

“TREAT ME LIKE I’VE GOT SOME KIND OF ABILITY”:
PERSPECTIVES OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES ON
THEIR COMMUNICATION WITH DIRECT SUPPORT PROFESSIONALS

by

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(Under the Direction of Zolinda Stoneman)

ABSTRACT

Interaction with direct support professionals is a primary source of communication for individuals with intellectual disabilities and, therefore, vital to their social integration. Despite growing recognition of the importance of supporters listening to what individuals say about their needs and preferences for services, few researchers have obtained the perspectives of individuals with intellectual disabilities on their communication with direct support professionals. Six focus groups comprising 32 individuals with intellectual disabilities were conducted and their statements about communication were gathered. Analysis of transcripts revealed the following seven themes representing perspectives of focus group participants: *Be Friends with Them When You Talk to Them...and Listening; I Would Like Them to Respect Me; You Got to Show Me That You Can be Trusted by the Way You Talk to Me; Some People Get Too Involved Into Your Life Where You Don't Want Them; Treat Me Like I've Got Some Kind of Ability; I Told Myself I Made a Good Choice; and We're Grown People, We Have the Same Feelings Like They Do.*

INDEX WORDS: Intellectual disabilities, Communication, Direct support professionals, Focus group, Respect

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DEDICATION

This dissertation is dedicated to Amy for many years of devotion and hard work, and to our children, Samuel, Nathan and Claire, who throughout my academic career have approached me with open hearts in ways that seldom failed to make mine smile.

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I am grateful for the trust and acceptance of the study participants who told me how life is for them and how it could be in the future. Whatever this study has achieved in representing their perspectives came about through the help of Vici Decker who took notes of the discussions and edited the transcripts. Her ideas and questions suggested numerous connections in what participants were saying.

This research reflects the influence of colleagues I have observed treating others with respect. Dr. Dale Bertram first invited me to learn how words can create a reality of respect. Dr. Douglas Flemons and Dr. Shelley Green demonstrated respectfulness in their interactions with the individuals they sought to assist, providing lasting impressions of how respect increases choice and possibility for oneself and others.

During this work, my mother's interest and concern was always evident, and my siblings, Mary, Ann, Edward, James, Carol, Paul, Thomas and Raymond offered words of kindness and humor, providing a lifeline I reached for on many occasions. In recent years, my father's writings about the preciousness of all life helped sustain my belief in the value of the effort. Income provided by my wife, Amy, and financial assistance from my father and my brother, Thomas, allowed me to pursue this research.

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CHAPTER ONE

INTRODUCTION

Over the past three decades in the United States, tens of thousands of individuals have been moved from institutions and resettled in community residences. Between 1977 and 2002, the number of persons living in state-operated MR/DD institutions declined from approximately 150,000 to just over 44,000, while the number residing in settings for six or fewer persons increased from approximately 20,000 to over 298,000 (Braddock, Hemp, & Rizzolo, 2004). Deinstitutionalization has been driven by various factors including rising costs of institutional care and shifts in funding strategies (Spreat, Conroy, & Fullerton, 2005) and a continuing awareness of the desirable effects of normalization (Wolfensberger, 1983) and benefits of living in the community (Bradshaw & Carnaby, 2002; Cattermole, Jahoda, & Markova, 1990; Fisher, Haagen, & Orkin, 2005; Gregory, Robertson, Kessissoglou, Emerson, & Hatton, 2001). Community integration as a legal right was made clear in Title II of the 1990 Americans with Disabilities Act (ADA), requiring states and local governments to provide people with disabilities equal opportunities to all their programs, services and activities (Salzer, Kaplan, & Atay, 2006). The scope of this law was further defined in the *Olmstead vs. Lois Curtis and Elaine Wilson* Supreme Court decision in 1999, which ruled it a violation of ADA to provide services to people with cognitive disabilities only in institutions, when they could be served as well, or better, in community settings (Salzer et al.).

Expansion in community living represents a shift from custodial to more habilitative care (Repp, Felce, & deKock, 1987), with community contexts representing

primary social settings for many individuals with disabilities (Baker, Freeman, & High, 2000; Bartlett & Bunning, 1997; Dennis, 2002). Researchers have examined aspects of community living including costs of services (Braddock et al., 2004; Spreat et al., 2005), inclusion and social integration (Abbott & McConkey, 2006; Mactavish, Mahon, Lutfiyya, 2000; Werner, Horner, & Newton, 1997), access to medical care (Fisher et al., 2005), and stress and burnout of support staff (Hastings, Horne, & Mitchell, 2004; White, Edwards, & Townsend-White, 2006). Also, researchers have studied communication between supporters and individuals with disabilities (Baker, et al., Bradshaw & Carnaby, 2002; Golden & Reese, 1996; McConkey, Morris, & Purcell, 1999). Researchers interested in communication have shown a general emphasis among supporters on teaching individuals with disabilities to communicate (Repp et al.). However, the role of communication in integration and socialization of individuals with intellectual disabilities has been minimally acknowledged (Bradshaw & Carnaby), and communication generally viewed in isolation from other areas of a person's life.

Communication between Individuals with Intellectual Disabilities and Direct Support Professionals

Numerous observational studies have involved categorization of communication of direct support professionals and individuals with disabilities (see Literature Review, p. 14). Thirty-two observational studies, divided approximately between those conducted in institutional contexts and community settings, provided the primary literature reviewed for this study. Studies documented the influence that communication of direct support professionals has on individuals with intellectual disabilities, and the effects of intellectual disability on the language and communication of direct support professionals

(Kuder & Bryen, 1991). Communication between providers and recipients of disability supports and services has been influenced by factors including the structure of the interaction setting (Kuder & Bryen, 1993; Prior et al., 1979), ratios and groupings of supporters and individuals with disabilities (Felce, Repp, Thomas, Ager, & Bluden, 1991), and the interactive quality of specific activities within a communication setting (Baker et al., 2000). In addition to observational studies, position papers have described aspects of communication between individuals with intellectual disabilities and supporters (Banat, Summers, & Pring, 2002; Butterfield & Arthur, 1995; Bradshaw & Carnaby, 2002; Ferguson, 1994; Nind, 1996).

The study of communication between individuals with disabilities and direct support professionals has been influenced by research on interactions between children and attendants in institutions (Dailey, Allen, Chinsky, & Veit; 1974; Tizard, Cooperman, Joseph, & Tizard, 1972; Warren & Mondy, 1971; Veit, Allen, & Chinsky, 1976; Wright, Abbas, & Meredith, 1974). Researchers observed responses of attendants to appropriate and inappropriate behaviors of children (Warren & Mondy) and amounts and types of interaction (Wright et al.). Responses of attendants were influenced by child behaviors, with attendants directing a greater number of positive social interactions toward children they perceived as attractive and likeable (Dailey et al.). Differences in the effects of informative and control-based speech styles of attendants were reported (Tizard et al.). In subsequent studies of adults with intellectual disabilities, researchers observed similar differences between the effects of directive and conversational speech of direct support professionals (McConkey, Morris et al., 1999; Pratt, Bumstead, & Raynes, 1976; Purcell, McConkey, & Morris, 2000).

Research Considerations

Studies of communication between direct support professionals and adults with intellectual disabilities have included observations of the responses of supporters to behaviors (Cullen, Burton, Watts, & Thomas, 1983; Felce et al., 1987) and functioning levels (Hile & Walbran, 1991) of the individuals they support. Researchers have considered whether interactions are resident-focused or institution-focused (Pratt et al., 1976; Raynes, Pratt, & Roses, 1977; Raynes, 1980) and have found a *person-centered* focus to be associated with less controlling speech by supporters, greater conversational interchange and more frequent responses from the person receiving care (Pratt et al.). Individuals with disabilities have been found to give different verbal responses depending on whether the initiation of the supporter is directive or conversational (Paton & Stirling, 1974; Prior et al., 1979), with the frequency of responses being highest for informative talk and lowest for negative control statements (Pratt et al.). Communication of individuals with disabilities has been considered an indication of the effectiveness of supporter talk; however, the most favorably reported type of communication, conversation, has been found to occur the least frequently (Pratt et al.; Prior et al.).

Studies have included consideration of the quantity of verbal interaction between individuals with disabilities and support professionals (Baker et al., 2000; Cullen et al., 1983; McConkey, Morris et al., 1999; Paton & Stirling, 1974; Repp et al., 1987) and the quality of their interaction (Dobson, Upadhyaya, & Stanley, 2002; Hile & Walbran, 1991; Markova, Jahoda, Cattermole, & Woodward, 1992; Grant & Moores, 1977; Pratt et al., 1976). Researchers have found low rates of interaction (Markova et al.; Prior et al., 1979; Repp et al.) and high rates of interaction that is of low quality (Chan & Yau, 2002; Grant

& Moores; Markova et al.; Zilber et al., 1994) or neutral (Felce et al., 1987).

Additionally, researchers have considered *how* and *why* support professionals speak to individuals with disabilities, describing initiations and responses of supporters in terms of *forms* of speech (Bradshaw, 2001; Paton & Stirling; Prior et al., Zilber et al.) and *functions* of communication (Bird, Dores, Moniz, & Robinson, 1989; Hile & Walbran; Markova et al.; Pratt et al.; Purcell, et al., 2000; Owen, MacDonald, & Baine, 1994).

The influence individuals with intellectual disabilities and direct support professionals have on the speech of the other involves difference in the amount and type of communication each uses and in the responses each elicits from the other (Kuder & Bryen, 1991; Prior et al., 1979). Most studies reviewed for this research emphasized the classification of verbalizations of support professionals and their descriptions and evaluations of aspects of communication. However, the majority of the coding systems examined also included one or more codes for recording verbal behaviors of individuals with disabilities.

Physical Setting and Social Context

Researchers have examined the influence of environmental factors on the interaction of individuals with intellectual disabilities and supporters (Baker et al., 2000; Hile & Walbran, 1991; Kuder & Bryen, 1991; Prior et al., 1979). Some have compared amounts of social interaction in institutions and small community settings (Felce et al., 1987; Felce et al., 1991; Markova et al., 1992). Markova et al. found individuals living in hostels had significantly more interaction with support staff than individuals living in hospital wards. Improvements in interaction have been associated with decreases in the size of the groups served in small community homes and increases in levels of staff

interaction (Felce et al, 1991). However, the location of a residence is less likely than the size of the group receiving services to affect internal patterns of interaction between individuals with disabilities and supporters (Felce et al., 1987). Additionally, the location of the residence is less important as a determinant of the responses of supporters than the relationship between individuals (Zilber et al., 1994). Kuder and Bryen observed individuals with intellectual disabilities living in an institution initiated interaction more often than support staff.

Supporters have been observed initiating communication mainly in response to functional or physical needs of individuals with disabilities in structured settings more frequently than in unstructured ones (Kuder & Bryen; 1993; Prior et al., 1979). Functional interaction tends to be more common in institutions and social interaction more common in community settings (Kuder & Bryen); however, living in the community does not provide a guarantee of social integration (Markova et al., 1992). Differences in the roles of direct support professionals across community and institutional contexts are not always evident (Abraham, Lindsay, & Lawrenson, 1991) and commonalities in how support professionals speak to individuals with disabilities often are more salient than differences.

In addition to physical settings, researchers have considered social contexts (Emerson, Hatton, Robertson, Henderson, & Cooper, 1999; Hile & Walbran, 1991), including the influence that characteristics and behaviors of individuals with disabilities have on the speech, actions and perceptions of supporters (Grant & Moores, 1977; Pratt et al., 1976; McConkey, Purcell, Morris, 1999; Raynes, 1980; Repp et al., 1987). Communication has been found to be improved when supporters adapt and modify their

speech to more effectively support the communication of the person with a disability (McLeod, Houston, & Seyfort, 1996; Smith, Felce, & Lowe, 2002). Although staff members were able to predict and adapt their verbal acts across communication settings, their communication was dominated by the use or non-use of a teaching strategy, based on correction, instruction and reinforcement (McConkey, Purcell et al.).

Direct Support Professionals' Control of Individuals with Intellectual Disabilities

Most individuals regularly make choices and decisions that involve communicating with others; however, individuals with intellectual disabilities seldom experience choice, autonomy and personal liberty in their interactions (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988). Direct support professionals make most of the decisions for individuals with disabilities and do little to promote conversation related to the person's choices and preferences (Wareing & Newell, 2002). The provision of effective habilitation often involves support professionals exercising primary control over the lives of the individuals they support (Bannerman, Sheldon, Sherman, & Harchick, 1990) and directing conversations accordingly (Domingo, Barrow, & Amato, 1998; Jingree, Finlay, & Antaki, 2006).

Support professionals generally are controlling of individuals with intellectual disabilities (Prior et al., 1979), addressing with less informative speech individuals who are more severely disabled (Pratt et al., 1976). Additionally, supporters often ignore individuals with disabilities (Bradshaw, 2001; Chan and Yau, 2002; Cullen et al. 1983; Felce et al., 1991; Prior et al.), especially those they consider unattractive (Grant & Moores, 1977). Observations indicate direct support professionals use overly directive and controlling speech when interacting with individuals with intellectual disabilities

(McConkey, Morris et al., 1999; Prior et al.), which is more functional than social or conversational. Despite growing acknowledgement of the importance of individuals having self-direction over their support (Bedrosian & Prutting, 1978; Bird et al., 1989; Domingo et al., 1998; Jingree et al., 2006), supporters regularly control individuals with intellectual disabilities (Bannerman et al., 1990; McConkey, Morris et al.; Prior et al.; Wareing & Newell, 2002). An analysis of interactions of individuals with intellectual disabilities and direct support professionals revealed different ways power relations manifest between them (Jingree et al.).

Researchers have identified the controlling and directive nature of supporter utterances (Cattermole et al., 1990; Prior et al., 1979) and the roles supporters play in teaching and facilitating language and communication (Kuder & Bryen, 1991; Repp et al., 1987). They have regarded teaching to be a primary function of staff communication and have viewed informative speech, in contrast to directive speech, to be vital for teaching and providing communication to individuals with intellectual disabilities (Raynes et al., 1977; Repp et al.). Generally, researchers have emphasized instructional and informative characteristics of supporter utterances, not social or affective aspects (Banat et al., 2002; Markova et al., 1992). Researchers have examined communication between individuals with intellectual disabilities and support professionals mainly from the perspective of the supporter, reflecting an emphasis on functional improvements to communication (Bird et al., 1989). Studies of functional aspects of communication, including supporters' efforts to teach and facilitate language and communication generally do not include researchers giving attention to social aspects of communication or eliciting the perspectives of individuals with disabilities.

Supporter Perceptions

Researchers have emphasized perceptions of supporters and their estimations of communication competencies of individuals with intellectual disabilities (Banat et al., 2002; McConkey, Morris et al., 1999; Purcell, Morris, McConkey, 1999), highlighting differences between them (Linder, 1978). This emphasis has involved attention to mismatches between supporter estimations of communication competencies and the actual skills of the person (Banat et al.) and between supporter estimations and the complexity of the speech supporters use (Bartlett & Bunning, 1997; Bradshaw, 2001; Purcell et al.). Additionally, researchers have found mismatches between their observations of supporter talk and the reports supporters give of the types of speech they use (McConkey, Morris et al.), and between the form and function of supporter speech and the responsiveness of individuals with disabilities (Zilber et al., 1994). Researchers have considered adaptations supporters make to their speech to fit the competencies of individuals with intellectual disabilities and whether such adaptations promote changes in communication (Repp et al., 1987).

Mismatches and discrepancies in supporter perceptions of communication involving their estimations of communicative competence are based on assumptions of difference (Linder, 1978). Perceptions of difference are exemplified through words and actions of supporters that suggest individuals with intellectual disabilities are incapable of utilizing the linguistic code as competently as speakers without intellectual disabilities (Domingo et al., 1998). However, difficulties related to the communicative competence of individuals with intellectual disabilities are not all pervasive (Domingo et al.). Individuals with intellectual disabilities have been found to exercise appropriate

communication design strategies (Sabsay & Kernan, 1983) and to engage in conversational repair when communicative breakdowns occur (Abbeduto, 1991). Nonetheless, care staff, untrained in interview techniques, have been found to use non-neutral interview practices with individuals with intellectual disabilities (Antaki, Young, & Finlay, 2002), and have reported believing they need to manage conversations, in order to minimize “trouble” in communication related to differences (Linder). Linder surmised that the desire of individuals without disabilities to control conversations in order to avoid possible communication breakdowns is based on perceptions that the person with an intellectual disability would be unable to correct misunderstandings or handle problems that might occur in the conversation.

Supporters may assume individuals with intellectual disabilities are unable to exercise choice and self-direction and less able than others to make important life decisions and to recognize and value respectful conversation, or to be affected by its absence. Interviewers without disabilities have been observed speaking to individuals with intellectual disabilities about mundane subjects of little interest to either party, using repetitive questions or simple syntactic constructions (Linder, 1978). Linder noted the simplification strategies of interviewers in their attempts to avoid possible mismatches with conversational partners only highlighted differences between individuals with and without intellectual disabilities.

The attention of researchers to supporter perceptions of communicative competencies of individuals with intellectual disabilities (Banat et al., 2002; Bartlett & Bunning, 1997; Bradshaw, 2001; McConkey, Morris et al. 1999; Purcell et al. 1999), including mismatches and assumptions of difference, has not been balanced by

perspectives from the individuals themselves. Efforts to improve communication between a person with an intellectual disability and a supporter (Baker et al., 2000; Butterfield & Arthur, 1995; McConkey, Morris, et al.; Mirenda & Donnellan, 1986; Money, 1997; Nind, 1996) involves acknowledgement that each influences the communication of the other (Hile & Walbran, 1991; Kuder & Bryen, 1993; Chan & Yau, 2002). However, with few exceptions (Cattermole et al., 1990; Jahoda, Cattermole, Markova, 1989; Murphy, 2006) researchers have not represented the perspectives of individuals with intellectual disabilities on their communication with supporters.

Need for Perspectives from Individuals with Intellectual Disabilities

Conversation and social interaction is important for eliciting perspectives of individuals with intellectual disabilities, yet researchers have given little attention to social aspects of communication, in comparison to the attention given functional concerns (Butterfield & Arthur; 1995; Furguson, 1994; Markova et al. 1992; Nind, 1996). Social communication contributes to individuals with intellectual disabilities making choices and exercising control and, therefore, is as necessary as functional communication (Cooper & Browder, 2000; Markova et al.; Waring & Newell, 2002). However, researchers have devised few systems for defining conversation and social interaction, and have given little consideration to how supporter communication advances or hinders the choices and preferences of individuals with disabilities. Overall, researchers have not pursued methods for eliciting perspectives of individuals with intellectual disabilities, specifically their views on aspects of communication with direct support professionals.

Perspectives of individuals with intellectual disabilities, on issues other than communication, have been obtained through surveys (National Association, 1990) and interviews (Cattermole et al., 1990; Gregory et al., 2001; Jahoda et al., 1989; Kishi et al., 1988; Wehmeyer & Metzler, 1995). However, responses from individuals with intellectual disabilities have been used mainly to further researchers' narratives rather than to represent perspectives of the informants (Booth & Booth, 1996). Additionally, focus groups have been found useful in eliciting perspectives of individuals with intellectual disabilities (Abbott & McConkey, 2006; Barr, McConkey, & McConaghie, 2003; Bollard, 2003; Cambridge & McCarthy, 2001; Fraser & Fraser, 2001).

Researchers have shown the importance of listening to individuals with intellectual disabilities (Booth & Booth, 1996); however, few have elicited their perspectives, especially on the communication they experience with supporters (Cattermole et al. 1990; Jahoda et al., 1989; Murphy; 2006). Cattermole et al. and Jahoda et al. reported perspectives of individuals with intellectual disabilities on how support professionals talk to them, and Murphy reported perspectives from individuals with intellectual disabilities on their communication with medical practitioners.

Research aimed at furthering social aspects of communication would promote the perspectives of individuals with intellectual disabilities on their communication with direct support professionals. Accordingly, studies should be pursued that emphasize social and conversational aspects of communication (Kuder & Bryen, 1991; Markova, et al., 1992), thereby encouraging expression of perspectives by individuals with intellectual disabilities. Advancement of this orientation suggests a qualitative methodology and the use of focus groups. The purpose of this study is to provide a first step in gaining

perspectives and viewpoints from individuals with intellectual disabilities on their communication with direct support professionals. Accordingly, a focus group method will be used to obtain perspectives of individuals with intellectual disabilities on the ways direct support professionals communicate with them.

CHAPTER TWO

LITERATURE REVIEW

Social interaction is essential to interpersonal communication (Butterfield & Arthur, 1995) and communication partnerships to social integration (Bartlett & Bunning, 1997; Bradshaw & Carnaby, 2002). As communication partners, support staff are vital to the communication and social integration of individuals with learning disabilities (Baker et al., 2000; Dennis, 2002; Kuder & Bryen, 1993). The influence of support professionals on individuals with intellectual disabilities cannot be overstated, as the majority of contacts individuals experience in residential and day programs involve supporters (Bartlett & Bunning; Dennis; Hile & Walbran, 1991; Kuder & Bryen; Repp et al., 1987). Researchers have devised coding systems, or have modified and developed the systems of others, to observe and record aspects of verbal interaction between individuals with disabilities and direct support professionals.

Research on Communication between Individuals with Intellectual Disabilities and Direct Support Professionals

Observations of communication between supporters and individuals with disabilities have been conducted in institutions, group homes and hospitals (Bradshaw, 2001; Chan & Yau, 2002; Cullen et al., 1983; Golden & Reese, 1996; Grant & Moores, 1977; Hile & Walbran, 1991; Kuder & Bryen, 1991, 1993; McLeod et al., 1996; Paton & Stirling, 1974; Pratt et al., 1976; Prior et al., 1979; Raynes, 1980; Raynes et al., 1977). Researchers have observed communication in small-scale residences and in community-based programs and work settings (Baker et al., 2000; Bartlett & Bunning, 1997; Dobson

et al., 2002; Domingo et al., 1998; McConkey, Morris et al., 1999; McConkey, Purcell et al., 1999; Owen et al., 1994; Purcell et al., 2000; Purcell et al., 1999; Smith et al., 2002; Zilber et al., 1994). Researchers have contrasted effects of institutions and community residences on staff-resident interactions (Abraham et al., 1991; Emerson et al., 1999; Felce et al., 1991; Felce et al., 1987; Markova et al., 1992; Repp et al., 1987; Thomas, Felce, de Kock, Saxby, & Repp, 1986) and on amounts of staff-staff and staff-resident communication (Orlowska, McGill, & Mansell, 1991). The majority of observational procedures have included one or more codes for recording communications of individuals with disabilities, and coding systems have been developed specifically to code behaviors and communications of individuals with disabilities and the responses they receive from staff (Cullen et al.; Felce et al., 1987; Zilber et al.).

Studies of communication involving direct support professionals and individuals with disabilities have generated numerous data indicating individuals experience very low rates of interaction with supporters (Hile & Walbran, 1991; Prior et al., 1979) and few opportunities to engage as equal partners in conversational exchanges (McConkey, Morris et al., 1999). Researchers have examined quantity of supporter verbalizations (Baker et al., 2000; Cullen et al., 1983; McConkey, Morris et al., 1999; Pratt et al., 1976; Repp et al., 1987). Measures of quantity include frequency of dyadic verbal interactions (Paton & Stirling, 1974), frequency of supporter initiations and their responses to the behaviors of the individuals they support (Cullen et al.; Felce et al., 1987) and measures of communicative intent and subsequent turn taking (Owen et al., 1994).

Researchers have described quality of communicative interaction between supporters and individuals intellectual disabilities (Dobson et al., 2002) and quality of

care (Raynes, 1980). Additionally, researchers have considered level of complexity of supporter speech (Bradshaw, 2001) and topics of conversation initiated by supporters and by individuals with disabilities (Kuder & Bryen, 1993). Researchers have described type (i.e., form) of verbal interactions initiated by supporters (McConkey, Morris et al., 1999; Paton & Stirling, 1974; Zilber et al., 1994) and responses elicited from individuals with disabilities (Prior et al. 1979), and the function or purpose of communications (Hile & Walbran, 1991; Markova et al., 1992; Owen et al., 1994; Raynes; Zilber et al., 1994). Additionally, researchers have reported the effects of support professionals' speech on individuals with intellectual disabilities and their communication (Antaki et al., 2002; Dobson et al., 2002; McConkey, Morris et al.; Repp et al.).

In several studies, researchers considered perceptions of direct support professionals of the communicative competencies of the individuals with disabilities. Bartlett & Bunning (1997) looked at the extent to which the verbal expressive skills of supporters used during conversation complemented the comprehension of individuals with intellectual disabilities. Researchers have considered the degree to which supporters are able to predict and adapt their communications across different interaction contexts and predict and assess their use of verbal acts other than those based on corrections, giving instructions and reinforcements (McConkey, Purcell et al., 1999). Additionally, researchers have rated the appropriateness or inappropriateness of supporters' communicative behaviors in relation to the particular context and the supporters' knowledge of the communicative competencies of the person with a disability (McConkey, Morris et al., 1999). Researchers have considered the communicative performance of individuals with intellectual disabilities, finding they "initiate much of the

communication with staff who are generally responsive when initiations are focused and require a verbal response" (Kuder & Bryen, 1991, p. 331).

Bedrosian and Prutting (1978) found individuals with learning disabilities used conversational devices similar to those used by supporters, but rarely took the dominant role in conversations. Likewise, studies of interaction between support professionals and individuals with intellectual disabilities generally are organized around what supporters do and what the recipients of their support efforts receive (Chan & Yau, 2002; Felce et al., 1987; Hile & Walbran, 1991). Researchers have represented individuals with intellectual disabilities as submissive communication partners (Bedrosian & Prutting; Domingo et al., 1998) and generally have approached the study of interaction with greater emphasis on the involvement and purposes of supporters than on the concerns of individuals with disabilities. Staff estimations of the communication skills of individuals with intellectual disabilities (Purcell et al., 1999) and perceptions of the communications used by each (McConkey, Purcell et al., 1999) have been used primarily to evaluate the quality and effectiveness of *staff* communication (Bradshaw, 2001).

Supporters seldom use types of communication that elicit responses from individuals with disabilities or promote conversation with them, but instead give commands, instructions and directives that discourage verbal responses (Kuder & Bryen, 1991; Owen et al., 1994; Prior et al., 1979), and further an impoverished communication environment. Supporter communications have been studied in conjunction with the physical environment (Baker et al., 2000) and in terms of aspects of social context, including characteristics of individuals with disabilities (Grant & Moores, 1977) and supporter perceptions (Raynes, 1980). Features of the communication environment and

aspects of social context, involving perceptions of supporters, affect the amount and quality of interaction (Chan & Yau, 2002; Hile & Walbran, 1991; Prior et al.; Repp et al., 1987). Researchers have examined aspects of the physical environment and social context in relation to the amount, nature and function of interaction (Repp et al.).

Physical Environment

The influence of the physical environment on the interaction of staff and individuals with disabilities has been well documented (Baker et al., 2000; Hile & Walbran, 1991; Kuder & Bryen, 1991; Prior et al., 1979; Raynes, 1980), with an emphasis on differences between institutional and community settings. Factors relevant to the physical environment include the communication setting (e.g., large community residence, small community home, dining room etc.) and aspects of specific locations (e.g., number of individuals with disabilities and the ratio to staff) (Felce, et al., 1987; Thomas et al., 1986).

Differences in the communication of staff and individuals with disabilities have been found between work and day program settings (Zilber et al., 1994) and between small-scale residences and day programs (McConkey, Purcell et al., 1999). Staff in hospitals were more frequently seen by residents with learning disabilities as imposing regulation over their lives than were staff in community residences (Cattermole et al., 1990). Significant variations in staff communications have been reported between structured and unstructured settings, with more communication occurring in structured settings (Kuder & Bryen, 1993; Prior et al., 1979). However, findings also suggest the type of living arrangement may be less important than aspects of the interpersonal

relationship in determining the quality of communication between individuals with intellectual disabilities and supporters (Prior et al.; Felce et al., 1987).

Researchers have considered the effects of manipulating the interaction environment on the communication of staff (Baker et al., 2000; Bartlett & Bunning, 1997; Bradshaw, 2001; Butterfield & Arthur, 1995; Hile & Walbran, 1991.) Additionally, studies from speech-language therapy indicate that the development of an environment conducive to good communication is important to communicative interaction (Banat et al., 2002). Approaches for improving communication by manipulating the environment involve assumptions that staff members can adapt their communications to more effectively support the communication of individuals with disabilities (Dobson et al., 2002; McConkey, Purcell et al., 1999; McLeod et al., 1996; Smith et al., 2002.). Accordingly, researchers have studied effects of staff training and management on the amount and quality of communication (Orlowska et al., 1991; Purcell, et al., 2000.) Banat et al. suggested structuring aspects of the interaction environment makes it more conducive to good communication, while Nind (1996) suggested the *relationship* itself may be the aspect of the environment most important to communication between individuals with disabilities and staff members.

Social Context

Researchers have recognized the importance of considering the social context of interaction between staff and individuals with intellectual disabilities (Emerson et al., 1999; Hile & Walbran, 1991). The social context of staff communication includes factors related to characteristics of individuals with disabilities, including their behaviors and communication skills (Chan & Yau, 2002; Repp et al., 1987), and to the staff member's

perception of the communication of the other person (McConkey, Purcell et al., 1999; Raynes, 1980). Characteristics of individuals with learning disabilities have been found to affect staff speech in residential settings (Repp et al.; Grant & Moores, 1977; Pratt et al., 1976). Researchers have shown a reliable relationship between child attributes and aide behaviors (Dailey et al., 1974), with residents perceived as attractive, likeable, and more intellectually competent receiving more positive and social interaction from staff than those perceived otherwise. Repp et al. found a disproportionate number of interactions occur with a relatively few individuals with disabilities, while Grant and Moores reported a larger proportion of positive interactions received by individuals with disabilities who exhibited higher levels of adaptive behaviors than other individuals. Individuals with intellectual disabilities who were higher functioning than others received more socialization from staff (Hile & Walbran). Additionally, Raynes found the quality of care individuals with intellectual disabilities received in living units and classrooms was affected by the functional ability of the group to which the person was assigned. Less competent individuals were less likely than their counterparts to be spoken to in stimulating ways and when spoken to were denied the normal chit-chat of conversation and instead given directives about what they should and should not do (Raynes). Ambulatory individuals with intellectual disabilities living in a dual diagnosis treatment unit were found to receive significantly more socialization from staff members than individuals living in units that served predominantly nonambulatory individuals with profound learning disabilities and severe physical disabilities (Hile & Walbran). Studies have shown that care providers rely on verbal acts even when interacting with care-

recipients who communicate by using non-verbal means and gestures (McConkey, Morris et al., 1999).

Staff member perceptions are important to their decisions involving interactions with individuals with intellectual disabilities. For instance, a staff member's perceived involvement in decision-making affects the frequency of her informative speech (Raynes et al., 1977). McConkey, Morris et al. (1999) considered whether staff members see themselves as being paid to do a job rather than to engage in conversation, and if they regard care recipients as patients instead of peers. Further, McConkey, Morris et al. proposed communications are better understood in terms of their function (i.e., what they are trying to achieve) than as samples of conversational interchange, supporting the premise that the overall sense of an event affects how it is interpreted (Duchan, 1986). Researchers have shown that staff members who perceive their role to be supervisory are unlikely to promote two-way conversation with the individuals they support (Hile & Walbran, 1991; Prior et al., 1979; Raynes, 1980; Zilber et al., 1994). Staff members may perceive individuals with intellectual disabilities to have limited ability to assume responsibility for their learning, a perspective that would encourage the staff member to adopt a superior position toward the other person (Bartlett & Bunning, 1997.)

Perceptions of Direct Support Professionals on the Communication of Individuals with Intellectual Disabilities

Evaluations of the effect of supporter verbalizations on individuals with disabilities have involved staff perceptions of aspects of communication, including their estimations of the communicative competence of the other person (Kuder & Bryen, 1991; Purcell et al., 2000; van der Gaag & Dormandy, 1993). Studies of supporter perceptions

show they are aware of differences in the communications they and the individuals they support use and are able to adapt their communications to the needs and characteristics of others and to the different functions of communication (Banat et al., 2002; Bradshaw, 2001; McConkey, Purcell et al. 1999). McConkey, Purcell et al. found direct support professionals were able to adapt their communications across different contexts (i.e., social, consultative, or task-related), but had difficulty gauging their use of non-verbal signals, which accompany communication that is responsive to individuals with disabilities (i.e., consultative or counseling communication).

Communications of individuals with intellectual disabilities, and supporter estimations of such, vary across settings and individuals, and researchers have yet to reach consensus on how to define communicative competence of individuals with disabilities (Kuder & Bryen, 1991; Purcell et al., 1999). Generally, supporters misjudge comprehension skills and communicative competencies of individuals with intellectual disabilities (Bartlett & Bunning, 1997; Purcell et al.). Studies report mismatches between the complexity of supporter speech and their perceptions of communication skills of individuals with disabilities (Banat et al., 2002; Bartlett & Bunning; Bradshaw, 2001; McConkey, Morris et al., 1999; Purcell et al.). Mismatches have been found between supporters perceptions of their communication and the actual communications they use (Bradshaw), and between their estimations of the language comprehension of individuals with disabilities and test results obtained from individuals (Banat et al.). In one study researchers looked at the extent to which the verbal expressive skills of supporters used during conversation complemented the comprehension of individuals with disabilities (Bartlett & Bunning). Supporters have been shown to over-estimate the communication

level of the person with a disability, with discrepancies between their perceptions of the person's comprehension and the complexity of speech used by the supporter being greater in unstructured situations (i.e., open conversation) than in structured ones (Bartlett & Bunning). Mismatches also have been reported between individuals with disabilities and direct support professionals in terms of the form and function of one's communication and the responses provided by the other (Zilber et al., 1994).

Researchers have considered communicative exchanges between individuals with intellectual disabilities and supporters in terms of the speech acts and verbal skills of communicators, stressing the importance of language (Bartlett & Bunning, 1997). Focus on speech production, receptive and expressive language and pragmatics of communication can involve mismatches between the language of supporters and their estimations of the communicative competence of individuals with intellectual disabilities (Purcell et al., 1999). Improvements to interaction are more likely to result from supporters adjusting their perceptions of a person's communicative competence and adapting their communication accordingly than from trying to change the communication of the person with a disability (McConkey, Morris et al., 1999; Money, 1997).

Supporter estimations of the communication skills of individuals with intellectual disabilities and adaptations supporters make to their own speech can enhance interactions, as they pursue language more closely aligned with the other person's communication skills and preferences. However, a lack of attention to the relationship between individuals can lead to mismatches between staff estimations and the complexity of the language they use (Bradshaw, 2001.) Researchers have emphasized staff perceptions of comprehension levels and communication skills, but have not elicited

views of individuals with intellectual disabilities regarding aspects of their communication with supporters, which would represent a relational communication perspective. Researchers focus on language more than on the relationship between supporter communications and the communication needs of individuals with intellectual disabilities (Bradshaw).

Researchers report supporters overestimate the ability of individuals with intellectual disabilities to understand verbal language, and view improvements in communication as resulting from changes in individuals with disabilities, not changes on their part (Purcell et al., 1999). However, Purcell et al. recognized communication problems do not reside in individuals with disabilities and cannot be fixed by supporters, and suggested supporters are aware of their own style of communication and can adapt it as needed, although their ability to do so may be limited (McConkey, Morris et al., 1999). Purcell et al. acknowledged staff workloads and the perceptions they have of their role in services can interfere with them making the time and effort to respond to the verbal initiations of individuals with disabilities. The ability of support staff to adapt their language to the communicative skills of individuals with disabilities has been reported as a condition to improving their communications (McConkey, Purcell et al., 1999). Supporter estimations of the communicative competence of individuals with intellectual disabilities and adaptations supporters make to their own speech are related to functions of communication (e.g., improving communication of the person with a disability) (Banat et al., 2002). McConkey, Morris et al. noted the need for testing whether more accurate perceptions among support staff produce changes in their communication style.

Initiations and Responses of Direct Support Professionals

Communication initiations and responses can be described in terms of types, functions and frequencies, which refer to aspects of timing and the sequencing of verbalizations between individuals. Communication type has been represented as the *form* of speech used (i.e., how a person communicates), while function has been represented as the *purpose* of the communication (i.e., why a person communicates). Communication function includes aspects such as instructing, questioning, correcting, or generally conversing (Prior et al., 1979). Type and frequency of supporter *initiations* have been found to be different from type and frequency of supporter *responses* to interaction initiated by individuals with intellectual disabilities (Kuder & Bryen, 1991; Prior et al.). This distinction corresponds with findings that the most favorable type of support professional communication, conversation, as judged by how the individuals they support respond, occurs the least frequently (Pratt et al., 1976; Prior et al.). Researchers have devised systems for classifying the communication of support professionals and individuals with intellectual disabilities, emphasizing functions of supporter communication, not the functions of the communication of individuals with disabilities.

Paton and Stirling (1974) examined amounts of nurses' verbal communication toward patients with learning disabilities, and the types of utterances that elicit the greatest number of patient responses, classifying nurse speech according to four categories of verbal interaction. The categories were *comment* (a single personal comment soliciting an emotional type of response), *instruction* (a single authoritarian type of utterance), *question* (a single question relevant to the immediate situation with no attempt to make conversation), and *nurse-initiated conversation* (an utterance directly

solicitous of an extended verbal response from the hearer). Additionally, the authors included one code for patient-initiated conversation. Conversational utterances, representing nurse questions and nurse-initiated conversation, were about two and half times more likely than non-conversational utterances to elicit a verbal response from the patient (Paton & Stirling). Although, nurse-initiated conversation produced significantly more verbal response (71.6%) from patients than any other form of verbal stimulation, it represented the significantly least used interaction category (9%) (Paton & Stirling).

Pratt et al. (1976) used the dichotomy between controlling and informative speech, proposed by Tizard et al. (1972), to develop an observational system for describing functions of supporter utterances toward individuals with intellectual disabilities. Pratt et al. defined *controlling speech* as requests or orders to terminate or begin an activity, representing negative and positive control, respectively, and *informative speech* as statements concerned with explaining, giving new information, or asking the resident for information, but *not* with changing a resident's immediate behavior. The coding scheme included four major codes: (a) negative control, (b) positive control, (c) information, and (d) other talk. Pratt et al. reported that informative speech of supporters elicited the highest frequency of resident replies (64.9%) and negative control statements the lowest (26.2%). Pratt et al. found informative talk was positively related to the developmental level of residents, while resident ability was inversely related to supporter use of speech acts representing positive and negative control. Additionally, resident-oriented practices by support professionals were associated with less controlling speech and more conversational interchange with residents (Pratt et al.).

Prior et al. (1979) devised a coding scheme for classifying types of verbal interaction, using categories for recording the verbalizations of supporters and individuals with intellectual disabilities in terms of types of initiations and responses elicited. Prior et al. examined conversational and non-conversational initiations of supporters, finding a significant difference in the frequency of verbal responses of individuals with disabilities to these two types of initiation, with conversation eliciting significantly higher verbal responses than non-conversational comments, instructions or questions. The finding of Prior et al. that the most favorable type of supporter initiation for advancing verbal responses of individuals with disabilities, conversation, occurred least frequently is consistent with findings of Paton & Stirling (1974) concerning conversational utterances, and Pratt et al. (1976) concerning informative speech.

Researchers have observed supporters provide conversational responses more frequently than instruction-type responses, to interaction initiated by individuals with disabilities, but not respond routinely in potential interaction situations (Prior et al., 1979). Supporters ignore verbal interactions initiated by individuals with disabilities about one third of the time (Kuder and Bryen, 1991), approximately as often as the more desirable comment and conversation responses combined (Prior et al.). Researchers have reported low rates of interaction between staff and individuals with intellectual disabilities (Hile & Walbran, 1991), of poor or neutral quality (Felce et al., 1987; Prior et al.), with no interaction occurring during almost two-thirds of observation times (Chan & Yau, 2002). Kuder and Bryen observed individuals with intellectual disabilities initiated speech at least as frequently as direct support professionals, although, the overall quantity

of interaction was low. Kuder & Bryen concluded that verbal initiations and responses of supporters can improve the communication of individuals with intellectual disabilities.

Increased responsiveness of supporters has been shown to correlate significantly with increases in the communication of individuals with disabilities (Purcell et al., 2000). However, researchers have found supporters do not respond to the other person in the majority of potential interaction situations and infrequently use types of verbal communication that elicit responses from others (Prior et al., 1979). Chan and Yau (2002) found interaction between health care workers (HCAs) and adults with learning disabilities in institutional care occurred in only 37.2% of observation intervals, with HCAs initiating 98% of the interactions. When interviewed, most HCAs claimed they would smile and talk with residents; however, this was observed infrequently and the authors found 82.8% of interactions were neutral, defined as the initiator being expressionless during interaction. Bradshaw (2001) found support staff had no contact with residents with learning disabilities living in a hospital on average 89% of the time and Cullen et al. (1983) reported residents in an institution received no attention 93% of the time, regardless of what they were doing. Overall, researchers have found verbal initiations and responses of supporters toward individuals with intellectual disabilities to be infrequent and neutral, with supporters regularly ignoring individuals (Chan & Yau).

Felce et al. (1987) examined staff responses to appropriate and inappropriate behaviors of individuals with disabilities in three residential settings (institutions, large community units, and small community homes), replicating with adults a study by Warren and Mondy (1971) of institutionalized children. Felce et al. classified the behaviors of aides as *clearly encouraging*, *clearly discouraging*, *ambiguous* (i.e., a

mixture of encouragement and discouragement), *neutral* (i.e., neither encouraging nor discouraging), or *no response*. In institutions and large community units, only one-third of the intervals of *appropriate* resident behavior contained a supporter response, half of which (15%) were neutral and half encouraging (Felce et al.). Similarly, in small community homes, support staff responded neutrally in approximately 15% of the intervals of appropriate behavior. However, in contrast to the two congregate settings, a considerably higher rate of intervals of encouraging responses to appropriate behavior (42.6% on average) was found in small community homes (Felce et al.). In all three settings, Felce et al. found higher rates of supporter encouragement associated with appropriate resident *communication*, more than with any other resident behavior.

With regard to *inappropriate* resident behavior, Felce et al. (1987) found support staff in institutions and large community units ignored individuals with intellectual disabilities an average of 97% of intervals, giving virtually no encouragement or discouragement. In small community homes, supporters gave slightly more attention to inappropriate resident responses, responding in 21.1% of the intervals, 15.7% of which involved neutral responses. Supporter inattention to inappropriate behavior and failure to encourage appropriate behaviors was consistent with findings that initiations of individuals with intellectual disabilities are largely ignored and conversation is the least frequently observed type of supporter-initiated communication (Felce et al.).

In small community homes, supporters responded to appropriate behavior of individuals with intellectual disabilities more than to inappropriate behavior, and in encouraging ways more than discouraging ways; however, there was no satisfactory evidence of a strong supporter response promoting appropriate functioning (Felce et al.,

1987). Findings of Felce et al. for institutions and large community settings were consistent with Warren and Mondy's (1971) conclusion that patterns of supporter activity allowed the behavior of individuals with disabilities to develop in a nonsystematic fashion. Felce et al. proposed that appropriate behavior owed less to a staff ethos of support than to the ability of individuals with disabilities to act appropriately independent of support staff or to communicate with supporters appropriately, and suggested these abilities were associated with the self-direction of individuals with disabilities.

Studies have included findings that the primary functions of supporter communications are teaching and facilitating language (Prior et al., 1979; Repp et al., 1987) and controlling and directing individuals with intellectual disabilities (Pratt et al., 1976; Raynes, 1980). The importance of the teaching function of staff communications has been recognized (McConkey, Morris et al., 1999; Repp et al.). McConkey, Purcell, et al. (1999) found staff perceptions of communications they use were dominated by the use or non-of a teaching strategy based on correcting individuals with intellectual disabilities and giving them instructions and reinforcements. The functions of teaching/facilitating and controlling/directing correspond to support staff instructing individuals with disabilities and to the informative nature of staff speech (Raynes). Owen et al. (1994) reported 70% of staff comments to individuals with disabilities were directive in nature. Supporters' instruction and supervision of individuals with intellectual disabilities (Hile & Walbran, 1991) involves intrusive prompting (Cooper & Browder, 2001) and aspects of control (Cattermole et al., 1990). Low quality of interaction between support staff and individuals with intellectual disabilities is a primary shortcoming of the services they

receive (Felce et al. 1987; Prior et al.), with individuals often perceiving supporters as too controlling, or as providing too little support (Cattermole et al.).

Raynes (1980) coded sentences of support staff as *informative*, *negative controlling* or *positive controlling*, and defined informative speech as that which supporters use to explain, to give new information or to request information. Informative and conversational type speech by supporters is preferable to commands (Kuder & Bryen, 1991), and findings of the effectiveness of various forms of instruction indicate informative speech is the most significant speech type associated with learning for individuals with intellectual disabilities (Raynes et al., 1977). Informative speech is vital to providing communication to individuals with intellectual disabilities (Pratt et al., 1976; Repp et al., 1987). Mirenda and Donnellan (1986) noted adolescents with disabilities used higher proportions of spontaneous comments and questions when adults used a facilitative rather than a directive style in conversational exchanges. Although individuals with intellectual disabilities are more responsive to informative speech (Pratt, et al.) and conversation than to instructions (Kuder & Bryen), interactions involve mainly supporter instructions, with little evidence of conversation (Prior et al., 1979).

The importance of individuals with intellectual disabilities exercising control in their interaction with supporters has been examined (Bird et al., 1989; Domingo et al., 1998). Bird et al. studied the implementation of functional communication training for aggressive and self-injurious behavior, reporting the value of the person with a learning disability having access to and control over reinforcers. These researchers found significant reductions in maladaptive behavior came only after the person with a learning disability exhibited spontaneous use of communications rather than relying on teacher

prompts. Accordingly, a key to the efficacy of functional communication approaches is the supporters' willingness to give the control of access to reinforcers to the person being reinforced (Bird et al.). Domingo et al. found individuals with intellectual disabilities failed to demonstrate linguistic control in their interactions with supporters, and suggested this lack of demonstration of control may reflect the individual's feelings of subordination within the dyad.

Several researchers have advanced coding systems, which have provided findings of differences in the *initiations* of supporters and their *responses* to the initiations of individuals with disabilities (Kuder & Bryen, 1993; Paton & Stirling, 1974; Pratt et al., 1976; Prior et al., 1979). Felce et al. (1987) coded supporter responses that were encouraging of individuals with disabilities, and others have shown that staff verbalization can be informative as well as controlling (Raynes, 1980). Kuder & Bryen (1991) devised codes for conversation type (encourager or discourager), and Markova et al. categorized social and functional interactions. Additionally, Hile & Walbran (1991) defined the code *Socialization* as “engaging in warm, interpersonal relations with resident (e.g., staff member talks with resident)” (p. 36) and proposed that desirable interactive behaviors on the part of supporters are not complex or difficult to achieve. Cullen et al. (1983) defined the positive attention of staff toward residents as any response that includes “ordinary conversation, overt praise, affection and listening” (p. 580).

Kuder & Bryen (1991, 1993) studied communicative competence of individuals with disabilities and their conversational topics and those of supporters, incorporating the Interaction Recording System (IRS), provided in Veit's study (as cited in Dailey et al., 1974). Kuder and Bryen (1991) adapted the IRS, adding categories for observing and

recording the initiator and recipient of a verbal interaction and for identifying whether the initiation was a conversational encourager or discourager. Codes comprising the IRS represent the following six dimensions: (a) initiator, (b) mode of communication, (c) mand/tact, (d) affect, (e) response, and (f) context. Kuder & Bryen (1991) observed how direct support professionals involved individuals with intellectual disabilities in conversation, whether each used conversational encouragers or discouragers and how responsive each was to the other's conversational initiations. Kuder and Bryen (1993) considered the conversation topics of supporters and individuals with intellectual disabilities, finding supporters focused primarily on topics involving control of behavior, while individuals with disabilities initiated primarily social topics of conversation.

Kuder and Bryen (1991) examined the communicative competence of institutionalized individuals with learning disabilities, in terms of how responsive they and support staff were to each other's conversational initiations and the extent to which their use of the same conversational topics affected the quantity and quality of their interaction. Kuder & Bryen defined a *conversational encourager* as an initiation that required a response, as not responding would be impolite (e.g., "May I have a pencil?" and "Good morning, how are you?"), noting the similarity of a conversational encourager to the category of *informative remarks* (Tizard et al., 1972). However, unlike the emphasis of Tizard et al. on initiations that increased overall language development of children with learning disabilities, Kuder and Bryen were interested in defining a category of initiations that increased the chances of a verbal response. Kuder and Bryen defined a *conversational discourager* as an initiation that does not require a response from the listener and reduces the likelihood of conversational interaction (e.g., direct

orders, echolalia, repeated stock phrases, and simple reinforcements like "good work"). Kuder and Bryen devised the conversational discourager category to include functions related to statements of "control" (Tizard et al.) and "comments" and "instructions" (Prior et al., 1979). Kuder and Bryen found individuals with intellectual disabilities more responsive than previously reported; noting that earlier studies (Pratt et al., 1976; Prior et al.) had emphasized the role of support staff in conversational interactions, instead of the initiations of individuals being supported, and suggesting this focus had resulted in a lack of data on the communicative competence of individuals with intellectual disabilities.

Kuder & Bryen (1993) distinguished the function of an utterance from the topic of conversational interaction, identifying four topic areas including *Social* (conversation about noninstructional activities), *Control* (conversational topics centered on the management of behavior), *Instructional* (conversational topics directly related to activities in the classroom or residence), and *Idiosyncratic* (vocalizations for which no clear topic could be determined). Social topics comprised nearly half of the verbal initiations of individuals with intellectual disabilities, while topics of control represented almost the same proportion in the conversation of supporters, who talked primarily about instructional and behavior management topics (Kuder & Bryen). Kuder and Bryen's findings of differences in the topic preferences of supporters and individuals with intellectual disabilities support findings of Prior et al. (1979) that high rates of instructional and control-type initiations by supporters evoke infrequent responses from others. Additionally, although overall quantity of interaction was low, Kuder and Bryen found individuals with disabilities initiated over half the interactions with supporters.

Kuder and Bryen (1993) found that the way conversation was initiated affected responsiveness to communication attempts and that responsiveness was more closely related to whether the conversation was opened with a conversational encourager or discourager than to the topic of the conversation. Responsiveness to communication was highest when supporters and individuals with intellectual disabilities used conversational openers that encouraged further interaction. However, when supporters used a social comment to open a conversation, responsiveness of the other person was high whether the initiation was phrased as an encourager or discourager (Kuder and Bryen). These authors proposed that the ability to share topics of conversation is important to developing communicative competence, and suggested individuals with intellectual disabilities could be taught communicative strategies that would increase the response they receive from others. Kuder and Bryen emphasized the importance of social topics of conversation and the ways supporters involve individuals with intellectual disabilities. Similarly, Markova et al. (1992) examined sociability of communication between supporters and individuals with intellectual disabilities, from the perspectives of the initiator and recipient of verbal interactions.

Markova et al. (1992) compared supporter interactions with individuals with intellectual disabilities living in hospitals with their interactions in community hostels, categorizing interactions as either *social* or *functional* depending on the purpose of the interaction, as perceived by the researcher. Markova et al. defined *functional interactions* as those concerned with basic necessities of everyday life and with the rules and routines of the environment in which the person lived, and provided the following sub-categories and examples:

Physical needs (e.g., meals, having a bath, medication, toileting); *living skills* (e.g., cooking, crossing the road, cashing one's pension at the post office); *routines* (e.g., a call 'dinner's ready' or 'the minibus has arrived'); and *rules* (e.g., a staff member saying 'let's go' when she or he has decided to let the participants know that it was time to go home from the pub; or a staff member saying 'now it's time to do this' when instructing the participant to start another activity at therapy). (p. 119).

Markova et al. considered functional interactions less spontaneous and personal than social interactions, which they defined as interactions not intended for any particular purpose, other than to address the resident socially as a fellow human being, and provided the following sub-categories and examples:

Leisure and work interactions (e.g., sharing sweets, holding hands on the way to the shops, or jointly putting records on the record player); *conversations*; *comments* (e.g., greetings or attempts to initiate interaction); *choices* (e.g., interactions that were concerned with choosing amongst several possible activities, meals or other events or making enquiries about social activities, such as whether the participant would like to go to the pub). (p. 119).

In the hospital and hostel settings, brief comments, such as greetings, were the most common social interactions, followed by leisure and work interactions and conversations; however, there was a lack of interaction involving social choices (Markova et al., 1992). Markova et al. coded the attitude of the recipient of the interaction toward the person with whom he was interacting, defining *attitude* as the expression of feeling towards or dominance over the person who initiated the interaction in question. The following six kinds of attitude were identified: *friendly*, *impersonal*, *ignoring the person who initiated the interaction*, *annoying/intimidating attitude*, *offering help* and *controlling*. Supporter attitudes were considerably more friendly and helpful in hostels than in hospital setting, while attitudes of individuals with disabilities were largely friendly in both settings (Markova et al.) Overall, the hostel offered individuals

with intellectual disabilities significantly more interpersonal interaction than the hospital, with the predominance of social interactions in the hostel contrasting sharply with the functional interactions in the routine-based hospital settings (Markova et al.).

Characteristic patterns of interaction between supporters and individuals with intellectual disabilities suggest supporters may interact according to a conscious or subconscious mental set (Grant and Moores, 1977). Supporters give greater attention to meeting the physical needs of individuals (Chan & Yau, 2002) than to promoting social interaction and conversation, indicating an emphasis on the function of communication. Researchers have found functional interaction more common than social interaction (Jahoda et al., 1989; Markova, et al., 1992) and have noted an emphasis on language rather than on social communication (Butterfield & Arthur, 1995). Supporters generally do not interact with individuals with intellectual disabilities in ways that advance their communication of preferences or their social involvement. Few researchers have stressed social aspects of supporter communication (Butterfield & Arthur; Nind, 1996), or their promotion of choice and self direction of individuals with intellectual disabilities (Cooper & Browder, 2000).

Involvement in relational communication is crucial to the choice and self-direction of individuals with intellectual disabilities, and researchers have considered the need for supporters to pursue conversation and social interaction (Hile & Walbran, 1991; Kuder and Bryen, 1991, 1993) in order to advance the self-direction of individuals with intellectual disabilities (Markova et al., 1992). Concern for the self-direction of individuals with intellectual disabilities has involved examination of whether their interactions with supporters are functional or social in nature (Markova et al.).

Researchers have emphasized functions of supporter communication (Zilber et al., 1994), without considering functions of communication of individuals with intellectual disabilities, or the effect supporters have on their expressions of ideas and preferences.

Researchers have indicated the need to improve the communication of direct support professionals and have considered the kinds of choices they provide individuals with intellectual disabilities (Cooper & Browder, 2001; Wareing & Newell, 2002; Wehmeyer & Metzler, 1995). However, there is little research on pragmatic communicative interactions between supporters and individuals with intellectual disabilities (Owen et al., 1994). Additionally, the lack of attention supporters give to the personhood of individuals with intellectual disabilities affects the person's sense of social membership (Ferguson, 1994). Nind (1996) proposed the responsiveness of supporters to individuals with intellectual disabilities can be a primary teaching resource, and Hile and Walbran (1991) suggested the necessity of examining interactions between the staff member and the person with an intellectual disability from the perspective of both individuals. There is need to identify supporter verbalizations that promote social and conversational aspects of communication with individuals with intellectual disabilities (Kuder & Bryen, 1991).

Researchers have emphasized how often supporters speak to individuals with intellectual disabilities (Hile & Walbran, 1991), with an interest in increasing the frequency of communications (Baker et al., 2000). Baker et al. found the creation of rapport between staff and individuals with intellectual disabilities an effective behavior support intervention, and suggested rapport-based interactions provide the foundation for support. Generally, researchers have not considered how supporters might advance social

interaction (Hile & Walbran; Markova et al., 1992) or the preference of individuals with intellectual disabilities for conversation (Kuder & Bryen, 1991). Observations of communicative interaction involving individuals with intellectual disabilities often lead to inferences regarding their needs and perspectives. In this study, *perspectives* of individuals with intellectual disabilities will not refer to such inferences, but only to individuals' *expressed* views and opinions.

Perspectives of Individuals with Intellectual Disabilities on Communication
with Direct Support Professionals

Individuals with intellectual disabilities have expressed wanting their interactions with supporters to be relevant to their needs and aspirations (Cattermole et al., 1990). However, few researchers have examined the expressed needs and desires of individuals with intellectual disabilities (Cattermole et al.). Researchers of communication between supporters and individuals with intellectual disabilities have not emphasized social interaction or the preferences and perspectives of the latter. Efforts aimed at furthering social and conversational aspects of communication, thereby making possible the expression of preferences by individuals with intellectual disabilities, call for studies that emphasize eliciting the perspectives of individuals with disabilities on their communication with direct support professionals.

Researchers have not considered the perspectives of individuals with intellectual disabilities regarding their communication with direct support professionals; however, they have obtained their perspectives on parallel issues. Focus groups have been used to elicit the views of individuals with intellectual disabilities on barriers to inclusion (Abbott & McConkey, 2006) and issues of social integration (Mactavish et al., 2000). This

method also has been used to review existing support and accommodations (Barr et al., 2003) and adult placement, outreach and day services (Cambridge & McCarthy, 2001). Ippoliti, Peppey, & Depoy (1994) used a focus group to promote self-determination of individuals with intellectual disabilities and give them a voice in developing their own recreation opportunities. As participants in focus groups, individuals with intellectual disabilities have provided their perspectives on health promotion (Fraser & Fraser, 2001) and visiting the doctor (Bollard, 2003). In three studies, researchers have given brief attention to the perspectives of individuals with intellectual disabilities on the communication they experience with supporters (Cattermole et al. 1990; Jahoda et al., 1989; Murphy; 2006). Murphy reported statements of individuals with intellectual disabilities related to their difficulties expressing health concerns to general practice staff, and Cattermole et al. and Jahoda et al. reported statements concerning the type of talk individuals hear from direct support professionals. In the current study, a focus group method will be used to obtain perspectives of individuals with intellectual disabilities on their communication with direct support professionals.

CHAPTER THREE

METHOD

The researcher used a qualitative methodology to gather the views of individuals with intellectual disabilities on their communication with direct support professionals. A focus group method was considered appropriate since existing studies of communication involving providers and recipients of disability supports do not include the perspectives of individuals with disabilities. Focus groups have proved successful in promoting discussion among individuals with intellectual disabilities (Barr et al., 2003) and in eliciting views of individuals with limited societal power and influence (Morgan & Krueger, 1993) who traditionally are excluded and marginalized (Cambridge & McCarthy, 2001). Additionally, focus groups have been shown to be advantageous in bridging the gap between professionals who occupy decision-making roles and the target audience affected by their decisions (Morgan & Krueger).

Communication is a main function of focus groups and interaction between participants is essential (Robinson, 1999). However, verbal expressions of group members represent only a slice of group interaction and do not account for aspects of non-verbal communication and the interactive nuances and contextual factors of group process. Barr et al. (2003) found reciprocal encouragement between group members involves their use of brief verbal comments and non-verbal communication (head nods, eye contact, facial expressions, leaning forward, pausing to listen) and noted active encouragement of interaction within a focus group promotes in-depth discussion. Accordingly, in facilitating the focus groups in the current research, the researcher

responded to various nonverbal indications related to the context of the conversation and encouraged individuals to interact around ideas as they arose, especially ones group members affirmed verbally or by nonverbal means. Focus groups involve the sharing and discussion of candid, in-depth responses among participants, and diverse opinions are more likely to be obtained than would be possible through individual interviews (Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005).

Participants

The researcher contacted directors of disability service agencies and advocates for people with disabilities and asked them to identify individuals with intellectual disabilities whom they knew well and believed would enjoy and contribute to a group discussion on how direct support professionals talk to them. The pool of potential participants included individuals who had experience with People First, a self-advocacy organization led by individuals with disabilities who interact in local groups around issues of interest to the members. Because of the familiarity some potential participants had with group discussions, the focus group was considered especially appropriate for this study. Directors and advocacy group representatives who agreed to assist in identifying potential participants were sent a cover letter explaining the purpose of the study and describing the inclusion/exclusion criteria. Directors and advocacy group representatives told individuals about the focus group and asked those who expressed interest if their names could be provided to the researcher. In addition, the researcher contacted individuals he knew through People First. The inclusion criteria include:

- being at least 18 years of age;
- having a mild form of intellectual disability;

- having support-related communication, currently or in the past;
- using verbal communication that is intelligible enough for group discussion;
- understanding the purpose of the focus group and desiring to be in it.

Exclusion criteria include:

- having an intellectual disability that interferes with enjoying and contributing to a focus group discussion;
- using augmentative communication or another mode of assistive speech.

Thirty-two individuals with mild intellectual disabilities met in one of six focus groups, with between three and seven individuals in each group. The selection of participants involved convenience sampling, with the researcher asking directors of disability service programs and representatives of advocacy groups to identify prospective participants who would provide information (Padgett, 1998). Individuals who agreed to participate in a group discussion expressed an understanding of their rights, which they signified by signing a consent letter. All participants were receiving some form of paid disability support, involving interaction with direct support professionals, or had received such support in the past. Six groups were conducted in a Southeastern state. Individuals comprising four groups came from areas that were mainly urban, with a degree of rural influence. One group represented an area that was predominantly metropolitan, while individuals comprising another group represented an area that was largely rural. Table 1 provides gender and race of participants by group.

Table 1 - Focus group by gender and race of members

Focus Group	Male	Female	African American	White
Group 1	3	4	0	7
Group 2	2	3	0	5
Group 3	2	4	1	5
Group 4	1	4	1	4
Group 5	3	3	4	2
Group 6	3	0	1	2
Total	14	18	7	25

Ages of participants across groups ranged from 21 to 63 years. Table 2 provides age of participants by group.

Table 2 – Focus group by age of members in years

Focus Group	20-29	30-39	40-49	50-59	60+
Group 1	1	4	2	0	0
Group 2	2	0	1	0	2
Group 3	2	1	3	0	0
Group 4	1	3	1	0	0
Group 5	2	1	2	0	1
Group 6	0	2	0	1	0
Total	8	11	9	1	3

Although many participants lived with family, others lived in homes or apartments with support. In terms of primary daytime activity, some participants spent time at home or in the community, others attended sheltered workshop programs, and some had regular employment. Across these various situations, there were individuals who received disability services and individuals who did not. Table 3 presents the number of participants across groups in each living arrangement.

Table 3 - Focus group by living arrangement and use or non-use of support *

Focus Group	Family no Support	Family with Support	Independent no Support	Independent with Support	Host Home
Group 1	1	1	1	4	0
Group 2	3	0	0	1	1
Group 3	3	0	3	0	0
Group 4	3	0	1	1	0
Group 5	2	0	1	3	0
Group 6	2	1	0	0	0
Total	14	2	6	9	1

* Support involves agency staff supporting individuals living independently, with family members, or in a host home, ranging from several hours a week to 24-hour care.

Table 4 presents the number of participants across groups in each of day activity.

Table 4 – Focus group by day activity and use or non-use of support *

Focus Group	Community no Support	Community with Support	Workshop	Independent Employment	Agency Job Coach
Group 1	0	4	0	2	1
Group 2	0	0	0	0	5
Group 3	0	0	5	0	1
Group 4	0	1	4	0	0
Group 5	6	0	0	0	0
Group 6	0	0	1	1	1
Total	6	5	10	3	8

* Support includes agency staff supervising activity in a workshop, providing transportation, accompanying individuals in community activities, and job coaching.

Participants used various words to identify direct support professionals including, attendant, caretaker, caseworker, companion, counselor, friend, overseer, staff, supervisor and supporter. The kinds of support reported included transportation, shopping and money management, assistance with taking medication and meal preparation, job coaching, verbal interaction, and recreational and training activities in the community and in sheltered workshop settings. Support occurred in a person's home or in daytime activities away from home, including employment supports, with participants often receiving support in more than one setting. Groups differed in numerous ways, which will be considered from the perspective of the supports individuals received, aspects of group cohesion and differences in group settings.

Differences in Supports Individuals Receive

Differences in the supports a participant received involved consideration of whether a support was provided by a direct support professional employed by a disability services agency or represented another source including friends, employers and family members. Experiences of supports from sources other than disability service agencies undoubtedly influenced the meanings and interpretations of support participants provided in response questions they were asked. In facilitating each discussion the researcher consistently stressed to participants that their perspectives on paid staff supports was the objective of the discussion. Therefore, responses to questions involving support experiences beyond disability agencies were treated as points of contrast and comparison during discussions.

Individuals received different types and degrees of support. In some groups, the type of supports individuals received was fairly consistent across members, and similarities were evidenced across groups, as well. Tables 3 and 4 provide group totals for the different types of support situations individuals experienced in their living situations and day activities, respectively. Supports individuals received in their day activities and home situations serve as a context for interactions with supporters and relationships among members within groups. Both day activity and home settings provide valuable information on group and individual differences, which informed the responses individuals offered to focus group questions.

There were notable variations in the amount of support individuals across groups received in their home situations. Ten individuals were living independently and had daily interaction with supporters who attended to personal care needs. For a couple of

individuals this involved primarily support in the administration of medication. Five of the ten individuals who lived on their own used wheelchairs and received in-home supports that included assistance related to their physical function and mobility in activities of daily living (e.g., hygiene, dressing, food preparation, etc.) at specified times each day, generally in the morning and evening. Several individuals received overnight and weekend agency support, or lived with family with minimal agency support in the home. The most common home situation was represented by 14 individuals living with family and having no in-home agency support.

Support situations for individuals who received overnight and weekend support represented the greatest involvement of agency staff; however, this accounted for the support provided for fewer than five individuals. The home situations for the ten individuals who lived independently with in-home support were, perhaps, the most informative of the meanings of support individuals brought to the group discussions, especially since eight of the ten individuals were clustered in two of the groups. The 14 individuals who lived with family members without agency support were spread fairly evenly across all six groups. These individuals also provided a variety of meanings of support, based perhaps on their interpretation of support being informed by contrasts and comparisons they made between the supports they received from agency staff in day activities and the support they received from parents or other family members at home.

The degree of involvement individuals had with supporters during the day depended on what the person did. Individuals in the two groups that were associated with workshops had support dynamics that were different from the supports experienced by those in one of the four groups comprising individuals who spent their day in community

pursuits or employment situations. In three of the four non-workshop groups (i.e., Groups 1, 2, and 5) individuals had day support in the community or in supported employment job situations. Individuals in Group 1, representing four of the ten who lived independently with in-home agency supports, spent their day in community pursuits. These individuals were closely supported and in some cases were supervised in the community and at home, depending on the intellectual disability of the individual. Individuals in Group 5, representing three of the ten individuals who lived independently with in-home services, also received supports to live independently and to pursue community activities. Although the day supports of the seven individuals comprising Groups 1 and 5 who lived independently coincided with activities at home and in the community, there were marked differences between the supports individuals in each group received. Unlike the individuals in Group 1 whose contact with supporters at home and in the community involved supervision and close direction, members of Group 5 spent much of their time in the community or at home without support and would never have considered their support to involve supervision. Individuals in Group 5 had comparatively greater control over their supports than individuals in Group 1, which were organized primarily around their functional and mobility needs.

Group Cohesion

Individuals within each group had differing degrees of relationship with one another. Levels of relationship varied across groups depending largely on what the members of a group did during the day and whether they did it together. This consideration was a primary factor affecting cohesiveness of group members during focus group discussions. At the time of the study, members of Groups 3 and 4 (totaling

11 individuals) were involved in daily interaction with supporters in one of two workshop settings. Individuals in each of these two groups spoke to one another as friends and among some of the dyads and triads represented in each group relationship were close and even personal.

Members of Group 2 and Group 6, representing a combined total of 8 individuals, had previous involvement in one of two workshops, but had not been part of such settings for some time. Instead, at the time of the study, most members of these two groups were involved in separate, unrelated employment situations. These individuals had regular contact with one another as a result of their common provider and shared agency staff, or through time shared in the community and in ongoing advocacy activities. The members of Group 5 had no shared contact related to a common disability services provider, but knew one other through community and advocacy activities and generally considered one another friends. Most members of Group 1 had a common provider but did not have regular contact with one another, spending their day pursuing separate community activities. These individuals recognized one another and called one another by name, but did not share a context of regular interaction.

Across groups there was varying evidence of bonds of friendship and concern. Individuals comprising Group 1 and Group 5 were involved primarily in community activities during the day, with two individuals being independently employed and one pursuing supported employment, and all members of Group 2 were involved in different supported employment situations. Accordingly, within each of these three groups there was less group cohesion than among members of Groups 3, Group 4 and Group 6. Of the six groups, cohesiveness among members around shared experiences of support was most

apparent among participants in Group 3 and Group 4, which in each case shared daily experiences in a workshop setting. Although, members of Group 6 had a prior history of attendance at a workshop, the workshop was no longer a setting for interaction between them, as only one of the individuals was currently at the workshop and the other two were in unrelated employment situations.

Cohesion within groups was the highest for the individuals who spent their days interacting in workshop settings (Group 3 and Group 4). Cohesiveness among participants within both of these groups was associated with their current, shared experiences of support. The cohesion evidenced among members of these groups appeared to be based on shared experiences of interacting with staff and on how they and other individuals with disabilities were treated.

Group cohesion was lowest for members of Group 1 who had infrequent contact with one another, although individuals mentioned interacting with common supporters. In addition to similarities in the support situations of members of Group 3, and of members of Group 4, individuals comprising Groups 2, 5 and 6 expressed having common interests and in some instances regular contact. For some individuals within these three groups, commonalities were based on previous, shared workshop experiences and current community and advocacy involvement. This resulted in individuals in these three groups having good group cohesion, which they expressed in terms of understanding and empathy for one another, similar to the two workshop-based groups (i.e., Groups 3 and 4), but without the common element of daily shared support experiences.

Differences in Settings

Perhaps the most consequential difference between groups involved the settings within which individuals were provided support. This difference was exemplified most clearly in the contrast between conditions of control in workshops and in all other settings represented in this study including home, community and employment contexts. The essence of the difference between supports provided in the workshop and other settings is the use of control that cannot be qualified on the basis of external criteria. The control commonly practiced by direct support professionals in workshop settings is based on the continuation of the status quo of some individuals controlling others and on the sense of permanence this arrangement promotes. This arrangement creates clear “Us and Them” conditions between supporters and individuals with intellectual disabilities whose interaction is characterized by the impermeability of the boundary between individuals representing each group. Accordingly, individuals with intellectual disabilities who receive supports in workshops will continue being controlled and within this setting will never achieve the position of those who control them.

Differences between groups involved the physical settings in which discussions were conducted. Two groups were conducted in a conference room at an institute involved in the promotion of multiple disability support initiatives. Additionally, one group was conducted in each of four settings including a county library, a community health center, a suite of a disability rights organization and the home of a group member. All meetings were private and the space and seating in each setting was adequate and comfortable. Differences in these contexts were assumed; however, no physical features in any location interfered in a known way with the discussion.

Focus Group Method

All focus group meetings followed a similar pattern. Individuals arrived at the focus group location and were invited to have refreshments as others were assembling. Once all participants had arrived, the researcher began the meeting by emphasizing that participation in the study and in the discussion was voluntary and asking the following question: *"What would happen if you said you wanted to be in the focus group and then changed your mind and decided you didn't"*? The researcher allowed individuals to answer this question and stressed that the focus group was voluntary and that a person could stop answering questions and just listen anytime during the discussion. The researcher also explained the importance of confidentiality and asked the following question: *"Suppose that after being in tonight's discussion, someone who supports you asked me to tell something you said at the meeting, what do you think I would say"*? The researcher explained that what was said in the group would be kept private and that nobody's name would be used outside the group. Participants were reminded that being part of the focus group did not mean they would receive additional services and that deciding to stop participating in the discussion would not result in a loss of services. The researcher's assessment of a person's understanding of informed consent reflected recommendations and guidelines for assessing understanding of individuals with intellectual disabilities (Weisstrub & Arboleda-Florez, 1997; Woodring, Foley, Rado, Brown, & Hamner, 2006).

Following each participant's signing of the consent letter, the researcher began the focus group discussion. The researcher facilitated the discussion, while a research assistant took notes, reflecting key points of speakers' statements, notable quotes, and

group dynamics (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). The assistant also supported the discussion by encouraging involvement of individuals who were having difficulty joining the discussion or supporting those who needed to leave the group. Focus groups lasted approximately 60 to 90 minutes.

Focus Group Questions

The focus group questions reflected concerns associated with the author's review of literature on communication between direct support professionals and individuals with disabilities, specifically observational studies. The choice of questions was influenced by the author's regular consultations with his dissertation advisor and by several years of work and volunteer experience in which he had observed communication between individuals with intellectual disabilities and individuals who were in positions to provide support or assistance, especially those who were paid to do so. In framing questions, the researcher sought open-ended questions that would allow diverse opinions to emerge (Shapiro, Monzo, Rueda, Gomez, & Blacher, 2004) and that would invite participants to express their perspectives on communicating with direct support professionals. The questions were conceptualized specifically in terms of how they might advance the description of communication between direct support professionals and individuals with intellectual disabilities. The following questions represent the ones used in Group 1 and adapted and differently emphasized and probed in subsequent groups:

1. What do you do during the day (e.g., work, attend workshop, stay home, etc.)?
2. How are you are supported, or how have you been supported in the past?
3. Who provides you support, or has provided you support in the past (e.g., one supporter, multiple supporters, family members)?

4. How regular is the support you receive, or have received in the past (e.g., around the clock, several times a week, only for certain activities, etc.)?
5. What are some things you talk about with supporters?
6. What kind of things do you like to hear from supporters?
7. What kind of things do supporters say that you do not like to hear?
8. What are the most important things supporters say to you?
9. What would you like a supporter to say when you need to do something that you don't really want to do?
10. Which of the things that supporters say make you feel happy?
11. Which of the things that supporters say make you feel sad?
12. What do supporters say that make you feel you can do things on your own?
13. What kind of things do supporters say that show they are listening to you?
14. What types of things do supporters say that encourage you to talk to them about things that are really important to you?
15. How has this experience talking with each other been for you today?
16. Is there anything you'd like me to take back from today's conversation to the people I work with?

Evolution of Questions

Prior to the start of data collection, I was advised by my dissertation committee that the process of conducting the first group would likely reveal issues and concerns that would call for adjustments in the procedures and questions. This was found to be true. Additionally, we discussed the importance of more precisely defining the concept of support. This point was verified across groups by comments related to the different kinds

of services and supports participants received and the names they used to refer to those who provide it, with one participant commenting on differences between the concepts of “help” and “support”.

The predicted adjustments to the focus group questions and procedures occurred throughout data collection, mainly over the course of the first three groups, specifically after Group 1. Impressions related to conducting each group were discussed and incorporated into the questions asked in subsequent groups. In Group 1, participants were asked to describe aspects of their daily activities and the comments of supporters, which individuals did and did not like to hear. The focus on daily activities appeared to set the tone for much of the discussion, and the researcher experienced difficulty making clear to several participants the objective of discussing how support professionals talk to them. Aspects of context, including types of disabilities represented, affected all groups, and in the case of Group 1 contributed to a low degree of group cohesion and interaction among members around the discussion of questions.

In discussing with my advisor and the assistant the lack of interaction between participants and my difficulty in communicating the purpose of the discussion, I acknowledged that my facilitation of the discussion was organized mainly by my attempt to elicit comments related to what supporters say to participants. We discussed how in subsequent groups I might more clearly communicate that I was interested in each participant’s communication with a specific supporter, and ask participants to give the first name of a person who provided them support, or who had done so in the past. Additionally, we talked about the possibility that group members’ responses to questions might reflect their experiences with various supporters beyond paid direct support

professionals, particularly parents and employment supervisors. From a procedural perspective, the decision was made to shorten questions, avoid hypothetical questions and ask questions in more colloquial manner that merged with the language of participants.

Beginning with Group 2, I emphasized the individual support experiences of each participant. Participants were invited to consider situations in which they communicated with support professionals and encouraged to identify a single supporter, using their personal interactions with that person as a context for answering focus group questions. My increased attention to specific instances of support mentioned by participants involved more frequent and lengthy one-on-one exchanges between myself and individual group members. Accordingly, I relied less on the prepared questions and more on the responses provided by individuals to guide my formulation of prompts and additional questions. However, in the follow-up conversations with the research assistant, I recognized that in Group 2 I had focused too exclusively on the comments of single individuals, without inviting input from others. This tendency was exacerbated by the seating arrangement that placed one participant at the end of the conference table directly to my left and the others either across from me or to my right, including two participants seated immediately to my right. This seating configuration resulted in me turning my back on one or more of the participants throughout the discussion and required me to continually shift my gaze 180 degrees. In subsequent groups I was mindful of positioning myself in a way that allowed equal or nearly equal eye contact with all participants, without turning away from others.

The research assistant expressed her impression that participants in Group 2 often provided answers to the question they were asked, but did not give details of the specific

statements a supporter had said to them. Although this was recognized and acknowledged early on in the data collection, in subsequent groups I often found myself requesting that participants provide greater detail of specific words used by supporters. Nonetheless, in later groups I sought to avoid working too hard to get participants to recount actual statements of supporters and to avoid framing my questions and prompts as “either-or” scenarios. Additionally, I decided to adopt a less leading role by beginning more generally and allowing the participants’ responses to provide the more specific direction to the discussion, as I had been advised earlier by a member of my research committee.

Individuals in Group 2 talked more about their interaction with staff than they did about their activities during the day. In contrast to Group 1, where I believed my questions were not clearly answered, the responses by members of Group 2 seemed to exhaust my question script within the first 30 minutes, leaving me uncertain what to ask next. The assistant and I discussed this difference and decided it would be useful to allow more frequent periods of silence following the responses of participants, and to ignore the impulse to redirect the discussion toward previously covered ideas in hopes of gaining more specific information or of simply providing greater assurance that questions were being adequately answered. Additionally, the assistant and I discussed the importance of eliciting greater interaction among participants, and agreed this might be accomplished by asking one person what s/he thought of another person’s answer to a question. Overall, my attempt to follow a specific order or script in the questions, during the first two groups, had not produced the desired interaction between participants.

Group 3 represented a more casual process than the preceding two groups, with clear and consistent interaction between group members. The interactive tone of Group 3

was enhanced by my decision not to dwell on trying to find out exactly what supporters said to group members. I went with the flow of the conversation, asking questions related to the comments of participants and inviting them to continue discussing their thoughts. Additionally, I did not attempt to fill the brief periods of silence that arose, but allowed others to take the lead, with the result that I felt that I was affected by the comments of the group as much as I sensed my statements and questions affected them. The interaction in Group 3 reflected the group members' trust in one another. This trust may have been influenced by my comment that their daily lives would not change as a result of the meeting and my request that participants use caution in generalizing from each other's experiences to their own situations beyond the meeting. Participants in Group 3 interacted in ways reminiscent of the interaction of coworkers.

In considering the highly interactive nature of Group 3, the assistant and I were curious about the way participants more readily focused on how supporters talked to them, than had been the case in the two previous groups. Our conclusion was that in the first two groups I had focused on what individuals did during the day (Group 1) and on their description of support situations (Group 2), in each case assuming that this direction would lead naturally to participants discussing how supporters spoke to them. After discussing with the assistant our experiences of the first three groups and consulting with my research advisor, I realized that in facilitating the first two groups, I had tried too hard to anchor the conversation to the prepared question script. My attempts to direct the attention of participants to my questions may have interfered with them connecting with me and, more importantly, with one another's experiences of communicating with

supporters. This lack of connection between group members in the first two groups was in stark contrast to the high degree of connection between participants in Group 3.

Differences in group culture and context were apparent between all six groups and existed independent of how the group was facilitated. In the case of interaction, the contrast between Group 3 and the first two groups was noteworthy. Additionally, the frequent reference to parent-child dynamics evident in Group 2 and Group 4 was largely missing in Group 3, which, instead, was marked by individuals expressing awareness to themselves as adults with adult issues. Nonetheless, the context and culture of a particular group contributed to differences in how individuals saw themselves, affecting the discussion and the group process. In the follow-up discussion to Group 3, I decided to continue trying to more clearly establish the context within which participants received supports by focusing initially on what each person said to a supporter before asking what the supporter said to the participant, an approach that seemed to generate more direct responses and increased interaction among participants in subsequent groups.

The approach following Group 3 of asking group members to talk about what *they* say to supporters before asking what supporters say to them was carried forward in the remaining three groups. The benefit of shifting the emphasis from enquiring initially about the supporters' talk to asking what the person with a disability says, may have been associated with a phenomenon that was observed in all groups, but not articulated until after the final group had been conducted. The observation of the research assistant was that in each of the six groups, participants initially reported primarily positive aspects of their communication with direct support professionals. Only later in the discussion did some group members balance positive comments with descriptions of their frustration

and resentment over the ways certain supporters communicated with them. Incidentally, there usually was unanimity among participants regarding their view on supporters whose communication was hurtful or helpful. My adaptation of the questions following Group 3 may have unknowingly complimented this tendency of participants to begin with the positive and only gradually express negative aspects of the talk of supporters, by encouraging participants to talk first about what they say *before* asking them to comment on the ways supporters talk to them.

The decision to depend less on scripted questions and more on the comments of group members, and to shift the initial emphasis from what supporters say to what group members say to them represented a primary adjustment to the data collection process. Despite, my tendency to ask about specific statements group members had heard from supporters, as data collection continued I became less directive and adopted a more conversational stance. I discovered I could modify my tendency to be overly directive by organizing my facilitation around a few straightforward questions that had the potential to elicit more specific responses. The following two questions provided the framework for facilitation following Group 4: (a) "What does your communication with supporters look like?" and (b) "Does this communication work for you?" Additionally, I recognized the importance of approaching discussions from the perspective of "Tell me..." rather than with the view of trying to create connections between the comments of participants or between their comments and my ideas.

Responses to questions in Group 5 reflected a relatively higher frequency of experiences of autonomy in daily activities for members of this group than in previous groups, which complemented my effort to allow the members' knowledge of their

situations, not my assumptions about them, to inform the direction of the discussion. The effort to divest from ownership of the process and outcome of the discussion created a space for individuals to tell their stories of support, providing a more casual, less strategic feel to this group than had been the case in Group 1 and Group 2.

Another adjustment to the data collection process over the course of data collection, involved the researcher having an agenda related to assumptions of what interactions between supporters and individuals with intellectual disabilities generally look like. I did not realize the extent to which my agenda controlled my facilitation of discussions and framed my role of facilitator as that of a “professional”. As data collection progressed, the emphasis of facilitation shifted from trying to obtain information from study participants about what supporters had said to them to trying to support participants to provide their perspectives on relationships involving communication with direct support professionals.

The interaction in Group 6 was causal and friendly without my perceptions that the conversation needed to go in a certain direction or arrive at a specific place. This lack of facilitator-imposed direction was a primary difference between the first and final group. The sense of difference in the facilitator’s role in these two groups was influenced by changes the facilitator underwent during the process of data collection, and by the mere fact that repetition in the comments of study participants over the course of the six groups had evolved a framework for facilitation that was not possible earlier in the process. The evolution of questions resulted in the following ones being used to encourage discussion in Group 6:

1. What are some of the things you have said to the individuals who support you?

2. What have you heard supporters say that gives you a sense they are listening?
3. How have you heard supporters respond to you when you ask them for help?
4. How would you like to hear supporters talk to you?
5. What have you heard supporters say that has helped you believe you can do things on your own?
6. What have supporters said that has given you the sense you can trust them?
7. What do you hear from supporters that might encourage you to help others?
8. What might a supporter say that would let you know you could go to her with a difficult situation and she would have your best at heart?
9. How has this experience of talking with each other been for you today?
10. Is there anything you'd like me to take back from today's conversation to the people I work with?

Process of Transcription

All focus group discussions were digitally recorded and transcribed. In addition, data collection included the impressions of the researcher as he facilitated the focus groups, his conversations with the research assistant and their consultations with his dissertation advisor. Impressions and reflections from these conversations were written in a journal describing procedural and analytical aspects of the data collection process. Conversations with the research assistant occurred daily throughout data collection, often as a follow-up to a completed group or in preparing to conduct an upcoming group. Our conversations revolved around the consideration of procedures and specific focus group questions that seemed to be more or less helpful in eliciting comments of participants and

encouraging their interaction. We also discussed changes that we considered necessary to incorporate in subsequent groups.

Following completion of a focus group, the corresponding audio file of the discussion was transcribed verbatim for analysis. This involved uploading the digitally recorded audio file to a personal computer in the student office at the university and then sending it via email to a transcriber, who prepared the transcript and returned it to the researcher by email. Upon the researcher's receipt of a transcript, a review and correction procedure was followed in the preparation of the final transcript for each group. This involved the assistant completing an initial comparison of the transcripts and the notes she had taken during the focus group discussion. Her review revealed omissions, which needed to be addressed prior to analysis of the transcribed data. Following this, the researcher and assistant reviewed the notes and transcripts, with attention to omissions and to portions of conversations that had been identified by the transcriber as "unintelligible" or "multiple voices". During this review and correction phase, portions of the audio recording were replayed to address omissions and repair discrepancies between the transcript and the assistant's notes. Ongoing discussion of the coherence between the recording, the transcript, the assistant's notes and each individual's memory of points of conversation guided the preparation of final transcripts.

CHAPTER FOUR

RESULTS

The researcher used the QSR NVivo7 qualitative data analysis program to categorize statements of research participants. Seven themes were identified in the data. The themes and supporting statements of research participants extended beyond the researcher's original objective of obtaining specific statements of direct support professionals that contribute to the perspectives individuals with intellectual disabilities have of their communication with them. The themes represent the views of individuals with intellectual disabilities regarding concerns and expectations they have related to communicating with direct support professionals. The culture and context of each group and the process of conversation between individuals within a group contributed to the participants' understanding of focus group questions and the purpose for the discussion. The meanings and interpretations participants have of their communication with direct support professionals contributed to the seven themes, reflected in the following statements of participants:

1. *Be Friends with Them When You Talk to Them...and Listening*
2. *I Would Like Them to Respect Me*
3. *You Got to Show Me That You Can be Trusted by the Way You Talk to Me*
4. *Some People Get Too Involved Into Your Life, Where You Don't Want Them*
5. *Treat Me Like I've Got Some Kind of Ability*
6. *I Told Myself I Made a Good Choice*
7. *We're Grown People, We Have the Same Feelings Like They Do*

Themes

Be Friends with Them When You Talk to Them...and Listening

Across groups, study participants offered perspectives on the value of supporters listening to them, and some participants gave accounts of being asked to listen to supporters. The overlap between listening and being listened to was expressed by one study participant, “Let’s talk and listen and just show me you can be trusted”. A primary finding to this theme involved ideas participants gave relating to how a supporter shows she is listening to them. Some individuals answered an unrelated question by volunteering the idea of supporters listening to them, while others responded to questions specifically about supporters listening by giving their understanding of what this means to them. An individual who receives home and community supports talked about a supporter listening to him.

Facilitator: How would you like a staff person to talk to you?

Speaker: Treat me nicely and friendly

Facilitator: What would it sound like if they were treating you nicely and friendly?

Speaker: Be friends with them when you talk to them...and listening.

Facilitator: Do you hear certain things from your staff people that tell you that they are listening to you and are being friendly, what do they say, what are some of their words?

Speaker: You can go out to library and have fun, and movie, go to park and have picnic, and go back home.

Another person in this group who also received supports in the home and community described the importance of supporters listening to her and how she assured herself that she was heard by them.

Facilitator: I’m curious, what kind of things do supporters or paid staff say to you that show you they’re listening to what you say? Do they say things to you that give you the idea that they are listening.

Speaker: I know mine do, cause I make them sit down and listen to me.

Facilitator: What do they say to you [Speaker] that shows you they're listening?

Speaker: Cause I'll keep talking to, you know, I'll look them in their faces, I won't let them just walk away from me, you know. They try walking away and I'll come back, you know I won't leave them... In other words I won't leave them alone, see, until they say something I want to hear.

Another study participant described what she wanted to hear from supporters.

Facilitator: What you would like them to say to you when you need to do something maybe that's hard to do or you have a problem. What would you like to hear?

Speaker: I'd like them to support me. And listen to my problems.

Facilitator: And what would you like to hear them say at those times?

Speaker: Support me, though. Listen to my problems, and not really say anything about them, but listen to my problems.

Two participants from a workshop gave accounts of supporters listening to them.

Facilitator: What are some other examples of questions or needs, maybe requests that individuals have made to the people who will say work with you. The people that are trying to help or support you, what are some other ways you talk with them? Anything?

Speaker 1: I just tell them that I'm having a problem with this or I'm having a problem with that and they just, they try their best to help me. I mean sometimes it will work, sometimes it won't. It depends.

Speaker 2: ... Someone that will just stop and listen to you, when you've had a bad day or whatever. That's important. But people...

Facilitator: You say...if they want to stop and listen?

Speaker 2: Yeah, care enough to take the time to want to know what's happening with me.

Facilitator: Is there a way ... helpers tell you that they really want to listen to what your need is? Is there something that you've heard supporters or helpers say that tells you that they're really trying to key in on what you have to say?

Speaker 1: So-so. I mean they'll let it out but then they don't let it out, kind of surly. Basically, they know you need this and they know you need that, or and whatever, and then it's basically up to you to go to them. Nine times out of ten, rarely that you see somebody come up to you.

Later in this discussion, Speaker 2 offered her view on the importance of listening in one's efforts to treat others fairly, "A lot of times, too, when you start to listen to somebody you don't fit everybody in the same mold". Another person from this

workshop described his relationship with a supporter in terms of the benefit he derived from, “Just having someone that would take time out to listen to what I had to say”.

A participant from a different workshop program provided an account of being told by one supporter to listen to another, and the difficulty she had doing so.

Facilitator: From staff, does something stick out that has been an important statement you’ve heard from them?

Speaker: I heard that people, staff tells me, like [Supporter 1], she tells me to do this, and [Supporter 2] tells me, “You need to listen to [Supporter 1].” I listen to what staff says, but sometimes [Supporter 1] gets on my nerves. She gets like she’s going to holler at me or something. So I don’t like; I like [Supporter 1], but I don’t like her that much.

When asked about suggestions that might be used in training future supporters of individuals with disabilities on the kinds of things people with disabilities like to hear, two participants volunteered the idea of the importance of listening.

Facilitator: I’m curious if you all have a suggestion about what [research assistant] and I might take back to the people we work with.

Speaker 1: Is, you know, just listen to the people and you know, just hear them out. And, I don’t know, I’m sure you’ve done that before, just, you know, pay attention to what they want, you know. And I don’t know if [Speaker 2] has anything, but, you know, just be aware of what they want.

Facilitator: Okay, [Speaker 2] can you suggest something that [Research assistant] and I might take back to the people we work with about the importance about how staff or employers talk to you.

Speaker 2: Just tell them to, you know, be courteous, treat each other with respect. Listen to what each other has to say.

The importance of supporters listening to individuals they support was evident across groups, and it was clear individuals wanted supporters to listen to them. Few participants specifically suggested supporters were not adequately listening to them, or that a lack of listening on the part of supporters was reason for some of the difficulties they were encountering. Perhaps, individuals assumed they were being heard because that which they were saying was so straightforward and had been said so many times before

Additionally, study participants may have supposed that their comments about concerns and difficulties related to supports and to their communication with supporters indicated they were not being heard, and did not bear being stated again or more explicitly.

Individuals who talked most about being heard were those who likely were not taking for granted they were. Listening as a response and a practiced and modeled skill may have been part of the interaction between supporters and individuals with intellectual disabilities comprising certain groups. In one group I asked the question concerning how individuals know supporters were listening to them more than once, likely in response to my assumption that supporters were listening to them. I considered that individuals in this group were heard by their supporters and felt they would be a good resource for information concerning what supporters say to indicate they are listening to individuals they support. Contrarily, in another group I heard accounts of individuals that suggested supporters were not listening to them and therefore, I did not give as much attention as I had in the previous group to what individuals were hearing to let them know supporters were not listening.

I Would Like Them to Respect Me

In response to questions about how individuals wanted supporters to speak to them, study participants from several groups offered the term *respect* and provided understanding of what this term means to them. A participant who lived independently and received daily support in the home and community suggested the importance of having respect for others and treating them as you would like to be treated. “Everybody has different dreams, everybody has problems we all have problems... But, my thing is I try to respect people like I want to be treated, you know”.

In the same group, individuals who received regular support, in some cases on a 24-hour basis, offered their understanding of respect in answering the question of how they would like a supporter to tell them something they really needed to do. One participant supplied the term *respect* to describe how she would like a supporter to speak to her, while the other answered the question about what respect looks like.

Facilitator: So let me ask, if you had to do something that you really didn't want to do...how would you like the staff person to tell you...

Speaker 1: I would like them to respect me.

Speaker 2: Respect you.

Facilitator: Alright, what would that sound like if they were respecting you.

Speaker 1: I would like them to talk nice to me.

In response to a question about how a supporter might communicate that individuals were going to be treated equally, a participant from a group comprising individuals who spent their day together in a workshop, knew one another well and exhibited a high level of group cohesion during discussion said she wanted to be treated with respect. Participants in this group said supporters show respect by treating those who are at different levels and have need to be treated differently as individuals, regardless of a person's disability. Participants in this group expressed frustration that some individuals in the workshop were expected to behave in ways that were different from others, while some were treated as less able or received preferential treatment from supporters for no apparent reason related to individuals' disabilities. Several referred to respect in terms of treating others as they themselves wanted to be treated.

Facilitator: What would you like to hear that would tell you that you're going to be treated, that everyone's going to get treated equally? Can you think of things that they might say?

Speaker 1: Yeah.

Speaker 2: Treat me with respect, you know? I understand that people are at different levels here, They got to treat people different like individuals,

but just treat people with respect, like they're human beings, and regardless what disability you have, God created you, and you should treat others like you want to be treated.

Facilitator: So do they say that, like "I treat you with respect", or is it how they act, or...

Speaker 2: They don't treat me with respect...

One individual in this same group described prior employment situations and experiences with employers to illustrate her views on how individuals should be treated, "This respect goes both ways, you need to respect the boss and do the job you're supposed to do, and the boss will respect the employees. I mean, it's a two-way street".

Participants in another group had daily interaction in a workshop and demonstrated concern for each other and high group cohesion. They responded to the question of whether there was anything I should take back to the individuals I work with.

Facilitator: [Speaker 1] is there something you might think I could take back to the other people who are interested in this topic?

Speaker 1: Here's a, you know, way you can take back, well, some of the information we said you can, and some of the information, like you know, the staff, you treat the people with respect.

Facilitator: Okay, so you want me to take that piece of information back. To treat people with respect.

Speaker 1: Right.

Speaker 2: To be treated like others want to be treated.

When participants in a group of individuals who had prior experience together in a workshop setting were asked how they would like supporters to talk to them, one person introduced the idea of respect, which would run throughout the discussion. This person described respect in terms of supporters not treating him as a child and addressing him by name and talking to him as they would to a family member.

Facilitator: Do others have thoughts about how you would like staff to talk to you in the situations that are a part of your life? [Speaker], do you have any ideas about how you would like to hear staff talk?

Speaker: Just treat me with respect. Don't treat me like I'm a child.

Facilitator: And what would indicate, what would you need to hear to know that say an attendant – or say - is it [Supporter] at work?

Speaker: Um hmm.

Facilitator: That [Supporter] is treating you with respect and not kind of looking at you as, “Oh, that’s [Speaker] and he’s kind of not the same as us.” How would you know that a person is treating you with respect based on what they’re saying? Or maybe something else would tell you that.

Speaker: Just come up to me, talk to me, you know, address me, call me by my name. You know, just talk to me just like they were talking to a member of their family.

Facilitator: Talking to you just like they would talk to a friend?

Speaker: Yeah.

A second member of this group was asked if he was aware of what Speaker 1 was talking about and brought forth his experience of being disrespected and talked to with rudeness, which he described in terms of being required to participate in volunteer work at the last minute.

Facilitator: [Speaker 2] are you, you’re not, are you aware of what [Speaker 1] is saying? Not necessarily the person he was talking about, but have you heard people talk to you in ways that are, like, “where did this come from.” You know?

Speaker: Sometimes I wonder, cuz we’re supposed to get respect, instead of the opposite.

Facilitator: And what do you sometimes feel you get, instead of respect?

Speaker: Sometimes it’s rude, take it from me.

Facilitator: Uh huh. You would know what it sounds like, when it’s rude?

Speaker: When you gotta, you know, do this, when you want. Whether you know it, it’s at the last minute. You know.

Facilitator: Tell me a little more about that...

Speaker: And they don’t let you know a certain thing that you gotta do, until the last minute. You know how it is when during the day and I be sitting down, enjoying myself, you know maybe just a little bit.

Facilitator: ...You’re sitting down, and I guess you’re talking over there at [agency], and you’re, yeah, you’re enjoying yourself, and what’s an example of something that just all of a sudden just might come up at the last minute?

Speaker: Sometimes they’ll tell you that you have to go to a certain place. That worse, you have to rush, and get ready.

Facilitator: Well, how will they tell you that you have to go to a certain place? Is there...

Speaker: Kind of rude.

Facilitator: Kind of rude.

Speaker: Yeah.

Facilitator: What's the kind of thing they might say?

Speaker: You gotta go, you know, do a certain thing, like clean the church, whatever. I can't believe its volunteer instead of paid.

Facilitator: It's a voluntary situation.

Speaker: Yeah, but I do a lot of that.

A person in this group with a significant visual disability described his experience of not hearing supporters communicate their understanding that his lack of vision might affect his ability to do certain things they ask him to do. This participant volunteered the idea of disrespect in response to questions about how supporters speak to him and said that not receiving this type of consideration from supporters makes him feel disrespected.

Speaker: (sigh) Let me explain something, [facilitator], if I may please.

Facilitator: Absolutely.

Speaker: If you don't want to do something, there's things - I have trouble with vision. And that is my worst thing – the vision problem.

Facilitator: With your vision, sure.

Speaker: And, it makes it difficult, you know, to do the things I want to. And I'd like to hear them say, "We're sorry that it's affecting your vision." Or something like that. Which I don't never hear.

Facilitator: You've never heard that?

Speaker: No.

Facilitator: What a shame. Yeah. So what do you, what does that tell you, [Speaker], if they're not willing to talk about what makes sense to you – your vision – that's a very reasonable way that you don't want to do something, because of your vision? When you don't hear that, what does that tell you?

Speaker: Its makes me feel like I'm disrespected.

Facilitator: Because that's a pretty big part of your life, being able to see things less than other people. And so you're expected to do things as though you can see. Is that what you're saying?

Speaker: Yes. Instead of being disrespected.

Facilitator: And I don't know if you can, you know, it's almost like something you would imagine they would understand on their own. I mean, if you have to tell a person, "Look, let me give you a heads up here. I can't see what you're asking me to do. So can you back off?" If you have to tell them that, or have you ever told a person that?

Speaker: Yes. Once.

Facilitator: And what was the response?

Speaker: He said, "You have to go, whether you want to or not." That's just...

Facilitator: Wow.

Speaker: And that's disrespect. That's why I don't like it.

This same person also indicated occasions when he had felt respected.

Speaker: I used to didn't get as much respect...got disrespected sometimes. Now it's leaning towards the opposite.

Facilitator: Leaning toward the opposite. And is that because of things they're saying to you, or they're just keeping out of your way, or, what's it like? How do you know its leaning more toward respect?

Speaker: When I do something to help someone out, they'll appreciate it and all.

Facilitator: Who will all appreciate it?

Speaker: Lots of others, you know, like I try to help somebody with something that they need, I mean.

Facilitator: The staff will appreciate it?

Speaker: Yeah.

Facilitator: Okay, will they tell you that? Will they say, "Good job, we appreciate you helping out?"

Speaker: Yeah. Sometimes. It's rare.

In response to the question of what the researcher might take back to those with whom he worked, individuals provided statements describing what they thought were important aspects of their communication with supporters.

Facilitator: Okay, [Speaker 1], can you suggest something that [research assistant] and I might take back to the people we work with about the importance about how staff or employers talk to you.

Speaker 1: Just tell them to, you know, be courteous, and treat each other with respect. Listen to what each other has to say.

Facilitator: [Speaker 2], any ideas about what you think would be important for [the research assistant] and I to tell the people that we work with about this whole idea of how staff and attendants and job coaches talk to you?

Speaker 2: I think, they ought to, you know, keep on treating the ones with respect and be, you know, generous with their instructions on what to do, and what not.

Another member of this group offered his ideas on what would be important to take back to others regarding how supporters communicate with individuals with disabilities.

Facilitator: What could they say to you, or what would you like to say to them so that they would treat you, or continue treating you respect?

Speaker: I don't know, just, like to him, well, comes up most of the time and, you know, tells me like, "You're doing a good job, keep it up." And sometimes he'll just nod and smile at me. And most of the time he'll just come by and say, "Good job." It makes me feel good.

Finally one participant in a group involving individuals who had daily interaction with each other and with staff in a workshop provided his perspective on what would be important for the researcher to take back to be used by others.

Facilitator: Are there any final thoughts or, we've said it all, but if anybody has a final thought, now would be the time. Something we could take back to our people.

Speaker: Just treat us with the same dignity and the same respect as you would yourself or anybody else.

Across groups, participants indicated awareness of respectful treatment or the lack of such in their interactions with supporters. Participants whose day activities were associated with workshops seemed to focus more on issues of respect than participants who were not in a workshop setting. Participants comprising groups not associated with workshops may have viewed their interactions with supporters and one another to be consistent with typical relationships and therefore had less cause to consider whether respect was an aspect of their situation.

Individuals in workshops provided numerous accounts of interacting with supporters and with one another, showing their desire for respectful interaction and associating respect with having abilities and being helpful to others. Individuals across settings indicated that supporters show respect when they focus on a person's abilities, and several talked about the sense of satisfaction they derived from being asked to give assistance that went beyond their usual routine in the workshop. One individual even

described feeling respected when he was asked to help a younger, less experienced person with a task.

The predominance of this concern for respect among individuals who spent their day in workshops was not surprising, and the close and consistent interaction individuals in workshops have with one another needs to be considered a factor in their awareness of interactive concepts such as respect. The significance of the workshop context to the study participants' understanding of respect and feelings of being disrespected likely was related to aspects of control and to the nature of hierarchical interactions with supporters common in this setting. Groups comprising individuals whose days were spent in workshops evidenced greater cohesion than other groups. Relationships and friendships among individuals in workshops revolved around aspects of supports and services, providing participants a common frame of reference for seeing respect in ways others may have missed. Clearly, individuals with intellectual disabilities desire others to respect them and to feel that their time is being spent in ways that are important. Perhaps individuals who have less frequent experience of ordinary respect and more occasions that cause them to question the relevance of their activities are most aware of the lack of respect and mindful when it is provided them.

Another possibility informing the relatively greater concern for issues of respect in groups associated with workshops involved the observation that these groups were not the first ones conducted. Facilitation of the first two groups included the facilitator's expectations of what groups were supposed to look like and provide in the way of data. My awareness of imposing a structure on the initial two groups, related to expectations of what I would derive from the discussions, was thrown into question during my reflections

of the process of the groups involving individuals from workshops (i.e., Groups 3 and 4), in which the concept of respect seemed prominent. Upon reflection, I realized I had been as influenced by individuals in the Group 3, as I believed I had influenced them, which was likely related to me beginning to relinquish the “professional” expectations prominent in my stance in the first two groups.

You Got to Show Me That You Can be Trusted by the Way you Talk to Me

Across groups, participants mentioned numerous instances of trust in their interactions with supporters. Several individuals independently supplied the term *trust* in describing these conversations. Other participants responded to the facilitator’s questions of how they know they can trust supporters, making statements that illustrated the way they experience a supporter to be trustworthy. Accounts of conversations with supporters indicated participants depend on supporters in a number of ways that can be represented by a theme related to trust. Individuals described talking with supporters about problems, and the need to be able to trust the person, a trust that was earned through a supporter's words and deeds.

A person in one group answered my question about what a supporter might say to communicate she can be trusted. The meaning of trust this person supplied included the concept of supporters needing to earn his trust by getting to know him and doing things with him for a while.

Facilitator: If you didn’t know me that well, and I’m supporting you, I’m giving you some kind of help on the job or at the center. What would you want me to say to let you know that I respect you, and that I want you to trust me?

Speaker: I’d say well, “I’d want.” I’d say, “Well, show me you can be trusted, I mean, come with me places, go with me places, and let’s talk and listen and just show me you can be trusted. ‘Cause if you use the right thing in me, if right now we just met, how can I know whether or not to

trust you. You got to show me, you know, you can be trusted by doing what, you know... Stuff like talk to me some about, you know, what do you like and what kind of work you got. You have to show me that you can be trusted; because I'm not going to get in the car ...I don't know you. We might even be kind of fighting the first day. You got to show me that you can be trusted by the way you talk to me and stuff like that. If you want to ask me personal stuff I want you to ask my permission first. And, if I don't know you for all I know you could be somebody dangerous. And, I'm not saying that in a bad way, but if I don't know you and I'm in the car with you, why should I tell you anything if I don't know you. You got to earn that right to ask me questions and by doing that, keep going with me and stuff and then, after so long, then you can ask me questions about my life. But I'm not going to let you know stuff on the first day.

In another group involving individuals who spent time together in a workshop setting, a person responded to my question about a participant's trust in a certain supporter. Speaker 1 talked about the supporter taking a couple hours of his own time to be there and listen to Speaker 2 during a difficult time in his life. Speaker 2 went on to describe how personal time with this staff member had resulted in them building trust.

Speaker 1: ... that same [Supporter] when he (i.e. Speaker 2) was so upset sat there and talked to him for two hours on his off time.

Facilitator: This same staff person talked with you for 2 hours?

Speaker 1: I mean, he just sat down and just talked and took the time to do it.

Facilitator: So you must have trusted this person, [Speaker 2]

Speaker 2: I did, and I still do.

Facilitator: What did this, how did this person get to a place in your life, [Speaker 2], where you trust him. What, how did that happen?

Speaker 2: He was, the tone of his voice, the reaction to it, my situation which was a personal crisis, I'd rather not go into details for you. But, just being there; just having someone that would take time out to listen to what I had to say. That means more than anything to me, even today.

In response to my question about the talk individuals have with supporters, a participant in a group of individuals who had daily interaction at a workshop mentioned going to supporters with his problems. The person talked about his conversation with a supporter in a time of personal crisis involving the death of a family member. This

description of talking with supporters during difficult times was echoed by others over the course of the discussion who also spoke of sharing difficulties with supporters and the responses they received from them. Three of the five participants talked about losing family members and difficulties related to family health problems and the ways supporters had spoken to them during the difficult times.

Facilitator: Okay, in these important life situations, as well as day in and day out, what are some things you are hearing from staff that tell you that you can trust them and they care enough about your situation? How do you know that you can really tell a staff some of this important stuff?

Speaker 1: Because they don't go around and...

Speaker 2: It stays between the staff and the client that the staff is talking with.

Facilitator: Okay, so [Speaker 2], you're saying you have the feeling that they'll keep it private?

Speaker 2: Exactly.

Facilitator: [Speaker 1], you were starting to say something as well, thanks.

Speaker 1: I was saying that they go, in ways, they don't go to other staff members.

Facilitator: Okay.

Speaker 1: If you have a problem, they sometimes do that, but they sometimes do not do that, it depends on the problem if they need to get another staff member involved.

Facilitator: [Speaker 3], what are some things that tell you, what are some things staff do or say that tell you, that they want to hear what you have to say? How do you know the staff want to listen to what you have to say?

Speaker 3: I talk to [name of supporter] and I tell her about my problems.

Facilitator: Who's this you talk to?

Speaker 3: [Supporter's name], the supervisor

Facilitator: Okay. And what do you tell her? I mean, how do you know that she's really interested in you?

Speaker3: I tell her about my problems, and like, when we go somewhere, I tell her that I'm going somewhere.

Facilitator: And what does she usually say?

Speaker 3: She says, "If you want to go somewhere, well you can go somewhere."

In the same group a participant offered this perspective on trust.

Facilitator: Alright. [Speaker], how do you know that the staff will really be interested in what you have to say? What do they tell you that gives you a sense inside that you can talk to them?

Speaker: Well, I know that within, if I have any problems, or any concerns, or questions, I know deep down that I can talk to them, and ask them questions and they're willing to answer those questions honestly.

The notion of trust was introduced by the facilitator when he asked participants if there was a supporter they thought they could go to when their situation didn't make sense to them. Participants described how they evaluated a supporter.

Facilitator: Is someone there you would trust enough to tell them, "Hey, you know, this doesn't make sense"?

Speaker 1: It doesn't feel right.

Facilitator: Yeah, it doesn't feel right.

Speaker 2: There are some members you can go and talk to and then there are some members of the staff you can't.

Facilitator: How can you tell a staff member that you can go talk to? What does that staff member do or say that tells you they're good people and they're going to listen to you? [Speaker 2], and then I'm curious what others might say.

Speaker 2: You have to get involved or in ways involved with the staff, get really close the staff member.

Facilitator: So you have to do some things to get close to the staff member. Are there some things that staff say to you guys that tell you that you're getting close and maybe they're the kind of person you can trust?

Speaker 1: [Names of two supporters] raise their voices at us and tells us to shut up. Y'all don't tell us to shut up! We're talking, so go about y'all's own business."

Speaker 2: But they don't do that.

Finally, participants were asked about the possibility of having a one-on-one conversation with a supporter that would give them the chance to express themselves as they had in the focus group. Two participants discussed the possibility of such one-on-one conversations, expressing the importance of space and privacy and having trust in the staff person enough to talk to her.

Facilitator: Maybe it would be possible to have one on one conversations that kind of hit on some of these ideas we talked about today. How do you think it might be possible to have that one-on-one?

Speaker 1: Well, I think in general that all one-on-one conversation with client and staff could be useful to real world job situation.

Facilitator: I agree. What would that conversation maybe look like?

Speaker 1: Possible job opportunities. That sort of thing.

Facilitator: Okay okay. [Speaker 2], you said the fact that things are so open there and that you're not there now, you had said, you could see that it might be possible to have a one-on-one conversation with a staff person. That kind of...

Speaker 2: It depends on the staff person. If you trust the staff person enough to go and talk to the staff person.

Facilitator: So trust?

Speaker 2: Right, if you go and talk to them, because it's so open, other people can drop in.

Individuals who did not have a specific community program talked about the importance of their relationships with attendants who provide home supports. In response to my question about what they had heard from attendants that promoted trust, one group member provided his understanding of the process of developing trust in a supporter.

Facilitator: Okay. Are there things you've heard staff or attendants say that really encouraged you to tell them some important things in your life? ... What things do you hear attendants or helpers say that let you know that they can be trusted with some of the important stuff?

Speaker: Well, first of all, if I'm dealing with and person and they're dealing with me, and anytime, I have to earn they're trust. Now once I earn their trust, I will tell them stuff that I won't tell nobody else. And to me, if they can keep the personal stuff that you tell them between you and them, then you earned their trust. When you find out they've done otherwise, then that person can't be trusted.

Facilitator: Is there something a supporter might say that would kind of clue you in that they can be trusted.

Speaker: Well, you know, they can say that, "[Speaker] can do this, [Speaker] goes here, [Speaker] goes there, and he also advocates for other people." Now, when they do that, that shows me that they, I can trust them with stuff that I've told them. You know, they build up confidence in me and go out can tell other people good parts.

Facilitator: So they get up on your abilities and they start about what you can do, and that builds trust.

Speaker: Right. And not just disabilities.

This person discussed trust as something he has to see in a person (i.e., something he has to gain or earn from the person supporting him). From this perspective, a supporter

earns his trust by listening to things he won't tell anybody else and keeping the information to herself. This person also said that a supporter indicates she can be trusted by talking about his abilities and not just his disabilities. Similarly, another participant in this group expressed an understanding of trust in terms supporters keeping private the information a person gives them and having a commitment to the person's support.

Facilitator: Go ahead, [Speaker], what about, what do supporters, maybe, what have you heard that might encourage you to talk to a supporter, feeling that you can trust that person?

Speaker: My person that I had (unintelligible speech), if I'm telling you something I would like to keep it you and not all over.

Facilitator: Keep it private, like your business is private? So...

Speaker: Yeah, like Dr. [Name], I ask her to keep it private.

Facilitator: Well, do...

Speaker: Well, ask me if it's alright for someone to spread whatever they want and tell people about you.

Facilitator: So ask you? Yeah. Is there anything that a person can say to you, let's say this person really wants to honor, keep your business private, what would they say to you to let you know that? That's a tough question. [Speaker 1] said it's kind of like they ask about his abilities, but I'm hearing that it's kind of like a sense you have that this person...

Speaker: I feel like this. If you have a kind heart and a love, sweet heart to help someone, and if you don't want to do the job, don't do it. That's how I see it.

Participants in a group of individuals who had previously known one another in the context of a workshop and now related primarily through ongoing advocacy and community activities talked about the importance of being able to trust supporters. They described supporters earning trust through their words and deeds, which included acknowledgement of the person's abilities. In response to the question about what they heard from support staff that told them they could be trusted, one participant expressed how supporters indicated they could be trusted by being friendly and encouraging him in his pursuit of employment.

Facilitator: What kind of things do you hear that tell you that maybe you can trust the staff people to pick up the ball for you, [Speaker 1], and help you get out and get a job.... What are you hearing staff say that gives you sense that you can trust them?

Speaker: They'll be more friendlier – friendlier than they used to be.

Facilitator: So if they're more friendly that's a good thing, of course.

Speaker: Encouraging.

This person provided further perspective on how he associated trust with the furthering of his objective of working.

Facilitator: What could you hear ... that would tell you that if you had a situation and you had the need you could go to this person and really trust that they've got your best interest at heart? What would you need to hear to know that?

Speaker: I would like to hear more encouragement on job hunting.

Facilitator: Okay, specific on job, specific to the job hunt. What would you like to hear a person say?

Speaker: More following-up on, "We will follow up more on the applications you put in." That's what I'd like to hear. That would be nice, instead of the opposite.

A second participant in the same group described the importance of his employment situation and his employer providing him the assurance he can go to them with important issues.

Facilitator: ...What would those people that are in your life, what would they need to say to assure you that you can really trust them with the important stuff in your life? Does that question make sense? What would you want to hear from the people you work with to assure you that you can go to them with some of the important things in your life?

Speaker: Well, in my case, I feel very comfortable, I mean, I'm really comfortable where I can I can tell my, I mean, to tell my employer who employs me, hey, you know, I feel like, you, I just feel like I can come to them with everything.

Trust was a common theme across groups, with individuals describing not just the statements of supporters that build trust, but also their actions and their reactions to the person. The concept of trust was often supplied by participants in the attempt to define desirable interaction with a supporter. In the accounts individuals gave of the trust they

had in a supporter, mention was commonly made of a relationship process they considered necessary for trust to exist. This process involved the exchange of words and deeds over time. Individuals talked about the significant conversations they had with supporters as providing a basis for the development of trust, and indicated trust involved the supporter keeping the personal affairs private.

Individuals clearly communicated their awareness of the importance of trust and their desire to trust supporters. An individual's concept of the trustworthiness of a supporter was based on activities that demonstrate the supporter has the person's best interests at heart and the supporter's availability and willingness to listen to the personal difficulties of the person. The challenge individuals with intellectual disabilities face in developing trust in supporters was not described as being related to aspects of the person's disability but to difficulties of interpersonal relationship common to all.

Some People Get Too Involved Into Your Life, Where You Don't Want Them

Individuals described the importance of supporters respecting privacy and allowing the person to control boundaries. Individuals gave numerous descriptions of their involvement with supporters and were clear about their desire to have support. Two participants who lived independently with in-home supports gave separate accounts, one successful the other not so successful, of the control of boundaries related to aspects of support. The first person described the good feeling she received when supporters thanked her for allowing them to bring their children to her home when they came to support her, an arrangement that had been made in agreement with the person with a disability. The second individual described the value of respecting a person's need for private time to develop relationships with others, without them being in the home, and

her frustration with not being able to prevail in situations where she wanted her supporter to give her space to pursue relationships.

Facilitator: Okay. What else makes you happy that you hear from a supporter? Anybody?

Speaker 1: Goodbye (Laughs).

Facilitator: Goodbye?

Speaker 1: Yeah.

Facilitator: Who else?

Speaker 2: A lot. Like I said earlier, a lot of its, my caretaker you know, they're good to us.

Facilitator: What do they say that shows they're good to you [Speaker 2]?

Speaker 2: They just tell me, you know, cuz I'm alone in the house.... I have kids come over my house, because I like kids, and I mean I do let them bring them, cuz I do like them.

Facilitator: Good.

Speaker 2: I don't have any problems, if they can't find no babysitter, I tell them just bring them to my home.

Research assistant: Do the people that support you, do they ever say things to you that make you feel good.

Speaker 2: Yes.

Research Assistant: What do they say that makes you feel good?

Speaker 2: A lot of it is like just thank you for letting me bring my kids over. You know. A lot of it's just because I am the only house they let kids come over, when I started [Agency] they had this thing they wanted me to sign a paper saying I didn't mind kids to come over and meet with me, I think it was [Name's] house. They had a meeting over there about parents and kids because they were fighting with me because they didn't want them to come to work with the parents when they had to work over. See that's mostly my trouble is, see I don't have any troubles, like say if somebody gets sick, like my momma, I don't have any backup.

Speaker 1: Relationships, that's what gets me.

Facilitator: Let's hear from [Speaker 1] for a bit, please. You were saying about relationships being big for you, [Speaker 1].

Speaker 1: Yeah, I mean. Say I want - I'm dating or something and he comes over and there sits my caretaker, which you know, and it's almost time for her to go home. But, you know how it is. So they think it's a big deal, about relationships, which you can't, they'd rather you not have one than to have one.

Facilitator: Do they say that?

Speaker 1: No, but I feel that.

Research assistant: What do they say that makes you feel that way, or is it something they say, or?

Speaker 1: They say, you know... we're not leaving just because you have a relationship with somebody. It could be a relationship with a friend or

something, you know, a good friend, but that's a no-no. You know. You can't do it. I mean, they don't want you to do it, but you want to. I think that's big.

Participants in several groups gave accounts of their satisfying conversations with supporters about situations related to their home situations and family members, and the sense of support they received from certain supporters. Participants described how supporters interfered in the area of a person's choice. Additionally, they described supporters' disregard for boundaries between the person's workshop activity and the person's home and family life, which included the supporter's statement of intention to go directly to the person's parents in responses to the person's behavior in the workshop. The first person described how supporters disregarded boundaries by arguing about him without including him in the discussion. This person said that supporters arguing about him in his presence made him nervous.

Facilitator: But what are some of the things that you do not like to hear from staff [Speaker 1]?

Speaker 1: I do not like to hear staff argue all the time cause that's one thing that drives me AWOL.

Facilitator: Argue with you?

Speaker 1: No, amongst other staff.

Facilitator: Oh, okay.

Speaker 1: That's how bad it gets.

Facilitator: What's that, how is that, you said they drive you AWOL. What's that?

Speaker 1: What I'm saying is it makes me nervous to hear them argue about me.

Facilitator: They're arguing about you?

Speaker 1: Exactly.

Facilitator: Are you part of that conversation?

Speaker 1: I had nothing to do it, and they were arguing about me.

Facilitator: But you're sitting there thinking, "Good grief, where is this going to end up, this is my life?"

Speaker 1: I'm like, where in the world is this argument going to end?

Facilitator: Do you try to say, "Hey, I'm out here, can I have a vote? Or can I get in this conversation?"

Speaker 1: Look ... [to staff] “I don’t want to interrupt, but you all need to quit arguing for real.”

Immediately following Speaker 1’s account, two other participants talked about supporters cussing in their presence. This is followed by one of the participants describing how supporters tell her what she should eat, communication that is out of line in adult relationships, especially ones in which a person is employed to support another. In this exchange, Speaker 3 described how supporters threatened to call her mother.

Facilitator: Sure, sure... I’ve never thought about that. Do other people have things that kind of, you’d rather not hear staff say? What are some of the things you don’t like to hear staff say?

Speaker 2: Cussing.

Facilitator: Cussing, [Speaker 2]? I’m sorry, [Speaker 3].

Speaker 3: Cussing, and telling me what to eat, when not to eat,

Facilitator: So they’ll try to tell you like, “Now is a good time to eat”? What are those conversations like, [Speaker 3]?

Speaker 3: That conversation makes me upset, and makes me angry, like yesterday, my caregiver was telling me not to bring my lunch box, we have lunch at 12:30, and she’s going to tell me, “Don’t bring your lunch box full of...”. And I don’t do that. She don’t tell me what to do, because she don’t deal with me. And I’m tired of it. I’m tired of them telling me what to eat and what to bring.

Speaker 1: I agree with [Speaker 3] on that one.

Research assistant: And is that a staff person?

Speakers 1 and 3: Yeah.

Speaker 1: Mine and her case coordinator.

Facilitator: And what do you say, [Speaker 3], when they try to tell you, when this staff person tries – do you say anything? Do you...

Speaker 3: I tell them, I tell her to leave me alone, let me be.

Facilitator: And what does she say, or does she...

Speaker 3: “I’m going to call your mama”, and my mama says, “What did you say?” And I say, I ain’t said nothing, she’s the one that started it first, and I ain’t said nothing to her. And so, my mama agreed with me.

Facilitator: Good, good.

Finally, a fourth participant joined the conversation and, along with Speaker 1, described how supporters attempt to find out personal information, getting too closely involved in the lives of the individuals they support. These speakers described supporters

attempting to find out things about their lives they considered to be personal, or simply asking too many questions, showing a lack of consideration for boundaries.

Speaker 4: Sometimes the way the staff gets into the clients,

Facilitator: They get into the clients?

Speaker 4: Into the clients. Too personal into the clients' life.

Facilitator: So you're hearing, [Speaker 4] you're hearing what [Supporter] is saying. Is there a story, or is there a way that staff have gotten too personal? I'm not going to get personal, but what does that sound like? What do staff say that tells you that they're getting too close into your life?

Speaker 4: It's like I'll say one thing, when I was there, when I was there, it got to the point where you get – you ask too many questions, like, you know, sensing how's your day, and stuff like that, its like, where, with some they get too involved into the person's life, you know, too involved. It's like some people can get involved into your life, where you don't want them there.

Facilitator: What are the type of things that staff say to you all that are getting too that are getting too close to that zone that [Speaker 4] is talking about? Too close to that border where they're crossing over and they're getting a little bit too personal or they're kind of maybe getting in there in places they don't need to be? What are some things you've heard? ...It sounds like they ask a lot of questions. But what are some things you've heard that show you that staff are getting too close to the edge?

Speaker 1: Well, I pretty much had that happen to me before when [Supporter] kept asking me too many questions at one time.

Facilitator: Who was this?

Speaker 1: [Supporter], one of the supervisors.

Facilitator: Got it.

Speaker 1: She kept asking me too many questions time and time again. Look [Supporter], you're asking one too many questions, you need to cut it out and back off. So, she pretty much ended it at that.

Facilitator: So, good, you could tell her what was going on for you. It sounds like she listened....

In the final exchange in this sequence, the question was posed about ways individuals might be able to tell supporters they need space and that they don't appreciate being asked so many questions. Speaker 3 described how she threatened to call her mama if the supporter didn't leave her alone. This represented the second time that the threat of

calling Speaker 3's mama was used, this time as an attempt by the participant to control boundaries between herself and the supporter.

Facilitator: Are there things you found that you can say to staff similar to [Speaker 1]? Things that will sort of give the staff the sense that "I'm talking to an adult here, and they're not appreciating all these kind of questions." Are there things you've learned to say back to staff?

Speaker 3: Yeah, I tell [Supporter], I'm working on [job], she hollered at me and tell me to be quiet and I tell her, leave me alone, let me work, if you don't leave me alone I'm calling my mama. And I tell her that. But she won't listen. She says, "Tell your Mama then, go ahead and tell her." Cause you don't boss me around. You're not my mama.

Comments of participants in this group suggested unclear boundaries between the workshop and the home and between supporters and family members, which supporters may have exploited. Participants gave numerous accounts of talking to supporter about family-based concerns.

The idea of supporters asking for information that is too personal or asking in ways that are inappropriate was mentioned across groups. In a group of individuals who spend their day mostly in separate supported employment situations, one participant said that supporters sometimes do not talk when they go on trips and expressed his enjoyment of the silence "It's good and quiet when you're on a trip. They don't say much when we're on a trip, we just ride." In response to the question if there are good times for supporters to be quiet, a second participant gave an account of supporters becoming too personal in the questions they ask of him, and talked about his desire for a supporter to know him before asking him personal questions.

Facilitator: Well, how about [Speaker 1's] idea about, are there good times for staff just be to be quiet?

Speaker: Yeah I think there is 'cause sometimes they get a little bit personal. I mean, you know, I think, I'm not saying they get bad, but I mean they get a little bit personal. Sometimes it's alright but, I mean, I

don't like the fact that, I mean, it's alright to ask me about my family but I don't want people to know so much that, you know. When I want somebody I don't know that well, and they're asking me about my stuff, I don't like it, because if I knew them that well...I know [Supporter] real well. I don't mind [Supporter] asking me how things are going at home. But if it's somebody that I don't know real well and they start asking me one question after another I don't like it.

Facilitator: And you've had that experience?

Speaker: Yes

Facilitator: And these are questions they ask about your family?

Speaker: Yeah. And I just don't think its right for them to...maybe till they get to know me better. But on the first day I don't think its right that they start asking stuff. And I wouldn't mind putting it down on a piece of paper but they're taught to ask questions when they don't even know you. And I don't like that and that's what I told [Supporter], you know, me and [Supporter] talk it out. I told [Supporter], I said, "[Supporter] I've known you for years, and you kept me and I...from my, I mean, and done stuff with me for years. That's why I go and tell you all the stuff because I've know you for years." But I don't want somebody, a stranger, telling me, asking me all this stuff. Just...I don't think it's a stranger's business.

This person provided further perspective on the disregard of supporters for his privacy.

Speaker: 'Cause, I mean, you know, you know in some places they're just like, will see if they know you, and some places, they want to know what you do at home. Its like anything you do if it's not what they want you to do, it's wrong. And that's where a lot of problems come in over there at [Location] where I was, I wouldn't say a slave, but they wanted to know what was going on at home and stuff like. That's just as nosey as all get out.

Facilitator: And if you did not tell them, what would they say to you?

Speaker: Not really anything, but I did tell them, "Why do you want to know what's going on at home? It's none of your business!"

Sensitivity to boundaries was represented in terms of supporter recognition of a person's right to a private life beyond the workshop and the importance of respect for an individual's personal space.

Speaker: They smother. They need to quit smothering people. We've got a brain, you know. And some of the things related to work are fine, but if it's not related to work but what you do when you leave those doors, its none of their business, unless you're getting drunk and you come in and can't work, it might be their business, but if it's something you're doing outside of work, and it don't blend in with the workforce, then leave it

alone. You know, I mean, I like to work here, but I'm so afraid to work here, cuz I'm afraid they'll start nitpicking into my private business. It's not their business what I do once I leave these doors.

However, another participant described enjoying spending informal, recreational time with his supporter at home where they interacted more like friends than employer/employee. Although this participant did not indicate that he and his attendant had discussed issues of boundaries, he had no problem with her staying around after her work was completed, suggesting the value of individuals feeling comfortable in the boundaries between themselves and their supporters.

Speaker: Late at night we come and talk, she did everything, she mopped, she cleaned, vacuumed the floor, make up every room. Ain't nobody there but me right now, make up my bed, clean my bathroom. She bathes me at nighttime. Half the time we look at television together, ain't nothing to do, she cook me something to eat. After that we just sit around and look at television 'til her time is up.

A participant who received support in a workshop described how boundaries had been negotiated between himself and a staff member, and how their decision to share personal time was challenged by a staff supervisor.

Speaker: Later on that evening, [Supporter]... stayed to ten or eleven o'clock that night watching wrestling with me and [my roommate]. The next day, he went into work and somehow another, I take it [a supervisor] had passed by the house and seen his car sitting there. She calls him into the office, and crawls all over him and threatens to fire him. Why? Because he was taking up time with participants, and she accused him of playing favorites to the participants. It's his off- time mind you. Not during work hours.

Individuals generally described desiring the involvement of supporters in their life situations; however, individuals were adamant that supporters need to avoid being too personal, unless the individual invites them to have a more personal relationship. Participants talked about boundaries involving the relationships with supporters and the

importance of being able to control and negotiate them. Issues of boundary violations were mentioned more in conjunction with the interactions individuals had with supporters in activities away from home than in the individuals' home settings. This likely was a function of the general tone of participants' comments that suggested an emphasis on day rather than home activities. The most egregious boundary violations were discussed among individuals who attended workshops, suggesting it is within this context that individuals need to be given greater control over who becomes involved in their lives and how closely. As discussed earlier, the context of workshops precludes individuals with disabilities exercising control over aspects of their lives, and from the comments of participants aspects of boundaries were no exception.

Treat Me Like I've Got Some Kind of Ability

Across groups, participants expressed their desire to have a job or other activity relevant to their abilities and interests. Individuals indicated wanting to be more involved in decisions about their supports and to receive services related to outcomes they desire. A 50-year man, who had spent his entire adult life in a single workshop, expressed his desire to be productive.

Speaker: They say, "I'm sorry we don't have no productive activities or what have you." That's why I was, why I done what I did in my staffing that I had recently. We discussed about doing the 30 hours out in the community. Have someone come and get me, and I gotta do what I gotta do and then go back home. I said it would beat sitting around doing nothing all day. I could be doing things at home. They didn't say a thing. Not one little -ity thing.

Similarly, a female in her late twenties described her desire to find a program to help her learn to read and the response she received from those in a position to support her basic request.

Speaker: My counselor, and I, we went to this school, I was trying to get into this school to read and every time I was telling her I need help in reading, she said, “well I took you all over everywhere, they just didn’t want to help you in learning and reading and stuff.” They put us in a lot of stuff, it was like drama, they took us all around, places to go. Went to another place, they didn’t want to do nothing. The lady was like “Come up to the office”. My counselor sat in her office, they didn’t let her go in there with me and like, and I ask her, “Really, I do want to, you know, read, that’s it. That’s all I come to do is learn how to read” and she said, “Well, we can’t help you, you’ve gotta leave.”...It would have probably been more balanced if my counselor could have been in there with me and we all sat down together, to see what’s going on, or whatever. The other lady didn’t want, she just didn’t. I don’t know what her problem was. And then she called me back and I went back out there and she still didn’t want to do nothing. I did not go back. I didn’t like her.

An individual with community-based employment expressed a desire for supporters to know what he was doing and said they should, “Come see where you work at and talk to ones that’s working with you where you work at. See if you’re doing what you’re supposed to be doing.” Another participant in the same group talked about the importance of supporters providing supervision related to his performance and emphasizing his abilities.

Speaker: It’s really, “Go do your work” that’s all they want to do, “Go do your work.” They say “Go do your work.” And then to concentrate on this, you know, I mean. I really thought at first, you know, they probably didn’t know me that well, but they wouldn’t help me write or anything; too much independence. They put me in room back there and she told me to write and stuff alone. They leave me alone forever. I don’t feel secure working independently that way. I like people, and I like to be around people. And the fact that I wasn’t around them enough. And you know, it’s just like that. They give too much independence. And, you know, I like to be around people. I like to be supervised.

This same individual further explained the difficulties that ensued when supporters emphasized what he could not do instead of his abilities.

Speaker: So I mean, you know, but they, with that bunch over there, if you don’t do what they want you do to and work on what they want you to work on, they’re just going to get mad. And, you know, I regret

(unintelligible speech). I wanted to go back, and see, I went there for 20-day evaluation.

Facilitator: To [Location]?

Speaker: Yeah. Well, I said, I decided that I wanted to go back. But knowing that ...the evaluation, the 20-day evaluation, went good. There wasn't any problems with the 20-day evaluation. After I graduated from high school, at first I went back over there back in June or August, July or August. First few days went good but as time went on it started being all heck. Them telling me to concentrate, in their words, they wanted me to concentrate on what I couldn't, can do, and what I couldn't do. And that's where the trouble started. If they don't know me as well as my momma, my daddy and stuff like that, and they really didn't have any business telling me I couldn't do what I wanted to do. 'Cause they don't know me – they didn't know me that well. So, I mean, but, I don't know, but they finally said they couldn't do anything for me anymore 'cause I wasn't behaving. It hurt for a little while but I said, "Thank goodness it's over."

A person who attended a workshop expressed the importance of supporters recognizing her efforts.

Speaker: Tell them, or them to tell you that you are doing a good job, and if you are fast at it, let them know that you are really fast at it, and it's a big surprise to them. What do you call that word? Their esteem. Self esteem. Because that boosts my esteem right there. If somebody tells me I'm doing a good job and if I can make it somewhere else, or whatever, make it out there, they get out there, that makes me feel good. I love someone to tell me I'm doing a good job. I might be 30- years old, but I still like it.

Another sequence of statements from individuals in a workshop followed the facilitator's question about final thoughts and ideas he could take back with him to be used in trainings and further research. The study participants recounted statements they had heard from supporters and spoke about the importance of supporters paying attention to individuals with disabilities and being flexible in their expectations of them.

Speaker 1: "...if you don't do it this way it's not going to work right".

Facilitator: They say that [Speaker 1]?

Speaker 1: "I said if you don't do it this way its not going to work you gotta do it the way I told you, not the way you want to do it."

Speaker 2: Sometimes with disability, you have to do it differently.

Speaker 3: We're not stupid, we're people.

Speaker 2: It's just that you can do it better in a different way, you know?

Speaker 1: Yeah, exactly, [Speaker 2].

Speaker 2: I mean, I've got a disability too....

Speaker 3: I do too, I try to say I'm a slow learner.

Speaker 1: So what, so have I.

Speaker 2: Me too! But my main problem when I get a job is that they are not flexible, they want you to do it, "This is the way you do it and I don't care if you did it a better way, no, this is the way you do it."

Speaker 1: Yeah.

These individuals further explained the importance of supporters honoring a person's abilities.

Speaker 2: And I can't get the way they want me to do it, so I find a way to improvise, to find a way to do it. Turn out just as good. I can do it better, but no, "We didn't teach you to do it that way. You have to do it this way now."

Speaker 1: But don't treat me like I've got a disability, treat me like I've got some kind of ability. Not a disability.

A person in a group of individuals who lived independently with in-home agency supports responded to the facilitator's request for ideas he might take back to the people with whom he worked.

Speaker: Well, the first thing I see [Facilitator] is, look at the disability second, look at the person as a person first. You talk to the person and look at them as a person first. Not at their weaknesses, at some of their stronger points. That's the main thing I would like for y'all to take back, you know, to tell people that we are people too, look at us as a person first and disability second.

Facilitator: Okay.

Speaker: We may do things a little bit different than other people, but we get it done.

Another person in different group who also lived in her own apartment with minimal in-home supports expressed her desire for supporters to become genuinely involved in her care and give her the guidance and support she desired.

Speaker: Open your heart a little bit. Don't just come in and do your meds and do all this or whatever, just because it's your job...Tell me to take my meds, tell me what to do, you know, see what I'm saying?

Many individuals across groups expressed wanting supporters to emphasize their abilities; however, this theme was particularly salient within groups comprising individuals who attended workshops. According to these participants, supporters often control the pursuit of simple tasks, requiring individuals perform them as instructed without deviating from their instructions. Participants expressed confusion and frustration at the interference they encountered from supporters, and at being treated according to the supporters' expectations of how they should act, not according to their needs and desires.

The involvement of supporters in the lives of individuals with intellectual disabilities is important. Study participants expressed wanting supporters to show interest in them and to provide guidance and supervision according to their abilities and preferences and not to emphasize what the person is unable to do or does not want to do. Despite individuals wanting to be involved in activity that is interesting and meaningful and to hear statements that show that supporters know and understand their preferences and the supports they need, the opposite was often reported.

Participants reflected the many ways supporters emphasize their disabilities. Analysis revealed that if supporters fail to recognize the abilities of individuals and provide feed-back on their efforts and activities, they are likely approaching individuals with an emphasis on their disabilities. Many of the individuals who reported receiving the least attention for their abilities also talked about the emphasis supporters placed on their disabilities. Additionally, study participants who needed greater supports frequently talked less about the lack of emphasis on their abilities than individuals who had fewer support needs. This suggests that a person's sense of ability may be influenced by the

interpretations others offer related to his abilities, which may be as important in the person's sense of competency and skill as actual abilities the person has demonstrated.

I Told Myself I Made a Good Choice

Participants across groups expressed their desire for supporters to not tell them what to do, but rather to offer them choices, describing the importance of being provided support to make decisions reflecting their preferences and talking about how supporters often limit their opportunities to choose. Individuals expressed frustration at the lack of choice and at the control others exercised over them.

A participant who lived independently with minimal support described how she felt about not being able to make choices.

Speaker: Like I was saying, they want me to go to the doctor. Well, I don't want to go to the doctor. If I say I don't want to go, I don't want to go, Anyway, we end up going to the doctor's office, and it's stuff like that that ticks me off.

Supporters can assist individuals to make choices that promote health and wellbeing by providing information and allowing them to make decisions on their own, while reinforcing the person's effort. A participant who received support in a workshop described his views regarding the importance of choice.

Speaker: Well, I've always heard other supervisors compliment me on my work...and my ability to help others...They commented on that right there at the spot..."Good choice that was a decision call."

Another participant commented on being told what to do without being offered a choice.

Speaker: I mean if they had it all figured out they would probably change the ways of doing stuff...I mean, I don't get it, you know, telling people to be quiet or whatever, you know. Telling people what to do is definitely wrong.

A person who attended the same workshop gave two separate accounts of involvement with a supporter involving choice. In the first, the participant indicated making a choice, despite the supporter's statements of control, and in the second she described the response of the supporter after she had made a good choice.

Speaker: [Supporter] say, "Go over there and sit down. Go over there and sit down! Don't talk to [other Supporter]..." She's trying to boss people around. Like, she said, "Go over there and do some work." I said, "I don't want to do my work."

Speaker: I had made a good choice. I told myself. I made me a good choice. And I got me a popcorn, I made me good choice...I told [Supporter] I made a good choice.... she said, "You made a good choice", I said, she say "Good, you made a good choice eating popcorn – you can't eat no sweets 'cause, sweets not good for you."

Another person whose day was organized by his involvement in a workshop program described his desire to choose his activities.

Speaker: You gotta do, you know, a certain thing like clean the church, whatever. I can't believe its volunteer instead of paid...I do a lot of that...I don't have any choice...Sometimes they'll give me two choices, sometimes they don't.

Speaker: I might get a choice once in a while, and that's about it. They give me one or two choices once in a while. That's about it....That ain't too much [of a choice]. It's hard to make a decision like that...I think they ought to, you know, get organized, and you know, say something in advance instead of, its like that [speaker snaps fingers]. You know, like one day in advance, instead of just, you know, like that.

Another person in this same group described his experiences related to choice and the responses he received from supporters

Speaker: It's like sometimes, they get you out, and then maybe, you decide you don't want to do it; it depends on who you're riding with. They feel you don't want to do it, they see you don't want to do it, and then they'll bring you back. But then you have some, once they get you're out, you won't be coming back until they get ready to bring you back. You just sit over there, and whatever they're doing, and you don't want to do it, then they just, they just sit on the van. Just sit out by yourself somewhere, [until] they get through.

A man who uses a wheelchair and had many years of self-advocacy experience described negotiating a workable support schedule based his choice and preference.

Speaker: Actually, when she [my Attendant] started with me, the agency told me, no, let me take that back, I told the agency, we're either going to have to work it my way, or not at all. 'Cause see, when they sign you up with these different agencies, they give them a schedule. Say they may give them two hours a day in your house, maybe three or four hours. But my schedule doesn't work as well as theirs. We [the Attendant] and I came to the conclusion some days she may not come, she may make up for it another day that I'm not home, you know, so we came to the conclusion that we had to work with each other's schedules. And it actually gave her some flexibility to do some of the stuff she needed to do.

Participants gave numerous accounts of interactions with supporters around aspects of choice. Across groups the desire for choice was defined mainly as having options that were meaningful to the person. Comments of individuals who participated in the study hinted at their awareness of the irrelevance of choices they are offered, suggesting that the experience of genuine choice requires that individuals be presented with options that are meaningful to them. Individuals want to have their abilities acknowledged, to be given choices and options and not be forced to participate, especially in activities they have been told would be voluntary. Individuals described being hurried by supporters who presented "choices" that had to be made immediately, without giving individuals time to decide between options, often requiring them to participate in activities they had not chosen. The expression of wanting choice was clearest among individuals who related accounts of not having it. Descriptions of interactions study participants have with supporters showed the limited choices individuals have. This was especially true in settings of high supporter control.

From the comments of participants, the most appropriate place to start when emphasizing one's choice appeared to be with the person's abilities. Individuals

expressed an awareness of the significance of being presented choices that reflect their abilities. The supporter's offer of choice in areas of ability appeared to limit the emphasis on disability common in interactions between supporters and individuals with intellectual disabilities, especially in settings involving supporter control.

We're Grown People; We Have the Same Feelings like They Do

Participants in every group discussed the need for supporters to treat people with and without disabilities as equal in terms of personhood and humanness, while giving consideration for differing support needs. Study participants who attended a workshop stated some supporters treat individuals unequally and unfairly by ignoring those who do not do what they are told, while expecting compliance from others. Individuals also described how supporters allow themselves privileges and considerations, which they do not allow individuals with intellectual disabilities.

Speaker: The supervisors they can talk and work and everything else so why can't we as long as we're doing our own work. That's a bunch of baloney if you ask me.

Facilitator: So you all want people just to treat you fairly.

Speaker: Like humans, like they want to be treated, but they [staff] don't understand that. They think they're better than you are. Treat other people as you want to be treated.

Another person gave her perspective on a supporter's unkind comments toward a group member and suggested the supporter was breaking rules about talking, which individuals with disabilities were expected to follow.

Speaker: When I say she just wants to hear herself talk, it's like you're getting involved...she'll go and other staff members and talk to them and then all of a sudden when you want to talk to say, another client, they're all... I feel like it should be that the client should be allowed to do what the staff member does, because in a way, they're breaking the rules.

Study participants who attended a workshop talked about supporters treating individuals with differing abilities the same, usually as though they were all similarly disabled. They also gave accounts of supporters treating individuals differently for reasons that did not appear to have anything to do with individuals' support needs, which included what appeared to be arbitrary distinctions between individuals who were and were not complying with rules. Participants said supporters treated individuals with intellectual disabilities as being different and less capable than they actually were. They said supporters viewed some individuals as being less for no reason other than their disabilities. Additionally participants talked about supporters treating them like children, as though that was an appropriate accommodation for their disability.

Speaker 1: Because everybody got a different degree of disability to deal with. They ain't all on the same peg. And I found a lot of times here, people try to put everybody on [a] peg. Everybody's different, Everybody's got a different type of disability, you need to look at individuals, not, oh your disabled, so we've got to treat you like a kid, some people might need it, others might not, and I notice a lot of people here try to treat everyone the same.

Speaker 2: I agree, 100 percent.

Speaker 2 offered further thoughts on the unfair treatment she had experienced.

Speaker: They treat me like a 10-year old over there right now. Put me off in a little corner by myself...because I'm talking to make time go by faster.

Facilitator: So you're talking, I'm sorry [Speaker 2], go ahead, you're talking, and they put you in a corner because you are talking, or....

Speaker: Yeah. I'm still doing my job, but I'm talking, too. He knows; I talk to him when he's over there. I mean, times goes by quicker. I mean time drags if you ain't got nothing to do. I mean, If they'd let somebody listen to a little stereo or something. You know, headphones or something. And just make sure the volume's minimized. You know that time would go quicker, people would probably to do their work more but they don't understand that. Everybody gets treated the same.

Facilitator: So [Speaker 2] ...Are there things that staff say to you that you like?

Speaker: They treat me like a kid.

Facilitator: I'm sorry

Speaker: They treat us like kids...And you know, and that's just not right to me...they all treat you like you are a ten-year old unless you got favoritism.

A third member of this group described how a supporter treated one of the individuals in the workshop.

Speaker: "[Name] its time to go back to work". If she don't go right back to work, instead of giving her, just a warning, a second chance, they go out and clock her out immediately. Or, if she gets upset about something, it don't make no difference what, they treat her like she was a little two-year old baby.

Another speaker added information about this same person's support needs.

Speaker: You've got to treat her differently because she has an IQ of a ten, but you see, not two! Don't treat her like a two-year old, treat her like the IQ she's got, a ten to a twelve-year old.

Study participants who were not in a workshop, but were supported to pursued activities of interest at home and in the community, also talked about wanting to be treated as equal to others, while being given consideration for their support needs. When asked what he heard from people that he would rather hear differently, one person who uses a wheelchair described how he was treated in the community.

Speaker: I'm an adult now, and I still have to tell adults that I'm an adult because they still treat me like I'm a child. Even people on the train, even on the bus.

Facilitator: Do they say things to you that indicate that they feel you're not on their level or whatever?

Speaker: Yes, not only that, I can go to get on the bus, and they'll stand there and they'll stare, and then they'll go, "Nnnnn." Nnnnn, what? Say what you've got to say. I get on this bus just like you do. I just get on it in a different way. And you have to move and let me on. I mean I encounter this stuff every other day. Even bus drivers get attitudes with people with disabilities, because they don't want to pick us up on the buses. And this is on the regular bus. So I've experienced it on all ends.

Facilitator: Right and even though those individuals aren't your attendants or your overseers, they're paid to help you, to assist you, so I appreciate you mentioning that.

Another member of this same group provided her perspective on equality between individuals with and without disabilities and said people need to decide whether or not they want to help others.

Speaker: One thing I want to say is God brought us on this earth today. If it wasn't for God, nobody in the world would be here today. And he brought some of the people slow and some of the people can't read; he made us like that. And its not people, its Him. But we've gotta look at it like this: People will talk about us, I tell them, Hey, God brought me here, and he brought you here too, so you should help me or don't help me.

Another person who uses a wheelchair and receives supports to live in her own home and to be involved in the community stated her desire to be treated as being equal to others and as a grown person

Facilitator: What would they say that you'd want to hear?

Speaker: Say for instance, like, if I said I want, like [NAME] said, I don't have any relationships with a guy, but I used to, and I know people with disabilities are, we're grown people. I mean people need to realize we're grown people. We have the same feelings like they do.

Facilitator: Is there something that the supporter could say that would tell you that they see you as a grown person, [Speaker]?

Speaker: Yeah, I mean, not a lot, but yeah.

Facilitator: What would one thing be that you might hear from a supporter that would show you they are listening to you and they value you as a grown person?

Speaker: Just that they, you know, like me, and they like how I handle my life, and how I sometimes I would like to get up and dress myself. And I get real, like I said earlier; I get real frustrated, because I've been like this since a child, so that does bother me from time to time. Really I don't know how to handle it.

Study participants expressed the belief that they are equal to others and should be treated accordingly. Individuals with intellectual disabilities talked about wanting to be regarded as equal to supporters and to other individuals with and without disabilities, indicating the importance they place on aspects of personhood and values related to their worth as human beings. Emphasis on disability involved direct support professionals

applying rules and conditions to individuals with intellectual disabilities, without applying them to themselves, and extending rights and privileges to themselves, which they did not allow for individuals with disabilities.

Study participants talked about their experiences of being treated unfairly. They described situations in which direct support professionals arbitrarily treated individuals with disabilities differently who were behaving the same, and situations in which supporters did not respond to the differing needs of individuals. Such inequitable treatment creates distinctions between individuals and emphasizes disability. According to participants, many direct support professionals demonstrated little sense of the importance of equality or concern for the fair treatment of individuals. Across groups there was scant mention of direct supporter professionals drawing positive attention to similarities in the strengths or abilities of individuals with intellectual disabilities. In the absence of statements connoting similarity, the practice of arbitrarily treating individuals with disabilities differently involves a focus on their differences, which for this sample meant an emphasis on disability.

Study participants communicated the importance of being viewed from the perspective of their support needs and shown accommodations that fit their needs. Participants involved in workshops provided statements of the unfair treatment individuals with intellectual disabilities receive. For participants in this study, workshops appeared to be the primary setting where such fundamental rights are most consistently overlooked. This likely has to do with the workshop context being one of control; however, control was mentioned across groups. Participants involved in workshops gave accounts of unfair treatment mainly in terms of some individuals being regarded as less

and less able than others. Although individuals with intellectual disabilities in non-workshop setting also gave accounts of unfair treatment and the disregard of supporter for their abilities, participants who were involved in workshops appeared to experience more of this than participants who were not. Individuals with intellectual disabilities in workshops experience much that can be defined as unequal treatment, including being shown less attention than other individuals for the abilities their abilities.

CHAPTER FIVE

DISCUSSION

The purpose of this study was to obtain perspectives from individuals with intellectual disabilities on their communication with direct support professionals, specifically on the statements supporters direct toward them. In describing their communication with direct support professionals, participants emphasized the situations surrounding their interaction more than the specific statements of supporters. Discussions revolved around participants' descriptions of support situations and their attempts to obtain services relevant to their needs and circumstances. However, participants consistently recounted aspects of their conversations with supporters, so that the themes that emerged were infused with elements of supporter communication.

Statements from study participants offered ample evidence of the influence direct support professionals have on individuals with intellectual disabilities. Across the six focus groups, participants commented on their interactions with supporters and with other individuals with disabilities, showing that relationships are important to them. Participants expressed a variety of views of their interactions with supporters and the supports they receive. The study generated rich qualitative data and provided an initial orientation to the question of how direct support professionals talk to individuals they support. Few researchers have considered statements from individuals with intellectual disabilities regarding their communication with people who provide them disability-related supports (Booth & Booth, 1996; Cattermole et al., 1990; Jahoda et al., 1989; Murphy, 2006); however, extant research supports the themes that emerged in this study.

Presence of Control

Differences in the experiences of participants were related to aspects of control they experienced in their interactions with direct support professionals and contributed to the themes that emerged. Supporter control was variably expressed in focus groups, representing a primary difference between groups and resulting in the themes themselves having varying relevance. “Workshop-type control” represented an important orientation to support in some settings and an equally important difference between groups. The emergence of themes was affected by the degree to which individuals sensed their activities were controlled by supporters, and the meaning they gave to such control. The saliency of a theme for a group depended partly on whether or not members of the group viewed such control necessary for advancing their purposeful efforts and compatible with adult interaction. Differences in the saliency of themes were related to contrasts in the meanings participants gave to their experience of being controlled, which they expressed during the discussion. Contrasts between interactions in workshop and non-workshop settings provided the clearest evidence of this difference in meanings of control.

Control is a normative aspect of an employer-employee relationship and represents a real world experience for both (e.g., an employer giving instructions to an employee). However, individuals with intellectual disabilities described the workshop as an artificial setting from the perspective of their expressed interests and preferences. Study participants described the control of direct support professionals in workshops as arbitrary and disability-based (e.g., a direct support professional exercising control over the eating habits of a person with a disability). The essence of the distinction between

normative and artificial settings of control has to do with the effort to control not with the actual location in which control occurs.

Relevance of Themes

Themes that emerged reflected perspectives of individuals with disabilities on how they want others to treat them. The attention given by participants to their relationships with supporters is consistent with the notion that membership in society, not improvements in communication, is the real point of communication (Ferguson, 1994) and the idea that the communication individuals experience with supporters is vital to their experiences of social integration (Baker et al., 2000; Bradshaw & Carnaby, 2002; Butterfield & Arthur, 1995; Dennis, 2002). Each of the seven themes has implications for interpersonal interaction. Individuals talked about the benefit of courteous, respectful relationships and their desire to view supporters as friends, describing supporters who did not demonstrate these attributes, as well as mentioning supporters who did. Desire for friendships with supporters is consistent with findings of the preference individuals with intellectual disabilities have for social interaction rather than functional interaction (Markova et al., 1992), and for conversational topics rather than ones based on control or instruction (Kuder & Bryen, 1993). The many comments of participants concerning aspects of social interaction underscore the importance of relationships to them.

Participants' provided perspectives on how they want to be treated by supporters. Respect for feelings was a common idea and individuals described being able to sense when supporters cared about them. The theme *I Would Like Them to Respect Me* and the theme *You Got to Show Me That You Can be Trusted by the Way You Talk to Me*

represented the views of participants that supporters earn their trust by respecting their abilities and allowing them to control relationship boundaries.

Individuals described occasions when supporters would become too personal and assert themselves in areas of the person's life without requesting permission, or would ask personal questions that had nothing to do with the person's services. Examples of each are reflected in the theme *Some People Get Too Involved Into Your Life, Where You Don't Want Them*. In addition to this theme, the theme *Be Friends with Them When You Talk to Them...and Listening* points to the common desire of participants to have supporters in their lives who will listen to them and attempt to truly affect their situations for good. Several participants talked about positive experiences of getting close to supporters, noting that this occurred as the supporter listened to the person's troubles, emphasized the person's abilities and honored the person's privacy and personal space.

The need for balance between becoming truly involved in the life of a person with an intellectual disability and respecting boundaries is the same as in any relationship. Emphasis on control makes this relational endeavor as great a challenge in relationships between individuals without disabilities as it is in relationships that involve a person with an intellectual disability. The violations of boundaries described by participants, especially in workshop settings, involved supporters' attempting to control some aspect of the life of the person. Alternatively, participants described supporters who sincerely listened to them, providing a space for them to assume control of their situation.

Individuals in workshop programs, accounting for approximately 30% of participants, generally reported being capable of doing tasks they were presented, often in

ways that were more effective than they had been shown, by devising approaches that accommodated their disabilities. However, participants from workshops talked about supporters treating them as less capable than themselves and not expressing belief in their abilities, but instead attempting to control them. Participants said supporters show true interest in them, beyond just doing a job, by highlighting the person's abilities and by not insisting the person do things exactly the way the supporter does.

Participants want supporters to offer guidance and show interest in them as persons, and in what they are doing or would like to do, not limiting their involvement to simply controlling them (Cattermole et al., 1990; Jingree et al., 2006). Person-centered approaches have long been associated with less controlling speech by supporters and greater conversational interchange (Pratt et al., 1976). However, direct support professionals generally tend to be controlling of individuals with disabilities (Bannerman et al., 1990) and do little to promote conversation about the person's choices and preferences (Wareing & Newell, 2002). These findings were supported in the current study by the many comments of participants regarding the lack of courtesy and respect, trust, and boundary control they experienced in their relationships with supporters.

The theme *We're Grown People, We Have the Same Feelings Like They Do* was informed by numerous statements across groups describing participants' desire to be treated with equality and supported according to their actual needs, not according to the views others have of what they cannot do or how they are different. In describing encounters with supporters and their experiences within disability service programs, study participants expressed awareness of differences in how they are treated and how they would like to be treated. Statements across groups showed participants' awareness of

their situations and their clarity regarding services they desire. In general, participants expressed uncertainty over whether supporters truly understood their needs and were interested or willing to offer them support relevant to their situations. However, in every group participants were unanimous about certain supporters whom they believed were truly interested in their best and went out of their way to help.

Participants described how supporters generally limited their choices and treated them like children, although some mentioned being told they had made good decisions or had performed well on a task. Limitation of choice or childlike treatment by a supporter may suggest to a person with an intellectual disability that he lacks the necessary priorities to exercise choice and self-direction. Participants rarely talked about supporters emphasizing the equality of individuals or positive aspects of their similarity to others; however, without exception, within each group most participants mentioned at least one supporter who exemplified kindness and respect in her interactions with them.

According to participants, supporters pursued actions related to supporting them that made little sense, while offering no explanation for their behavior. This lack of connection between a person's concept of what should happen and what actually occurs was most often discussed with respect to individuals not being supported to access services they needed and desired, not being able comment on whether services were useful or relevant, and not being able to affect their situation. Statements of dissatisfaction with services were accompanied by questions of the relevance of supports for advancing the desires and interests of participants. Statements of individuals were characterized by the absence of a space from which to affect, or even comment upon, decisions regarding their ongoing support, regardless of how dissatisfied the person was.

Supporters generally were described as the source of the person's experience of disconnection from the desired supports. Individuals provided numerous examples of words and actions of direct support professionals that pointed to their inability to advance situations that were more relevant to the person being supported.

Statements and actions of supporters that indicate they are not able to advance the support needs of a person with an intellectual disability may convey the message that the person is different and less than an individual without a disability. The likelihood of this is supported by findings of mismatches between supporter estimations of the communication competence of a person with a disability and the actual skills of the person (Banat et al., 2002), which highlight assumptions of difference. Emphasis of supporters on the ways individuals with intellectual disabilities are different from them may further the sense of inequality between them.

Points of Discovery

The primary learning that occurred for the researcher over the course of this study involved him shifting his role of facilitating the discussion groups from that of a professional to that of a prompter of interaction between study participants. The researcher initially approached the role of facilitator as a "professional" with the objective of obtaining the perspectives from individuals with intellectual disabilities on the words and statements supporters used with them. This stance approximated the functional approach of direct support professionals whose perspectives have defined the literature on communication with individuals with intellectual disabilities. Individuals with disabilities have shown a preference for social interactions rather than ones that are functional (Markova et al., 1992), and for conversational topics rather than ones based on

control or instruction (Kuder & Bryen, 1993). Despite the desire of the researcher to elicit perspectives of individuals with intellectual disabilities, his initial stance as a professional limited the voices of individuals he sought to represent. Although participants in the first two focus groups expressed their views, their voices were constrained by the researcher's construction of what the discussion should look like.

Data obtained from the first two groups showed the researcher the need to modify his questions and adopt a stance that was based less on the role of a professional needing to obtain data for analysis. The highly interactive quality of the third group awakened the researcher to the realization that he was being affected as much by the discussion members as he had believed he was affecting them. The importance of the difference in the researcher's stance became clear in Groups 4, 5 and 6, during which the researcher focused less on attempting to get the right answers to questions and more on advancing relationships between participants and the process of interaction. The casual nature of the discussions in Groups 4, 5, and 6 provided participants the opportunity for more social interaction than had been the case in the first two groups. The researcher's discovery of adopting the role of a professional will be important in training and guiding others to approach interaction in ways that clearly advance the perspectives of individuals with intellectual disabilities.

Implications for Future Practice

Statements of individuals with intellectual disabilities call for consideration of practices that will improve the ways direct support professionals interact with them. Themes arising from the data can contribute to the development of materials for training direct support professionals working in disability service programs. Many of the

comments provided by participants can be viewed as requests for supporters to treat them differently, pointing to modifications on the level of the practices of supporters working within individual agencies and involving minimal training.

Training on the level of direct support professionals could be based on the concept of the “ability-promoting” quality of their relationships with individuals with intellectual disabilities. The incorporation of practices based on characteristics of respect and equality would sharpen our understanding of communication issues facing supporters and individuals with intellectual disabilities, allowing for the expansion of practices that take into account the needs and preferences of both. Features of such trainings could include supporters listening to individuals with intellectual disabilities and practicing pragmatic approaches for communicating with them, providing a frame of reference for expanding person-centered approaches to other contexts (e.g., job coaching). Discussions would center on approaches for treating individuals with intellectual disabilities with equality and interacting with them in ways that are respectful and relevant.

Trainings would enhance supporters' awareness of the expectations individuals with intellectual disabilities have for interacting with them, equipping supporters to interact more in keeping with these expectations. Through training, it is reasonable to expect orientations of direct support professionals can be modified. Modifications would involve supporters recognizing their ability to communicate respectfully with individuals with disabilities, and provide them ideas for interacting personally and with spontaneity, in ways that more closely resemble typical conversation and social interaction.

Many of the requests of study participants could be addressed through training at the level of the supporter working in a specific disability services program. However,

comments of participants also highlight the complexities of disability service contexts. Disability service agencies represent complex cultures, and the work of direct support professionals involves difficult decisions. Direct support professionals occupy a tenuous middle position between the service agency and individuals with disabilities. Supporters must remain accountable to the agency that employs them, while promoting the needs and preferences of individuals with disabilities who are, in truth, their real employers. In this middle position, direct support professionals frequently encounter competing issues between the priorities of the agency and the pragmatics of supporting the person. Generally, the priorities of the agency are privileged, while envisioned supports are not pursued (e.g., supporters might say: “We would do this if we had more staff an extra vehicle or, simply, more time and money”). The reasons supporters tend to gravitate toward the priorities of their employer are not simple, and the larger structures of disability services that underlie and promote this tendency are complex and multifaceted.

Although no less consequential in affecting the wellbeing of individuals with disabilities, practices on the level of the larger system do not “respond” to modifications in the orientation of individual supporters. Aspects of the larger disability service system involve a contextual milieu calling for changes, which, no amount of training is likely to advance. Certainly, such larger issues cannot be altered through trainings on the level of direct support professionals. However, in addition to proposing training appropriate for supporters, it is worthwhile to consider the implications that the voices of individuals with intellectual disabilities have on the larger system.

Factors maintaining the level of the larger system represent an ethos of disability services, which is of a different order than the disability service agency and its

employees, involving dynamics such as Medicaid policy and compliance, changes in service criteria and the utilization of funds. The larger disability services system includes policy makers and others who want the voices of individuals with disabilities to be heard and desire appropriate changes be made. All seven themes contain information useful to representatives of the larger disability services system. Each theme has relevance to the consideration of how Medicaid services are envisioned and waiver funds dispersed and utilized. Each theme was grounded in comments of individuals who want to lead a regular life, to make true choices in real situations, and to be supported in ways that are understandable to them. These desires are based on principles of self-determination (Wehmeyer & Metzler; 1995).

Many individuals who develop policies involving disability services recognize the value of choice and self-determination for individuals with intellectual disabilities and are committed to finding ways to allow individuals to choose how their money will be spent for services. Flexibility in the utilization of funds must involve the person with a disability, or someone acting in the person's behalf, directing how his or her money is used. Within this framework, disability service agencies can offer choices and implement ability-based, relational approaches to support.

Future Directions

Information gained through this study would be useful in future research on communication between providers and recipients of disability services. Despite a growing body of research representing views of individuals with disabilities, there is a relative shortage of perspectives from individuals with intellectual disabilities, especially on issues of communication. Given the ease with which data were obtained in this study

and the saliency of the themes derived, future research aimed at gathering perspectives from individuals with intellectual disabilities is warranted. A clear approach to such research would involve the use of focus groups.

Future focus group methods might involve more narrowly specifying the residential and day activity settings of the individuals involved, which serve as the orientation for their perspectives. In this study, the primary orientation to support involved participants interacting with direct support professionals in disability service programs; however, orientations provided by the context of the family and the employment setting also were represented. In the six groups comprising this study, the most common living arrangement involved individuals living with family members, without agency support.

In future research, the orientation provided by one's experiences within the family context might be specified and explored. This orientation would involve support being interpreted partly as the praises, reprimands and encouragements one receives from a parent, or other family member, eliciting views of individuals with intellectual disabilities on aspects of communication within the family context. A second orientation that might be explored involves perspectives of individuals who are in competitive employment, or who are being supported actively in to pursue such, in which support would be considered in terms of an employer, job coach, rehabilitation counselor, etc. Perspectives of individuals with intellectual disabilities of the communication they experience in employment settings and in family-based contexts would be valuable to compare to perspectives gained through this research.

Future research might include eliciting the views of individuals with disabilities in areas of interest in addition to support or communication. Possible directions might include eliciting the voices of individuals specific to friendship and recreational interests and preferences. Additionally, individuals with intellectual disabilities could provide information on where they actually spend their time during the day and what they do. Finally, individuals with intellectual disabilities could provide perspectives on health and their efforts to care for themselves. The pursuit of individuals' perspectives regarding health and medical concerns is clearly important to their wellbeing.

Future research could involve examining the perspectives of direct support professionals on their communication with individuals with intellectual disabilities. Focus group procedures and other methods could be used to gain perspectives from supporters and their supervisors on the communication they have with the individuals they support. Data from such studies could be combined with the focus group data presented in this study, contributing to the development of constructs useful in the validation of a coding system for evaluating communication between these two groups.

Limitations

The procedure for this study involved using a question script that was prepared without specific information regarding the participants' residential and day support situations. The researcher did not take into account the saliency of family and employment orientations, which were central to some participants' views of support and definitions of supporters. The researcher did not know details of participants' support situations and orientations prior to the group discussions, and did not believe there was

adequate time to gather this information during discussions. This lack of awareness of support circumstances and the orientations of participants proved a limitation.

Although, the various support circumstances and differing orientations to support added to the richness of the data, the researcher's lack of advance knowledge of some of these support conditions affected the preciseness of the questions participants were asked and may have limited discussion. Information related to participants' support situations would have been useful in establishing the direction of the discussion and offering participants a common frame of reference, at various points throughout. Awareness of these issues would have allowed the researcher to ask questions, from the outset, that were more inclusive of participants, providing a basis for more specific questions as the discussion progressed. This information potentially would have been valuable in the researcher's efforts to promote increased interaction between participants.

In addition to having a less than complete appreciation for differences in support situations and orientations, the researcher's lack of understanding of the different group cultures and contexts may have limited the discussions. Differences in group culture existed independently of how groups were facilitated (e.g., Group 3 was defined by members' consistent mention of themselves as adults with adult issues, with seldom reference to issues of parent-child interaction, while issues related to parent-child interaction were central to Groups 2 and 4). Such differences contributed to each member's understanding of the purpose for being involved in the discussion and would have been useful for the researcher to know. Although not a serious limitation, the researcher's lack of awareness of group culture and context may have reduced his sensitivity to the participants' views of the focus group and their involvement in it,

influencing their understanding of what they were being asked to provide. Finally, a limitation involved the time allotted for discussion of the topics of concern to participants. Although all comments of participants were given attention, the ideas they provided could have been more thoroughly explored, if there had been more time.

Conclusions

There were limitations in this study; however, these did not limit the richness of the comments provided by participants. Few criteria were placed on the ideas to be discussed, and participants appeared to express themselves freely and to enjoy the experience of doing so. Participants in the study gladly offered information regarding their communication with direct support professionals and demonstrated concern that what they said was fair and balanced. Although individuals with intellectual disabilities are often in situations where they feel hindered to express their concerns and preferences they clearly know what these are. They want to let others know what they are experiencing and their beliefs regarding how their situations could be different. Individuals with intellectual disabilities are able to tell others what they want and need and do so effectively when they are with those they believe are concerned about them.

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