. When this institutional control was exerted it seemed to limit the autonomy that these participants expressed. Alex pointed this out when talked about how it was difficult for his support staff to take him places. He said "yeah we have 10 people here. And I heard that some (residential

provider) homes have as many as 17." Alejandra commented on the institutional support

that she received where institutional objectives are favored, when she said "I end up

having to fit to their schedule and their lifestyle instead of the other way around, instead

of a mutual appreciation for someone's lifestyle." Carmen aptly stated:

> I'm just against how it's [the Individual Support Plan that guides the services
>
> people with ID receive] set up, and like how we have to write the… goals and the
>
> outcomes and everything, and it's like everything is turning into this big ole
>
> bureaucratic government thing, when it should be… if it's person centered, then it
>
> should be person centered.

These DSPs walked a fine line in establishing boundaries of support and

promoting autonomy because of the institutional control that was part of their jobs. The

DSP participants spoke about the rigidity and inflexibility of the programs used to

support people with ID that seemed to prioritize objectives of the support agencies over

those of the individuals served within the support agency. Matthew said that the programs

"put em in an environment that's maybe you know, more uhm, more controlled, more

where they don't have a lot of flexibility. You know their their routine is very

controlled." All of the DSPs involved in this study worked in residential support settings,

and their comments illustrated how the homes they worked in had the distinct feel of an

institution. Christian said "it just feels like they, even though the house is part of the

community, and it's just there's something still about the way it is that feels like it's a

little bit more like an institution."

All but one of the DSPs interviewed in this study discussed the safety, protection,

or well-being of the people that they supported. These issues seemed to be the

cornerstones of the decisions that DSPs made in their professional roles. DSPs seemed to walk a fine line between supporting autonomy and balancing safety and protection. Some of these comments also seem to suggest that DSPs did not value the competence of the people that they supported or that they imposed values of safety on the people that they supported even though the people they supported might not value those things themselves. Matthew, a DSP talked about feeling a responsibility to protect the dignity of the people that he supported:

> I'm gonna check my consumers as best I can… I take that as a matter of pride, and there are times… I've had people on the outside make demeaning comments about my consumers. Don't do that in front of me because I will go off… I'm sure that's not appropriate. We're not supposed to deal with them that way, but if they ever question me. I'm like hey I'm protecting my client's dignity.

This statement, although about protection of dignity, also seems to indicate that this DSP does not perceive the person that he supported as being competent to defend his own dignity. Stephanie, a DSP, discussed protecting the emotional well being of people she supported when she said "uhm safety and welfare, I consider that also their emotional well being. Uhm I mean for me that's most important, to make sure that their… emotional needs are taken care of, that they're safe."

The following statements seem to indicate that DSPs may be imposing the value of safety on the people that they support (or indicate that people with ID need safety and protection because they lack competence). They also seem to hint at supporting institutional objectives for safety and thus might contribute to an institutional control, wherein these DSPs act on institutional rather than individual aims of the people they

support. Karen, a DSP, talked about balancing safety and dignity of risk "Uhm safety is a big thing. You know, the balance of safe- safey and dignity of risk, which is a constant discussion topic." She also wanted the people she supported to be in charge of their own safety. "To me it's teaching them about how to keep themselves safe is number one," indicating that she perceived that safety was something the people she supported should value. Charlie succinctly stated, "the policies are structured so we're ensuring the health and safety of the individual."

However, as the following comment illustrates, the DSPs interviewed and the participants with ID may have different ideas about safety and protection. Because participants with ID rarely brought up safety, protection, or health, it seems that it may not have the primacy that DSP participants gave it. This could, however, be the result of being overprotected and not having to face consequences of being unhealthy or making unsafe decisions. DSPs walked a fine line in providing safety and protection to the people that they supported and in allowing them to have dignity of risk. Alex, a participant with ID illustrated his feelings about protection. He talked about feeling that the protection that he received (albeit from his family rather than support staff) prevented him from making friends. He said:

> Every time I would say hi to strangers and they [his family] would say "we don't know them." I thought they were trying to prevent me from making new friends. And I'm not afraid to talk to strangers but I've been told that it's dangerous.

The institutional concern for safety, sometimes lead to fairly extreme actions by DSPs and support agencies. Karen, a DSP, provided an example of protecting safety

wherein she told a story about a person that she supported who was prevented from going to church independently in an attempt to protect his safety. She said:

> There's the fear that he's gonna choke. The fear that, you know, that if that does happen even though he does have good natural supports at church, they're going to freak out, and then you know he's not going to get to go by himself anymore cause they won't be willing to support that anymore.

In this example the fears of the agency, based on the organizational goal to minimize aspiration risk interfered with the autonomy of the person supported. He was no longer allowed to rely on his friends (natural supports) at church, but was now experienced institutional control where he was observed by DSPs who mandated adherence to his eating restrictions.

The DSP participants walked a fine line in knowing when to ask a person that they supported to compromise or to concede. Every single DSP participant brought up compromise as a way to deal with tough situations, either in their responses to decision-making scenarios (refer to Appendix B for specific scenarios) or through the stories that they told. These DSP participants used compromise when they perceived the decision that a person with ID might make as unsupportable because the decision was unrealistic. They used concession when they perceived the decision of the person they supported as unsupportable because the decision was poor.

DSP participants used compromise to help the people that they supported to get closer to their goals. Charlie said that in supporting people with ID, it was important to "look at what the individual wants. Okay, how can we make that happen… if it sounds like a bad idea, how can we make it a better idea?" This participant seemed genuinely

interested in supporting the goals of the person he worked for, and used compromise as a way to support that individual's autonomy.

Although DSP participants in this study perceived that compromise was a natural part of life, they used concession as a way to coerce or control the people that they supported. In this sense they were actually using concession. Every DSP interviewed brought up compromise as a way to deal with challenging situations they faced in supporting people with ID. Jennifer said "everyone doesn't get what they want all of the time, and that is real life. So I would really try to explain explain all of that, and ask for a… compromise." Karen stated that "other people are involved in almost everything you do, and it's not just your world. It's other people's world, and so you have to make compromises and just give up things, because it's not going to happen." In speaking of compromise, they seemed to be indicating that they asked the people they supported for concession. These DSPs seemed to have an idea about how an issue should be resolved, and would then ask the person they supported to "compromise" or concede to that idea. Jennifer provided an example of forcing a concession of the person that she supported. She said "I told her that she has to bathe, you know wash prior to me picking her up, or if not I would not take her. You know I would not put her in my car." There are several reasons why this may have occurred. It may have occurred because Jennifer was under institutional pressure by her agency to ensure that this person was clean, or it may have been because Jennifer thought that this person's poor hygiene reflected on her own ability to do her job as a DSP. It might have been because she was genuinely concerned about the health of the person that she supported, or it may have been simply because she could exert the control. The person Jennifer supported was, after all, dependent on Jennifer for

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a ride. Regardless, Jennifer was forcing this person to comply with a decision that she had made.

The DSP participants also expressed difficulty in ensuring that people they supported understood the decisions that they made and the potential consequences of those decisions (or in supporting informed choice). They seemed to walk a fine line in helping those they supported make informed choices and in repressing information and experiences that would have provided these individuals with natural consequences that they could learn from. The DSP participants wanted the people that they supported to have natural consequences, but they also perceived that they had to restrict their access to certain kinds of information and experiences for various reasons.

The following examples illustrate how DSPs tried to support informed choice. In response to a decision-making scenario (where DSPs had to walk through the decision-making process about how to support a person who wanted to have a physical homosexual relationship), Stephanie said "my first decisions would be, is this person capable of making an informed choice? Is she being manipulated? Is this what she actually wants?" Christian expressed that she was concerned with "trying to help them [the people that she supported] create their own more logical thought process to resolve or get done what it is they want done… that's what it seems like my job is." She indicated that she not only wanted the people she supported to understand the consequences of their decisions, but wanted them to be more independent in going through the decision-making process and thinking through the consequences.

Though DSP participants discussed the difficulty of supporting informed choices in the people they worked for, they also discussed repression. Many of the DSP

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participants talked about repressing information that they would share with the people

they supported, and sometimes repressed their experiences by preventing them from

engaging in certain activities. DSPs walked a fine line in allowing for natural

consequences, providing information, and repression. This repression necessarily limits

their autonomy because they do not have information or experience on which to base

decisions. Karen said "I'm like, 'Oh I love your nails, we were talking about boys. Aren't

boys silly?' But half the times it was something that I couldn't share with her, I mean

that's that's what I would make up." In this comment Karen was talking about how she

lied to the person that she supported so the individual would not know the information

her support entailed that Karen was sharing with another staff member. Maria, in

response to a decision-making scenario about helping a person with ID who was lesbian

purchase a sex toy (refer to Appendix B), said that she would "try [sic.] to discourage her.

I I would make it very difficult to find that place, the place for her to go purchase, for me

and her to go purchase that object." In this way Maria, repressed the experience, so that

the person that she supported was unable to meet her goal. Charlie used protection from

danger as a means to repress the experiences of the people that he provided support to.

He said "protecting them from danger is really just making sure we don't put them in a

bad situation, where bad things are likely to happen."

     Participants with ID and DSP participants both discussed the importance of

people with ID experiencing natural consequences. The DSPs in this study specifically

discussed allowing the people that they supported to experience the consequences of their

mistakes or from their challenging behavior. The DSPs in this study, it seems, walked a

fine line in allowing people with ID to experience natural consequences, providing them

with information, and repressing the kinds of information and experiences they had

access to. Because safety, health, and protection of people with ID seemed to be priorities

of the provider agencies, it seemed to prevent people with ID from learning from their

mistakes or having experiences to learn from in the first place. Alejandra, a participant

with ID, stated "it's like "everyone is so into making sure I don't reap any consequences.

I think that I su-, you know I could suffer, you know what I'm saying?" Matthew, a DSP

said "There's very little consequences for these guys." Charlie, a DSP told a story about

feeling pressured to prevent a client from experiencing natural consequences for

something illegal that he had done. About this experience, he said:

> once again like I said, there really aren't too many sanctions or consequences for
>
> these guys. Uhm, and when something like that does happen, and you know that
>
> they were totally doing wrong, you're somewhat tempted to let em face those
>
> natural consequences, or I mean you know they should be allowed to face the
>
> natural consequences.

One participant with ID discussed how DSPs sometimes acted as a buffer to her

having authentic interactions with others. In this case, the DSP navigated the experiences

of Alejandra, so that Alejandra did not get to fully engage in the experience herself. DSPs

might dilute the authenticity of the experiences that people with ID have if they are not

careful to allow the people that they support to engage fully in the relational aspects of

typical life. Alejandra, a participant with ID, in speaking about her job coach said "the

job coach develops a relationship with the boss or supervisor or whatever, and I fell out

of the loop." She indicated that the job coach formed the relationship with the supervisor

and she was left out. She also discussed how the supervisor would not talk to her, but relayed messages through her job coach.

Institutional barriers. The second subtheme identified from the interviews that presented a challenge to supporting autonomy was institutional barriers. Both participants with ID and DSPs contributed to this theme. As discussed briefly above, DSPs sometimes enforced institutional control that highlighted how agencies agency objectives were prioritized over individual objectives. This subtheme was called institutional barriers because it illustrates the issues involved in managing support (at the federal, state, and agency level). These issues related to the participants with ID, only because they received support under this system. The issues discussed in this section, however, had profound effects on the support that participants with ID received and how DSPs engaged in their work, especially in how they supported the autonomy of people with ID. For example, DSP participants and participants with ID discussed issues with support being inflexible or inappropriate for people with ID, especially in the areas of local transportation and travel to other places. This presented problems when people with ID autonomously expressed interest in travel, and DSPs literally could not support those interests. This theme seems to demonstrate that when managing support systems, the institutional (the entire support system at the federal, state, and agency level) objectives are more highly valued than the autonomy of the people served within the system. This prioritization presents institutional barriers to supporting autonomy.

Services in the support system provided under the DD waiver (the waiver that pays for the support that most adults with ID receive, and that nine of the participants with ID in this study received) are rigidly defined (i.e., there are service categories such

as: supported living, community membership, day habilitation, job coaching, respite

services, etc. that have been predetermined and are the only services offered to people on

the waiver). Because of this, there is little flexibility within the DD waiver to

accommodate individual choice. This seemed to cause problems for participants with ID

because services did not meet their self-identified needs or interests, and sometimes the

processes of providing support directly conflicted with their autonomy. There is more

flexibility within the self-directed waiver; however, very few people within the state are

served on this waiver (and only 1 participant in this study, who actually received job

coaching, which is a typical DD waiver service).

Participants with ID and DSP participants both spoke on the issue of inflexible

services provided to persons with disabilities. Some services that participants with

disabilities wanted or needed were not perceived as adequate to meet their needs. Katrina,

a participant with ID, expressed her perceptions of the inflexibility of job coaching

services to meet her needs, when she said "well let's see jobs could be better because

when you have a job coach they only work with you six weeks and then they're done, or

you have them forever and forever if you're on the waiver." It seems that in managing

support systems, sometimes people with ID are forced to adhere to rigid systems that are

already in place, rather than the system accommodating to their individual needs and

preferences. The participants with ID also discussed services that were inadequate

because they could not depend on them. Alejandra, a participant with ID, in discussing

special transportation said "I wouldn't want to count on them to get me to a job because I

highly value being at my job on time, and that [the historical undependability and

inflexibility she experienced from the service] would give me a heart-attack." In fact,

several DSPs and participants with disabilities listed local transportation and travel to

other places as a needed support, that as currently provided, is inadequate and inflexible.

Matthew, a DSP, in talking about a trip one of the people that he supported was supposed

to take, stated:

> A lot of the restrictions come because of staffing issues and money you know…
>
> when we took that gentleman to California, it was planned, he was ready to go,
>
> and we find out by our executive director that from the governor on down, no out
>
> of state trips. We're not going to pay the staff, and we're like "oh my god" this is
>
> like a couple of days before they're they're going to take off. So what had ended
>
> up happening was that he had to pay the staff out of his own pocket.

Both issues of inflexible (services offered in a way that participants with ID

perceived as not meeting their individual needs or interests) and inappropriate (services

that were not individualized to the person with ID) services also seemed to be apparent in

the issue of employment. Most of the participants with ID stated that they wanted to work.

Inflexible and inappropriate employment services, however, did not support their

autonomy. Further not having jobs, when these participants wanted them, meant that they

perceived this support as inadequate. Juan, a participant with ID said "only thing is, only

problem is, I don't have a job, I'm not even happy about that." All but one of the

participants with disabilities brought up less than ideal work experiences that did not

seem to recognize their capabilities or their autonomy, and that were inappropriate work

experiences. Alex, for example, discussed the unimportant and meaningless work his

inflexible job entailed, "I used to work for a company called People Working Together…

and my job was to count nails. I'm not sure how I ended up counting nails exactly, but

that seems to be what everyone did." They also discussed the inappropriateness of

working in jobs where they didn't make money, as Tito stated "but that job that job that

job didn't pay at all," and David stated:

> I worked at (names thrift store) and… Brett Baker wanted me to work for free,
>
> and I said "If you're gonna do that to me, I'm getting out of here. You're gonna
>
> do this to me. I'm not gonna take this kind of garbage. I'm a self-advocacy. I
>
> wanna stand up for what I believe in cause I wanna make money. I don't wanna
>
> just work for free. I don't wanna do that.

 Some of the participants with ID also talked about the inappropriateness of the jobs

being too stressful or difficult for them, such as Carmen who stated "it was just so much

stress on me, and I was like you know I don't want to do this job." Matthew, a DSP

participant, echoed the participants with ID, when he said "we could get em jobs, that

would be good for em," and discussed further how he believed the employment services

provided to people with ID were inflexible.

Both DSP participants and participants with ID discussed the inappropriateness of

some of the programs (those discussed above: supported living, day habilitation,

community membership, job coaching, etc.) or plans (ISPs discussed below) offered

through the DD wavier to people with disabilities that were not individualized to support

the autonomy of the person for whom they were developed. Under the current system

Individualized Support Plans (ISPs) are a required component. These plans are written

for people who receive support that identify the kind of support the individual with

disability needs and the goals that s/he will work on for the year. They are created by a

team of individuals who know the person with ID and who provide services directly and

indirectly to the individual with disability. The individual, as well as people that they

choose to advocate for them, or that legally advocate for them are also members of the

team. Katrina, a participant with ID, spoke sarcastically about community membership

services (support for individualized integration into the community to develop natural

supports that are specifically concerned with individualization) that she received when

she stated:

> There were places I wanted to go to, but they [community membership staff]
>
> didn't want to take me to there and it's supposed to be what you want. And I have
>
> this other person with me cause they like you know how they like to have more
>
> than one person.

This quote illustrates how, in order for the provider agency to make sufficient money

from supporting Katrina to access the community, they had to provide her and another

service user with services simultaneously. When service provider agencies provide

services in this manner, it seems that they are set up in a way that cannot be

individualized. The goal, it seems, is to be as cost-efficient as possible. For Katrina this

meant that the service did not do what it was intended to do, and was not individualized

or appropriate for her.

Some of the participants with ID discussed how the ISP process itself clashed

with their expression of autonomy. The ISP process is necessary for agencies to receive

funding to pay for the support services that they provide to people with ID. The intent of

the process is to create a plan that will allow for an individual with a disability to receive

supports that are individualized and help them to meet self-defined goals. The ISP

process, it seems for these participants with ID, seemed to be yet another institutional

prioritization, wherein they were forced to adhere to its rigid structure, regardless of their

personal preferences. For some participants this process was in contrast to their identity

and the way that they would pursue their autonomy. The following quotes seem to

indicate that the ISP process (required for agencies to receive funding, and for every

participant with ID involved in this study to receive services), though it promotes the idea

of person centered planning, does not actually promote the autonomy of these

participants with ID served within the system. Instead it promotes the goal of the

agencies to be paid for the support that they provide to these participants. The ISP is

developed annually at ISP meetings. Carmen discussed how her autonomy was impinged

upon by the very ISP process that was supposed to support her goals, specifically ISP

meetings. She said, "I'm a person who does not… take well to things like you know ISP

meetings and stuff [a required annual meeting for receiving support services]… You

know it just just does not belong in my world I guess you could say." Under the current

system, as a form of accountability, agencies are required to provide evidence of

monitoring goals (as evidence that they are providing necessary supports) for agencies to

receive federal funding to provide support services. These goals are created at an annual

ISP meeting and continue for one year, unless any member of the ISP team calls for an

ISP meeting to change them. Jesus felt pressured to keep working on the goals identified

in his ISP, even though he didn't seem interested in them anymore (or for that matter,

may have never been interested in them in the first place). He said:

> Uhm just go to, one day we have art class, so we do art a lot, so I don't do art
>
> anymore, and he [a dayhab support provider] says we have to keep going we have
>
> to keep going, that's the goals, we have to keep going and trying to make it up.

This quote seemed to indicate that Jesus perceived the ISP process of working on the same goal for an entire year, even after he had decided he did not want to work on it anymore, as not promoting his autonomy (evidenced in his statement of not wanting to do art anymore, even though it was his goal). One participant with ID, Alejandra, discussed how agencies promote person centered planning, but instead enforce institutional objectives. She said "I think it's funny that… they create this idea about being people-centered, and they don't even know how that's supposed to look. They miss it, you know."

DSP participants addressed some of the same concerns about the ISP process's inadequacy to promote the autonomy of the people they supported. Matthew said "one of my consumers was supposed to make a garden and tend it [as a goal listed in his ISP]… Uh he didn't really seem interested in it, and he turned out pretty much pretty much we were doing all the work." Christian talked about how the agency she worked for was more concerned with meeting its own objectives (providing documented evidence of support specified in the ISP in order to receive compensation) than the individual objectives of the people that the agency supported. She said:

> It's like the outcomes they're pretty limited in terms of, and it seems ultimately
> like that's all that anybody cares about, that the outcomes sheet is checked off
> [documentation required to receive funding], and that that's been achieved. And
> it's like well if someone cooks twice a week, is that really them having a
> meaningful life?

All but one of the DSP participants interviewed for this study, discussed issues relating to the administrative management of the provider agency that they worked for.

These DSP participants discussed issues such as administrative staff not caring about DSPs, promoting fear in DSPs, being controlling and coercive, and limiting the DSPs ability to provide what they constructed as good support. Administrative problems such as these would seem to affect the ability of these DSP participants to promote the autonomy of the people that they provided support to because their autonomy as employees did not seem to be supported. In sharing these stories, it seems that DSPs perceived that in addition to prioritizing agency goals before the goals of the people supported, agencies also prioritized agency goals over the knowledge, experience, and safety of DSPs, and that in doing so may have prevented these DSP participants from supporting the autonomy of the people that they supported because they were not able to advocate for them, or lacked power themselves. Matthew told a story about a time when he was injured by a person that he supported who was aggressive towards him, and the agency he worked for demonstrated more concern about the agency's liability than Matthew's safety. After this situation, he was questioned about what he did to the person that he supported to cause the aggression, not how he was injured He expressed his frustration in this statement:

> You know, most often not they're gonna get hurt, it's gonna be the staff, you know. Uhm all of the rules and regulations are there to keep them safe and not the staff, and that's just not right. You know I have the right to be in in an environment that's safe," and that "Uhm they only concentrate on the bottom line. Everything is money, period.

In expressing his frustration, Matthew seemed to be indicating that he did not feel cared about by the agency that he worked for.

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Christian provided an example of the pressure that she and he co-workers faced, from administrative staff, and how it promoted fear in DSPs, when she said "it just really seems that people [her co-workers] are so defensive and afraid for their jobs that they don't, you know the blame and concern about who's doing what wrong, and will they get fired for it." Sandra discussed how administrative staff were coercive and controlling in the kinds of support that they asked DSP participants to provide. She said that "she [a service coordinator] would make these suggestions that just didn't make any sense at all if she had actually known him. But she was the boss so that's what we had to do." Maria told a story about how her knowledge about what constituted good support was dismissed when she tried to advocate for consistency for the people she supported. She talked about how she felt that staying at the house was better for her and the people that the she supported. In expressing her frustrations she said:

> I did speak up. And they told me you had no choice, you going back over here… oh I was disappointed… but I was like okay… they keep on telling us this is sort of like the job description. And… we could be moved at any time and everything, and and I guess we shouldn't get so in involved."

This comment illustrates how Maria was at the mercy of the provider agency and had to do something that she did not believe was in support of the autonomy of the people that she supported.

There are many problems typically associated with DSP work (Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Larson et al., 1999; Larson & Lakin, 1999; Test et al., 2003a) that the DSP participants in this study also listed. These DSP participants highlighted the problems of staff turnover, lack of good wages and benefits, and lack of a

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career trajectory. These problems were often things these DSPs had no control over, but that seemed to affect their jobs because the problems contributed to the challenges of the job, and the challenges in supporting autonomy. In expressing their concerns in this area, these DSP participants seemed to be indicating that the DSP job did not support their own autonomy. These issues may have also affected the kind of support that they and their co-workers provided to the people that they supported. Stephanie stated:

> I've been here 15 years, and I make under 10 dollars an hour... they take a third of your check before you even see it. And then you're trying to make a living, and you're like "I work so hard and get so little."

Christian addressed those concerns, and also the lack of investment by DSP providers possibly because of it. She said:

> I mean those are basically the challenges of the job... that's kind of the nature of the funding of of this kind of projects... you just kind of have to accept that you're not going to get paid very much, and there's not a lot of support, and there's not enough people ever to help with everything that has to get done. So uhm, and then the people that you work with, you know, you're hoping that they're going to help, and then you know sometimes they don't even really care that they're there.

A challenging role. The third subtheme identified that presented challenges to supporting autonomy was a challenging role. Just as these DSP participants walked a fine line in defining boundaries of support and were limited by institutional barriers, they also discussed the challenges of their role as a DSP. This issue delineated just how complicated the role of direct support professional was for these participants. DSP

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participants contributed to this theme. In this subtheme, they discussed the parts of their

jobs that presented challenges to supporting autonomy. Specifically they discussed

dealing with people with ID who engaged in challenging behavior, imposing restrictions

on the people with ID that they supported, and making difficult decisions within their

daily practice. These participants perceived that the challenges they faced in the role

impacted their interactions in daily support provision. It seemed that for these DSP

participants, promoting the autonomy of people with ID that they supported might be less

of a priority than some of the more immediate aspects that their positions entailed.

My interviews with DSP participants did not include any specific questions

related to supporting individuals who engaged in challenging behavior (refer to Appendix

B). Every single DSP participant, however, brought up the issue of supporting people

who engaged in challenging behavior. It played heavily into how they supported people

with disabilities. Dealing with the challenging behavior of the people they supported

seemed to be the most frustrating and overwhelming part of their position. Anthony

expressed the emotional toll that supporting people who engage in challenging behavior

took on him when he stated:

> It's just kind of mentally draining too, just uhm always looking for triggers, and
>
> looking for, always observing their behaviors to see, you know are they escalating
>
> or are they you know in a good state. Just to see what kind of things, their likes
>
> and dislikes, what will make them snap.

Stephanie provided an example of what she believed to be the significance of the

challenging behaviors and how they affected her, when she said:

Because they're angry with someone else, like something happened at adulthab
[day habilitation; a service provided during the day to advance daily living skills,
vocational skills, and educational skills] something happened with their family,
then they'll take it out physically or verbally on you because they don't have the
capability of processing, "well I'm mad at so and so, so I'm gonna, you know, go
tell them I'm mad." They keep it bottled up and then sometimes they explode, and
sometimes you get it all, even though you may not be the reason, you're gonna be
the target… It's hard because you know that it's nothing that you've done, but it's
still just, you just get so upset. Sometimes you get angry at them too, and you just
want to vent yourself, but you can't. So you have to just like leave it all at work
and go home and just like, chill.

When behavior was reported as being less challenging, DSPs seemed to be a little more
relaxed, as Matthew pointed out "at my new house, you know, I'm better. I'm dealing
with consumers with less [aggressive] behaviors you know, before the types of people
that I was dealing with, you know for the last 8 years."

For many DSPs controlling their own responses to challenging behavior was, both,
difficult and extremely important to the outcome of the situation. Matthew stated "there's
my instinctual way I wanna deal with it, which is kinda confrontational… I've learned to
say… 'okay look, I know you're upset let's, can you stop cussing at me and we'll talk
about this." Karen said "control of yourself when you're involved in a high conflict or
frustrating situation. I think that's one of the hardest things to do when everyone around
you is going crazy." Although the DSPs interviewed expressed how difficult it was to
support people with challenging behavior and to control their responses to challenging

behavior, they also expressed concern that the challenging behavior of the people they supported reflected on their performance as DSPs. Christian expressed this sentiment when she said "if a behavior happens on my watch, I must not be doing something right. So therefore no behaviors happen on my watch." In this statement she seemed to indicate that the DSPs did not always document challenging behavior due to concern about how incidents of challenging behavior reflected on them. After this she expressed how she perceived that this lead to more challenging behavior in the long run because when her co-workers pretended that it didn't happen, it was never addressed.

The DSPs interviewed reported that they imposed restrictions on the people with ID they supported for many reasons. Restrictions, as these participants discussed it, meant that people with ID were prevented in some way from doing something because either the agency, people in positions of authority over people with ID, or institutional objectives prevented them from doing it. They perceived having to do this as contributing to the difficulty that they had in supporting the autonomy of the people that they worked for. For example, challenging behavior often led to restrictions that DSP participants had to impose on the people that they supported. Maria said "with the behaviors they had, they may have had to be restricted at home or not to go different places." The restrictions that these DSPs spoke of seemed to be imposed because of the institutional concern for safety, health, protection, and the perceived lack of ability of people with ID to make good choices. Matthew said:

> Those are restrictions that we don't, you know, like me and you, we don't have. I wanna be a pig and have high cholesterol and high blood pressure, I can. No one's

going to restrict me. Them, you know, we try to monitor and keep them under,

you know, on a healthy level.

DSP participants also discussed having to enforce restrictions imposed by the

prioritization of agency objectives or by people in positions of authority over the people

that they supported. Karen indicated that there were often many people with ID living in

the homes she worked in with few support staff, so that supporting the autonomy of one

of those individuals was difficult. She said "I think trying to balance schedules of the

three to four, or how many people are in the house can be difficult sometimes." It also

seems to indicate that people live in congregate settings so that provider agencies can

earn enough money to be able to support them by prioritizing institutional goals over

individual goals. Matthew discussed the issue of guardians having authority over the

goals of the individual that he supported when he said "it gets really complicated when

people have guardians. Because… if the guardian says 'well you will follow this diet,' we

kind of have to go with that."

I directly asked DSP participants to guide me through their decision-making

process in problem-solving scenarios (refer to Appendix B). The factors that these DSP

participants considered when making decisions included what they thought would make

the most people happy (i.e., service coordinators, co-workers, people with ID, etc.); what

would make their jobs easier, how to support safety or best interests of the people they

provided support to, and simply keeping their jobs. Some decisions DSPs perceived as

being completely out of their hands, and some DSPs perceived that they were at the

mercy of their challenging roles. The issues DSP participants brought up made it clear

that they had many competing factors to weigh in making decisions, if they got to make

them at all. The issue of decision-making also demonstrates how DSPs might experience

difficulty in promoting the autonomy of the people they support. Sandra and Maria

discussed trying to please everyone. Sandra, in speaking about what she considered when

making decisions, said:

Probably uhm not making myself insane because you could easily do that just

trying to keep everyone happy in a job like that. Sometimes it was just, you know

path of least resistance. Usually I tried to keep everybody as happy as possible, try

to keep the program director happy, try to keep the staff happy, and obviously the

guys [that she supported] happy.

Maria said that she made decisions where "everyone is okay I'm I'm I'm I'm at peace,

and they're at peace in whatever is going on. And when it's peace, it's peace (laughs).

It's peace, everything goes, you know, okay." Stephanie discussed decisions that made

the job easier. She said:

Sometimes it's easier to do it yourself [rather than expecting a co-worker to do it]

than to deal with the whole drama. Sometimes that goes with consumers too.

Sometimes it's just easier for me to make their bed, then to deal with the half hour

(laughing) "I'm not gonna do it."

Karen addressed the issue of using safety as a guide to make decisions when she

said she weighed "that balance of letting them [the people with ID that she supported]

have their lives, but also trying to keep them from hurting themselves or making

themselves sick." Anthony used the idea of best interests to make decisions. He said

"what influences me are the needs of the person, wants of the person with, what's in his

best interest. Try to find the happy medium." Several DSP participants stated that they

rarely had to make big decisions and sometimes just went along decisions to keep their jobs, indicating that they were at the mercy of their challenging DSP role. Matthew said "most major decisions are out of my hands. I'm a, you know I'm a grunt." Sandra said "Well the only tough decisions were with me and they weren't that tough because it was either go along with it or lose my job."

Caring in support of autonomy. The third primary theme that was identified in this study was caring in support of autonomy. Both participants with ID and DSPs contributed to this theme. This theme is in stark contrast to the previous theme "challenges for DSPs are challenges to supporting autonomy" because the issues the participants brought up in this section demonstrate how DSPs go above and beyond some of the institutional barriers that they face to support the autonomy of people with ID. All of the issues raised by participants within this theme contributed to demonstrating a caring relationship between these DSP participants and the people they support or these participants with ID and their DSPs. It seemed that when DSPs engaged in actions that demonstrated that they really cared about people with ID, they were more likely to promote and support their autonomy.

This theme encompasses participants with ID's positive feelings about DSPs, as well as the positive feelings that DSPs had about their job. Participants with ID also discussed the kinds of actions that DSPs engaged in that these participants perceived as being supportive or helpful. DSP participants provided comments on the importance of advocating, discussed the compromises they sometimes had to make to promote the autonomy, and defined their role of teaching the people with ID that they supported. Both participants with ID and DSP participants talked about teamwork, trust building, having a

positive attitude in the work setting, offering and supporting choices, having difficult conversations, and providing acknowledgement and encouragement. Both groups of participants discussed stigma and the value of treating people with ID with respect and dignity. DSP participants stressed the magnitude of really getting to know the people that they supported and demonstrating care.

Overall the participants with ID were happy with the DSPs who supported them and appreciated the assistance that DSPs provided. Most of the participants with ID regarded their current staff members as being helpful, friendly, or good, as evidenced by some of the statements that they provided in the interviews. It seems that having positive feelings might lead to a caring relationship that might foster autonomy. Pastor said "they [the DSPs who provided his respite care] are cooperative and helpful." Alex said "this living situation's good at least the staff tries to make it good." Carmen said "most of them are really really good… I really feel like I, you know like I'm comfortable with them." Jesus when asked for clarification about why he liked his support staff, said "cause they're helping you out with your goals, and it helps you with different things in your life… I like the staffs a lot too, and so staffs is really gives me support." Juan succinctly stated "they're [DSPs] good to me, they support me."

All but one of the DSPs interviewed in this study discussed liking their jobs or feeling drawn to the field of ID. It seemed that they cared about their jobs and enjoyed providing support to people with ID. Caring about their work might imply that these DSPs would also care about supporting the autonomy of the people that they support. Anthony said "there's a lot of freedom in it, and we get to go out and do a lot of fun activities, and a lot of the things I do, you can't really do in any other jobs." Sophia stated

"my mom worked here years ago at (names provider agency), uhm and I just always liked

being around everyone that I met here, and so I decided to come work here. I love it."

Stephanie discussed how even though it was sometimes difficult, she still enjoyed it. She

said:

> Ninety percent of the time I really like it. Of course there are times when
>
> everyone gets frustrated with their jobs, when things are slow to get resolved, or if
>
> they're having a bad day and take it out on you. It's like any job, most of the
>
> times it's really good, sometimes it's really bad. But I also can't imagine doing
>
> anything else.

Because both participants with ID and DSP participants discussed enjoying the support

relationship, their comments seemed to indicate that they cared about the support

relationship.

Both groups also discussed the importance of building trust. Their comments

about taking the time and effort to build trust also seemed to indicate that these

participants cared about each other. Carmen, for example, talked about the necessity of

trusting her support staff. She said "if it's like going into my room and helping me out

with something… I have to like really really trust them." Christian, a DSP, said "there's a

lot of trust building; that they know I'm gonna do what I say I'm gonna do." The

previous comment seems to indicate that in developing a better relationship with the

people that DSP participants supported, they built trust, and Anthony's following

comment seems to indicate the converse—that in building trust they developed a better

relationship. Anthony, another DSP, talked about how understanding the people that he

supported could build trust. He said "I guess that's kind of, once there's like a mutual

trust between you, the job gets a lot easier, and I think by understanding them, that trust can be built up a little easier and quicker." Matthew also reflected this sentiment when he said "they tell you in your training, don't get, don't make anything personal. Stay very very professional, but you really can't do that if you're planning on, get them to make, getting them to be be trustworthy with you."

DSP participants and participants with ID also spoke about the benefits of working together as a team (all of the DSPs and all of the people with ID receiving support in the support setting) and being compatible with each other. If these participants are able to have cohesive and compatible teams it might improve the autonomy of the people supported because the team may share values and have a common understanding of what the individual goals of the people they support are. Jesus, a participant with ID said "I kinda like people really working with us, work- working together." Both DSP participants and participants with ID discussed the importance of compatibility in teams. Carmen, a participant with ID, in talking about a staff member that she liked said "she appreciates my sense of humor," indicating she appreciates DSPs who valued the way she is, and who had a compatible sense of humor. Maria a DSP said "I told my supervisors and I told (provider agency) if uh, if they would to put me with the people that would like to, you know get out and about," indicating that she wanted to be around people who had compatible interests, so that they could do things they both enjoyed. Sandra discussed the potential implications of not working in cohesive and compatible team when she said "there has to be like a fluid thing between all the staff otherwise problems could occur." Maria similarly stated that "teams need to come together, and and like I said it's their their best interest."

The importance of DSPs having a good attitude at work was discussed by both participants with ID and DSP participants, and seemed to be something that both groups appreciated. As their responses indicated, having a good work attitude meant having fun on the job, laughing, smiling, and joking. Although participants with ID wanted their support staff to be able to draw the professional line, they also wanted them to be to act in a friendly lighthearted manner in the support relationship. When these DSPs had a good work attitude, they demonstrated care for the people they supported, and could better promote their autonomy. Carmen, a participant with ID, in describing a DSP that she liked, said that "they like to, you know, they like to laugh a lot." Tomas, a participant with ID, expressed what he appreciated about his support staff when he stated that "they try to make it happy for us around here… just by smiling and laughing and joking with us, and having a good time." Alejandra, a participant with ID, in describing her favorite support staff said "I mean we were like a married couple it was crazy. It was fun though, you know we joked about it and we had a fake anniversary and everything. It was quite funny." DSP participants similarly expressed the importance of having a good attitude. Matthew said "we [himself and the people that he supported] joke around… we always kid around and, you know, we we enjoy, you know, when we're there at work to make it as light hearted as possible." Maria said "so… we do things to uh keep em, keep em smiling, keep em from breaking their spirit you know, so many ways."

The DSP participants often discussed the importance of getting to know the people that they supported well. They expressed that getting to know and understand them supported the autonomy of the individuals with ID. The DSPs stated that they made an effort to learn about the people that they supported. Christian provided an example

that demonstrated that she was capable of determining how to promote the autonomy of the person that she supported, and more importantly that she had an interest in doing so. She stated that to determine what was important to the people she supported she tried "listening… and just being attentive when you're out and about… seeing what they're interested in and if they start talking, or what they point to, and then you know repeat over and over and over again." Matthew said he supported the people with ID he provided services to by "learning them. We can say 'okay he's saying no, but maybe he wants this, or he's getting upset you know, or he's pointing at', one points at his lip when he wants a cigarette." Karen expressed her care and concern for the people she supported and her desire to learn about them so that she could provide them with better support. She said "I really really like uhm being a part of their lives, and uhm being able to… figure out what what they need, what they want, what makes them tick, you know, so that I can help them better."

Participants with ID discussed their desire to be recognized and encouraged. Every participant with ID interviewed in this study brought up some of the things that they had done well or achieved, and indicated that they wanted me to recognize their achievements. It seemed that they were indicating that DSPs could recognize their achievements as a way to demonstrate care and support their autonomy. It also may have been an attempt by these participants to demonstrate their competence by pointing out their achievements. In addition, these participants discussed how their support staff could encourage them within the support setting to achieve their goals. Pastor said "like like when I do something right… they should say 'keep it going' and such." Juan in describing a positive interaction that he had with a DSP said "they'd [DSPs] say 'Juan,

think positive, think about your good time Juan.' 'That's a good idea…' 'Juan you have a good day at (dayhab) Juan.' 'Okay I will,' and… she goes 'That's what I like to hear.'"

DSP participants discussed the necessity of supporting choices of people with disabilities, and even encouraging them to make choices. In providing encouragement to make choices, it seems that these DSPs truly cared about supporting autonomy. Christian said "I mean the goal is really to help them live their lives the way they want to live their lives. So as best as you can, try to create opportunities, or be able to support them in their opportunities." Maria discussed how she encouraged the people that she supported to make choices. She said:

Always even in in our meetings [ISP meetings] "no what do you want? You done heard a lot of things, and you're you're, we don't want it to be an influence on you. Now what do you want?" And it is about them… that's my thing. It's all about them.

DSP participants also talked about the importance of providing encouragement to the people that they supported, especially encouraging them to express themselves and their autonomy. The DSPs' comments expressed that they cared about the autonomy of the people that they supported. Christian openly encouraged the people that she supported to express their autonomy, even if doing so offended her. She said "I try to really encourage all of them to just say whatever they need to say to me. They can offend me… they don't have to be nice to me. If they don't like something just tell me straight."

In addition, both groups of participants discussed the importance of offering choices. Offering choices seems to indicate that these DSPs cared about supporting the autonomy of people with ID. A participant with ID, Carmen, said "I'm very picky about

what I eat sometimes. So like she'll say uhm 'we're having this and this and this, would you like this or would you like me to make you this,' and I'm like 'I want this.'" Stephanie, a DSP said "You need to ask them how they prefer to be helped, or how they like their choices to be."

Several DSP participants discussed the importance of keeping the people that they supported informed about what was going on around them (sometimes informing them of the institutional objectives that were occurring within support provision). DSP participants, who were forced to support institutional objectives and who were often at the mercy of their challenging role, seemed to demonstrate care in keeping people with ID aware of what was occurring. It seemed that DSPs cared enough to keep them informed and garner their input. Anthony said that it is important to:

make sure that they're on board with what you're gonna do for the day… you can't just go out and go do it because that's what we normally do… they might not wanna go do something on a certain day. So it's… getting to know them and being being aware of what they want and like on a daily basis you gotta ask them.

Christian similarly said:

Well I try to make sure that whenever we go to do something, or if we're going to be someplace for awhile, I just try to talk to them about what I think is going on… ask them how they feel about it. Is it what they want to do? I ask for their opinions, their input with pretty much everything… if I agree or disagree, then I'll explain why.

Both groups also discussed the necessity of having conversations with each other about how support should be provided. Alejandra, a participant with ID, said "I make

them [DSPs] have those kinds [difficult] of conversations with me." Christian, a DSP said "the moment a grumble happens is really just, you know, taking 10 minutes to sit down and talk to him, you know, talk it through," indicating that she recognized and discussed the feelings of the people that she supported.

Both participants with ID and DSP participants discussed the importance of DSPs expressing a caring demeanor in their interactions with people with ID. Both groups of participants provided examples of things that did and did not seem to express care and support for autonomy within support settings. Carmen, a participant with ID, gave an example of how a DSP who didn't demonstrate care in speaking to Carmen, made her feel. She said

> Maybe they don't intend to lecture me, but they do… I'm sure they don't mean to
> be mean… it just comes out that way sometimes. Cause there are some staff who
> work here… if they're too outspoken sometimes they can get really you know…
> this whole shrinking me 6 different sizes kind of thing."

Alejandra, a participant with ID expressed how she felt when a DSP tried to change her words. She said that when she said something, and someone responded:

> "No you don't really mean that…" and someone's trying to communicate my
> feelings back to me, like they're in my head, and that makes me feel very livid.
> I'm like "why do you think you have charge and authority over what goes on in
> my brain?"

Stephanie, a DSP, demonstrated how she showed care in the way she spoke to the people that she supported. She said:

It's not belittling their choices, but maybe showing them another option. So it's

not "oh those dishes don't look right." It's "oh I really appreciate your helping

with the dishes, let's you know make sure they're done really good and then we'll

put them away."

Maria expressed the importance of demonstrating care by maintaining calmness in her

interactions with people that she supported as she stated "they [trainers?] tell us, on some

of em to talk softly, you know you know, you're not going to get anyone to calm down

when you're screaming and everything, or saying obnoxious things and and whatever…"

Both participants with ID and DSP participants conveyed the importance of

intently listening and hearing people with ID to demonstrate care in support of autonomy.

Intently listening meant that these participants listened to what people with ID wanted.

Sophia, a DSP participant stated the importance of "respecting the voice" of the people

that she supported to demonstrate care and support their autonomy. She said that she

found out what is important to them by:

Listening to them, and respecting their voice… and not thinking that anything

isn't important, or wanting them to do something that you want them to do instead

of what they want to do- When they tell you something, don't just ignore it. Don't

brush it off. If they tell you something that is on their minds, and they are thinking

about doing it, or wanting to do it, or wanting to try something new, and just uhm

helping them reach whatever goal they wanna reach, or do whatever they wanna

do, and not just brushing it off, like it's not important.

Participants with ID also expressed their desire to be heard. If DSPs intently

listened to and heard these participants with ID, they would be better able to support their

autonomy, while demonstrating that they cared enough to value what these participants had to say. Katrina said that "there's people [in general] who don't listen to me, acting like they don't listen to me. They don't want to hear what I have to say…That's not a good thing." Alex said:

> Well I've been trying to advocate for myself as well, but sometimes I find that people people have a problem with listening… sometimes they misunderstand or just ignore me… sometimes I notice that I'll try to say something here and nobody seems to hear me, and sometimes I'll even be in the same room.

Sophia, a DSP, echoed these statements when she said "some of em [people with ID] just sit there and they just wanna talk to you, they wanna tell you about their day or whatever, and there's people that don't care."

The DSP participants talked about the importance of advocating for the people who they supported. In doing so, these DSPs seemed to indicate that they really cared about the people that they supported, and often took risks to advocate for them. Maria told a story about how she advocated for the people that she supported in ISP meetings, in ways that confronted institutional barriers (of prioritizing the objectives of the agency, in this case administrative staff and co-workers time, over the objectives of people with ID). The following story demonstrates how she seemed to be willing to put her job at risk and increase tensions with her co-workers in an attempt to promote the autonomy of the person she supported. She said:

> And they [administrative officials] be like "would you hush? This meeting's supposed to been over 20 minutes ago." I said "no no these are some valuable points, and not only that you thinking, I'm meeting, I'm wanting to get over this.

It's about them, that I see when I'm with them. I see this. And I I want them to to

have what they want, or or or whatever whatever. It's about them. It ain't about

me. It ain't about you." So I end up talking it's what I do.

Matthew also explained how he might put his job in jeopardy to advocate for someone he

supported. He said:

Sometimes even if we think that the state is doing something, or my agency is

doing something that they, bad, we need to step up, even if it's contradictory to

what our agency says. You know we have a fiduciary duty to do that, to talk you

know, even if it's against our own company. We are, you know overall we are

responsible to the consumers.

Another example of this type of advocacy was when DSP participants refused to follow

plans that they did not believe were appropriate for the people that they supported. For

example Christian said "then a lot of times you know, just the menu plans aren't followed.

You know they just don't get implemented."

Some DSP participants indicated that they compromised their own interests,

beliefs, and values to support the autonomy of the people that they provided services to.

When they engaged in activities that they did not want to, it showed that they cared for

people with ID and were willing to support their autonomy, even when they did not

support their choices. Anthony said "I don't necessarily always want to go to Dave and

Busters every weekend, but one of the guys does," indicating the he would have to

compromise his desires and go with the people that he supported. Maria said:

It's not as much as my feelings that I'm gonna be concerned about. I'm gonna get

self out of the way, and uh since this is my job and my responsibility is for them,

that I make sure that whatever it is that I need to do for them, that I do for them.

This statement seemed to indicate that she was willing to compromise her feelings to

support people with ID.

Both participants with ID and DSP participants communicated an understanding

of the stigma of disability, and the effects that it might have on people with ID, or the

way that they are supported. In demonstrating concern about the stigma of disability, it

seems that these participants cared about how others perceive people with ID, and

possibly wanted others to view them as autonomous. Jesus, a participant with ID

indicated that he wanted people in general to refrain from using discriminatory language

and further stigmatizing people with ID. He said that "the R-word [retard] [is] really a

hard thing in their [people with ID] lives right now, and that's really that's really hurting

other people. Alejandra, a participant with ID, indicated that she was trying to reject

negative labels and the stigma that accompanies them when she said "you know all those

labels should be things that we're proud of, and not something that somebody just uses to

define us. You know let us define ours-, you know who we are in and of ourselves."

DSPs also discussed how they themselves experienced stigma because of their

association with people with ID. The DSP participants felt they were marginalized along

with people with ID. Christian, a DSP, talked about the stigma that she experienced in

providing support. She said that it "feels really humiliating… like if you're out in the

community, you… get grouped with the folks… it's just sort of this oppressed group.

You feel like… people really look at you like dirt." Jennifer, a DSP participant, hinted at

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how the stigma about people with ID might affect her interactions with the people that she supported, and how working with them changed her perceptions so that she might be better able to support their autonomy. She explained that working with people with ID had helped her to realize that any stigma she placed on the people she supported was related to her own ignorance. She said "I truly truly expanded my impressions of people with disability, because I think my impression was more negative than positive. It was pure ignorance, that and nothing more."

DSP participants and participants with ID talked about treating people with ID with dignity, respect, and equality. These participants seemed to indicate that when DSPs understood that the people they supported were worthy of dignity, respect, and equality, these DSPs cared to support their autonomy. Alejandra, a participant with ID indicated that she wanted to be treated with equality when she said "so I felt like an equal with her [a DSP]. I never felt like uhm, I never felt like she was there to do prompts." Carmen, another participant with ID, talked about how DSPs should treat her with dignity and respect. She said "just treating me like I want to be treated, not like a little kid or a pet." Jennifer, a DSP, made the following statement that seemed to indicate that she recognized the importance of treating the people she supported with equality because they are just like everyone else, and therefore worthy of it . She said:

> I think it's very its its its it was enlightening for me to understand people with
> disabilities, and to understand they're no different than people without disabilities.
> You know I used to consider people with disabilities as "those people." Well
> they're no different. You know they have the same heart, the same compassion,
> the same desires, likes, dislikes. You know we're all, we're all the same.

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Maria, a DSP, similarly said that she thought of them as "regular people… and I treat em

as such, you know with the… maybe little handicaps that they have you know. They still

very educated and they, you know they know what's going on."

Lastly most of the DSP participants discussed caring about the people with ID

that

they supported. Karen said:

You have to care about the people. You have to care about the work. You have to

like the people that you're working with, uhm, and not not in a general, you

abstractly like the idea of helping people, but when you're in it, do you still want

to be here, and I think you you have to say, if you can't say yes, then you're in the

wrong field. Not saying you can't have a really bad day and say "God I just want

to go home." That do you still wanna go back the next day? Do you still wanna,

when you're faced with a hard decision, do you still wanna work it out and be

there, and I think that that is the most important part of this, is wanting to be there,

and caring about what you do, and the people that you work with."

Sophia, in a very emotional statement said:

I feel like we're in their homes we're with them… almost every day and we

should be… like, I just wanna say respecting them… I see staff that come in…

and they're just here for a paycheck… this isn't a field for that.

Both of these statements indicated that these DSPs believed that caring was essential to

support the people that they worked for. Stephanie, also indicated that she believed that

DSPs should care about their jobs, when said 'it's not fair to come in and it just be a job,

and be a paycheck. These are people, they have emotional needs. They have feelings."

Despite all of the challenges that the DSPs in this study faced in supporting people with

ID to express their autonomy, all of the DSPs interviewed seemed to really care about the

people that they supported, and expected other people to care about them. In response to

a question about what the hardest part of her job was, Maria responded:

> I know we don't supposed to hug or or be friends be friend with em or whatever,
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> and and it's really hard… not to feel some kind of feelings for them, and what
>
> what they're you know going through… it's so hard not to care. It's just, that's
>
> hard.

Chapter 5

Discussion

This chapter will cover discussion of results, implications of results, strengths and limitations of this study, and directions for future research.

Discussion and Implications

The purpose of this study was to investigate the perceptions of persons receiving support and the persons providing support regarding the autonomy of people with intellectual disability and how they believe that it is either supported or denied within daily interactions between DSPs and people with disabilities. The research questions of this study were:

1. How do people with intellectual disability and DSPs perceive the role of the direct support provider?

2. What are the understandings and experiences of DSPs and people with disabilities in regard to the autonomy of people with intellectual disability?

This study, I believe, met its purpose. It was an attempt to determine the perceptions of DSPs and people with ID about how to improve the expression of autonomy by people with ID. These results have implications for informing support services about what actions by DSPs promote a greater expression of autonomy of people with ID.

Participants with ID were able to demonstrate their competence. They demonstrated their ability to talk about the support that they received and the kinds of support that they would or would not like to receive. They also discussed plans for their lives that they could autonomously pursue. Participants with ID seemed to have a better role definition for what a DSP should do than that of the DSP participants. The ability

and competence of these participants with ID indicates that they should have more direction over the kind of support that they receive and more opportunities to express their autonomy.

Analysis of participant interviews revealed that although DSP participants advocated for the people they supported, they also often engaged in subtle, pervasive, obvious, and overt control over people with ID. They appeared to do this for several reasons: because they worked in a challenging job, perceived the people that they supported as being incompetent, had to deal with challenging behavior, emphasized their role in the lives of those they supported, and held people with ID to idealized values that the people with ID may not have had themselves. DSP participants enacted this control by using repression, forcing concession, enacting undue safety measures, and otherwise buffering or preventing the people that they supported from having experiences that are typical of people without ID.

The major findings discussed in this section are that safety, health, and protection trumped autonomy, and that institutional goals were prioritized over individual goals. Both of these findings led to undue control and coercion of people with ID. These are discussed in detail. The DSP participants and those with ID discussed aspects of the relationship that contributed to demonstrating care in the relationship that seemed to suggest that DSPs should go above and beyond the institutional definition of their role as DSPs. Because of the difficulty of mandating care, I discuss the issue of paid caregiving. Based on the way that participants talked about choice and autonomy I discuss how, as constructs, choice and autonomy are problematic within the support relationship.

People with ID as competent, capable, and caring individuals who can autonomously direct their support services. The participants with ID in this study capably advocated for themselves. They provided examples of being caring towards others, and recognized that other people with ID might need people to speak up on their behalf. They also demonstrated their ability to talk about the support that they received and the kinds of support that they would or would not like to receive. They talked about things their support staff did well that contributed to their expression of autonomy, and things that their support staff did that prevented them from expressing their autonomy. They capably talked about their interests and the kinds of relationships that they had and wanted to have in the future. They discussed plans for their life that they could autonomously pursue, such as improving their education, and capably discussed their ideals and values. Their ability to discuss all of these things demonstrates that that they are, in fact, autonomous people. It seems that the only autonomous component that these participants did not meet was the freedom from external constraint discussed by Stainton (1994). Perhaps if they were free from external constraint, they would be able to provide more direction over the kind of support that they receive and they would have more opportunities to engage in the expression of their autonomy. In order to be fully autonomous it seems that they need the cooperation of the support systems from which they receive support.

Every participant with ID interviewed in this study was able to provide examples or tell stories of times when they had to advocate for themselves. More fascinating, was that the participants with ID in this study talked so passionately about supporting or helping other people (especially, but not exclusively, people with ID). People with

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disabilities, are often seen as incapable of understanding important issues relevant to

managing their lives and acting autonomously (demonstrated in this study by the fact that

DSPs often treated them as though they were not competent to make choices for

themselves). The fact that they capably spoke about issues of importance to them and

importance to people with disabilities as a whole, however, implies that what they have to

say should be valued, and their voices should be respected. It also implies that they have

some insight into their unique situation (of being in support relationships that allow for

coercion and control), and that they themselves can be caregivers. This finding echoes

Perske's (1983) description of people with ID working to donate money to people that

they identified as needing help. People with ID, in this study competently and capably

demonstrated their own autonomy and supported the plight of other people with ID to

express their autonomy. Their advocacy on behalf of others also demonstrates that the

people with ID in this study truly were self-advocates. Pennell (2001) stated that self-

advocates stand up for themselves and others, just as the participants in this study

expressed that they did.

People with ID often described the DSPs who supported them as helpful and

caring. Many people with ID require support, so it is necessary that the support provided

to them, contributes to their expression of autonomy when it is provided in the proper

way (not too much or too little) and when DSPs can define the boundaries of their role.

The results of this study seemed to indicate that people with ID could better express their

autonomy when they had appropriate individualized support. This corroborates with

Wadensten and Ahlstrom (2009a) and (2009b) findings that participants with disabilities

recognized that having support allowed them to have some control over their lives and

some degree of autonomy. Grimby (2002) stated that DSPs have the greatest potential to support the autonomy of people with ID and this seems to be the case in this study. This was evidenced by Alejandra when she stated that "I feel like I can live my life when everyone around me knows what they're supposed to be doing." In providing this comment it seemed that Alejandra understood that the support she received contributed to her autonomy, and that when DSPs did what they were supposed to be doing, it contributed to a greater expression of her autonomy. The support that participants with ID received (though problematic in some ways) contributed to their expression of autonomy when it was provided in ways that were consistent with what the people with ID wanted (which clearly they were capable of speaking about).

Ippoliti et al. (1994) reviewed self-determination literature and found that people with disabilities could articulate what they perceived as quality in supports, a finding that is supported by the current study. Participants with ID capably discussed the kinds of support situations and relationships that contributed to appropriate support, often providing the same kinds of examples that DSPs provided. One thing both participants with ID and DSP participants discussed as needed was keeping a positive attitude within the support relationship. This finding was also noted by Williams, Ponting, Ford, and Rudge (2009), when they found that DSPs used shared knowledge to engage in positive interactions with the people that they supported. It was also important to both DSPs and people with ID that the relationships between them involved trust. This finding was confirmed by both Wadensten and Ahlstrom, (2009a) and Clarkson et al. (2009) who both found that trust was an important aspect in the DSP relationship.

The participants with ID were capable of determining the appropriate boundaries of the support that they received, and often provided explicit examples of what they did and did not need in terms of the assistance that they received. They seemed to have a better recognition of what these boundaries should be than the people who supported them. The DSPs expressed difficulty understanding how and when to provide support and how much was enough. DSPs also frequently said that they did everything for people with ID, Jennifer, for example, in speaking about how she assisted people that she supported, said "I did everything." None of the participants in this study stated that they needed help in every aspect of their lives; instead they discussed specific areas in which they needed support. Although no people with significant intellectual disability participated in this study (who might have more extensive support needs), it is doubtful that DSPs do everything for anyone that they support. Participants with ID competently and capably expressed their autonomy by discussing their specific needs within the support relationship.

The participants with ID, in this study, capably determined the boundaries of the relationship that they had with DSPs, understanding that DSPs are professionals who help them, and not friends or family. Healy et al. (2009) found that participants with disabilities expressed that relationships contributed to their lives. Although the participants with ID in this study discussed the importance of various relationships that they had, it is important to note that none of the participants with ID identified their DSPs as a friend or compared them to a family member. The DSP participants, however, often provided statements that emphasized their importance to the people they supported, as demonstrated by Karen who stated "you are one of the most important people in their

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[people with ID that she supported] life." A similar finding was noted by Antaki et al. (2007) who in discourse analysis of residents' meetings found that DSPs tried to get the people that they supported to call them friends.

On one hand the finding from this study indicated that people with ID defined the boundaries of their relationship with DSPs more accurately than the DSPs, but on the other hand it seemed to indicate that DSPs emphasized their necessity to people with ID, possibly because they perceived people with ID as being incompetent (clearly not the case). It does not seem unreasonable that DSPs emphasize their importance when it is a job they attend nearly every day where they provide intimate support in an intimate setting. The participants in this study discussed that DSPs also have to get to know the people that they support, have a positive attitude in the working environment, and care about them. This might mean that DSPs actually form attachments to the people that they support and may feel more valuable because of the attachments they form. Maria addressed this issue when she discussed the difficulty that she experienced in not caring. The people that these DSPs support, however, have had countless DSPs who have worked with them. Demar (2005, as cited in Gaventa, 2008), for example, discussed a woman who had over 500 different DSPs who supported her in one provider agency. When people with ID have had many different people involved in their lives throughout the time that they receive support, it seems reasonable that they would regard those people with less importance. This issue seems to be compounded by the issue of staff retention. Test et al. (2003a); Larson et al., (1999); and Hewitt and Larson (2007) all found that issues with staff retention directly affected the people with ID supported within the system. It is doubtful that people with ID, when supported by many different

DSPs over time, would be inclined to form any kind of significant attachments to DSPs, in the sense that they would regard them as being like a friend or a family member.

Participants with ID spoke about things that they wanted to do, things that they did not want to do, dreams that they had for the future, and their value systems. Based on these findings, the participants in this study were clearly capable of defining what they wanted to do and achieve in life, and what goals they could work to autonomously pursue. This corroborated with Stainton's (1994) definition of autonomy, wherein people plan and pursue their plans. They were capable of expressing their autonomy, and even encouraged and supported autonomy in others.

Challenging behavior may not prevent autonomy but may be caused by the prevention of autonomy. A significant finding in this study is that when people with ID exhibit challenging behavior they are often prevented from expressing their autonomy. Every single DSP participant discussed dealing with challenging behavior of the people they supported, even though it was not a topic specifically included in the interview questions. In DSPs' recounting of these incidents, challenging behavior often led to restrictions that prevented people with ID from expressing their autonomy. There may, however, be more to the issue of challenging behavior and restrictions than these findings imply. Goodley (2001) proposed that behavior is shaped by the environments in which people live, and that behavior is often misunderstood as a symptom of a disability. He suggested that sometimes the "maladaptive behavior" might actually be rational behavioral responses to a "maladaptive environment" (p.215). Goodley further said that because people have disabilities, behaviors that they engage in tend to be viewed more

negatively than such behaviors in people without disabilities (possible, considering the overall negative perceptions of their competence).

The DSPs in this study often engaged in control and coercion, and the participants with ID often experienced control and coercion (discussed below). Because of the control and coercion often present in support situations it seems reasonable that people with ID in these situations might engage in challenging behavior. Matthew, a DSP interviewed in this study said:

> I would not want people to be telling me what to do every single thing… when these guys have some behaviors you know I could understand it because I'm like dude, if we did this, if someone did this to me, I'm going to do something else, worse.

Other DSPs provided similar comments to the one above, and demonstrated that they understood that sometimes challenging behaviors resulted from their interactions with people they supported. The DSPs also discussed the difficulty of controlling their responses to challenging behaviors in an attempt to positively affect the outcomes. Their comments indicate their awareness that their interactions affected the kinds of challenging behavior that the people that they supported engaged in. Cannella et al. (2005) reviewed the literature on choice and found that increased choice opportunities led to decreased inappropriate behavior, and led to increased positive behavior. In light of this finding, it seems that when people with ID engage in challenging behavior it may be because they are controlled and coerced. The restrictions may not be due to the challenging behavior that people with ID sometimes engage in, but the reasons why the challenging behaviors occur in the first place. This finding seems to indicate that positive

behavior could be supported by making greater efforts to support the autonomy of people with ID.

Safety, health, and protection trump autonomy. Levinson (2010), in a study about the work that takes place in a group home, found that:

> When there is no warrant for intervention, the work of assessment never ends, because as group home residents they are by definition 'at risk'… The idea that something can and must be done is a fundamental organizing assumption of a group home. (p. 231)

Because people are in group homes, it seems that they are perceived as being in need of some degree of oversight and that constant infringement of their autonomy is deemed necessary. One of the major findings of this study involved DSPs supporting safety, health, and protection. Analysis of participant interviews revealed that one of the major barriers to supporting autonomy occurred when protecting the safety and health of people with ID was given greater priority than their individual choices and preferences. This also occurred when DSPs perceived that they were supporting safety and health, but were actually supporting an idealized version of safety or health and exerting control over the people that they supported. Robertson et al. (2001) had a similar finding in a study of self-determination. They found that when it came to supporting decisions of people with ID, DSPs had the final say if the decisions involved safety or health.

In discussing this, I do not mean to presume that autonomy is more important than health, safety or protection. In fact, autonomy may be better supported by protecting health and safety. People with ID, though competent in many ways, often have challenges in exactly these areas. Certainly one of the reasons for their need for support in the first

place, is to provide some level of protection because they may experience difficulties in determining what is safe and healthy. In fact, autonomy might even be another protection that DSPs provide. Fyson and Kitson (2007) implied that it can be difficult to support autonomy when protecting vulnerable individuals. Autonomy, however, should only be restricted for the sake of autonomy (Stainton, 1994). In other words, autonomy should only be restricted when it contributes to experiencing greater autonomy. For example DSPs should impose a restriction on an action that will result in incarceration, because incarceration will further restrict autonomy. Restricting autonomy to prevent incarceration means that this person will have greater autonomy because they will not have to have the additional restrictions of incarceration imposed upon them.

On one hand, when DSPs support protection, safety, and health, this may positively contribute to the autonomy that people with ID experience because it prevents them from engaging in actions that might further restrict their autonomy (as the example above demonstrated). On the other hand, supporting only choices that are safe and healthy may contribute to unnecessary restrictions and control over people with ID. In these cases, DSPs may exert control beyond restricting autonomy for autonomy's sake because they perceive that they are protecting the safety and health of the people that they support. Nearly every DSP in this study provided and discussed examples of how they had restricted autonomy for autonomy's sake. Stephanie, for example, described when she called Adult Protective Services because she was concerned that a person that she supported was being sexually abused by a boyfriend. Although Stephanie was able to determine when she should restrict autonomy to support greater autonomy, the experiences discussed by the DSPs in this study illustrate how it can often can be difficult

for them to draw the line between when they are restricting autonomy for autonomy's sake, and when they are restricting autonomy because they assume that individuals with ID should only do things that are safe and healthy.

Perhaps more surprising, is that autonomy was often restricted because DSPs imposed their own beliefs and values about what constituted protecting safety and health. The participants with ID in this study, in discussing all of their capabilities and areas in which they needed support, rarely mentioned safety or protection as a needed support. In fact, only one participant with ID mentioned feeling protected by his support staff. Further, the only times participants with ID mentioned health-related supports was in regard to needing assistance with medical issues. The DSP participants, however, commonly cited safety, health, and protection as needed supports, and constructed them differently than the participants with ID. The DSP participants usually talked about health supports as controlling what someone ate or preventing them from engaging in other unhealthy behaviors (e.g., hygiene was frequently cited as a health issue by DSPs). The DSPs in this study used their own assumptions or institutional objectives to judge how to protect safety and health. In promoting the institutional objectives of protecting safety and health, these DSPs may have been holding people with ID to an idealized standard of safety or health, or a standard that was higher than typical people might hold themselves.

The comments of both groups of participants demonstrated that DSPs and participants with ID did not have the same ideas about what health or safety meant, and may not have assigned the same value to them. It is doubtful that people without disabilities would affirm that being protected was one of the major components of their autonomy, though most people would certainly appreciate feeling safe. It is also likely

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that people rarely have exactly the same ideas about what safety or health mean. The issue of health (making healthy choices) is probably just as contentious outside of disability services as it is within, although people without disabilities often get to define for themselves what health means or the value of it in their lives. When DSPs are using health and safety to determine when to impose restrictions on people with ID, they need to be clear about the value of these constructs to the person that they support, and carefully determine when they are being unnecessarily restrictive.

Protection of safety and health seem to be institutional objectives. These services are provided under the DD waiver, which is configured under a medical model. Medical practice is constantly under scrutiny and liable for seemingly impossible outcomes. This may be related to the medical imperialisation in society that Oliver (1990) discussed because medical knowledge is given dominance and thought to be able to solve insurmountable problems. The liability that provider agencies experience may mean that they have to promote certain values over others. Promoting health, safety, and protection directly addresses what agencies are liable for, and are therefore good objectives for the agencies to promote. It seems that this institutional objective of protecting safety and health (though worthy when it restricts autonomy for autonomy's sake) was not supported by the participants with ID in this study. This finding also illustrates why it is difficult for DSPs to support autonomy while determining where to draw the line in supporting health and safety.

Karen, a DSP, provided an example that illustrates the complexity of these issues. She told a story about a man who was prevented from attending church by himself because he had an aspiration risk. This man was capable of attending church, and had

done so by himself for many years. Aspiration risk, an issue that has gained significant

attention from the Long Term Supports Division (the state agency that manages the DD

waiver) in the past few years, is now regularly monitored throughout the state. This

represents a liability to the company that Karen works for, so they've made safety an

institutional objective. The man, when attending church alone (as he had for many years),

was making a choice to eat donuts and drink coffee. His choice may cause him to have an

aspiration incident. He was aware of the health concern, but continued to eat donuts and

drink coffee, expressing his autonomy (as many people do when they reject medical

advice). Although he had never had an aspiration incident at church that threatened his

safety, the agency took a proactive stance and decided to send someone to church with

him to monitor his donut-eating and coffee drinking. In this story it seems that the agency

had noble aims of protecting his health and safety, but it also seems that they have done

so at the expense of his autonomy, and in ways that may be unnecessary restrictive. He

was, after all, at a church that he had been attending for many years surrounded by

natural supports, many of whom could have intervened if an aspiration incident occurred.

The outcomes of this situation might also have been very different if aspiration risk had

not become a statewide initiative, or prevention of aspiration risk an institutional

objective.

  Subtle, pervasive, obvious, and overt DSP control and coercion. DSPs

engaged in subtle, pervasive, obvious, and at times overt control over people with ID.

This control often seemed to go unnoticed by the DSPs; they rarely described their

interactions with people they supported as being controlling. Control also seemed to

permeate beyond what was necessary to support the people that they worked with (e.g.,

control was often used under the guise of protecting health or safety). Ellis (1992) stated

that people who provide support to people with ID "often assume and exercise

decisionmaking authority over people with mental retardation in ways that are not

described in, or authorized by the law" (p. 1802). The control exerted by DSPs may have

occurred because of the challenges that DSPs had in defining the boundaries of their

support provision and because they emphasized their role in the lives of those they

supported (as discussed above). Perhaps control was used because DSPs based their

decisions for people with ID on their own assumptions or held people with ID to

idealized standards, or higher standards than they would hold themselves to. There were

situations discussed by participants in this study when it was obvious that DSPs had to

use control to support people who engaged in significant challenging behaviors. There

were also situations where the participant demonstrated control by forcing undue safety

measures (as discussed above), using concession and repression of the individuals they

supported, and otherwise buffering or preventing the people who they supported from

having experiences that are typical of the experiences that people without ID have.

DSPs and participants with ID provided many examples of subtle control and

coercion, such as the control exerted over David who wanted to go on walks and instead

was taken in the car. David also talked about wanting to go to K-Mart, but always had to

go to Wal-Mart instead (a subject he brought up several times in our interview). This kind

of control seemed to be pervasive within the support that people with ID received. When

DSPs exert subtle control, like choosing where to shop, they may not even recognize that

they are being controlling.

The DSPs also exerted control that was obvious and overt such as the kind that Alejandra experienced when she asked a DSP to help her move a picture and the DSP flatly told her no. Alejandra was living in her own home, and her request was blatantly denied. Though in some of these examples it would be difficult to understand why the control occurs, it seems that it may stem from a number of issues.

The DSPs may have acted in a controlling manner because of the way that they perceived their role. The DSPs, in this study, had difficulty defining the boundaries of their roles, and often asserted their importance to people with ID, even comparing themselves to parents, as Christian did. Even when they did not compare themselves to parents, they overemphasized their importance to the people that they supported in relation to how it seemed people with ID perceived their support. This was evidenced by statements that they did everything for people with ID. This could clearly lead to paternalistic interactions with people with ID. Karlsson and Nilholm (2006) found that DSPs in their study often acted paternalistically towards people with ID. Paternalistic relationships imply that people with ID are incompetent, and that they need other people to make and enact decisions for them (which did not seem evident in my interviews with competent people with ID as discussed above). The controlling interactions can be understood (though not justified) when considering this complex relationship between DSPs and people with ID where boundaries can often be difficult to define.

Another issue that may have influenced DSPs' use of control was that some of the DSPs in this study worked in situations with individuals with challenging behavior where control may have been warranted. Some challenging behaviors exhibited by people with ID led to the imposition of significant restrictions. Charlie, for example, worked in an

agency that specialized in providing services to people with ID who engaged in sexually challenging behaviors (e.g., they had been accused of engaging in sexual acts with children). He discussed protecting the safety of the community by restricting the choice of the people that he supported. Charlie's job necessitated control and restriction of autonomy, so that the autonomy of potential victims could be protected. In this way he was probably also promoting the autonomy of the person that he supported (i.e., by preventing his incarceration and the restricted autonomy that accompanies it). He also had to restrict the experiences of the people that he supported so that they could not engage in actions that would compromise the autonomy of others.

Despite examples like Charlie's in which DSPs may have exerted warranted control over the people that they supported (control that restricted autonomy for autonomy's sake, Stainton, 1994), DSP participants provided many examples of minor challenging behavior leading to control and coercion of people with ID that did not seem to be warranted. For example, Anthony discussed preventing an individual from getting free magazines. Anthony thought this individual had too many magazines in his room, and used coercion over the person that he supported.

The DSP participants in this study also sometimes exerted control because they enforced their own standards or idealized standards on the people that they supported. Maria provided an example of this when she talked about having a discussion with the people that she supported about keeping her own house clean and neat, and how they, too, should also keep their homes clean and neat. In having this conversation with them she was exerting subtle control by assuming that they ought to value keeping their homes clean and neat because she did. Alejandra, a participant with ID, discussed this specific

value for cleanliness when she talked about not "giving a rat's butt' about keeping her

home clean, in spite of the wishes of her support staff. The value of cleanliness is a good

example for discussing the kinds of standards used to justify control and coercion on

people with ID. Keeping a home clean is something that people typically do, and that the

DSP participants in this study (by their admission) do. Enforcing cleanliness might also

be subjecting people with ID to an idealized standard of maintaining a perfect house.

Cleaning, in the institution-like settings that the participants described people with ID as

sometimes living (and with the role of hygiene in health that the participants discussed)

might be imposed upon people with ID, even though it is not a value that they themselves

hold. Juan, a participant with ID, for example, discussed the issue of cleanliness when he

talked about feeling insulted because his support staff told him that he had too much stuff

in his room. I held the interview with Juan in his room, and no doubt it was cluttered (as

many people's bedrooms are), but it was not problematic. It did not pose risks to his

health or safety. Having a clean, clutter free room, is something that it seemed DSPs tried

to coerce Juan into doing because either they assumed that he should have a clean room

because that is what the DSPs would want, or they expected that he should have a clean

room because they held him to idealized standards.

DSP participants also exerted control over the people that they supported by

asking them to compromise or concede and by using repression. I asked DSPs to respond

to problem-solving scenarios that required them to go through the process of their

decision-making (see Appendix B). In responding to these scenarios, every DSP

discussed trying to get the people that they supported to compromise. Life often involves

compromise, as the participants in this study discussed. Karen, for instance, talked about

the role that other people play in our lives, and how relationships naturally involve compromise. The notion that people with ID who receive services should make compromises because it is a typical part of life is problematic for a number of reasons. First, it implies that the person who is supported is incompetent to make his or her own decisions, (regardless of whether these are good or bad decisions), and must therefore make compromises to make better decisions. Another problem with compromise for people with ID is that their support often involves settings and situations that they did not choose. They often live in homes with people that they did not choose to live with, and often work in jobs that they consider being inappropriate or meaningless. Not having a choice about their work or living situations was true of many of the participants with ID involved in this study, a finding also noted by Gardner and Carran (2005), and also discussed by Wiltz (2007). This means that they may not have similar interests or values as the people when they live or associate with, and that they are supported by people who may also not have interests or values similar to their own. This is in contrast to most adults without ID who choose who they live with and who they engage in social life with. People with ID may not have opportunities to choose where they live or work, and may not have the same interests or values as the people that are around them. For them compromise may be something that they experience more frequently than people without disabilities. Karen, a DSP, provided an example of this. She said that she was "trying to puzzle piece everyone together so that everyone involved in the agency gets, you know the best services possible. Sometimes they can't get exactly what they want." It seems that for people with ID the mere involvement in support services impedes their autonomy and forces their concession.

DSPs also engaged in control and coercion by repressing information or experiences for people with ID. Sometimes they did this to support greater autonomy for the person and the community (as was discussed in the example provided by Charlie, above). Other times they did it because they were unable to support a choice that the person that they worked for made. Barron (2001), in a study to determine the effects that Swedish legislation had on autonomy, found that DSPs did not assist people with disabilities when they did not support the choices they were making. The example that Maria gave about repressing the experience of the person that that she supported by making it hard to find a place to purchase a sex toy illustrates this second situation. In this interview, Maria said that she did not agree with the choice that the person made (the scenario choice involved a woman with ID who wanted to engage in a sexual experience with another woman, see Appendix B). After accounting for the person in the scenarios' understanding of the situation and ability to provide consent, Maria still opposed the decision based on her own religious beliefs. While this illustrates some of the issues about people with ID being surrounded by people who do not have the same interests or values (highlighted above), it also demonstrates how DSPs may hold the people that they support to their own standards and use control and coercion to do so.

Maria also discussed some of the compromises that she had to make in her position of providing support to people with ID, illustrating that she (like all people) had a life that involved compromise. From her response to the scenario described above, it seemed that engaging in actions that conflicted with her moral values might be compromises that she was unwilling to make. I am not suggesting that the compromise of either (DSPs or people with ID) are more or less important, but highlighting the difficulty

of supporting autonomy in another person with whom you may not share values. Maria's compromise is yet another illustration of why some of the control and coercion in support situations may occur. Although Wadensten and Ahlstrom (2009b) found that people with ID wanted the DSPs who worked with them to support their choices, a finding that was consistent with the current study, the stories and examples provided by DSP participants and participants with ID in the current study illustrated that it can be quite difficult to do when DSPs have to balance their own values and the values of the people they support.

Alejandra provided a final example of how DSPs exerted their control in support situations. Alejandra, a participant with ID, explained how she believed that her support staff buffered her experiences. The DSP did this by navigating Alejandra's experiences for her so that Alejandra did not get to fully engage in them. She told about a work experience in which the job coach who supported her interacted with all of the people with whom she worked, while she only interacted with the job coach. Though she was the only participant to specifically bring up the issue of buffering, it seems likely this could occur in support situations. In her example the DSP exerted control by preventing Alejandra from participating in typical work interactions herself. This DSP, in attempting to support Alejandra in her work setting seemed to take over the better aspects of the work experience (bonding with co-workers) while leaving the less desirable aspects (the work) to Alejandra. This subtle control exerted by her job coach prevented her from having a typical work experience where she interacted with co-workers and her supervisors. She specifically said that she "felt like they sucked away the relationship aspect of it." Alejandra's example demonstrates how pervasive the control is that DSPs exert over the people that they support may be. The DSP in this situation probably was

not even aware that Alejandra felt this way or that s/he prevented Alejandra from having natural interactions with her co-workers and boss. Wilson et al. (2008), in a study about the ethical issues in direct support, found that DSPs exerted control over people with ID so that the DSPs were not perceived as being irresponsible. This may have been the case for the DSP in this situation who may have been acting in a way that s/he perceived as being an effective job coach, and these actions may have been constituted as the correct way to do the job by the agency that s/he worked for. Alejandra's story illuminates the subtle and pervasive way that DSPs may exert control over people with ID and buffer their experiences so that they are not similar to the kinds of experiences that people without ID have.

Institutional goal prioritization. The institutional goals, discussed briefly in the safety section and hinted at in the previous section above (when the DSP acted as a buffer to Alejandra's experiences), and their effect on the autonomy of people in support situations are discussed in detail in this section. Walker, Calkins, Wehmeyer, Bacon, Palmer, Jesien, Nygren and Heller (2011) stated that "it is usually not the physical environment itself that limits choice opportunities. Instead the rules and regulations implemented in that environment and the way in which other people interact with the person are the likely reasons" (p. 13). One of the reasons DSPs might act in controlling or coercive ways is because institutional goals are prioritized over personal goals of people with ID receiving support. This is consistent with findings of both Levinson (2010) who studied the work that takes place in group homes and found that the DSP role is often in conflict with the organization demands, and Finlay et al. (2008) who studied residential support services and found that DSPs supported agency objectives over the

choices of the people they worked for. Some of the controlling interactions described by

the DSP participants and participants with ID in the current study seemed to be the result

of the institutional objectives imposed upon DSPs by their employers. These institutional

objectives seemed to have a profound effect on the kind of interactions that the DSPs

engaged in with the people that they supported. Roman (2010) stated that "a mechanical

regularity turns everyone into machines, regardless of who is being served and who is

being cared for" (p.140). In this section I discuss how DSPs sometimes acted like

machines in support of agency objectives, or acted in a mechanistic prioritization of

agency objectives because they are parts of the machine that make up the support system.

I do not, however, want to imply that DSPs did so in a deliberate or calculated way.

The DSP participants in this study discussed many things that made their jobs

challenging, particularly how they constantly walked a fine line in supporting conflicting

values (i.e., the agency's objectives, their own values, and those of the individuals they

supported). They expressed that they rarely made big decisions, and that they often had to

go along with agency decisions or lose their jobs (as Sandra stated in chapter 4). Their

statements illustrate that DSPs do not have a lot of control in their jobs, and may not feel

that their own autonomy is supported within their jobs (see discussion in chapter 4).

Although they reported that they often acted against their agencies to advocate for the

people that they supported, they also had to enforce agency objectives as a requirement of

their jobs. It seems that the control that occurs because of institutional goal prioritization

is just part of the job that DSPs are mandated to exert.

Several of this study's participants discussed the issue that when support was

provided in the homes of people with ID, it made them seem like institutions. When I

asked Christian, a DSP to expand on why she thought it was like an institution, she said:

> There's uhm, a formality I think… that is always present in their lives… I have to
>
> consider myself a professional, you know and hold up a high standard you know.
>
> And I don't have some professional in my house everyday with a set of standards
>
> that I have to, you know, deal with.

Christian, it seems, had awareness that her job entailed imposing standards or values on the people that she supported. Christian's example illustrates standards under which DSPs operate and the sometimes conflicting standards under which people with ID are supported.

As evidenced by the story that Alejandra told about her job coach buffering her experiences, it is clear that prioritizing institutional objectives is not limited to residential settings. It is quite possible that Alejandra's job coach believed that his or her job was communicating with Alejandra's supervisor, maintaining friendly interactions with Alejandra's co-workers, and so forth. If this was the case, this DSP was acting under institutional standards in a way that prioritized them over Alejandra's personal goals of getting to fully experience having a job. This DSP may not have been overtly acting to neglect Alejandra's goals, but in the process of doing his or her job, may have been imposing institutional standards on Alejandra's experiences.

Levinson (2010) found, in a study on the work done in group homes, that goals "translate specific individual 'needs' and 'preferences' into systematic and accountable clinical work" (p. 178) and that goals are based on government ideals. This seemed to be the case when agencies used the ISP process to prioritize agency goals in ways that directly impacted the autonomy of the participants in the current study. Carmen, a

participant with ID talked about this when she discussed how she felt that the ISP process

was not person-centered. In speaking of her Individualized Support Plan (ISP) she said "I

don't see why, you know, I need to you know, change anything, you know do anything

different." The institutional objectives of writing a plan (supported by state and federal

legislation) for the agency to continue to receive money for Carmen's support prioritized

institutional objectives over her personal objectives. I am not simplistically stating that

plans or programs do not have useful intentions. Plans and programs allow for many

positive outcomes to occur as well as provide protection for people with ID from abuses

within the system (e.g., by ensuring that DSPs are aware of what the people that they

support need), and provide documented proof of what should be occurring. This issue

highlights the difficulties that the support system (at the state level) experiences in

attempting to manage large numbers of people. The state has to enforce some sort of

accountability to ensure that agencies are providing support in the way that it is needed

by the people who receive it. They use systematic approaches (e.g., requiring individual

support planning, requiring monitoring of goals, etc.) to obtain proof that agencies are

doing what they should be doing, but these approaches can also act to restrict the

autonomy of people supported within the system when they do not align with individual

goals and objectives.

In addition to highlighting how institutional goal prioritization restricts autonomy,

goal prioritization also illuminates some of the complexities that DSPs face in supporting

autonomy. DSPs, to maintain their employment, are dependent on support systems for

their jobs. Therefore they have to promote institutional objectives. Because DSPs provide

support that prioritizes institutional objectives the personal autonomy of people with ID

can be easily neglected. Institutional objectives it seems, often overpowers what is important to people with ID, and subjects people with ID to undue and unnecessary control and coercion in meeting objectives that are not their own. Though people with ID may need support and protection in many areas, "voices" rather "vulnerability" should direct services for people with disabilities (Bernert, 2011, p. 139). In other words, despite the fact that many people with ID may truly need some level protection; the services that they receive should be focused on what they want, or focused on supporting their greater autonomy. Bannerman et al. (1990) reviewed choice literature and determined that people with ID should be able to make choice, even if they are not perfect choices. Although the DSP participants in this study often held people with ID to idealized standards, people with ID have a right to make poor and unhealthy choices, to have cluttered rooms, to fully engage in their experiences, to learn or not from their mistakes, and to lead less than perfect lives.

   Constructing choice and autonomy in support services. Stainton (1994) stated that the only time that autonomy should be restricted, is when it is restricted to provide greater autonomy. In my interviews with DSPs, however, it became apparent that this was not always the case (see section "safety, health, and protection trumps autonomy" above). Anthony, a DSP, told a story about controlling the amount of ketchup that a person that he supported ate. Anthony's decision to restrict the amount of ketchup that this person ate was an overt form of control and a restriction of that person's autonomy, and did not seem to follow Stainton's rule. This story brought up problems that often arise in supporting autonomy (and choice-making) within support services. In telling this story, Anthony didn't mention the gravity of this restriction, or even define it as such. His

lack of awareness demonstrates the pervasive and subtle control and coercion that occur within support delivery, and may be demonstrative of his imposition of his own or idealized standards on this person. This story also illustrates the mechanistic support for institutional rather than individual goals, if Anthony was, in fact, supporting an agency objective to promote health. Anthony's act was a small act that over time might significantly impinge upon the experience of autonomy by the person that he supported. This was an insignificant choice by the person he supported, but one that still subject to Anthony's control. Anthony's subtle interaction sheds insight into the difficultly in the construction of choice and autonomy for people who receive support because the control that DSPs exert is so subtle and pervasive that they don't realize that they are being controlling. Therefore the choices seem to be choices that DSPs allow people with ID to make, rather than choices that people with ID make because their lives are full of choices.

Throughout the interviews in this study, it became clear that choice and autonomy were constructed by DSP participants in artificial and unrealistic ways for people with ID. They constructed choice as a persuasion wherein DSPs attempted to gain accord from the people they supported about a choice that DSPs had already made. Both Antaki et al. (2009) and Antaki et al. (2006) both found that choices in residents' meetings often aimed to get people with ID to subscribe to predetermined choices. In Anthony's example he had already decided that ten ketchups were too many and tried to get the person he supported to agree with that choice. In the current study DSPs talked about supporting and offering choices, teaching, ensuring understanding of consequences, and getting to know the people that they supported to provide better assistance. The stories that they told, however, often involved compromise, repression, and control. Constructing choices

that involve compromise, repression, and control seems to be counterproductive to actually supporting choices that people with ID make. Choices that involve persuasion to come to a predetermined outcome (e.g., not "What do you want to eat?" but "Would you rather eat salad or lettuce?") are not choices at all. Storey (2005) stated that informed choice does not occur when the choice is limited to doing or not doing something, without knowing the range of options. The issues surrounding how choice is constructed indicate that people with disabilities may not be making truly informed choices. The DSPs in this study, themselves, indicated that they wanted to ensure that the people they supported made informed choices. They did not, however, construct choice in a way that would allow for the people they supported to make truly informed choices. Choices provided in this way may serve an entirely contradictory purpose of their intent (i.e., allowing people with ID to manage important aspects of their lives) and may in fact be used to control people with ID.

The kinds of controlling and coercive support that is sometimes provided by DSPs may affect the way that people with ID receiving support services advocate for themselves. Alex, a participant with ID, told a story about wanting to go somewhere and feeling that he wasn't allowed to ask his support staff to take him. Healy et al. (2009) found that choices may be something that people with ID feel like they're "allowed" to do and that they do not communicate with DSPs for fear that they will not be supported. Choices constructed in this way may be extremely problematic for people with ID. They also may impact how people with ID interact with DSPs over time and contribute to less meaningful expressions of autonomy.

Defining the boundaries of what kinds of choices to support may be difficult. A significant finding in this study was that safety, health, and protection trumped autonomy. Brown and Brown (2010) suggested that choices should be restricted to those that are safe and legal. However, safety may be more subjective than typically assumed. The results of this study may have hinted at this subjectivity. DSP participants frequently cited concerns about ensuring the safety of the people they supported as necessary to their jobs, while participants with ID rarely mentioned it as vital to their support. Further, for people without disabilities, choice is not restricted in such a way. On the daily morning commute, most people without ID have the opportunity to break several laws (and many people choose to do so daily). Further, people without ID often engage in unsafe activities. It seems that people with ID are often held to stricter standards, then people without, in terms of the kinds of choices that they make. Rather than supporting autonomy, it seems that narrowly defining choices as ones that are safe and legal holds people with ID to idealized standards. Again, it is not my intent to imply that people with ID should be encouraged to engage in dangerous or illegal actions. Certainly Charlie's story about restricting the actions of people who engage in significant challenging behavior demonstrates the potential consequences of not seriously addressing safety and legality. My intent is to illustrate how it is problematic to draw the line of supporting choices at safety. Though it can be incredibly difficult to determine how to support both safety and autonomy, Stainton (1994) provided a rule that the only time autonomy should be restricted is when doing so promotes greater autonomy. This rule can be difficult to apply, and may only be applicable in unequal relationships (such as paid caregiving relationships), but seems to provide at least a guide to better support autonomy. When

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DSPs support only choices that are safe and legal it does not seem to support the autonomy of people with ID, in the way that people without ID experience their autonomy. It holds them to idealized standards.

Despite the promotion choice and autonomy, some people with ID may never be able to make certain kinds of choices. Charlie's story about being unable to support the choices of the person he worked with who had engaged in challenging sexual behaviors illustrates another problem in choice construction for people who receive support services. People with ID may not always make choices that are in their best interests or that even support continued autonomy (Wolff, 2009). The challenging behaviors of people with ID that the DSPs in this study discussed sometimes lead to restrictions that severely limited the kinds of choices that the persons engaging in those behaviors could make, and significantly restricted the autonomy of these people with ID. People with ID may be legally prevented from making certain choices (e.g., having a guardian, and in Charlie's illustration, engaging in illegal behaviors). In spite of any attempts to support autonomy, some people may never be able to make certain choices. Under the current system, guardianship (though legally not intended to be all-consuming), often effects the kinds of opportunities that certain individuals with ID experience in expressing their autonomy. The participants in this study demonstrated awareness of the influence of guardians. Further, many people with ID may have made decisions to engage in illegal activities which might result in self-imposed restrictions of autonomy.

Promoting choice-making and autonomy may result in additional problems for supporting choices in actual practice. Agran, Storey, and Krupp (2010) found that often people with ID are asked to make choices that could not be supported. A finding in the

current study was that DSPs often had to determine how to compromise unsupportable

goals that the people that they worked for had expressed. For example, in a casual

conversation with one of the participants with ID involved in this study, he relayed to me

that one of his dreams was to go to space. This goal would be difficult for most people to

achieve and certainly was a goal that DSPs might find exceedingly difficult to support

him to achieve. It is not unusual for people with ID (or anyone for that matter) to have

such dreams, but it might be unrealistic to support these dreams (and perhaps unrealistic

to support his autonomy in this situation). DSPs in this study seemed to thoughtfully

consider how to make choices more attainable to the people that they supported by using

compromise. Stephanie spoke of supporting someone who also wanted to be an astronaut.

She said:

> It's unrealistic, but you still wanna say 'okay what are the things you wanna do to
>
> become an astronaut...' we find out what it is about that they like, maybe it is just
>
> looking at the moon and starts... Break it down to what they actually want, and
>
> then supporting—.

DSPs, in this way seemed to be capable of coming up with ways to address some of the

issues they encountered in supporting choice and autonomy. Although these participants

were able to determine how to support aspects of what the people they worked for wanted,

there will likely be goals that people with ID are unwilling to compromise, and that DSPs

are unable to support that will continue to present problems in supporting the autonomy

of people with ID. Asking people with ID to express their autonomy might result in them

defining goals that seem unsupportable. After people with ID realize over time that their

goals are not supported, it might cause them to less meaningfully engage in the pursuit of autonomous achievements.

Control seems to be what ultimately defines support services. Storey (2005) discussed that people served within the support system were often asked to create goals that the agencies from which they received services were unable to support. People with ID are regularly asked to provide input into the goals that they have for their lives. This occurs annually at the ISP meeting when they provide their vision statement (i.e., a statement about what they see as the vision for their lives). For the participants with ID, however, the very process of being involved in an ISP meeting may be in conflict with their autonomy and some of the choices they make in the ISP may be unsupportable.

In this study institutional goals were often prioritized over individual goals. This prioritization presents innumerable problems in supporting autonomy at the practical level. If the focus of agencies is on furthering their own objectives, when agency and individual objectives clash, agency objectives seem to be favored. The DSP participants in this study discussed that they did not get to make many decisions, and seemed to have to mechanically promote institutional goals. They didn't seem to have very much power, and the people that they supported didn't seem to have power because of their controlled relationships with DSPs. Therefore, it seems that the agencies were in control and their objectives were prioritized over any other objectives. This presents obstacles to the autonomy of people with ID because most of the interactions between them and the DSPs are controlled by the agencies. On a practical level, this might mean that autonomy is restricted in the ways that DSPs are controlled and coerced to promote institutional objectives.

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Autonomy is an extremely difficult concept to define and discuss and may even be an institutional objective of supporting people with ID. This may be evident by the fact that all of the DSPs involved in this study talked about autonomy, and spoke eloquently about how they could support it. They also, however, provided numerous stories of how they restricted autonomy. This seems to indicate that although it maybe frequently discussed, it may not translate well into actual practice. A finding of this study was that DSP work is challenging and DSPs have difficulty determining where to define the boundaries of the support they provide. The DSPs also tried to simultaneously promote autonomy and provide protection and safety. These might be competing institutional objectives that DSPs have to promote. It seems that they perceived that autonomy was a worthwhile goal of services, but often experienced difficulty in supporting autonomy at a practical level. This could be because they are seemingly pulled in so many contrasting directions. If autonomy is an institutional objective, then within the current system of supports, it may be an unsupportable objective.

Absolute autonomy may not be the best framework with which to structure support services. If autonomy is an unsupportable institutional objective then it is important to apply it on an individual level that supports the needs and desires of the individuals served within support programs. Saadah (2002) stated that autonomy is a concept that may not homogenously apply to everyone. This seemed to be apparent in the casual conversation that I had with the participant discussed above who dreamed of going to space. An absolute support of autonomy without taking into account the limitations that everyone experiences in becoming autonomous would not be productive to supporting the autonomy of this individual. The issue that everyone's autonomy is

dependent on other people was frequently cited by the DSP participants in this study. It is difficult to imagine that anyone in the world experiences absolute autonomy, wherein their autonomy is not restricted in some way by others. In being human, people experience restriction. For example, a man may conceive of himself as being a world traveler who in his absolute autonomy would spend the majority of his days immersed in other cultures, languages, and would teach his children the knowledge of the world. Because of the autonomous restrictions that humans face, this person may in actuality be someone who struggles to get through his boring construction job all year to be able to afford a one week vacation for himself and his family. Autonomy, as a construct might present challenges because DSPs may assume that absolute autonomy is the goal on which services should based. Just as support agencies should not allow denial of autonomy, they should not promote absolute autonomy as the goal of support services. Autonomy should be constructed for people with ID, in the same way that it is for people without ID. It should be constructed as something that entails limits, but that should be doggedly pursued.

Another troubling issue for constructing autonomy for people with ID is that the restrictions, control, and coercion that are part of everyday life in support services, might mean that people with ID do not understand the need to be autonomous or ever acquire the skills to become autonomous. Lotan and Ells (2010) stated that relationships with others are what inform learning about autonomy. This might mean that the kinds of experiences that people with ID have had contributed to their understanding and expression of autonomy. Matthew, a DSP participant, discussed the fact that many of the people that he supported had previously lived in institutions. He illuminated how much

better being supported in the community was for them, and provided some insight into how they might feel. Matthew recognized that the lives of the people he supported were not consistent with what he considered a typical life, and explained it in this way "a person tends to be happy with what they have if they don't know anything better. They don't know it exists they have nothing to compare it with." Because many of the people who are currently supported within the support system once lived in institutions, to Matthew, their current situation (though far from what he would consider good for himself) was much better for them than living in an institution. This is a reminder of how recent our institutional past was, and of how many restrictions of autonomy people with ID have faced throughout this history. Though it was not a finding of this study, it may be true that people with ID are satisfied with their current experience of their autonomy, but it is also true that others (for example, Matthew) perceive the degree of autonomy that people with ID experience as inadequate. It seems that, in this study, autonomy was constructed as people with ID living better lives than they did in institutions. The problem in constructing autonomy in this way is that it allows for an entire population of people to continue to be controlled, coerced, and restricted. Because their situation is better than it was at one point, does not mean that their situation is one that promotes their autonomy.

Paid caregivers. One of the major findings of this study was that DSPs and participants with ID perceived that DSPs have to care about the people that they support to effectively promote autonomy. This finding was consistent with Clarkson et al., (2009) who, in a study to determine the perceptions of people with ID about their support staff, found that participants with ID deemed caring an important aspect of the relationship. In

the current study caregivers had to be willing to go above and beyond their defined role

to advocate for the people that they supported, to teach them, to get to know them, to

listen to them, to treat them with dignity and respect, and to care about them. For this

reason, I've discussed the issue of paid caregivers in detail below.

Kittay (2011) stated that.

as an attitude, caring denotes a positive, affective bond and investment in

another's well-being. The labor can be done without the appropriate attitude. Yet

without the attitude of care, the open responsiveness to another that is so essential

to understanding what another requires is not possible. (p.52)

Many of the issues that caregivers discussed in demonstrating care illustrate their

responsiveness to the needs of people with ID (e.g., getting to know them, determining

how to appropriately talk to them, supporting their choices). If caregivers are not

responsive to the needs of the people that they support, they would not be able to support

their autonomy.

Wilson et al. (2008), in a study examining the ethical issues in direct support,

found that DSPs experienced an extreme duty to act as advocates for the people that they

supported. The DSPs in the current study discussed advocating for the people that they

supported. Though they worked in a system that prioritized institutional rather than

personal goals for people with ID, the caregivers often went above and beyond to

advocate against the support system in an attempt to provide better care to the people that

they supported, potentially risking their jobs and damaging their relationships with co-

workers. DSPs should not have to risk their jobs or relationships with co-workers to

promote the autonomy of the people that they support. DSPs should not have to repress

the autonomy of the people that they support in order to impose institutional objectives upon them. Institutional objectives are necessarily part of the system, but these objectives ought to be defined by the people who serve and who are served within the system. If institutional objectives were consistent with what people with ID wanted in the first place, then enforcing them would be in support of the autonomy of people with ID.

Though the DSPs and people with ID involved in this study provided many practical examples of how to demonstrate care, the finding of "caring to support autonomy" presents additional difficulties. There is literally no way to pay someone to care. The DSPs interviewed in this study listed many of the typical problems associated with DSP work such as low pay, lack of career trajectory, and staff turnover (findings confirmed by Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Larson et al., 1999; Larson & Lakin, 1999; Test et al., 2003a). The interviews did not include any questions specifically related to typical DSP problems, though nearly every DSP brought up these issues. Matthew, in telling the story (presented in chapter 4) about not being able to support a person to travel, said "everything is money, period." He seemed to imply that the bottom line is money, although there may be an institutional goal to support autonomy, and ultimately decisions are made that allow agencies to make or save money. Cardol, et al. (2002) support Matthew's observation; they stated that money is the major factor that determines how support is provided. Though people cannot be paid to care or to treat others with dignity and respect, raising DSPs' salaries could potentially lead to a more competitive job market where people who do care are more likely to seek jobs and develop careers. Some of the caregivers in this study indicated that they had problems with administrative management or did not feel cared about by the agencies that they

worked for. The National Direct Service Workforce Resource Center (2011) suggested that caregivers can provide better care when their own needs are met.

This study found that to support autonomy and other worthy goals for people with ID, it is necessary to bring back the care in "caregiving." The National Direct Service Workforce Center (2011) stated:

> The needs and interests of caregivers cannot fully be separated from the needs and interests of the people that they support. To the extent that public policies support the interests of people with disabilities, caregivers benefit, and to the extent that caregivers are supported, people with disabilities benefit," (p. v).

In other words, the caregiving needs to apply to both people with ID supported within the system, and the DSPs that support them.

The Social Model

Earlier in this dissertation I discussed the value of the social model as it relates to people with disabilities. The social model played a significant role in the way that I perceive disability and the way that this research was designed, conducted, and analyzed. The social model is a way for people with disabilities to define for themselves what disability is. In conducting and analyzing this research, I made sure that people with ID were the primary focus. In this study I asked people with ID to speak about their own situation, as I believed that this would be the best way to acknowledge and respect their voice. The participants with ID truly may need support, but that does not mean that they lose the right to speak about how they would like that support to be provided to them. This study was set up in a way that I hoped would allow them to speak about their needs. It also provided a means for them to self-define their needs (Oliver, 1990). Further, it

allowed people with ID to discuss their situation as they perceived it, and act as advocates

for themselves. In fact, the participants with ID seemed to be attracted to this study

because it allowed them to express themselves, and many of them specifically stated that

their goals were to help people with disabilities.

The fact that the social model factored into this study meant that I assumed that

ID is socially constructed and that social practices are what restrict the autonomy of

people with ID (Campbell, 2002). Though the social model is meant to impart control to

people with ID (Campbell), the social construction of disabilities means that people with

ID are treated under a model seems to disempower people with ID. For this reason, I

perceived that the role of the DSP is a more powerful role than the role of the person with

ID as a support recipient. These perceptions meant that I saw the DSPs as having more

autonomy then the people they supported and the ability to support autonomy in the

people that they worked for. Because of these perceptions I was subjective throughout the

research process. I centered the questions on the participants with ID and how to support

them, and people with ID were the focus of this study. Because of this I may have

weighed the responses provided by participants with ID more heavily than those of DSP

participants. With the social model factoring into this study, I wanted to impart control to

people with ID and to see their truth. I did that by analyzing the data in a way that may

have favored their perceptions and views over those of the DSPs. Though I believe that

the DSP participants were caring and thoughtful, I may have been more critical of their

responses in an attempt to impart greater control to people with ID.

The findings of this study revealed that, consistent with the social model, there

are indeed issues within the social structures that prevent people with ID from expressing

their autonomy. There were many areas in this study where it seemed that people with ID were perceived as being incompetent, indicating that their disabilities had been socially constructed in a way that necessitated controlling them. Oliver (1990) stated that when disability is defined for social policy, actions must be taken to minimize the disability. This seemed to be the case in this study where some of the processes mandated by policy intruded on the personal autonomy of the people supported. The very actions that were meant to minimize the disability were actually disempowering to the people with ID. Though advocacy is highly regarded by the social model, on a practical level it may be difficult to implement.

The findings of this study reinforce the notion of social construction. It seems that how disability is perceived affects how people with ID are supported at every level (federal, state, and local). If people with ID are not perceived as having autonomy, it seems that there will be no support for autonomy. Lack of support for autonomy seems evident in support services, however, a broader acceptance of the social model could better support could better support the autonomy of those receiving support. If services were to impart control to people with ID, it seems that these services would better support their autonomy. Also if the voice of people with ID was acknowledged and respected, they would perhaps be seen as being capable of advocating for themselves, and capable of exercising control. Likewise, some of the negative social constructions of intellectual disability would be minimized, and in this way disability might actually be minimized. In the social construction model people would be perceived as being less disabled if they exercised and managed more control.

Strengths

This study has many significant strengths. One of the most significant strengths was that it gave people with disabilities a voice. Actually, it not so much "gave" them a voice because they've always had one. According to their own testimony in this study, they were clearly capable of using their voice. More appropriately, this study was an attempt to respect their voices. The people that I interviewed seemed very interested in talking about their situations, being heard, and listened to. In fact, I recruited most of the participants with ID by speaking about the importance of them contributing to this kind of research. Most of the participants that I interviewed understood that they helped me and helped other people with disabilities by participating in the study. They stated this in casual conversations before and after the interviews, as well as within the interviews (a finding in this study was that participants with ID wanted to help others). Therefore people with disabilities expressed their autonomy by participating in the study.

The questions prepared for the direct support professionals, allowed them to think through complex situations they might encounter in their jobs, come up with problem-solving solutions, tell personal stories about their jobs, and vent some of the things related to their jobs that caused unhappiness. Whereas the questions for the participants with ID underestimated their abilities, the questions for the DSP participants seemed very appropriate and led to fruitful and interesting interviews. They seemed to be very well developed.

Although I also discuss this as a weakness, it should also be noted as a strength that due to recruiting efforts, the participants with ID and the DSP participants were people who might be more likely to express their autonomy or support the autonomy of

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the people that they supported. By the very nature of this study, the DSPs who might have been attracted to participation were likely more involved and more interested in speaking on such matters in the first place. Though it limited the variety of the kinds of responses shared, the responses were most likely well thought out.

A final strength noted in this study is that participants with ID and DSP participants verbally expressed their feelings on matters, that if observed may have yielded different conclusions. They expressed their reasoning for different aspects of the care that they provided and received. For these reasons, some of the "why's" of this study were answered. If observed, the intricacies of the DSP role may not have been revealed. In witnessing these interactions, it may have appeared as though DSPs were controlling and coercive, and may not have revealed the intricacies of institutional goal prioritization. In speaking about it, they provided explanations to address these research questions.

Limitations and Implications for Future Research

There are several limitations of this study that need to be accounted for in future research. The first limitation of this study is that I did not collect certain self-identified demographic information such as age, race, ethnicity, income level, education level (other than questions for participants with ID that asked about educational experiences), and so forth. I did not collect this information due to concerns about confidentiality. Because of this there may have been discrepancies based on those demographic issues, rather than specifically linked to disability, that this study did not account for. Future researchers should attempt to carefully collect demographic information when appropriate from these participants. Future research might look at how other factors, such as these demographic issues, affect how services are provided.

This study used a small number of participants which means that the results of this study cannot be generalized to all DSPs or people with ID. Further, a primary purpose of this study was to provide people with ID an opportunity to voice their perceptions of autonomy. The participants had to be capable of relaying complex information based on abstract questions. They had to have an understandable communication system and had to be able to demonstrate the ability to provide consent or assent to participate in this study. This obviously limited the participation of people with more severe disabilities, who might be said to have the most limited ability to demonstrate their autonomy in the first place. I regret that I was not able to include such individuals in this study. Future research might explore ways to include individuals with more significant disabilities in studies dealing with abstract topics. Researcher might look at ethnography as a means to include people with significant forms of ID in such a study.

Another limitation of this study was that participants provided their own perceptions. I did not personally witness interactions between DSP participants and participants with disabilities that contributed to or hindered the expression of autonomy. The participants provided their own perceptions, which although valid, may not have reflected situations or events accurately or holistically. The DSP participants might have been inclined to advertise service philosophies (i.e., promoting autonomy.) rather than providing details about what actually happened within daily practice. This might have also been true of participants with ID, who might have responded in ways, that they thought I wanted them to, rather than providing details about what actually happened. If I had been able to view the interactions between DSPs and those they supported directly, it is quite possible that the study may have yielded very different information. Witnessing

actual interactions would have provided a clearer picture about which interactions support or inhibit autonomy, but would have also presented additional problems (i.e., DSPs adjusting their interactions because of my presence, people with ID engaging with me, so that I would not be able to witness their interactions with DSPs). Future researchers should attempt to support verbal data from participants with observed data. This would allow them to relate questions to specific interactions they witnessed and to obtain detailed information on how (observed) and why (verbally reported) DSPs engage in interactions with people with ID to support or restrict their autonomy.

Another study limitation was that recruiting participants presented difficulties. The people likely to respond to my recruiting efforts were more likely to be individuals with ID who already had a strong self-advocacy background, and DSPs who demonstrated an interest in their jobs and the people that they supported (e.g., evidenced by both groups' willingness to speak about autonomy). This means that the perceptions of participants may not have matched those of other individuals with ID who might have been less inclined to discuss their own autonomy or other DSPs who may not have been as invested in facilitating the autonomy of the people they support. Another recruiting issue that came up was that the agencies providing services for people with disabilities were often so big that my requests to recruit people were often lost well before they made it to the individuals themselves, thus limiting the potential pool of participants. Further, some agencies made the decision to refuse to distribute my recruiting materials, thereby expressing their institutional autonomy, but also potentially restricting the autonomy of every person that they supported or employed to participate in the study. Future researchers might use different recruiting methods to include more varied participants.

They might also use research questions to reflect areas related to autonomy, rather than, explicitly, autonomy.

The interview questions used in this study also represented a limitation. The interview questions developed for the participants with ID were designed to be easily understood and to ensure that the important questions would be addressed and answered. The questions, it turned out, were very repetitive. The individuals interviewed for this study were more than capable of talking about the topics presented and the questions may have limited their responses. More appropriate questions might have asked them for stories about their lives and about different experiences that they've had. The interviews with people with ID could have been much more informative if I developed better and more appropriate questions. Future researchers might engage in interviews that are less formal. They might have several versions of questions so that they are prepared to respectfully engage in interviews with people with ID.

The interviews with people with ID often took place in their homes. Though this may have increased comfort of participants because they were in a familiar setting, it may have also contributed to fears about talking about their support staff. I asked all individuals to secure a private location for the interview; however, even when I was in a participant with ID's room, DSPs often came in and provided messages or did chores. For a portion of one interview, the participant and I were within ear shot of a DSP. This may have contributed to his fears in speaking about his support staff, and may have altered the responses that he provided, particularly in regard to the questions that related to DSP improvement, where it was extremely difficult for me to garner a response. Future researchers might take more precautionary measures to ensure the absolute privacy of the

people that they support (i.e., acquiring approval to meet in a room with a closed door out of earshot of staff members), and might actually examine research questions that look at the role of privacy in support of autonomy.

Autonomy is a difficult construct to define. Therefore, developing questions to determine how people experience autonomy is also difficult. The questions that I constructed, in the eyes of the participants, may not have been about autonomy at all, as well as my resulting interpretation. Attempting to find out what is important to people, by using interviewing techniques, necessarily pre-constructs some of their answers. Future researchers might look to participatory action research as a means to allow people with ID to develop concepts for themselves as well as to respect their voice, and engage them in the pursuit of autonomy. They might also do engage in some of the practices that this study's participants identified such as engaging in less formal interviews in attempt to get to know individuals with ID, having conversations with them about the services they receive, and encouraging them to talk about their lives. Researchers might spend time just talking to people with ID and getting to know who they really are. They might spend time with people with ID to determine what autonomy means on an individual level by doing an ethnography or case study. They might also interview people that the person with ID has identified as important to them and knowledgeable about their lives, in addition to interviewing people with ID themselves.

Lastly, this study sought to determine how interactions between DSPs and people with ID act to support or restrict the autonomy that people with ID express. One of the major findings, however, was that institutional control permeated support. A limitation was that I was not able to conduct this study at an agency or state level to determine how

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the larger support system restricts autonomy at the individual level. Future research

should examine this issue.

Conclusion

People with ID interviewed in this study demonstrated that they were competent,

caring, and capable members of society. They should be treated with dignity and care,

their voices should be respected, their choices should be valued (even when they are not

the most ideal choices), they should have opportunities to fully engage in experiences that

are typical of everyday life, they should be allowed to lead less than perfect lives, and

support should be about them, rather than institutional objectives (unless, or course,

people with ID define the institutional objectives themselves). The paid caregiving

relationship is one that is quite complex, and the issues that are involved in it, may be

irresolvable. The institutional issues still apparent in paid caregiving may be better

resolved outside of the support system altogether.

Perske (1983) stated that "this is the way civilization betters itself: change begins

with highly visible revolutions but ends with unpretentious ones" (p. 72). Autonomy is

not something that can just be given to people with ID, and stipulating that people with

ID should be able to express their autonomy will have little effect if the social situation

that prevents them from having autonomy is not changed (Megret, 2008). It will be

impossible to change the care that people with ID receive, when the attitudes that inform

the thinking about care remain the same. Rather than working from within the support

system people who are interested in promoting the autonomy of people with ID should

look to facilitating care and autonomy throughout the life span, by fostering the

participation, inclusion, and acceptance of people with ID. They should always promote

their competence, abilities, and contributions, rather than their limitations. After people in

society truly know people with ID, it is my hope that they will care about them, and care

about their expression of autonomy. In this way, society at large will have a vested

interest in promoting the autonomy of people with ID. As people with ID are better able

to express their autonomy, there will be no need to specifically define it for them in the

first place.

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Appendix A

Questions for Initial Interviews with participants with intellectual disability.

Questions may be rephrased to adjust for cognitive limitations. Additional questions may be asked based on information provided to elicit additional information from the participants. Additional questions may also be used to assist participants to expand upon thoughts that they have shared in the interview.

1. Tell me about where you live.

2. Tell me about the kind of support that you get.

3. Tell me about any experiences you have had being a self-advocate.

4. Tell me about your work experiences.

5. Tell me about your school experiences.

6. Tell me about your family, friends, hobbies, interests.

7.   What is a good day like for you? What does your support staff do during that day?

8. What is a bad day like for you? What does your support staff do during that day?

9. Tell me about your support staff. ? How do you feel about them?

10. Tell me about what you think that your support staff should do.

11. Tell me about some of the ways that support staff help you.

12. Tell me about what you would like for your support staff to do better.

13. Tell me about what it's like to work with support staff.

14. Is there anything else that you want to tell me about your support staff?

Appendix B

Questions for initial interviews with DSP participants

If participants are stuck on a particular question (i.e., don't seem to know how to answer it), I may provide an example that occurred in my work with people with disabilities. Additional questions may be used to elicit information from the participants or to get them to expand upon insights that they have provided in the interview.

1. Tell me about the work that you do with people with intellectual disability.

2. Tell me about how you came to work in this field. How long have you worked in this field?

3. Tell me about the ways you support the people that you work with.

4. Tell me about how you feel about your job.

5. Tell me about what you think is the primary responsibility of your job.

6. What do you think is the hardest part of your job?

7. Tell me about how you think that you protect people with disabilities from danger.

8. How do you know what is most important to the people that you support? How can you support them in a way that they approve of?

9. Can you tell me a story about something that happened at work when you had to make a tough decision? Tell me about how you came to that decision and what influenced your decisions.

10. Can you tell me a story about a time when you were not able to support the decisions of the person that you worked with? Why weren't you able to support their decisions?

11. Tell me about what matters most to you when you have to make decisions at work. What about when you have to make tough decisions?

12. I'm going to give you a short scenario and I want you to tell me about what decisions you would need to make in the scenario and about how you come to those decisions and what issues guide your decision-making process (participants will only respond to scenario a or b, not both).

   (a) Suppose that a man that you work with who is extremely overweight wants to fry and eat a whole pound of bacon every morning before going to dayhab. He does not currently have any health issues. These eating habits are leading to increased weight gain. You are pressured by your supervisor to decrease the amount of bacon that he eats. What decisions would you need to make in this scenario? Describe to me what would influence your decisions. Are there any other factors that would come into play in making decisions in this area? What do you think would be the right way to support the person in this situation?

   (b) Suppose that you work in a home where you provide support to three individuals without any other assistance. One of the individuals prefers to stay at home after 4:00 in the afternoon, and immediately puts on his pajamas at that time. The other two individuals always want to go out after 4:00 (to the mall, the movies, out to eat). What decisions would you need to make in this scenario? Describe to me what would influence your decisions. Are there any other factors that would come into play in making decisions in this area? What do you think would be the right way to assist the people that you support in this situation?

13. I'm going to give you another short scenario and I want you to tell me about what decisions you would need to make in the scenario and about how you come to those decisions and what issues guide your decision-making process (participants will only respond to scenario a or b, not both).

(a) Suppose that one of the people that you work with wanted to get a tattoo in a visible area. Imagine that this person is their own guardian and they have saved up enough money to get a tattoo, but you have witnessed their parent telling them that they thought that it would be awful for them to get the tattoo. They would also not be allowed to show the tattoo at work and you think that they would get tired of finding ways to cover it up every day. What decisions would you need to make in this scenario? Describe to me what would influence your decisions. Are there any other factors that would come into play in making decisions in this area? What do you think would be the right way to support the person in this situation?

(b) Suppose that a young woman that you support has recently begun a relationship with another woman. She has disclosed to you that she has no prior sexual experience, and that she had only gone as far as holding hands. She and her partner have been dating for a month. She asks you to help her purchase a sex toy and tells you that she is planning on having sex with her partner. You are worried because she can be vulnerable and her partner can be somewhat aggressive. What decisions would you need to make in this scenario? Describe to me what would influence your decisions. Are there any other factors that would come into play in making decisions in this area? What do you think would be the right way to support the person in this situation?

14. Is there anything else that you want to tell me about that relates to supporting

people with disabilities?

Appendix

Graphic of Analysis of Data

Being an Autonomous Person

Advocacy, Benefiting Others, Quest for Knowledge, Authentic Relationships, Ideals, and Values

Challenges to DSPs are Challenges to Supporting Autonomy

Caring in Support of Autonomy

Good Feelings, Trust-building, Teamwork, Having a Good Attitude, Getting to Know Them, Acknowledgement and Encouragement, Offering and Supporting Choices, Difficult Conversations, Demonstrating Care in Interactions, Advocacy, DSP Compromise, Stigma, Treating with Dignity and Respect, and Caring

Walking a Fine Line

Drawing a Professional Line, Defining Support Boundaries, Institutional Control, Informed Choices, Repression, Natural Consequences, Safety/Protection, Buffers to the Real World

Institutional Barriers

Inflexible Services, Inappropriate Services, ISP Process Problems, Administrative Issues, and Typical DSP Problems

A Challenging Role

Dealing with Challenging Behavior, Restrictions, and Making Difficult Decisions (Factors in Decision-Making)

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