Exploring Client Participation in the Individual Planning Process

By

KELLY KOOMLER
B.S., Western Kentucky University, 2000

THESIS
Submitted as partial fulfillment of the requirements for the degree of Master of Science in Disability and Human Development in the Graduate College of the University of Illinois at Chicago, 2013

Chicago, Illinois

Defense Committee:

Glenn Fujiura, Chair and Advisor
Tamar Heller
Mary Kay Rizzolo
This thesis is dedicated to Stephen James Dowling. Your love is a presence every day.
ACKNOWLEDGEMENTS

I would like to thank my thesis committee, Glenn Fujiura, Tamar Heller, and Mary Kay Rizzolo, for their support to see me through the process. They not only provided me an education and guidance but are responsible for shaping the work I do on a daily basis that affects the lives of many.

I would also like to express my undying gratitude to my family and friends for their support, encouragement, and love. Without them I never would have made it this far.

Eric M., you are my inspiration every day to great things.
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FAMILY ATTENDANCE AT IP MEETINGS
LIST OF ABBREVIATIONS

CDDS  Center for Developmental Disability Studies
DSM   Diagnostic and Statistical Manual of Mental Disorders
DSP   Direct Support Professionals
ICAP  Inventory for Client and Agency Planning
ID    Intellectual Disability
IDEA  Individuals with Disabilities Education Act
IP    Individual Planning
IPP   Individual Program Planning
IPPPC Individual Programme Planning Participation Checklist
MR    Mental Retardation
PCP   Person-Centered Planning
PDDCACB Persons with Developmental Disabilities Central Alberta Community Board
PI    Principal Investigator
QOL   Quality of Life
SUMMARY

This study explored the participation of 25 adults with intellectual disabilities (ID) in their individual planning meetings. The study looked at the degree to which clients participated in their individual planning meeting, their understanding of the basic purpose of the meeting, and their feelings regarding the meeting and their role in it. Client participation during each meeting was recorded with an adaptation of the Individual Programme Planning Checklist, created by Alexander and Hegarty (2001). On average, subjects participated 68 times per planning meeting and lower participation was observed when subjects had a greater degree of impairment. Higher rates of participation were also seen when subjects had prepared before their meeting. The rates of participation were highest when providing information or joining in group discussion and lowest was observed in making choices at the meeting. Qualitative data were gathered through structured interviews with each subject. Approximately half of the subjects interviewed stated that the meeting was for them to choose goals to work on over the next year with 69% remembering at least one goal. The data gathered represents a small snapshot of client participation specifically during their planning meeting.
I. INTRODUCTION

This study is an exploration of the participation of clients with intellectual disabilities (ID) in their individual planning meetings. The study considers the degree to which they participate in their individual planning meeting, their understanding of the basic purpose of the meeting, and their feelings regarding the meeting and their role in it.

There has been a great deal of literature developed in the area of individual planning with respect to how to support individuals to be self-determined. Self-determination in service planning typically includes individuals identifying hopes and dreams for their life, the goals they wish to work towards to meet those dreams, and what supports they need in order to be successful. The model of service planning for individuals with ID has been shifting away from 'professionals' having the control towards the individual identifying their own wants and needs are rather than being told what should be important to them. Research in this area is expanding as well, focusing on issues of program planning, self-determination, and the human rights of individuals with ID and their right to have control of the services which they receive. Despite progress, gaps remain in support services that individuals with ID currently receive. The gold star standard remains person-centered planning (PCP). Current individual program planning practice demonstrates a lack of consistency in providing individualized services to people with ID and control over programming and other important decisions which still largely remains in the hands of service providers.

This study explores one facet of program planning practice -- client participation in the individual planning process. The process was evaluated through observation of
individual planning meetings where data were gathered on client level of participation, how much participation occurred and whether that participation was independent or prompted. In addition, participation was compared across topics discussed during the planning meeting. Interviews were conducted with clients to determine their understanding of the purpose of the meeting, their perceived role, and control in the process.

This study gathered information from both small community based residential providers as well as large, single site providers. Though relatively low rates of participation were noted for all of the subjects, participation rates were higher when the subject had a higher IQ and when more people attended the meeting. The majority of subjects identified that the meeting took place for them, were able to state at least one goal they were going to work towards, and stated that they chose their own goals. The majority of subjects also reported being generally happy with their meeting.

The results of this study provide a snapshot of what individual planning looks like in a small sample of service providers in northeast Illinois and establishes a basis for further exploration of self determined planning issues. Additional research is recommended for determining how best to create not only a planning meeting that is truly person centered, but the daily programming which is driven by the planning meeting itself.
II. LITERATURE REVIEW

A. Background

Individualized person-centered program planning now dominates the rhetoric associated with both the design and delivery of residential, vocational, educational, and recreational supports for adults with intellectual disabilities (ID) (Robertson et al., 2007). In fact, person-centered planning (PCP) has become a required practice in England and in many US states (Robertson et al., 2007). The rise of PCP has a significant history of development spanning more than 150 years, beginning with state schools and institutions for individuals with ID in the 19th century, through the self-advocacy movement of the 70’s and 80’s, to the rapidly changing practice of fully involving people with ID in making the decisions about the types of support they receive.

1. The traditional service planning model

The following sections briefly trace the historical transition from the traditional service planning model of support for individuals with ID where professionals were the ultimate authority to the most currently used, person-centered approach, with focus remaining on the participation of the client receiving services.

a. A brief history of intellectual disability services and supports

In 1848 the first American institution opened its doors in Boston, Massachusetts. The prevailing belief regarding service delivery at the time was that people with disabilities could be taught more effectively if they were separated from society (Pennell, 2001). Similar institutions opened across the country for the professed benefit of both individuals with disabilities as well as the communities they would be returned to. It was the intention of these establishments to educate and provide
vocational training to disabled individuals so they may be returned to society and be contributing members of their communities (Braddock & Parish, 2001; Pelka, 1997). After some initial success, enrollment increased rapidly until the populations of these institutions became unmanageable and conditions quickly deteriorated (Braddock & Parish, 2001). With too many residents and not enough staff, education and training became scarce if available at all, and individuals who were sent there were subject to abusive treatment and neglect with little hope for discharge (Pelka, 1997).

From 1848 through the mid 1900’s, perspectives on institutions changed from places which sought to protect the residents from society to the protection of society from individuals with ID (Ippoliti, Peppey, & Depoy, 1994). Residents of these institutions were largely seen as less than human and had little voice in their care and treatment (Wolfensberger, 1972). Families lacked influence in decisions as well. No longer were parents encouraged to institutionalize their children to learn skills and be returned to them, but were pressured to institutionalize them into a custodial care setting (Ferguson, 2001).

Throughout the 1960’s “custodial care, depersonalization, block treatment and rigidity of routine were the norm. ... There was no expectation of change and therefore no need to plan anything” (Mansell & Beadle-Brown, 2004, p. 3).

The concept of normalization began in Denmark in the late 1950’s and was introduced to Americans in 1969 by Niels Erk Bank-Mikkelsen and Bengt Nirje at a conference sponsored by the President’s Committee on Mental Retardation (Wolfensberger, 1972). The normalization concept provided the conceptual framework for deinstitutionalization and exposed “institutions as facilities that strip individuals of
their humanity and connection with society” (Pennell, 2001, p. 223). The normalization principle as described by Nirje (1969, 1972) argues that individuals with ID should live with the same patterns and conditions found in the typical mainstream lives of individuals without ID. This includes efforts to ‘normalize’ all aspects of the individual’s life from residential settings and vocational placements to leisure and recreational opportunities. Nirje (1969) also introduced that individual’s wishes and desires should be taken into account in these decisions. This was the first time that the individual with ID was identified as part of the program planning team.

Initially the concept of normalization was met with skepticism and largely rejected (Pelka, 1997). In 1972 Wolf Wolfensberger published *The Principle of Normalization in Human Services*, expanding the theory of normalization (Pelka, 1997). Here Wolfensberger (1972) characterized normalization as providing a person with ID a typical life experience which requires total integration, both socially and physically. This approach was employed to directly counter the fact that individuals with disabilities had traditionally been allowed only marginal roles in society which led to their being devalued as individuals (Persons with Developmental Disabilities Central Alberta Community Board [PDDCAB], 2001). Nirje (1972) believed that the extremely important concept of individuality was created through a person’s experiences with others.

Additional attention to issues of institutionalization was stimulated through federal involvement in the 1971 *Wyatt v. Stickney* ruling by the U.S. District Court for the Middle District of Alabama which established the constitutional right of individuals living in residential state schools and institutions “to receive such individual habilitation as will
give each of them a realistic opportunity to lead a more useful and meaningful life and return to society” (Bannerman, Sheldon, Sherman, & Harchick, 1990, p. 79). Individuals with disabilities could no longer simply be locked away without treatment or education (Pelka, 1997). However, the ruling did not automatically give the disabled individuals or their families a voice in the kind of treatment or education they would receive or what the desired outcome of treatment would be, only setting minimum standards for treatment (Bannerman et al., 1990). In fact later, in the 1983 Supreme Court case Youngberg v. Romeo, the court ruled in favor of establishing a standard of care which “guaranteed only as much habilitation as needed to ensure freedom from undue restraint” (Bannerman et al., 1990, p. 79).

During this hundred year span, it was the biomedical model of disability which dominated, presenting people as patients to be cured and created distance between the roles of professional expert and client. Many critics of the biomedical model assert that the perspective perpetuated the dynamic patriarchal power structure in which ‘experts’ or ‘professionals’ indisputably knew what was best for their ‘patients’ (Clare & Cox, 2003). Therefore, the goals, supports, and programs of individual clients were planned in full by professionals.

b. **Program planning: Background and characteristics**

The historical service planning model of deciding how and what kind of support to give people with ID involved professionals participating in ‘case conferences’ which included reviewing a client’s history, agency records, and assessments. Professionals commonly included speech, occupational, and physical therapists as well as psychologists, psychiatrists, social workers, and vocational
specialists creating an interdisciplinary team (PDDCACB, 2001). Clients and their families were typically not a part of this process and their ability to provide input was minimal. Case histories contained information that would be useful to professionals, such as IQ and medical diagnosis. Such information allowed professionals to place people into categories which determined treatment and aided prognosis. Planning would begin through an assessment which was used to “uncover what a person needs, and what their problems or disabilities are” (PDDCACB, 2001, p. 4). It would have been acceptable at this time for any individual to receive the same services as another person with the same diagnosis on the assumption that needs were defined by the label. Residential decisions were often based on the preferences of parents, guardians, staff, or current openings at a home (Faw, Davis, & Peck, 1996). Service providers are able to minimize options in life choices for individuals with ID in ways not otherwise tolerated for the rest of our society. Individuals without disabilities are not only given housing options of institutions or group homes; nor can they be restricted to work in a setting with other people who all share some physical or mental attribute, or legally work for less than minimum wage (Hagner & Marrone, 1995). Even in the smaller, daily life decisions, clients often feel as if they have little opportunity to exert control. Because staff continue to believe that individuals with ID lack the ability to convey their wishes and make decisions about issues affecting their lives, clients continue to be given only minor roles and are often completely removed from the planning process (Clare & Cox, 2003; Crocker, 1990).

Proponents of individualized planning have criticized traditional program planning methods as providing a limited or non-existent role for the client, family, and friends, and
as being deficit-based (Center for Developmental Disability Studies [CDDS], 2004; Greasley, 1995; Shaddock & Bramston, 1991; Stancliffe, Hayden, & Lakin, 1999). In the pursuit of effective habilitation, service providers, as the experts in the field, chose goals, residential and day treatment settings, and made choices for their clients not necessarily based on what the client wanted but what the provider already offered (Bannerman et al., 1990; Carnaby, 1997; Wright & Moffat, 1992).

Individuals with ID have historically been left out of their program planning for a variety of reasons including that it was believed that individuals with ID simply were not capable of making choices or being self-determined. Their input would not be sought by the treatment team as it was only the ‘professionals’ who had knowledge about what the disabled client needed.

2. **The rise of individual planning**

The disability rights movement followed in the footsteps of the civil rights movement and similarly sought equal access, opportunity, consideration and respect for those born with disabilities. Though the beginnings of advocacy for disability rights has long historical roots reaching back more than a century, the emergence of the disability rights movement is linked to key events beginning in the 1970’s with the opening of the Berkeley Center for Independent Living and the Boston Self-Help Center. It was with the help of activists of this time that legislation such as the Rehabilitation Act of 1973 began sweeping change for disability rights (Charlton, 2000). The emergence of the disability rights and self-advocacy movements in the 1970’s was a critical key in improving the supports that service providers offered and the roles that individuals with ID took in the process of their own program planning.
a. **Self-advocacy movement**

Pennell (2001) identifies self-advocacy as knowing your “rights and responsibilities, to stand up for them, and to make choices about your own life” (p. 223). The self-advocacy movement fought for the belief that everyone is able to determine their desires and the support they wish to have to realize their dreams and have control over their own life regardless of the severity of disability (Joyce & Shuttleworth, 2001; Pennell, 2001).

In 1974, People First developed and became the largest U.S. organization composed of and led by people with intellectual disabilities (Pelka, 1997). People First fought for recognition of personhood and their right to be self-determined. People First has lobbied and advocated for improved living and working conditions, elimination of the word “retarded,” and successfully lobbied the Association for Retarded Citizens to change its title to ARC (Pelka, 1997). The group has been highly influential in all areas of support services for individuals with ID including work which resulted in a change of role for professionals. Service providers began as the decision makers of support services and as the movement has progressed, in large part to organizations like People First, the role of professional has changed to advisor, encouraging the client to make the “right decision”, and ultimately then to the role of consultant. In this role of consultant, professionals are no longer the decision maker but are simply providing education, training, and assistance so an informed decision can be made by the individual (Pennell, 2001).
b. **Self-determination**

It is through the normalization, independent living, and disability rights movements of the 1960’s and 1970’s and the self-advocacy/self-help movement of the 1980’s that self-determination developed (Wehmeyer & Schwartz, 1998). By the 1990’s self-determination emerged by integrating ideas about self-advocacy into a single philosophy which focused on shifting power away from service providers and placing it with the individuals with disabilities (Pennell, 2001).

Wehmeyer (1998) identifies self-determination as “determination of one’s own fate or course of action without compulsion or exercising control or rule over oneself” (p. 5). Self-determination is based on four principles: freedom, authority, support, and responsibility. These principles communicate the importance of individuals being free to choose a life plan with necessary supports, to control funds to purchase their own supports, to arrange resources and support to assist with daily living, and to be a valued member of a community (Pennell, 2001). For people with ID, the self-advocacy movement has been a significant driving force toward self-determination. Wehmeyer and Schwartz (1998) identified self-determination as referring to “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (p. 4). In order to be self-determined in this framework, Wehmeyer and Schwartz (1998) say that an individual must act autonomously, be self-regulated, initiate and respond to events in a psychologically empowered manner, and act in a self-realizing manner.

For most people without disabilities, self-determination is taken for granted, for individuals with ID, however, opportunities to make choices about their lives are often
extremely limited. Individuals’ quality of life (QOL) is directly related to the degree to which individuals are allowed to express preferences and exercise choice (Faw et al., 1996).

c. **Individual program planning**

The Principle of Normalization, legislation like *Wyatt v. Stickney*, the self-advocacy movement, and the efforts of President Kennedy and his special President’s Panel on Mental Retardation were all key in the development of Individual Program Planning (IPP). The development of individualized planning is the result of efforts by advocates and allies to change the attitudes and opinions regarding the value and capabilities of individuals with ID. The foundation of Individual Program Planning (IPP) can be attributed to several influential US public laws primarily in the areas of special education and rehabilitation services. These laws include The Education for All Handicapped Children Act of 1975 (PL 94-142), now known as the Individuals with Disabilities Education Act (IDEA) which established Individualized Education Plans and was last reauthorized in 2004; the Rehabilitation Act of 1973 (PL 93-112) which mandated Individualized Written Rehabilitation Plans; and the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (PL 94-103) which called for Individual Treatment Plans (Shaddock & Bramston, 1991). The 1970’s saw widespread implementation of individual program planning based on these laws and the idea that individuals with ID had the right to be involved in decisions about their own lives (Carnaby, 1997).

Individual Program Planning goes by a variety of names including Individual Habilitation Plans, Individual Service Plans, and Individual Treatment Plans, though
they all serve the same purpose. The term ‘Individual Planning’ or ‘Individualized Planning’ will be used in this study.

While service providers employ varying practices for conducting their IPP meetings, there are general guidelines typically followed, most important among these is that the plan be individualized by taking into consideration the individual’s wants and needs (Alexander & Hegarty, 2001). IPP can be found across diverse service settings but is the method largely utilized in residential facilities for individuals with ID (Stancliffe et al., 1999). Similar to traditional service planning, IPP’s are driven by a multidisciplinary team process which includes key individuals in a client’s life including professionals, family members, advocates, and now, the client is included, who work together to design a program of services which are meaningful and beneficial to the client (Greasley, 1995). Alexander and Hegarty (2001) identify the participation of the client as crucial for the success of individual program planning and there are now requirements for clients to be participants in their program planning as a way to help ensure quality and meaningful services (Joyce & Shuttleworth, 2001). Individual planning creates an environment where clients are placed in the center of the process where service providers have to address the individual preferences and qualities of each person and tailor services around individual needs. Beyond the obvious benefit of receiving individualized services, individual planning is also more likely to include the additional benefit of increased family and support staff involvement instead of being a strictly professionally driven process (Shaddock & Bramston, 1991).

Individual program planning is a four-stage process which consists of information gathering, decision making, implementation, and review (CDDS, 2004). A well written
IPP will include in its assessment or information gathering phase, information about a client's background, communication style, preferences, social relationships, likes and dislikes, hopes and dreams, and current and future desired living arrangements (CDDS, 2004; Greasley, 1995). The plan would also include formal goals identifying things which a client wishes to achieve and the supports which will be needed to achieve those goals. The individual program plan also includes objectives which are to be measured over a shorter time frame that help the client meet his or her goals. The three critical elements of objectives are that they must be written in measurable and observable terms, include the conditions under which the objective or task will occur (who, what, where, when), and a standard or criterion for success (Shaddock & Bramston, 1991).

d. **Person-centered planning**

In recent years Person-centered planning (PCP) has become not just a new technique of individual planning built off of IPP, but a new way of thinking about support planning for individuals with ID. Person-centered planning is a process in which creative solutions are made to deliver individualized services, ideally focused on the desires of individuals with ID (CDDS, 2004; Taylor, 2007).

Unlike IPP, PCP is whole life planning, not deficit driven, but like IPP is guided by the person with the disability rather than the service provider. Individual, person-centered planning extends the logic of focusing services on the unique needs of each client and giving decision making authority to the client (Greasley, 1995).

Agencies across the country have begun adopting person-centered planning in which person-centered outcomes focus on establishing a long-range vision for the individual's life course (Certo et al., 1997; Clare & Cox, 2003; Hulgin, 2004).
Both IPP’s and PCP’s are individualized. PCP, however, has three additional components and a change in philosophy. First, PCP considers the aspirations of the person with disabilities instead of their deficits (Mansell & Beadle-Brown, 2004). Goals are created by the individual. Second, PCP requires the participation of the “family and a wider social network” which is referred to as a circle of support (Mansell & Beadle-Brown, 2004, p. 1). These are the people willing to support the individual in achieving his or her life’s vision (Heller, Factor, Sterns, & Sutton, 1996). Third, PCP identifies the support necessary for the achievement of goals. For example, if the goal was to obtain employment, supports may include support to develop job readiness skills necessary for the type of desired work, building connections with the relevant employment community, obtaining a job coach, and practicing interviewing skills. Identification of supports recognizes that no one is completely independent and one must be taught and supported in being interdependent. These three additional components make PCP decidedly different from individual program planning.

O’Brien and Mount (1989) provided a telling example of the significant effect a social network has on the creation of a PCP though the story of one man told by two different groups. The first group was his interdisciplinary team, which did not include him, who used data from his psychological, social work, nursing, speech therapy, and occupational therapy assessments to tell a story about him and create a plan. The result was a “story in compliance with state regulations in order to control the routine work of direct service staff. Their story justifies [the man’s] eligibility for the program and the program’s responses to his problem behaviors. It takes existing service arrangements as a given” (O’Brien & Mount, 1989, p. 4). The story was predominately
needs based, creating a negative image of him and took the position that he would be the same no matter what placement he was put in. The second story told of the same man looked quite different. Though it is the same man, it was written by people who cared about him and had a vested interest in his well-being and who included him in the process. The result was a story written by people in his social circle that “assumes capacity, interest, and preference” (O’Brien & Mount, 1989, p. 7) as well as his likes and desires. The differences in language and the final outcome were astounding. Based on their assessment, his interdisciplinary team was ready to refer him to the state hospital for admittance. At the completion of the report by himself and his support circle, it was decided that there was no justification for such a move and three years later, the individual continued to work in the setting his support circle helped establish and was a happier, more accepted member of his community.

Person-centered planning has been the object of considerable research and most of the evaluations have been positive. A longitudinal study by Robertson et al. (2007) was the first to look at what factors produce successful PCP. This study began by providing extensive training for managers and facilitators at several agencies that were dedicated to implementing PCP. Data collection took place for each of the 93 subjects over a period averaging 1.5 years and resulted in developing and maintaining PCP’s for 65 (70%) of the participating subjects. Robertson et al. (2007) found PCP effective in improving lifestyle-related outcomes and saw many positive changes in areas such as social networks, contact with family and friends, community-based activities, scheduled day activities, and choice. Individuals not receiving PCP had very little change in their lives. Based in part on previous research showing that individuals with ID lacked
information and voice in later life options, Heller et al. (1996) set out to test a person-centered later life training program for adults with ID to increase knowledge of later life planning issues as well as increase individual empowerment skills and choice in decisions affecting the participant’s life. The study used a comparison and intervention group, observing subject’s service planning meetings one year after the training program. The training intervention provided information about available options for later life planning and participants learned about recreational and leisure activities. The outcome was that there was “greater participation of family members in the planning meeting, more encouragement by staff of the individual’s participation, and greater incorporation of the individual’s preferences in the written service plan goals” (Heller et al., 1996, p. 82).

Through the development and use of such training programs, dedication to the practice of PCP, and respect of the individual central to the planning, PCP has the potential to produce positive long-term changes in the quality of life of individuals with ID (Kincaid & Fox, 2002). Not only does the individual benefit directly from the planning process and resulting empowerment, support professionals perceptions of the capabilities of individuals they serve improve, helping to create a cyclical effect. As Wolfensberger (1972) wrote so many years earlier, as individuals are provided more valued roles, they become more valued as individuals.
B. **The Individual in the Individual Planning Process**

Without active client participation there is a danger of IP meetings replicating the reviews or case conferences of the past (Carnaby, 1997). The commitment of professionals is an important factor in ensuring that individual planning does not become simply just another meeting to plan goals which are not individualized and are repeatedly used for the majority of individuals in a single agency, and do not address individual needs. The importance of including the individual in the planning process can be broken down into three categories: (1) control and quality of life, (2) successful outcomes, and (3) respect.

People who have more control over their lives are generally happier than those that do not and it is well documented that presently, individuals with intellectual disabilities are generally given very little control (Cullen, 1999). Individuals with ID continue to express the desire to have more control and choice in their lives and generally, as a group, they have limited self-determination and opportunities to make choices and decisions regarding their lives (Wehmeyer & Schwartz, 1998). MacEachen and Munby (1996) found from listening to residents of group homes that the number one concern was lack of personal control. Despite the aim of community placements to provide residents with a "normal" lifestyle, group homes, though they may be smaller than institutional settings and have different goals, they are in a manner very similar to institutions lacking opportunity for autonomy and self-determination (Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012; MacEachen & Munby, 1996). Residents in the MacEachen and Munby (1996) study thought it was more important to have control over their own lives than independence or integration.
Having choice and the ability to be self-determined is a factor in improving quality of life (Smyth & Bell, 2006; Stancliffe et al., 1999). Lachapelle et al. (2005) identified a direct link between self-determination and quality of life in their international study. "Quality of life is a complex construct which… can be viewed from multiple perspectives and operationalized in many ways, and which has gained increasing importance as a principle in human services" (Wehmeyer & Schwartz, 1998, p. 4). The eight components of quality of life as suggested by Shalock (1996) include emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.

Bannerman et al. (1990) reviewed experimental research on choice across different populations and found not only that individuals with ID participate more in activities which they are provided choice in, but that their performance was improved in these situations. Additionally, maladaptive behaviors appeared less when the choice of goals and reinforcers were chosen by the individual instead of the professional (Bannerman et al., 1990, p. 84). Providing individuals control over their lives enriches their life experience through greater social networks, stronger family relationships, increased contact with friends and more social, community based experiences (Robertson et al., 2007).

As previously discussed, individuals with disabilities have historically been an undervalued, underestimated, and segregated population. Self-advocacy groups, families, and advocates have fought for decades for the recognition of personhood and worth of individuals with disabilities. Making the service user the director of the services...
being provided to them underscores his or her individual value and capability to be self-determined.

1. **Increasing participation in the planning process**

   Based on all of the available research indicating that individuals with ID have the ability to make choices and that having a say in decisions improves QOL, it is critical that service providers employ the means to provide opportunities to do so.

   Increasing client participation begins with open-mindedness, creativity and more importantly, a change from the traditional mindset of “working with” and “planning for” people with disabilities (Timmons & Whitney-Thomas, 1998). Support staff must shift their role from an authority responsible for setting the expectations and outcomes to that of a consulting role (Certo et al., 1997). To begin this shift, service providers need to acknowledge personhood and respect the individuality of each person as a unique individual and recognize that the desires, dreams, and needs of the client may differ significantly from what service providers believe is important and worthwhile (Clare & Cox, 2003). In addition to a change of perception, service providers need to be able to release some of their control which may be one of the most difficult things for them to do. Allowing clients to demonstrate their ability to be self-determined and run their own meetings, owning the process, is giving control to clients when service providers are used to having ultimate jurisdiction. Relinquishing control could be the most difficult adjustment service providers will make in transitioning to a true person-centered approach where the client not only participates in the process but runs it. Timmons and Whitney-Thomas (1998) call for allowing the client to control both the structure and content of the planning process. When professionals relinquish control it provides
clients the opportunity to further practice their self-determination. Since traditional program planning has been largely criticized for excluding the individual who the plan is being created for, it is paramount that every effort be made to keep those individuals front and center in their meetings.

According to Clare and Cox (2003), all behavior has meaning and is a form of communication. Arguably the most important requirement for improving services and increasing the participation of clients in the planning process is to observe and listen. For clients with limited communication, all behavior including reflexes, actions, sounds, and facial expressions need to be correctly interpreted and validated to ensure that preferences are correctly identified (Taylor, 2007). Taylor (2007) found that direct service providers were not always accurate in identifying client preferences. Wehmeyer and Schwartz (1998) identify assistive technology as an underutilized tool to assist individuals. Both high and low tech options can make a significant difference in the ability of an individual with ID to participate in his/her meeting. Taylor (2007) listed use of cue cards, graphic facilitators, as well as the use of real objects, objects of reference, and true object-based icons to facilitate participation.

Client education and empowerment is critical to assure client participation and success. One cannot be expected to successfully control the process when no control was given before. Helping not only the individual with ID but support staff, family, and other interested parties to understand the change and the process will help increase participation and support of the client. Individuals should have opportunities to role play and be provided simulated situations. Timmons and Whitney-Thomas (1998) also suggest allowing individuals the opportunity to observe other meetings as a means of
making the process more concrete. In a study by Faw et al., (1996) four individuals living in an institutional setting who were scheduled to be discharged to community placements were taught how to evaluate potential group homes. They used an evaluation worksheet with individual preferences which they helped to create and were empowered to ask questions during the tours of each possible group home. The instruction they were provided was generalized from simulated group homes on the grounds of their facility to real group homes in the community (Faw et al., 1996). Simulations and practice are excellent ways to help individuals become more self-determined. “Teaching clients how to exercise their freedoms responsibly should be an integral part of the habilitation process” (Bannerman et al., 1990, p. 86). In addition to direct teaching, Nirje (1972) identified providing social training to help individuals with ID gain the capacity to be self-determined. There is no shortage of curricula. Examples include, Person-Centered Planning Made Easy (Holburn, Gordon, & Vietze, 2007) and free on-line tools like It’s my Choice (Allen, 1989) from the Minnesota Governor’s Council on Developmental Disabilities, among others. These curricula typically contain easy to follow step-by-step guides for clients involved in individual planning. Such tools can help encourage participation and provide guidance to both the individual and their support staff.

Flexibility is an important characteristic in successful individual planning. To create a plan which is individualized, flexibility is a requirement. This also applies to the meeting itself, not just the plan. Center for Developmental Disability Studies (2004) recommend that the meeting size, tone, and conversation flow all need to fit the client’s needs in order for participation to occur. Timmons and Whitney-Thomas (1998)
suggest experimentation with a variety of planning styles to foster communication, participation, and effectiveness, including multiple short meetings in place of one long meeting and the use of props and/or pictures. As with the choices each of us make, respecting the client means that if he or she is unhappy with their decision, then it can be changed (Hulgin, 2004). Timmons and Whitney-Thomas (1998) identify taking time to evaluate the planning process in order to ensure that it is truly working.

Direct support professionals (DSPs) can be an important source of support for individuals with ID. Unfortunately DSPs are often undervalued (Clare & Cox, 2003) and left out of the IP process as well. Yet these professionals are often with the person with ID providing services on a day to day basis and have intimate knowledge that could help the person feel confident leading his/her team.

Reflection from the whole team is key in individual participation and success and should not only happen at the beginning of an IP meeting when revisiting the progress from the previous meeting, but rather a continuous process of improvement. The process should help everyone understand what worked, what did not work, and how best to support the client to own his/her IP process. There are a variety of ways to elicit this kind of reflection. Ippoliti et al. (1994) suggested structured interviews to elicit perceptions about service providers’ current practices as well as other desired outcomes. “Self-governed social clubs” could be used to provide a safe space for self-expression and support as well as a place to increase self-esteem and the ability to practice self-determination (Ippoliti et al., 1994). Taylor (2007) suggested keeping a written record from the individual perceptions of each participant in the IP process of what is and is not working.
Surprisingly, choice making is rarely taught (Bannerman et al., 1990) and if it is, the options given as choices may not be of interest to clients. Service providers must relinquish the bias against giving individuals with choices because of the potential for bad decisions and recognize that every individual is capable and that research suggests its value even with the simplest of decisions as what to eat for lunch or what to wear (Bannerman et al., 1990). Service providers’ ability to teach individuals with ID how to make choices is vital (Smyth & Bell, 2006).

2. **Barriers to individual participation**

   Often cited, and arguably the most important problem in program planning, is the lack of involvement of the person with ID in the planning process (Alexander & Hegarty, 2001; Carnaby, 1997; CDDS, 2004).

   Research has identified many reasons for this lack of involvement. Key findings include the perception that individuals with intellectual disabilities do not have the ability to be self-determined, the lack of opportunity service providers give to their clients to make choices, the severity of the disability, and the resistance of service providers to change.

   Despite the significant progress of the self-advocacy movement, direct support providers continue to dismiss the notion that people with intellectual disabilities can be self-determined (Bigby et al., 2012; Ippoliti et al., 1994; Wehmeyer, 1998; Wehmeyer & Metzler, 1995). While service providers attempt to provide “humane alternatives for people with disabilities, [they] continue to overlook their fundamental human right to self-determination” (Ippoliti et al., 1994, p. 454). There remains a culture of power in which non-disabled support providers believe they know what is best for the people they
serve and as a result often continue to make the decisions regarding the clients’ lives (Bigby et al., 2012). Even with the shift from institutional to community based group home care and the work of the self-advocacy movement, people with intellectual disabilities continue to have little input in the decisions of their daily lives (Bannerman et al., 1990; Smyth & Bell, 2006). Beyond the day-to-day decisions, there also continues to be an assumption that individuals with ID lack the ability to articulate their wishes and plan for the future so service providers continue making choices for them without their input (Ippoliti et al., 1994). Heller et al. (1996) noted that families often made decisions for their disabled family member due to a lack of confidence that the individual would be able to comprehend more complicated issues such as later life planning.

In short, people who work with individuals with ID often are overzealous in their efforts to protect and comfort which can endanger the individual’s human dignity, keeping him from experiencing personal growth through ordinary risk-taking (Perske, 1972). An alternative perspective is that it is the responsibility of service providers and families to prepare individuals to face challenges rather than protecting them from hardship. It should be a main focus of service providers to teach these skills and give individuals an opportunity to practice self-determination.

In addition to staff having limited faith that individuals can make good decisions (Faw et al., 1996), there can also be intentional or unintentional influences from family, staff, and society. When individuals are given an opportunity to make choices, often the beliefs and attitudes of direct service providers and client’s families have been found to play a major role in affecting the choice made by an individual with ID. Individuals with
ID can be influenced inadvertently by others as values and beliefs often affect behavior (Smyth & Bell, 2006).

Dependency is another barrier in systems providing services for individuals with intellectual disabilities (Barton, 1989). It is the very service culture that promotes dependence by limiting choice-making opportunities, self-determination, and involvement (CDDS, 2004; MacEachen & Munby, 1996). For example, even when individuals are participants in their meetings, Carnaby (1997) found that half of the people with ID in his study were unclear what the goals of their individual planning meeting were and that just over half of individuals interviewed understood that the meeting was being held on their behalf. Among those who understood the purpose of the meeting, only half felt that they actually had made decisions in the meeting. Few felt they had influence on the format or the proceedings of the meeting (Carnaby, 1997).

Lack of client participation is often attributed to the severity of an individual’s disability and limited communication skills. In such cases, clients are often excluded in the planning process all together (Joyce & Shuttleworth, 2001). Wright and Moffat’s (1992) study identified limited time as one of the main reasons staff felt that clients should have limited participation in their meetings. It was felt that client’s with more severe disabilities would be too time-consuming if they were to fully participate.

Even individuals with the most complex needs communicate, though often it is through means which professionals deem as inappropriate. Difficulties in expressive communication were identified by Certo et al. (1997) as a major reason that individuals are not provided opportunities to participate in major life decisions. The lack of expressive communication leads many individuals to communicate through challenging,
aggressive, or self-injurious behaviors which in turn, creates additional barriers to participation. Professionals are often unaware or insensitive to these types of communication by persons with significant disabilities (CDDS, 2004). In the case study reported by Certo et al. (1997), a mother admitted to being stunned at how much her daughter had to say. It was clear that although her family and small support network have been great backers of the daughter, only when given the opportunity to lead did she communicate ideas about what she wanted her life to look like.

Mansell and Beadle-Brown (2004) provided evidence that professionals often underestimate the receptive language capabilities of people with ID, focusing too heavily on verbal expression abilities. A study by Purcell, Morris, and McConkey (1999) identified significant disparities between ratings given by direct support staff on communication functions such as giving information, initiating conversation, and describing feelings and those given by language therapists. Additionally, Purcell et al. (1999) noted an inaccurate picture of the communication ability of clients among staff could cause problems with their interactions. This study found that staff underestimated client hearing loss, overestimated their ability to understand verbal language, and had difficulty identifying non-verbal behaviors as a means of communication.

One of the difficult issues ‘professionals’ face is accepting that the client’s idea of an ‘ordinary life’ may not match their own values or expectations (Clare & Cox, 2003). “In order to assume control in one’s life, one must have the opportunity to express preferences, indicate choices, and make decisions” (Wehmeyer & Metzler, 1995, p. 111) and be heard and for them to see their input put into action.
Change comes very slow and is difficult for service providers and they have a long way to go before the change needed to practice PCP can be realized. Black (2000) created an extensive list of the reasons the human service field is slow to change. Some of those reasons have been previously touched upon. Her list includes the generally low expectations of the field and employees and the clients they serve. She believes there is a lack of imagination when it comes to what ‘could be’ and that there is a demand for simplicity and predictability. Also there are often problems with lack of communication throughout agencies. It is important to recognize that the type of program setting does not perfectly predict autonomy for individuals with ID. MacEachen and Mumby (1996) listened as participants in their study expressed feeling as powerless in their group home placement as they were in the institutional setting they had previously lived in. Increased research is needed to identify what factors contribute to successful client participation regardless of setting.

C. **Study Purpose**

While PCP is widely accepted as current best practice in service delivery for individuals with ID, its implementation has a long way to go before its promise can be realized. Today service providers use a mix of IPP and PCP. Some providers are doing a good job with the transition while others continue to provide program planning lacking individualization and reminiscent of the case conferences of the past. More research is needed to better understand the barriers and to identify strategies and tools to help service providers implement the ideals of person-centered planning. Despite all the work that has been done by self-advocates and those advocating on their behalf,
individuals with ID continue to have very limited opportunities to be self-determined if it is not supported in the basic IP process.

Carnaby (1997) suggested offering the clients more control over the format and agenda of their meeting to address the concern of staff and support persons forgetting the purpose of and who the meeting is for. CDDS (2004) recommended improving supports provided to clients in the areas of communication, preference assessment, and scheduling. Even if clients are given more opportunities to participate or have increased control over their meeting, many clients may have little experience in exercising this kind of control and may need at least initial support to do so (Alexander & Hegarty, 2001).

To improve the quality of individual planning, Carnaby (1997) suggested that research focus on meaningful modes of communication especially for those with communication difficulties, as well as better understanding the roles clients play in developing the services which they receive. Stancliffe et al. (1999) called for future studies of individual planning where the relation between residential type and individual planning effectiveness are examined.

There remains limited study directly focused on client participation in the IP process (Alexander & Hegarty, 2001; CDDS, 2004). Most research in client participation review the increased cost or quality of goals. The focus of such research continues to focus off the individual and their active participation. Whether it is on PCP or traditional IPP’s, the research has not been focused on the personal participation and control of the individuals the plan in written for including what kind of participation clients have, in what form, and to what degree.
Though PCP is currently the gold standard in supporting client participation in program planning, there are many issues in its use across agencies. Despite the goal of PCP being driven by the individual, there can be a division between its design and implementation (Cullen, 1999). Cullen (1999) noted that there are those who claim that person-centered approaches are just the latest ‘fix’ to a longstanding problem with the only benefit being to make professionals feel better about the services which they are providing. Robertson et al. (2007) found that PCP does not have an equal impact for everyone and that factors such as personal characteristics, level of ID, and adaptive behavior, all affect lifestyle outcomes.

Care, programming, and support have come a long way since 1848 when the first American institution opened its doors. The next hundred years saw individuals with ID locked away, devalued, and seen as less than human. While there remains much work to be done, people with ID have more opportunities today to be heard and supported in the manner which they choose. The control of their care, training, and education is slowly moving out of the hands of professionals and into their own. The importance of the transfer of control has been documented in previous sections. Not only are service users being involved in the creation of their own service plans, there are new pressures that they be involved in both service and strategic planning (Clare & Cox, 2003).

Continued research is necessary to clearly evaluate where we are right now in order to take steps to get where we need to be. This study documents the participation of a small sample population of individuals with ID in their individual planning processes in order to identify: (1) the degree to which they participate in their planning meeting, (2)
their understanding of the basic purpose of the meeting, and (3) their feelings regarding the meeting and their role in it. This information will be useful to help build a basis for exploring how participation occurs and the client’s relationship with the process.
III. METHODS

A. Research Questions

This study utilized an in-depth assessment of the extent to which individuals with intellectual disabilities living in residential facilities, including large institutions and community based group homes, participate in their Individual Planning (IP) meeting. The study explored: (1) the clients’ level of participation during their meeting and (2) their understanding of the basic purpose of the meeting as well as their perceptions of the meeting.

B. Research Design

This research used an observational, parallel form mixed-method design, gathering both qualitative and quantitative data to answer the research questions. The decision for this choice of design was to increase the richness of the data in order to get a more complete illustration of the IP experience (Mertens, 2005).

The quantitative and qualitative data were gathered separately to answer different research questions. The quantitative data was represented by numerical ratings of the level of client participation in their IP meeting. Qualitative data was in the form of clients’ self-reported understanding of the meeting collected in open ended interviews. Additionally, data were documented through taking notes of observations made before, during, and after the meetings.

C. Research Subjects

Research subjects included individuals with intellectual disabilities living in Illinois residential facilities in the Chicago metropolitan region, including institutional settings and community based group home placements. Eligible subjects were adults, aged 18
or older with a diagnosis of intellectual disability, which is defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM) as having an IQ below 70. Persons excluded from the study were individuals with an IQ above 70, under the age of 18, and those who have a primary diagnosis other than intellectual disability.

1. **Recruitment**

   Agencies were selected to be contacted through a review of service providers in the area and suggestions from professionals familiar with local service providers. Service providers who were contacted included those providing residential services to individuals with intellectual disabilities. Each provider was contacted by the investigator to identify the appropriate contact person or office responsible for internal review of research proposals. Letters were sent to the appropriate contact person with information about the research study. The investigator then made follow-up phone calls to the contact person from each of the service providers to answer any questions they might have had and to inquire about their willingness to participate in the study.

   Those service providers who agreed to participate were asked to identify clients with IP meetings scheduled from August 2008 through October 2008 who fit the criteria for this study. They were then asked to send out letters of invitation provided by the investigator to the client’s guardians (see Appendix C). A consent form and contact information for the investigator was included with the letter of invitation (see Appendix C and D). The invitation letter requested confirmation of agreement to participate by phone or the return of the consent form to the Principal Investigator (PI). Assent was obtained from each of the clients who had guardians before their IP meeting began (see Appendix E).
Facilities also identified clients who were their own guardians. The investigator provided consent forms and information about the research for facilities to give to these individuals as well (see Appendix F).

2. **Consent**

Consent forms were included with the invitation sent out to the guardians, or clients without guardians meeting the study criteria by the individual service providers. These were mailed to each guardian’s home in order to give them ample time to make an informed decision about whether or not to allow their ward to participate in the study before the IP meeting. Clients who were their own guardians were provided the consent form before their IP meeting as well and provided assistance reading the forms by their case manager or other senior staff when necessary.

Though instructed to return the consent form to the investigator, only about 50 percent were initially returned. Approximately half of the recruited persons contacted the service provider to check the legitimacy of the research at which time they provided verbal consent to the service provider. In those cases the service provider contacted the investigator directly and the signed consent forms were collected on the day of the meeting before it began.

Prior to the start of the IP meeting, the investigator reviewed the consent forms to make sure the proper signatures had been obtained. All subjects and their guardians were asked if they understood their rights as research participants, reminded that they could discontinue participation at any time, and asked if they had any questions before the meeting began. All subjects were given a copy of their signed consent and/or assent form for their records.
Assent was obtained from clients with guardians prior to their IP meeting and a signature obtained if he or she was able to do so. Assent included a description of the research study, the role and importance of the individual’s participation, the risk and benefits of his or her participation, and an explanation of their right to stop participation in the research at anytime without negative consequences. Subjects were asked to tell the researcher, in his or her own words, what was explained to them through the assent process to ensure understanding. If unable to do so, the researcher asked yes/no questions to check for understanding. If the subject was still unable to provide evidence of understanding, the researcher utilized the guardian’s consent for permission to continue and relied on individuals attending the meeting who knew the subject, to inform the researcher if they believed at any time the researcher was a cause of distress at which time the data collection would cease. A subjects’ dissent would have been honored even if consent had been obtained from the guardian, though no subjects refused to participate.

Of the 25 subjects, six were their own guardian and provided their own consent to participate while 19 had a legal guardian who consented for them. None of those 19 dissented to have their meeting observed by the investigator. As described later, an interview followed the meeting as part of the qualitative data collection. Of the 19 subjects interviewed, 13 were successful, three were attempted but the individual was unable to answer the questions, two chose not to be interviewed, and one subject answered the first question before choosing not to continue.

Precautions were taken to protect the confidentiality of subjects. Each subject was given a pseudonym to protect his or her identity. Names, contact information,
personal information, and interview data was kept in a locked cabinet that only the investigator had access to. All electronic data was kept on a password protected computer.

3. **Subject characteristics**

Table I shows the age, gender, disability level, and guardianship status of subjects. Before each subject’s meeting, information was gathered identifying his or her disability, gender, age, level of communication based on their Inventory for Client and Agency Planning (ICAP) score, vocational status, and the type of facility in which he or she lived. This information was provided by each subject’s case manager.

<table>
<thead>
<tr>
<th>TABLE I</th>
<th>SUBJECT CHARACTERISTICS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>47.2 years</td>
</tr>
<tr>
<td>Range</td>
<td>25-65 years</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>52%</td>
</tr>
<tr>
<td>Female</td>
<td>48%</td>
</tr>
<tr>
<td>Disability a</td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>28%</td>
</tr>
<tr>
<td>Moderate</td>
<td>36%</td>
</tr>
<tr>
<td>Severe</td>
<td>20%</td>
</tr>
<tr>
<td>Profound</td>
<td>16%</td>
</tr>
<tr>
<td>Guardianship</td>
<td></td>
</tr>
<tr>
<td>Own</td>
<td>24%</td>
</tr>
<tr>
<td>Ward</td>
<td>76%</td>
</tr>
</tbody>
</table>

a All subjects had a primary diagnosis of Mental Retardation.
As shown in Table I subjects had an average age of 47.2, with both genders well represented: 52% male and 48% female. Twenty-four percent of subjects were their own guardian while 76% were under the care of a guardian, typically being a parent or sibling. All subjects had a primary diagnosis of “mental retardation” (MR) with over one-third labeled as having severe or profound levels of impairment.

Table II shows testing scores for all subjects. The test information used was from the Inventory for Client and Agency Planning (ICAP). The total ICAP score and the Social/Communication scores were documented.

| TABLE II |
| ICAP SCORES |
| Total Score  |  |
| Mean         | 55 |
| Range        | 31-76 |
| Social/Communication  |  |
| Mean         | 453.8 |
| Range        | 381-495 |

<table>
<thead>
<tr>
<th>Social/Communication</th>
<th>Subjects Within Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>375-400</td>
<td>4%</td>
</tr>
<tr>
<td>401-425</td>
<td>8%</td>
</tr>
<tr>
<td>426-450</td>
<td>24%</td>
</tr>
<tr>
<td>451-475</td>
<td>40%</td>
</tr>
<tr>
<td>476-500</td>
<td>24%</td>
</tr>
</tbody>
</table>

The ICAP is a comprehensive, structured instrument designed to assess the status, adaptive functioning, and service needs of clients with ID to aid in program planning and in the evaluation of services. The Social and Communication section specifically evaluates interactions with others in social settings as well as language
comprehension and expression. For this study only the total score and the Social Communication scores were documented. The total ICAP scores in Table II indicate subjects fell in an average range between 31 and 76. This indicates a good representation of ability level as an individual with profound intellectual disability would receive a score of under 20 and a non-disabled adult would receive a score of 90 or above. The majority (88%) of subjects had a social/communication score between 426 and 500 which indicates social/communication functioning age between three years, five months and fourteen years, three months.

Table III below shows the work and day programming status of subjects.

<table>
<thead>
<tr>
<th>TABLE III WORK AND DAY PROGRAMMING PARTICIPATION&lt;sup&gt;a&lt;/sup&gt; (N=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based work site</td>
</tr>
<tr>
<td>Segregated/Campus work site&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Non-paid work skills and/or social classroom</td>
</tr>
</tbody>
</table>

<sup>a</sup> Some subjects participated in more than one area of employment or programming.
<sup>b</sup> One subject remained in a sheltered workshop after a diagnosis of dementia as to not disrupt the familiar routine. However, no work was expected to be completed.

Table III shows that the majority of subjects, 72%, participated in sheltered workshop or other on-site work program. Of the 16% of subjects who had community-based employment, all were employed on a part time basis.
4. **Agency characteristics**

Five service providers participated in this study. Only service providers providing residential services participated though most provided additional services such as vocational training and day habilitation programming. The subjects participating in the study all received residential services from these agencies.

Table IV below shows the type of residential settings of the participating service providers. Community based group homes were identified as residential services being provided in a single setting with eight or fewer residents. A single campus facility was categorized as more than 8 residents living on a single property regardless of the number of apartment or house occupants.

<p>| TABLE IV |</p>
<table>
<thead>
<tr>
<th>SERVICE PROVIDER SETTING TYPES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based group homes</td>
</tr>
<tr>
<td>Service Provider A</td>
</tr>
<tr>
<td>Service Provider B</td>
</tr>
<tr>
<td>Service Provider E</td>
</tr>
</tbody>
</table>

Table IV shows that three of the five participating service providers, A, B, and E served their clients in group homes within the community and two agencies, C and D, provided residential services on a single campus, either in group home settings or large apartment style buildings.
Below, Table V describes the level of intellectual disability of the subjects from each of the service providers and the total number of subjects from each agency.

<table>
<thead>
<tr>
<th>TABLE V</th>
</tr>
</thead>
<tbody>
<tr>
<td>DISABILITY LEVELS BY AGENCY</td>
</tr>
<tr>
<td>Level of Intellectual Disability</td>
</tr>
<tr>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Service Provider A</td>
</tr>
<tr>
<td>Service Provider B</td>
</tr>
<tr>
<td>Service Provider C</td>
</tr>
<tr>
<td>Service Provider D</td>
</tr>
<tr>
<td>Service Provider E</td>
</tr>
</tbody>
</table>

Table V shows that service providers C and D had subjects at the highest level of functioning with 100% of subjects in agency C having a mild diagnosis and 100 of subjects in agency D having either a mild or moderate diagnosis. The majority of subjects in service providers A and E fell in the severe and profound categories as indicated by a greater degree of impairment.

D. **Instruments**

1. **The individual programme planning checklist**

An adaptation of the Individual Programme Planning Participation Checklist (IPPPC) was used to assess levels of client participation (see Appendix G). The IPPPC was created by Alexander and Hegarty (2001) in order to assess the participation of one client during an IPP meeting. The original instrument consisted of an observational checklist which included nine items to be graded on a 5-point scale,
ranging from not participating (1) to actively participating (5). The nine items included providing information, seeking information, joining in group discussion, expressing opinions, making choices, non-verbal behavior, providing feedback, suggesting goals, and responsibility for goals. The adaptation used for the present study included only 5 types of participation (providing information, seeking information, joining in group discussion, making choices, and non-verbal behavior) and did not use the 5 point rating scale. Instead, topics discussed at the meeting were recorded as they occurred and the subjects’ degree of participation within each topic was evaluated through observations with a 0-3 point scale. It was documented whether (0) there was no prompt to participate and no participation occurred, (1) the subject was prompted to participate but did not, (2) the subject was prompted to participate and did, and (3) participation was independent. To provide an example, a comment a subject independently made during a group discussion about their roommate like, “I like my roommate,” would be documented as independent participation. If the subject made the same comment after another individual asked what he/she thought of their roommate, it would be documented as responding to a prompt. Alternately, if a member of the team asked the subject what he/she thought of their roommate and no response was given, it was documented as prompted with no response.

2. **Interview**

Subjects were asked to participate in an eight question interview with the investigator. The aim of the interview was to identify whether subjects understood the purpose of the IP meeting and what their feelings about the meeting were (see Appendix H). The interview questions asked subjects to identify who the meeting was
for, what the purpose of the meeting was, what the goals which were written in their plan were, who decides what the goal will be, whether they felt as if they were listened to, whether they liked their new goals, what the best part of their meeting was, and whether there was anything they would have changed about the meeting. Each question was asked and subjects’ answers recorded by the PI. If a question was not understood by the subject, no prompt was given, nor was it reworded. If a question was not understood and an answer was not given it was skipped therefore not every question was answered by every subject who agreed to be interviewed. If an answer was given but it was suspected that the subject did not understand the question, the answer was still recorded. Responses to the interview questions were combined to create common themes.

E. **Data Collection**

Observations and interviews took place at a location designated by each participating service provider. IP meetings usually took place in a meeting room on the facility’s campus or at a central office. Occasionally meetings took place at the private residence of the subject. Each meeting was held at its regular location to aid in providing a comfortable and familiar location for each of the subjects.

In all but one occasion, the investigator was introduced to the subject and the rest of the group by the team leader or case manager. On this occasion the investigator arrived and the subject was the only person in the room so introductions occurred at that time. It was directly following the introduction that assent was obtained from subjects with guardians who had already provided consent. It was also at this time that subjects were reminded about the interview following the meeting.
To minimize disruption and to reinforce the group’s understanding that the investigator was only there to observe not participate, observation was done away from the main table where the group was sitting whenever possible. In only a few circumstances was this not possible due to the size of the room. Before each meeting began, subjects were reminded that the investigator’s role is only as an observer and that only participation indicators and general topic information would be recorded. All individuals in attendance were encouraged to go about the meeting as if the investigator was not there.

At the end of the meeting subjects were asked if they were willing to participate in the interview about their meeting. Those subjects that agreed were either taken to an adjacent room or waited until the other meeting participants left the room to begin the interview. The decision to stay in the same room as the meeting or move to another was informed by the decision of the case manager.

Data were gathered at 25 individual planning meetings observed over a three-month period.
IV. RESULTS

Observational data were gathered to answer the first research question: “how much do individuals with intellectual disabilities participate in their individual planning meetings”. The analysis of data included basic summaries of the observations of participation and their comparisons across service providers, setting type, level of disability, type of participation, and the meeting topics addressed.

Interview responses were used to answer the second research question: “what were subjects’ understanding of the purpose of the individual planning meeting and how did they feel about how their meeting went”. Responses were analyzed using basic content analysis where the subject’s responses were coded into common answers or themes.

A. Meeting Characteristics

Table VI summarizes basic information about the meetings: length of the individual planning meetings and the number of people in attendance, including the subject.

<table>
<thead>
<tr>
<th>TABLE VI</th>
<th>MEETING CHARACTERISTICS (N=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
</tr>
<tr>
<td>Length (min.)</td>
<td>39.4</td>
</tr>
<tr>
<td># of People Attending</td>
<td>7.6</td>
</tr>
</tbody>
</table>
The average meeting length was 39.4 minutes with the shortest being 15 minutes and the longest, one hour. More than 50% of the meetings lasted at least 40 minutes with 28% lasting one hour. Approximately one-fourth (24%) of meetings lasted 20 minutes or less.

The average number of people attending the meeting was 7.6 with the least being three and the most being 11. The meeting with three people was an outlier as almost all the meetings had between seven and eight people in attendance. In addition to the subject and the case manager, at least one family member typically attended as well as a workshop or vocational supervisor, medical and behavioral staff member.

Figure 1 shows the extent of participation by family members at meetings. Family members included parents, grandparents, and siblings.

FIGURE 1
FAMILY ATTENDANCE AT IP MEETINGS (N=25)
As shown in Figure 1, of the 25 subjects, 80% had family who attended their meeting. Of those families, 95% had at least one family member attend in person while 5% had a member attending by phone. The involvement of the family members in attendance varied significantly, ranging from those who simply showed up and thanked the service provider for their service and left to those who actively participated throughout the meeting by asking questions, providing information, making suggestions, and expressing preferences.
B. **Meeting Topics**

Table VII below summarizes the topics and how often they were discussed during each meeting.

<table>
<thead>
<tr>
<th>TOPICS DISCUSSED AT IP MEETINGS(^1) (N=25)</th>
<th>% of Meeting Topics Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work/Day Training</td>
<td>92</td>
</tr>
<tr>
<td>Health</td>
<td>88</td>
</tr>
<tr>
<td>Residential</td>
<td>76</td>
</tr>
<tr>
<td>Goals</td>
<td>76</td>
</tr>
<tr>
<td>Intro to Meeting/Overview</td>
<td>60</td>
</tr>
<tr>
<td>Assessments</td>
<td>52</td>
</tr>
<tr>
<td>Recreation</td>
<td>44</td>
</tr>
<tr>
<td>Behavior</td>
<td>36</td>
</tr>
<tr>
<td>Introductions</td>
<td>36</td>
</tr>
<tr>
<td>Meeting Conclusion</td>
<td>36</td>
</tr>
<tr>
<td>Community Participation</td>
<td>28</td>
</tr>
<tr>
<td>Personal Story</td>
<td>28</td>
</tr>
<tr>
<td>Family</td>
<td>12</td>
</tr>
<tr>
<td>Money</td>
<td>8</td>
</tr>
</tbody>
</table>

\(^1\) Topics occasionally overlapped.

\(^2\) Goals in fact were addressed at all of the meetings. When not discussed as a distinct category they were discussed within other topics.
As Table VII shows, the most discussed topics were work/day training at 92% and health at 88%. Both Residential and Goals were discussed as distinct topics at 76% of the IP meetings. Money was discussed as a distinct topic at only 8% of meetings; family was discussed at only 12% of observed meetings.

Introductions included only the introduction of individuals participating in the meeting. Often family members were not familiar with everyone attending the meeting or had only minimal contact with them. Occasionally the case manager, or subject if he or she was leading the meeting, would explain to everyone attending the purpose of the meeting and what the agenda was. One of the service providers completed a ‘personal story’ with each of their clients prior to the IP meeting which was a relatively short narrative about the individual including information about activities and accomplishments occurring since the last meeting, likes and dislikes, and other information the client felt was important to share. Discussion surrounding health included issues of healthy weight and dietary issues, medication changes, allergies, and doctor’s appointments. Assessment was occasionally discussed as an isolated topic but often overlapped across other topical areas such as goals, residential, and work/day training areas. When discussions were classified under Assessment in Table VII, they occurred as a distinct, separate discussion. Often this section included psychological, health, and vocational assessments. The residential topic included anything that occurred within the home including house chores, residential routines such as mealtime, roommates, and discussion of preferred living situations. Occasionally goals were discussed as a distinct topic. In these cases, progress from previous goals and new goals were discussed. Work/day training included discussion regarding work
performance, vocational preferences, and other topics associated with work or day habilitation programs. Community participation included discussion of community outings, community safety, and preferences for future activities. The topic of behavior was largely dominated by staff and not one that appeared to engage the subjects. Discussion typically included staff reviewing issues with the individual's behavior that needed correction. Recreation was discussed largely as recreation and leisure time within the residential agency including taking part in clubs, dances, and movie nights. As noted, family was rarely discussed as a distinct topic and typically involved sharing information about a subject’s family and activities shared with them. Money focused on spending and saving habits. Lastly, the meeting conclusion typically consisted of a wrap-up and summary of all the information which was covered during the meeting.

C. Participation

On average, clients participated 68 times per meeting both prompted and independently. The nature of this participation is further broken down in Tables VIII through XII.

Table VIII identifies the level of client participation broken down across the different service providers and the residential setting type.
### TABLE VIII
LEVEL OF PARTICIPATION BASED ON SERVICE PROVIDER AND SETTING

<table>
<thead>
<tr>
<th>Degree of Participation</th>
<th>Community-based group homes</th>
<th>Group homes on single campus</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Setting</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>1-25</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>26-50</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>51-75</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>76+</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>N</td>
<td>7</td>
<td>4</td>
</tr>
</tbody>
</table>

Table VIII compares service providers A, B, and E who provided their residential services in community-based group homes to service providers C and D whose residences were on a single site in group homes or apartment style settings. As shown in Table VII, service providers C and D had the highest levels of participation during the individual planning meeting. Service providers B and E had all of their clients participating between 1-25 times during their IP meeting.

Table IX summarizes how much subjects participated during the meeting broken down by the manner in which participation occurred. The number of times participation occurred is separated into ranges (1-25, 26-50, 51-75, 76+). For each activity, the percentage of subjects who participated whether through prompts or independently, is shown.
Table IX shows that the majority of participation activity was in the low range of 1-25 times per meeting. Subjects did not demonstrate a high rate of choice making or seeking information. The most common participation activity was providing information and joining in group discussion. As shown in the table, 8% of the subjects observed did not participate in providing information while 44% of them provided information 1-25 times during their meeting. Similarly, 68% of subjects joined in group discussions between 1 and 25 times during their meeting.

Table X further breaks down the degree of involvement across type of participation activity by the level of disability.
TABLE X
PARTICIPATION BY LEVEL OF INTELLECTUAL DISABILITY

<table>
<thead>
<tr>
<th>Type of Participation</th>
<th>% of Subjects Participating at Each Level</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1-25</td>
</tr>
<tr>
<td>% Clients Provided Information</td>
<td>8</td>
<td>44</td>
</tr>
<tr>
<td>Mild</td>
<td>-</td>
<td>14</td>
</tr>
<tr>
<td>Moderate</td>
<td>11</td>
<td>33</td>
</tr>
<tr>
<td>Severe</td>
<td>-</td>
<td>80</td>
</tr>
<tr>
<td>Profound</td>
<td>25</td>
<td>75</td>
</tr>
<tr>
<td>% Clients Sought Information</td>
<td>40</td>
<td>60</td>
</tr>
<tr>
<td>Mild</td>
<td>14</td>
<td>86</td>
</tr>
<tr>
<td>Moderate</td>
<td>33</td>
<td>67</td>
</tr>
<tr>
<td>Severe</td>
<td>40</td>
<td>60</td>
</tr>
<tr>
<td>Profound</td>
<td>100</td>
<td>-</td>
</tr>
<tr>
<td>% Clients Joined in Group Discussion</td>
<td>12</td>
<td>68</td>
</tr>
<tr>
<td>Mild</td>
<td>-</td>
<td>43</td>
</tr>
<tr>
<td>Moderate</td>
<td>11</td>
<td>78</td>
</tr>
<tr>
<td>Severe</td>
<td>20</td>
<td>80</td>
</tr>
<tr>
<td>Profound</td>
<td>25</td>
<td>75</td>
</tr>
<tr>
<td>% Clients Made Choices</td>
<td>48</td>
<td>52</td>
</tr>
<tr>
<td>Mild</td>
<td>14</td>
<td>68</td>
</tr>
<tr>
<td>Moderate</td>
<td>56</td>
<td>44</td>
</tr>
<tr>
<td>Severe</td>
<td>60</td>
<td>40</td>
</tr>
<tr>
<td>Profound</td>
<td>75</td>
<td>25</td>
</tr>
<tr>
<td>% Clients Non-verbal Participation</td>
<td>32</td>
<td>64</td>
</tr>
<tr>
<td>Mild</td>
<td>-</td>
<td>86</td>
</tr>
<tr>
<td>Moderate</td>
<td>33</td>
<td>67</td>
</tr>
<tr>
<td>Severe</td>
<td>60</td>
<td>40</td>
</tr>
<tr>
<td>Profound</td>
<td>50</td>
<td>50</td>
</tr>
</tbody>
</table>

Again, Table X shows that the majority of participation activity across all disability levels occurred in the form of providing information and joining in group discussion.

Two major differences across level of ID were: (1) higher degrees of participation were
evident only among subjects with mild and moderate ID, and (2) subjects at the severe and profound ranges of ID were most likely to have zero participation.

Table XI summarizes the degree of participation broken down by topics discussed during the meeting.

### TABLE XI
**PARTICIPATION BY TOPIC**

<table>
<thead>
<tr>
<th>Degree of Participation</th>
<th>0</th>
<th>1-25</th>
<th>26-50</th>
<th>51-75</th>
<th>76+</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introductions</td>
<td>-</td>
<td>9</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>9</td>
</tr>
<tr>
<td>Intro to Meeting/Overview</td>
<td>4</td>
<td>11</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>15</td>
</tr>
<tr>
<td>Personal Story</td>
<td>1</td>
<td>6</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>7</td>
</tr>
<tr>
<td>Health</td>
<td>3</td>
<td>15</td>
<td>3</td>
<td>-</td>
<td>1</td>
<td>22</td>
</tr>
<tr>
<td>Assessments</td>
<td>5</td>
<td>8</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>13</td>
</tr>
<tr>
<td>Residential</td>
<td>2</td>
<td>12</td>
<td>4</td>
<td>1</td>
<td>-</td>
<td>19</td>
</tr>
<tr>
<td>Goals</td>
<td>4</td>
<td>15</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>19</td>
</tr>
<tr>
<td>Work/Day Training</td>
<td>2</td>
<td>18</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>23</td>
</tr>
<tr>
<td>Community Participation</td>
<td>1</td>
<td>6</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>7</td>
</tr>
<tr>
<td>Behavior</td>
<td>2</td>
<td>7</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>9</td>
</tr>
<tr>
<td>Recreation</td>
<td>-</td>
<td>9</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>11</td>
</tr>
<tr>
<td>Family</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Money</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Conclusion</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>9</td>
</tr>
</tbody>
</table>

*Table does not include instances when the client was prompted to participate and did not respond.*

Table XI identifies the number of subjects and their frequency of participation during each topic discussed. Across all topics, most participation occurred in the 1-25 times per meeting range. Work/Day Training and Health were topics addressed the
most, 23 and 22 respectively, and had the highest level of participation. Residential issues were discussed at 19 of the 25 meetings but in those meetings there was a high rate of participation. The topics that were discussed the least, Family and Money, also had the lowest levels of client participation.

Table XII summarizes the frequency with which subjects participated independently, were prompted, and when prompted, their responsiveness to the prompt.

<table>
<thead>
<tr>
<th>TABLE XII</th>
</tr>
</thead>
<tbody>
<tr>
<td>PARTICIPATION: INDEPENDENT AND PROMPTED</td>
</tr>
<tr>
<td>Participation During Meeting (N=25)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1-25</th>
<th>26-50</th>
<th>51-75</th>
<th>76+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent Participation (n=25)</td>
<td>2</td>
<td>14</td>
<td>5</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Prompted to Participate (n=25)</td>
<td>1</td>
<td>10</td>
<td>4</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Responded</td>
<td>2</td>
<td>9</td>
<td>4</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Did not respond</td>
<td>15</td>
<td>10</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Table XII shows that the majority of participation occurred in the 1-25 range. Two subjects never participated independently and one subject was never prompted to respond. However, eight subjects were prompted to participate and did at least 76 times during the meeting.
D. **Interview Questions**

Research Question 2, “Do clients understand the purpose of the individual planning meeting and what are their perceptions about their meeting?” is addressed in Tables XIII through XVI which summarize the responses to the eight interview questions. The tables are organized around the themes of 1) information regarding general understanding of the meeting, 2) information about goals, 3) client’s feelings regarding the receptiveness of staff to their input, and 4) general likes and dislikes of the meeting. Subject responses to each question were analyzed and themes identified.

Table XIII summarizes the general understanding that subjects had regarding who the IP meeting was for and its purpose.

<table>
<thead>
<tr>
<th>Question 1: Who was this meeting for? N=14</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>For me</td>
<td>64</td>
</tr>
<tr>
<td>For me and others</td>
<td>7</td>
</tr>
<tr>
<td>Staff</td>
<td>7</td>
</tr>
<tr>
<td>Don’t know</td>
<td>14</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 2: Do you know what the meeting is for? N=13</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yearly review/goals</td>
<td>54</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>38</td>
</tr>
</tbody>
</table>
Regardless of participation during the IP meeting, subjects largely identified that the meeting was for them or for them and their staff. Fifty-four percent of subjects were also able to identify that it was a meeting they had yearly though there were varying answers of its exact purpose.

Table XIV summarizes information about the goals written during the IP meeting; whether subjects could identify their goals, and who decides what the goals will be. If subjects were able to identify goals that were written, they were also asked if they liked them.
TABLE XIV

KNOWLEDGE OF GOALS

<table>
<thead>
<tr>
<th>Question 3: If you remember, tell me some of the goals that were written for you today. N=13</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remembered at least one goal</td>
<td>69</td>
</tr>
<tr>
<td>Did not remember any goals</td>
<td>15</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 4: Who decides what goals you will work on? N=10</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Me</td>
<td>40</td>
</tr>
<tr>
<td>Me and others</td>
<td>30</td>
</tr>
<tr>
<td>Staff</td>
<td>20</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 6a: Do you like the goals that were written for you? N=10</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>90</td>
</tr>
<tr>
<td>Neutral</td>
<td>10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 6b: If so, What about them do you like? N=10</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>They help me</td>
<td>10</td>
</tr>
<tr>
<td>Trying new things</td>
<td>10</td>
</tr>
<tr>
<td>Don’t know</td>
<td>10</td>
</tr>
<tr>
<td>Other</td>
<td>40</td>
</tr>
<tr>
<td>No answer</td>
<td>30</td>
</tr>
</tbody>
</table>

Of the subjects asked, 69% were able to identify at least one goal they were going to be working on over the next year. Forty percent of subjects identified themselves as the primary decision maker in the goals they will work on, 30% identified themselves and staff, while 20% identified staff only as the primary decision maker.
Ninety percent of the subjects asked said they liked their goals with only 10% giving a neutral answer, “I don’t mind them.” None of the subjects who remembered their goals stated that they did not like them. The answers given for why they liked their goals included that the goals were in place to help them and that the goals were an opportunity to try new things. Based on the 30% who provided no answer and the 40% in the other category it is possible that this question was not well understood by the subjects.

Table XV identifies subjects’ responses when asked to identify their feelings of the receptiveness of staff to their input.

<table>
<thead>
<tr>
<th></th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>83</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
</tr>
</tbody>
</table>

Eighty-three percent of subjects believed that they were listened to by other people attending the meeting. Based on the responses of the other 17%, it is unclear if the question was understood.

Table XVI identifies responses to questions eliciting the things each subject liked and did not like about their meeting.
TABLE XVI
SUBJECT’S LIKES AND DISLIKES OF THE MEETING

<table>
<thead>
<tr>
<th>Question 7: What was the best part of your meeting? N=11</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control over meeting/life</td>
<td>27</td>
</tr>
<tr>
<td>Other</td>
<td>64</td>
</tr>
<tr>
<td>Don’t know</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 8: What, if anything, would you change about your meeting? N=10</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nothing</td>
<td>70</td>
</tr>
<tr>
<td>Other</td>
<td>30</td>
</tr>
</tbody>
</table>

Twenty-seven percent of subjects interviewed identified the control they had over their meeting and their lives as the best part of their meeting. Responses categorized as Other included “It was fun,” “Everything,” and “Talking.” Of the 10 subjects who were asked, 70% stated that they would not change anything about their meeting. The other 30% included responses about dissatisfaction with changing staff and hoping that a subject’s opinions provided during the meeting would be followed up by the team after the meeting.
V. DISCUSSION

The intent of this research was to provide an overview of the participation of individuals with intellectual disabilities in their annual IPP reviews. Were subjects participating, and if so, how much were they participating and in what manner? Secondly, the study sought to identify differences in participation levels among subjects, and if there were differences across level of disability, residential type, service provider, and the degree to which staff encouraged participation. Lastly, subjects were interviewed to determine their level of understanding of the IP meeting and their perceptions of how their own meeting went. Study findings were consistent with much of the current literature. The following discussion reflects on the findings and the research process.

A. Participation

Though more than 50% of the IP meetings lasted at least 40 minutes, nearly one-quarter of the meetings lasted less than 20 minutes. It is questionable whether a meeting that is supposed to review a subject’s progress from the past year and plan for the following year can be effectively run in such a short amount of time. In this study the shorter meetings also had very few people in attendance. In short meetings the commitment to supporting the dreams and aspirations of subjects is questionable and are examples of the potential of the IP meeting to be simply a paper exercise required for continued certification and funding (Carnaby, 1997; Herps, Buntinx, & Curfs, 2012; Mansell & Beadle-Brown, 2004). The observation of these short meetings with few participants was that they appeared to lack formality and a sense of importance in addition to a lack of observed respect for the subjects. In one case there was not a
room booked for the meeting and thus, the meeting took place in a common area where 
other people, clients and staff, were present. Additionally, at these smaller meetings it 
appeared that both professionals and family members believed there to be a lack of 
ability or understanding by the subject. This perception was evidenced by having the 
subjects sign forms at the meeting without explanation of what was being signed and 
comments made by professionals and family in front of the subjects such as, “I’m having 
a really hard time with this one,” and “She’s a routine child.” This observation illustrates 
the ongoing need for service providers to accept individuals as they are, respect their 
individual differences, and focus supports around self-determination and providing 
meaningful participation (Lotan & Ells, 2010; Wehmeyer, 1998; Wright & Moffat, 1992).

The shorter meetings were also often the meetings of individuals with greater 
degrees of impairment and lower communication abilities. Encouragement given to 
subjects to participate in these meetings was also greatly limited. This finding is in line 
with previous research done which identified the need to focus on improving 
participation for individuals with limited communication through observation and 
employment of often underutilized assistive technology (Taylor, 2007; Wehmeyer & 
Schwartz, 1998). At meetings where low participation was observed there was a low 
degree of prompting or encouragement to participate. At meetings where higher 
degrees of participation occurred there was often discussion of preparation work done 
before the meeting. No such discussion of pre-meeting preparation was heard during 
the meetings with low levels of participation.

Regardless of meeting size, there was a lack of direct support staff present and 
in meetings of greater size, mostly managers and supervisors were involved. Clare and
Cox (2003) highlight that direct service providers are often left out of the planning process despite the fact that they often have more significant knowledge of and closer relationships with the clients than other professionals. The observations made in this study support that literature.

Also notable was the lack of unpaid, natural support persons present at meetings. The circle of support necessary for the success of person-centered planning has been identified by many researchers (Heller et al., 1996; Mansell & Beadle-Brown, 2004). The only non-paid support present at the meetings were family members. This observation is consistent with research which has found that individuals with ID are largely isolated and lack natural supports despite the significant benefits such support provides (Certo et al., 1997; Mansell & Beadle-Brown 2004; Robertson et al., 2001). Notably, 20% of subjects had no family or non-paid support at their meeting. Even with the 80% who had family members in attendance, active participation and involvement of the family was not guaranteed. Several family members who attended appeared to leave all planning and decisions in the hands of the professionals. Many of the family members appeared grateful that their family member was receiving services at all. Such meetings were examples of professionals controlling not only the meeting, but the programming decisions as well (CDDS, 2004; Clare & Cox, 2003; Greasley, 1995; Shaddock & Bramston, 1991; Stancliffe et al., 1999). Though no formal data was collected on this dynamic, it appeared that family members were not given a significant role in making decisions at the majority of meetings and in large part were not provided with information before the start of the meeting. There were a few subjects who had family members who provided input and their contributions and expectations appeared
to be respected, though outcomes from their input are unknown. Several subjects had family members who were very passive about the decisions being made about their son or daughter. As noted in the results, discussion of family related issues was rare during planning meetings indicating an untapped resource or support for the person with ID.

B. Participation by Topic

Regarding the topics that were covered during the meetings observed in this study, Work/Day Training was most often addressed. Health, Residential issues, and Goals were the next most commonly discussed topics. Again, Family topics were discussed at only 12% of the meetings even though at least one family member was in attendance at 80% of the subjects' meetings. Lastly, money was only a topic of discussion at 8% of meetings. The lack of consistency with topics across the board was affected in large part by how agencies or case managers ran their meetings. Some meetings were conducted with clear order to their topics, beginning with a review of the subject’s progress from previous goals, an evaluation of the individual’s current state, and lastly creation of new goals. Other service providers in contrast discussed goals in a more fluid manner, embedded within discussion of the typical activities of each subject’s daily life.

To document each subject’s actual participation, an adaptation of The Individual Programme Planning Participation Checklist (IPPPC), created by Alexander and Hegarty (2001) was used. The original tool evaluated nine types of participation: Provided Information, Sought Information, Joined in Group Discussion, Expressed Opinions, Made Choices, Non-verbal Participation, Provided Feedback, Suggested Goals, and Responsible for Goals/Client Actively Participated. The five used in the
present study (Provided Information, Sought Information, Joined in Group Discussion, Made Choices, and Non-Verbal Participation) appeared to be sufficient for the scope of this study and occasionally, too many. The four that were not included were easily incorporated into the types of participation that were used. Participation observed that would have been covered under Providing Feedback by Alexander and Hegarty (2001) was documented through Joining in Group Discussion or Providing Information as deemed appropriate. Participation that would have been labeled Expressed Opinions was documented as Provided Information. Even with this shortened checklist, without audio or video recordings, it was difficult to keep up with documenting the type of participation and the topic of discussion when subject participation was higher.

Study findings indicate that subjects participated mostly by providing information; the second most common type of participation was actually joining in the group discussion. The type of participation that was seen the least was choice making. It is important to note, however, that several subjects met with their case worker and other members of their support team before the actual planning meeting where decisions were made so the data may not reflect the actual degree of choice making. Nevertheless, participation during IP meetings does not appear to automatically translate into choice making. Though data was not documented on any preparation which took place before the IP meeting with the subjects, several subjects and case managers mentioned preplanning and groundwork done including helping subjects create written material they wished to share, picture cues to guide them through the meeting, and goal planning. Participation during the meeting was significantly greater for the subjects who did preparation work and their control over the process appeared to
be greater as well as a result. Thus, practice and pre-meeting preparation may lead to
greater levels of participation (Bannerman et al., 1990; Espiner & Hartnett, 2012; Faw et
al., 1996; Heller et al., 1996). It is important to note that subjects with greater
participation were also subjects with higher communication skills and lesser degrees of
impairment than those with lower participation.

Data gathered on participation across severity of disability in Table X showed a
number of expected outcomes including higher degrees of participation among subjects
who had mild and moderate levels of ID while subjects at the severe and profound
levels of ID were more likely to have low or no participation. This accurately mirrors the
literature on the ability of service providers to include individuals with more significant
disabilities in their program planning as they are viewed as lacking the ability to be self-
determined. Furthermore, their communication needs are often not addressed which
limits their ability to provide accurate information on their preferences (Taylor, 2007;
Wehmeyer, 1998). These findings reflects the continued need to focus on providing
individuals with more significant disabilities opportunities for real communication,
training for support staff to recognize and respond to communication other than speech,
and practice for individuals to be more self-determined through opportunities for choice
making.

Participation by topic was used to try and provide richer data and a deeper look
into whether subjects participated more or less depending on what was being
discussed. Table XI follows the trend in Table VII with Residential and Work/Day
Training being the most popular topics covered during the IP meetings observed as well
as where most participation occurs with the addition of Residential showing high levels
of participation. Similarly, Money and Family were discussed least at the meetings and showed the least amount of participation when discussed. These findings possibly reflect the limited incomes and discretionary spending available to individuals with ID creating a lack of discussion due to that experience (Hughes & Avoke, 2010).

Additionally, the subjects in this study were all receiving residential services which could reflect priorities other than family including gaining independent living and work skills where higher levels of participation were seen.

Finally, participation was further analyzed by whether subjects participated independently, were prompted to participate, and whether they responded to the prompt. The majority of participation occurred in the lowest category of participation (1-25) per meeting. Only two subjects fell into the highest level of independent participation during the course of their IP meeting. One subject was never prompted to participate during the IP meeting while 10 were prompted 1-25 times, four were prompted 26-50 times, two were prompted 51-75 times, and 8 were prompted more than 76 times. The data reflects that higher participation correlated with lesser degree of impairment. Additionally, subjects with higher observed participation were more likely to have prepared material before the meeting, had more control over the direction of the meeting, and had more people present at the meeting. This again reflects the literature’s call to provide more meaningful opportunities for individuals with greater degrees of impairment and limited communication opportunities to have increased control over their lives and individual’s desire for that ability (MacEachen & Munby, 1996). Presence at the IP meeting does not guarantee participation and these numbers reflect a need for further investigation into how to provide not only more opportunity for
individuals to be involved but to have control over the process and programming outcomes (Espiner & Hartnett, 2012; Herps et al., 2012).

It appears that a significant factor in client participation was how the support provider designed the meeting and the attitudes and perceptions of staff regarding the importance of their client’s participation. While data was not directly gathered on the feelings staff had regarding client participation, observations during the meeting suggested that staff attitudes may significantly influence participation. Of the five participating service providers, the two single-site facilities designed their meetings with the subject at the head of the table and/or clearly in a position of power. In these meetings, the staff appeared to present themselves as being in a position to provide guidance and expertise in areas of need for the individual as opposed to the authority and final decision makers. Subjects in these facilities largely had a diagnosis of mild ID so it is unclear if staff positions would change with subjects who had more significant disabilities. Subjects in these two facilities overall appeared more satisfied with their meeting as well as the services that were being provided to them.

C. **Interviews**

The second research question focused on individuals' understanding of the purpose of the IP meetings and how they felt about the meeting. This was completed through a series of eight open-ended questions which were asked to the 14 subjects who were interviewed.

More than 50% of individuals identified that the meeting was in fact for them while another 7% identified it was for both themselves and their staff. Although 54% of subjects answered that the purpose of the meeting was for their yearly review of goals,
there was no expansion on that often narrow answer of “For my goals.” Noteworthy was the Other category that included answers such as, “Because they have it,” “We had this for a report every year. They have to put it in a file,” and “Annual staffing. I have one every year around my birthday.” These answers reflect the professional driven model where individuals with ID lack understanding and active involvement in the process, disconnected from the person-centered planning process where individuals are in control (Carnaby, 1997; Herps et al., 2012; Mansell & Beadle-Brown, 2004).

Despite the interview occurring directly after the planning meeting, only 69% of subjects remembered at least one goal they would be working on over the next year. This speaks to the question in the literature of who actually is responsible for the goal planning, especially since 20% of subjects said that staff are responsible for deciding on the goals and another 30% identified themselves and staff as responsible (Wright & Moffat, 1992). When questioned what it was about the goals the subjects liked, only 20% were able to identify answers such as “Because it helps me be more independent, happy.”

Most noteworthy may be the 27% of subjects who answered that the best part of their meeting was the control they had during the process. The lack of feelings of control may reflect the lack of true person-centered planning in the meetings observed in this study. The desire for control and purpose in service planning is reflected repeatedly in the literature as a key component of satisfaction and quality of life as well as in providing person-centered services (Clare & Cox, 2003; MacEachen & Munby, 1996; Timmons & Whitney-Thomas, 1998).
D. **Study Limitations**

The study was a field based observation and thus had a number of limitations. In addition to the small sample size, the program setting was limited to service providers within Illinois, constraining the capacity for generalizing results to other geographical locations.

The IPPPC, while used in a previous study, and despite its face validity as a measure of participation, has not yet been systematically evaluated and its validity is unknown. Difficulty with the tool presented itself during meetings of subjects with higher levels of participation. During the meeting, the correct type of participation (provided information, sought information, etc.) had to be chosen in addition to the level of participation (independent, prompted without a response, or prompted with a response), correctly identifying the topic of discussion, and documenting the participation under that heading. Had the meetings been tape-recorded, some of this difficulty could have been avoided.

The PI was not personally familiar with each of the individuals so the observations may be limited because of a lack of knowledge about each individual.

Selection bias may also operate in this study. How subjects from each participating agency were selected to participate was unknown. The majority of subjects who participated in this study from the large facilities all had a diagnosis of mild to moderate MR while smaller community based residential agencies were more likely to have a diagnosis of severe and profound MR.

Another limitation that is also a noteworthy study observation was that there were significant differences between service providers in both the preparation for and in the
meeting itself. Therefore, the data collected may not accurately reflect the individual’s actual participation in the entire IP process. In several cases, preparation for the meeting was a somewhat lengthy process, which included significant participation of the person with ID. For more than one of the service providers, it was common practice to meet with the subject more than once before the actual IP meeting to discuss his/her options and vision for the upcoming year. These meetings also on occasion included creating prompts such as pictures or narrative for the person with ID to read so that he/she could have more control of the information and flow of the meeting. Unfortunately this participation and choice-making prior to the meeting may not be accurately reflected in the data as collected.

E. **Implications**

The intent of the present study was to provide some basic descriptions of meeting participation in order to stimulate further research on individual planning for programming support and care. This study created more questions than it answered and identified additional areas of research that are needed. In addition to research expanding on this study, future research should include ways to support clients having more control over the IP process, how to increase participation of individuals with greater degrees of impairment, how to develop natural supports, how preparation for IP meetings affects participation, and how the perceptions of support staff affect participation. These were all identified in this study as possible factors affecting the level of participation of individuals with ID during their planning meeting.

The study results indicate that there remains a lack of control by the individual with ID in the process as the majority of subjects had low levels of participation and
were often not part of the conversations occurring. Not only were they not in a position of control, they only were present but not active participants at their own meeting.

As repeatedly noted, participants who had a higher level of functioning and stronger communication skills participated significantly more. Helping individuals with severe and profound disabilities participate and communicate their wishes has been a call in the research for decades. Attention should be given to identify how to increase the participation of these individuals.

There was a significant absence of non-paid, non-family member supports at the IP meetings. The literature identifies that individuals with ID generally have little natural social supports despite the positive outcomes they help create. It would be beneficial to not only examine how more natural support affects participation but how to help individuals with ID develop such supports.

There seems to be a lack of literature about how preparation before an IP meeting influences participation during the meeting. Whether individuals who prepare actually participate more would be of interest to evaluate. Additionally, whether such preparation correlates with better outcomes. There should be future focus on how to prepare individuals with ID for their meeting and on different types of training and tools which could be utilized to increase participation. This is especially important for individuals with severe disabilities with limited verbal communication.

From observations at the IP meetings where individuals had higher levels of participation, there appeared to be an attitude by the service providers that their clients were capable of making choices and being self-determined. The professionals did not necessarily agree with the clients but their input was respected. Those subjects were
provided a leading role in their meeting and appeared to drive the process. Future study should include the effectiveness of person-centered training for support staff as well as types of training and tools which could be used to develop positive attitudes about their clients’ capabilities.

Much research was done in the 1990’s on person-centered planning and best practices though in more recent years there has been minimal study of whether service providers are actually utilizing those best practices. There remains a lack of information in this area and further investigation should be done to identify how the person-centered process is working, or not.

The implications of the findings in this study as well as similar results reported in other studies are that there remains a great deal of work to be done to help service providers to be able to recognize the ability of individuals with ID, provide supports necessary for them to be active members in the process, and for true person-directed services to be realized.
APPENDIX A
IRB ACCEPTANCE LETTER

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Amendment to Research Protocol and/or Consent Document – Expedited Review
UIC Amendment #1

July 28, 2008

Kelly Koomler, BS
Disability and Human Development
1640 W Roosevelt Rd, Room 251
M/C 626
Chicago, IL 60612
Phone: (617) 935-1616 / Fax: (312) 413-4098

RE: Protocol # 2008-0296
“Exploring Client Participation in the Individual Planning Process”

Dear Ms. Koomler:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research and/or consent form under expedited procedures for minor changes to previously approved research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Period: July 17, 2008 – April 15, 2009
Amendment:
Summary: UIC Amendment #1 dated July 5, 2008 (submitted July 11, 2008) is an investigator-initiated amendment and includes the following:
2) Deletion of the following research question: “Are there differences in levels of participation and understanding between residential settings?”
3) Addition of questions to the resident interview guide (Amendment #4 – 7/5/08) to provide richer data about the client’s experience of the individual planning process.
APPENDIX A (continued)
IRB ACCEPTANCE LETTER

Approved Subject Enrollment #: 30
Performance Sites: UIC
Sponsor: None

Revised Recruiting Material(s):

a) Agency Letter of Invitation to Participate in Research (no version number, no date, as submitted July 11, 2008)
b) Guardian Letter of Invitation to Participate in Research (no version number, no date, as submitted July 11, 2008)

Revised Assent(s):

a) Assent to Participate in Research (no version number, no date, as submitted July 11, 2008)

Revised Parental Permission(s):


Please note the Review History of this submission:

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<th>Receipt Date</th>
<th>Submission Type</th>
<th>Review Process</th>
<th>Review Date</th>
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<tr>
<td>07/11/2008</td>
<td>Amendment</td>
<td>Expedited</td>
<td>07/17/2008</td>
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Please be sure to:

⇒ Use only the IRB-approved and stamped consent document(s) enclosed with this letter when enrolling subjects.

⇒ Use your research protocol number (2008-0296) on any documents or correspondence with the IRB concerning your research protocol.

⇒ Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB #2 has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 355-2908. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,
Charles W. Hoehne
Assistant Director, IRB # 2
Office for the Protection of Research Subjects
APPENDIX A (continued)
IRB ACCEPTANCE LETTER

Enclosure(s):

1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
2. **Assent Document(s):**
   a) Assent to Participate in Research (no version number, no date, as submitted July 11, 2008)
3. **Parental Permission(s):**
4. **Recruiting Material(s):**
   a) Agency Letter of Invitation to Participate in Research (no version number, no date, as submitted July 11, 2008)
   b) Guardian Letter of Invitation to Participate in Research (no version number, no date, as submitted July 11, 2008)

cc: Glenn T. Fujiura, Disability and Human Development, M/C 626
    Tamar Heller, Disability and Human Development, M/C 626
APPENDIX B
AGENCY LETTER OF INVITATION TO PARTICIPATE IN RESEARCH

“Exploring Client Participation in the Individual Planning Process”

Your participation is being requested for a research project being conducted at the University of Illinois at Chicago through the Department of Disability and Human Development. The study is being conducted by graduate student, Kelly Koomler for her thesis research project and is focused on the participation of clients with intellectual disabilities in their individual planning meetings.

If your agency agrees to participate, you will be asked to identify clients you are currently serving who fit the criteria for the study. For clients who meet the criteria, you will be asked to mail a letter of invitation and consent form directly to their legal guardian. Mailing materials, the letter of invitation, consent form, and postage will be provided by Ms. Koomler. All materials for a second mailing will also be provided to you to send to guardians who do not respond to the initial mailing. Lastly, you will be asked to provide basic information for each participating client such as diagnosis and level of communication.

The research methodology will consist of Ms. Koomler observing individual planning meetings and using a checklist to take notes on how clients participate during their meeting. For those clients who are willing and able to do so, Ms. Koomler will conduct a short interview following their meeting, using a semi-structured interview guide.

The information we will learn through this research study is very important in understanding how individuals with intellectual disabilities participate in their individual planning meetings. Your willingness to participate is greatly appreciated.

Kelly Koomler, Principal Investigator
University of Illinois at Chicago
Department of Disability and Human Development
1640 W Roosevelt Rd. Room 251
Chicago, IL 60608
(617) 935-1616
kkoomler@aol.com
APPENDIX C
GUARDIAN LETTER OF INVITATION TO PARTICIPATE IN RESEARCH

“Exploring Client Participation in the Individual Planning Process”

A research study is being conducted at the University of Illinois at Chicago
through the Department of Disability and Human Development on client participation
during individual planning meetings. Your son, daughter, or legal ward has been
identified by their service provider as fitting the criteria for participation and has an
individual planning meeting scheduled within the timeframe of this study.

If you provide permission for your son, daughter, or legal ward to participate, as
the principle investigator, I will attend their individual planning meeting and observe how
he or she participates. After their meeting there will be a short interview where I will ask
him or her a few questions about the meeting.

Participation in this study is completely voluntary. Even if you provide permission
for your son, daughter, or legal ward to participate, he or she may choose not to.
However, he or she may not participate without your permission.

There are no foreseeable risks to participating in this study but if you change
your mind, you may withdraw your permission at any time. Your son, daughter, or legal
ward may also chose to stop participating without negative consequences. All personal
and identifying information will be kept strictly confidential and only the researcher will
have access to identifying information.

While there are no direct benefits to the individuals who participate in this
research study, it is hoped that the information gathered will help other researchers
better understand individual planning and how clients participate in the planning
meeting.

This study is being done by Kelly Koomler (Principal Investigator) at the
Department of Disability and Human Development at the University of Illinois at
Chicago. If you have any questions you may contact Kelly Koomler at (617) 935-1616
or you can email her at kkoomler@aol.com. You may also contact Glenn Fujiura at
(312) 413-1977 or gfujiura@uic.edu. You may call either of these numbers collect. If
APPENDIX C (continued)
GUARDIAN LETTER OF INVITATION TO PARTICIPATE IN RESEARCH

you have further questions or concerns you may contact the University of Illinois Institutional Review Board (IRB) at (312) 996-1711 or uicirb@uic.edu.

The information we will learn through this research study is very important in understanding how individuals with intellectual disabilities participate in their individual planning meetings and your willingness to participate is greatly appreciated.

Please read the attached consent form and return it by mail in the envelope provided if you agree to participate.

Thank you,

Kelly Koomler, Principal Investigator

University of Illinois at Chicago
Department of Disability and Human Development
1640 W Roosevelt Rd. Room 251
Chicago, IL 60608
(617) 935-1616
kkoomler@aol.com
APPENDIX D
GUARDIAN LETTER OF CONSENT

University of Illinois at Chicago
Consent for Participation in Research

“Exploring Client Participation in the Individual Planning Process”

Why am I being asked?

You are being asked to provide consent for your son, daughter, or legal ward to be a subject in a research study about client participation in their individual planning meetings conducted by Kelly Koomler at the Department of Disability and Human Development at the University of Illinois at Chicago. You are being asked to give consent because your son, daughter, or legal ward had been identified by their service provider as fitting the criteria for inclusion in this research project and may be eligible to participate. We ask that you read this form and ask any questions you may have before providing consent for your son, daughter, or legal ward to be in this research study.

Participation in this research is completely voluntary. Your decision whether or not to allow your son, daughter or legal ward to participate will not affect their current or future relations with the University or their current service provider. If you decide to provide consent, you are free to withdraw your consent at any time without affecting that relationship. Your son, daughter, or legal ward will also be free to stop participating at any time if he/she chooses to do so.

Why is this research being done?

The purpose of this research study is to look in-depth at the extent to which persons with intellectual disabilities participate in their individual planning meetings. The study also will attempt to identify if he/she understand the purpose of the meeting. Lastly, the study will try and identify if there are any differences in these things between different types of residences.

The information for this study will be gathered by a researcher observing these individual planning meetings and taking notes on different kinds of participation and when participation happens. To identify if individuals understand the purpose of their meeting, the researcher will interview each client following their meeting. The researcher will then compare all of this information to identify any differences between types of residential service providers.

Because the research is taking place during their regularly scheduled individual planning meeting, there is no more than minimal risk for participants who agree to participate. While there is no direct benefit to individuals who agree to participate, it is hoped that the knowledge gained from this research will benefit future research and add to the knowledge base in this field of study.
What is the purpose of this research?

The purpose of this research is to try and understand how much individuals with intellectual disabilities, living in both group homes and institutions, participate in their individual planning meetings, if they understand the purpose of the meeting, and whether there are any differences between facility types in these areas.

What procedures are involved?

If you agree to allow your son, daughter, or legal ward to be in this research, we would ask them to do the following things: 1) Allow the researcher to attend his/her individual planning meeting and take notes on their level of participation during the meeting, and 2) Meet with the researcher after the meeting for a short semi-structured interview about their views on the meeting if he/she is able and willing to do so.

Their participation will be limited to the day of their meeting which will take place at the time and location determined by his/her service provider.

No more than 50 research subjects will be involved in this research at the University of Illinois at Chicago.

What are the potential risks and discomforts?

There are no anticipated risks with this research. The information will be gathered during a regularly scheduled meeting which would occur whether or not the researcher attended. However, if the research subjects are uncomfortable at any time with the researcher’s presence, they may stop their participation at any time.

Are there benefits to taking part in the research?

While there are no direct benefits to participating in this study, the information gathered will be used to inform other researchers, inform further research projects, and add to the knowledge base in field. General de-identified information will also be shared with service providers so they may use the information to reflect on and evaluate their individual planning practice.

Will I be told about new information that may affect my decision to participate?

During the course of the study, you will be informed of any significant new findings (either good or bad), such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation, that might cause you to change your mind about continuing in the study. If new information is provided to you, your consent to continue participating in this study will be re-obtained.
APPENDIX D (continued)
GUARDIAN LETTER OF CONSENT

What about privacy and confidentiality?

The only people who will know that your son, daughter, or legal ward is a research subject are members of the research team. No information about them, or provided by them during the research, will be disclosed to others without your written permission, except:

- if necessary to protect their rights or welfare (for example, if they are injured and need emergency care or when the UIC Institutional Review Board monitors the research or consent process); or
- if required by law.

When the results of the research are published or discussed in presentations, no information will be included that would reveal their identity. Any information that is obtained in connection with this study and that can be identified with them will remain confidential and will be disclosed only with your permission or as required by law.

Personal information, research data, and related records will be kept in a locked cabinet accessible only by the researcher. All records will be coded using a pseudonym for privacy protection.

What if I am injured as a result of my participation?

In the event of injury related to this research study, treatment will be made available through the University of Illinois at Chicago Hospital. However, you or your third party payer, if any, will be responsible for payment of this treatment. There is no compensation and/or payment for such medical treatment from the University of Illinois at Chicago for such injury, except as may be required of the University by law. If you feel you have been injured, you may contact the researcher, Kelly Koomler at (617) 935-1616.

What are the costs for participating in this research?

There are no costs associated with participating in this research study.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will not be reimbursed for any expenses occurred nor will you be paid for your participation.
Can I withdraw or be removed from the study?

You can choose whether to allow your son, daughter, or legal ward to be in this study or not. If you allow them to participate in this study, you may withdraw your consent at any time without consequences of any kind. You may also refuse to answer any questions you don’t want to answer and still have them remain in the study. The investigator may withdraw them from this research if circumstances arise which warrant doing so.

Who should I contact if I have questions?

The researcher conducting this study is Kelly Koomler. You may ask any questions you have now. If you have questions later, you may contact the researcher at (617) 935-1616. You may also contact Dr. Glenn Fujiura at (312) 413-1977.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or you have any questions about your rights, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 (local) or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

What if I am a UIC student?

You may choose not to allow your son, daughter, or legal ward to participate or to stop their participation in this research at any time. This will not affect your class standing or grades at UIC. The investigator may also end their participation in the research. If this happens, you class standing or grades will not be affected. You will not be offered or receive any special consideration if you participate in this research.

What if I am a UIC employee?

Your consent for your son, daughter, or legal ward to participate in this research is in no way a part of your university duties, and your refusal to allow them to participate will not in any way affect your employment with the university, or the benefits, privileges, or opportunities associated with your employment at UIC. You will not be offered or receive any special consideration if you allow for their participation in this research.

Remember: Participation in this research is voluntary. Your decision whether or not to allow your son, daughter, or legal ward to participate will not affect your current or future relations with the University or their current service provider. If you decide to allow them to participate, you are free to withdraw your consent at any time without affecting that relationship.
APPENDIX D (continued)
GUARDIAN LETTER OF CONSENT

You will be given a copy of this form for your information and to keep for your records.

Signature of Subject or Legally Authorized Representative

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to allow my son, daughter, or legal ward to participate in this research. I have been given a copy of this form.

_________________________________________  ____________________________
Signature                                      Date

____________________________________________
Printed name

____________________________________________  ____________________________
Signature of parent or guardian                  Date (must be same as subject's)

____________________________________________
Printed name of parent or guardian

____________________________________________  ____________________________
Signature of researcher                           Date (must be same as subject's)

____________________________________________  ____________________________
Signature of witness (if appropriate)            Date (must be same as subject's)

____________________________________________
Printed name of witness (if appropriate)
Exploring Client Participation in the Individual Planning Process

1. My name is Kelly Koomler.

2. We are asking you to take part in a research study because we are trying to learn more about your individual planning meeting. Specifically, I want to learn about how you participate and how often.

3. If you agree to be in this study I will first sit and watch your individual planning meeting and take notes. After your meeting, if you agree, I will ask you a few questions about the meeting.

4. I don’t think there are any risks to you if you participate in this research study. This means that you are not in any danger and are not going to be hurt by participating. But, if you feel uncomfortable at anytime, we can stop.

5. There are not any benefits to you by participating, but it will help me and other researchers learn more about individual planning meetings and how residents participate in them.

6. I will also be asking your parents or guardians to give their permission for you to take part in this study. But even if your parents or guardian say “yes” you can still decide not to do this.

7. If you don’t want to be in this study, you don’t have to. Remember, being in this study is up to you and no one will be upset if you don’t want to participate or even if you change your mind later and want to stop.

8. You can ask any questions that you have about the study. If you have a question later that you didn’t think of now, you can call me at (617) 935-1616.

9. Signing your name at the bottom means that you agree to be in this study. You and your parents or guardian will be given a copy of this form after you have signed it.

________________________________________________________________________  __________
Name of Subject                                                                 Date

________________________________________________________________________  ________
Signature                                                                       Age
Why am I being asked?

You are being asked to be a subject in a research study about your participation in your individual planning meeting. The research is being done by Kelly Koomler at the Department of Disability and Human Development at the University of Illinois at Chicago. You are being asked to participate because your service provider identified you as someone who could be included in this research. Please read this form and ask any questions you have before agreeing to be in the research.

Your participation in this research is voluntary which means that you do not have to participate if you do not want to. Whether or not you decide to participate will not change your current or future relationship with the University or your current service provider. If you decide to participate, you can choose to stop participating at any time without changing that relationship.

Why is this research being done?

The purpose of this research is to look at how much people with disabilities participate in their individual planning meeting. The research will also try to see what people think about their meeting and if they understand it.

The information for this research will be collected by a researcher watching your meeting and taking notes about your participation. The researcher will also ask you some questions about your meeting after it is over, if you agree.

Since the research will be happening during your meeting, there is no more than minimal risk for you if you agree to participate. Even though you do not get anything from participating, the information gathered during your meeting, if you agree to participate, will be beneficial to researchers in the future.

What is the purpose of this research?

The purpose of this research is to try and understand how much people with disabilities participate in their individual planning meeting and what they think about their meeting.
APPENDIX F (continued)
CLIENT CONSENT TO PARTICIPATE IN RESEARCH

What procedures are involved?

If you agree to be in this research, we would ask you to do the following things:
1. Allow a researcher to watch your meeting and take notes about your participation.
2. Meet with the researcher after your meeting to answer a few questions about the meeting.

Your participation in the research will be only during the time of your meeting and to answer the questions directly after the meeting.

No more than 30 research subjects will be in this research at the University of Illinois at Chicago.

What are the potential risks and discomforts?

There are no expected risks to you if you participate in this research. The information collected will be during your meeting which would take place whether or not the researcher was there. But, if you feel uncomfortable at any time with the researcher's presence, you can stop participating at any time.

Are there benefits to taking part in the research?

There are no benefits if you agree to participate in this research but your participation will help other researchers and add to the knowledge about individual planning.

Will I be told about new information that may affect my decision to participate?

During the course of the study, you will be informed of any significant new findings (either good or bad), such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation, that might cause you to change your mind about continuing in the study. If new information is provided to you, your consent to continue participating in this study will be re-obtained.
APPENDIX F (continued)
CLIENT CONSENT TO PARTICIPATE IN RESEARCH

What about privacy and confidentiality?

The only people who will know that you are a research subject are members of the research team. No information about you, or provided by you during the research, will be given to anyone else without your written permission, except:

- if necessary to protect your rights or welfare (for example, if you are injured and need emergency care or when the UIC Institutional Review Board monitors the research or consent process); or

- if required by law.

When the results of the research are published or discussed in conferences, no information will be included that would reveal who you are.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

Personal information and research data will be kept in a locked cabinet accessible only by the researcher. All records will have your name removed to protect your identity.

What if I am injured as a result of my participation?

In the event of injury related to this research study, treatment will be made available through the University of Illinois at Chicago Hospital. However, you or your third party payer, if any, will be responsible for payment of this treatment. There is no compensation and/or payment for such medical treatment from the University of Illinois at Chicago for such injury, except as may be required of the University by law. If you feel you have been injured, you may contact the researcher, Kelly Koomler at 617-935-1616.

What are the costs for participating in this research?

There are no costs for participating in this research.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will not be reimbursed for any expenses occurred by participating and you will not be paid for participating.
Can I withdraw or be removed from the study?

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

Who should I contact if I have questions?

The researcher conducting this study is Kelly Koomler. You may ask any questions you have now. If you have questions later, you may contact the researchers at: (617) 935-1616. You may also call Dr. Glenn Fujiura at (312) 413-1977.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or you have any questions about your rights as a research subject, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 (local) or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Remember: Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to stop participating at any time without affecting that relationship.
APPENDIX F (continued)
CLIENT CONSENT TO PARTICIPATE IN RESEARCH

You will be given a copy of this form for your information and to keep for your records.

Signature of Subject or Legally Authorized Representative

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I have been given a copy of this form.

__________________________  ______________________
Signature                                        Date

__________________________
Printed Name

__________________________  ______________________
Signature of Researcher                             Date (must be same as subject’s)

__________________________  ______________________
Signature of Witness (if appropriate)                  Date (must be same as subject’s)

Printed name of Witness (if appropriate)
### APPENDIX G
### PARTICIPATION CHECKLIST

Client: ____________________________________________  Date: ______________________

<table>
<thead>
<tr>
<th>Introduced Self</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<table>
<thead>
<tr>
<th>Provided Information</th>
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<table>
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<tr>
<th>Sought Information</th>
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<table>
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<tr>
<th>Joined in Group Discussion</th>
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<table>
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<tr>
<th>Expressed Opinions</th>
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<table>
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<tr>
<th>Made Choices</th>
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<tr>
<th>Non-verbal Participation</th>
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<tr>
<th>Provided Feedback</th>
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<table>
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<tr>
<th>Suggested Goals</th>
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<table>
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<tr>
<th>Responsible for goals/client actively participated</th>
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</thead>
</table>

0 - no prompt/no participation  1 - prompted/no response  2 - responded to prompt  3 - independent participation
APPENDIX H
INTERVIEW GUIDE

NAME:________________________________ DATE:___________________

1. Who was this meeting for?

2. Do you know what the meeting is for? (the purpose)?

3. If you remember, tell me some of the goals that were written for you today.

4. Who decides what goals you will work on?

5. Do the people at your meeting listen to what you say about the things you want and your suggestions?

6. Do you like the goals that were written for you? Why or why not?

7. What was the best part of your meeting?

8. What would you change about your meeting?
CITED LITERATURE


CITED LITERATURE (continued)


CITED LITERATURE (continued)


VITA

NAME: Kelly Koomler

EDUCATION: B.S., Exceptional Child Education, Western Kentucky University, Bowling Green, Kentucky, 2000

M.S., Disability and Human Development, University of Illinois, Chicago, Illinois, exp. 2013

PROFESSIONAL MEMBERSHIP: American Association Intellectual and Developmental Disabilities

Society for Disability Studies

LICENSURE: Massachusetts Educator: Moderate Disabilities (PreK-8)

EMPLOYMENT: Assistant Director of Residential Services
Jewish Family & Children’s Service, Waltham, MA