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The Benefits and Barriers to Person Centered Planning for Adults with Developmental Disabilities

By

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MSW Clinical Research Paper

Presented to the Faculty of the School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
In Partial fulfillment of the Requirements for the Degree of
Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

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Abstract

The purpose of this study was to explore the benefits and barriers to implementing Person Centered Planning as a replacement for, or in addition to traditional service planning for adults with developmental disabilities. Person Centered Planning was chosen because it's main focus is on enhancing quality of life and putting the "client" into the expert role over their own life. Person centered planning, or as many people call it, "person centered thinking" is not a new concept, however it is only recently that people have become more aware of it and steps have been taken to train people to implement it. A qualitative exploratory design was used to hear from the voices of people who have first hand knowledge and experience with using person centered planning for individuals with DD/ID. The strongest theme that emerged from this study is that PCP is individualized planning that puts the client into the role of expert over his or her life. This expert role allows for increased self-determination because it increases choices in areas such as types of living arrangements, type of employment, and leisure activities. The circle of support may be the most important component of helping the focus person achieve their future vision. The limitations of this research, along with recommendations for future researchers are also included in this study.

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Individuals with intellectual disabilities or developmental disabilities (DD/ID) are people who have a formal diagnosis of mental retardation. According to the American Psychiatric Association [APA], 2000), an individual with an intelligence quotient (IQ) of about 70 or below with some level of impairment in adaptive functioning may be diagnosed with mental retardation, however the diagnosis must occur before the age of 18. Traditionally, people with DD/ID have had limited control over their environments and limited choices in the services they receive due to institutionalized residential placement.

According to Pollack (2011), there was little if any federal aid to support programs and treatment for individuals with DD/ID prior to the 1950's. Due to stigma, limited resources, and lack of community support, it was a common practice to place children and adults with DD/ID in large institutional settings. In the 1950's, parents of children with DD/ID came together to raise awareness and support for their children by forming the National Association of Retarded Children (NARC). The Disabled Child (DAC) program emerged in 1956 and allocated entitlement security funds for adults with DD/ID when their parent, who was the primary working beneficiary retired or became deceased. In 1958 the Education for Mentally Retarded Children Act allocated federal funds to train teachers to educate children with DD/ID in various contexts.

In the 1960's Medicaid and Medicare was established and became the primary funding sources for DD/ID services. Medicaid became the funding source for services, which included long-term care, case management, education, and medical services. Medicaid also started funding community residential placements such as intermediate care facilities (ICF's) and home and community based services (HCBS) (Pollack, 2011).

HCBS is available across 48 states in the U.S. (Robinson et al. 2012). According to Lakin and Stancliffe (2007), the government supported these changes and the decreased need for institutional placement, but support fluctuated until the Americans with Disabilities Act (ADA) was passed. The ADA supports inclusion for people with DD/ID by requiring states to place individuals with DD/ID in the least restrictive and most integrated residential settings as possible with regards to what the individual with DD/ID deems appropriate or preferred.

As discussed by Lakin and Stancliffe (2007), the process of de-institutionalization for people with DD/ID began in 1967, however the movement progressed more rapidly starting in 1977. In 1977 83.7% of people with DD/ID receiving services lived in institutional settings compared to 16.3% in 2005. This caused a rise in people with DD/ID receiving services in community settings, such as group homes. There has been a continual growth and trend towards inclusion and self-determination that has been supported by state and federal laws and policies. Community settings align with these trends because they provide more opportunities for choice, social activities, and involvement with friends and families.

Person Centered Planning (PCP) was developed in the 1980's as a tool to enhance the quality of life for individuals with Developmental and Intellectual Disabilities (DD/ID) (Holburn, 2002). The application of person centered planning entails the development and implementation of a plan specific to the individual's needs and ambitions with the guidance of a circle of support. The circle of support is often made up of family, friends, and trained staff that is closely involved in the person's life (Robertson et al. 2007). PCP is linked to or perhaps grew from the concept of self-determination.

According to Smith, Morgan, & Davidson (2005), self determination is the use of one's own values to freely exert control over decision making and future goals. Levels of self-determination are associated with age, maturity, and autonomy of individuals in the general population. This is also true for someone with DD/ID, however there may be less choice availability for people based on the severity of their disability. In the past there was traditionally limited choice and control because people with DD/ID generally lived in institutional settings and there was limited access to additional resources.

States have the responsibility of developing and operating their own residential facilities for people with DD/ID. The federal government will then reimburse 50-76% of costs through Medicaid as long as the facilities comply with the minimum federal standards. As the population of people with DD/ID continues to grow and the people are living longer lives, there are concerns about continued care and support services. Medicaid is often targeted for cost-containment, which affects the level of services that can be provided (Lakin & Stancliffe, 2007).

Person Centered Planning uses self-determination and inclusion to promote human dignity and worth, and satisfaction with quality of life. It is in alignment with the values and standards set forth by the National Association of Social Workers (NASW) code of ethics. According to the NASW code of ethics (2008), It is the mission of social work to promote the well being of all people, particularly oppressed and vulnerable populations through advocating for change and social justice. PCP promotes the NASW core value of the dignity and worth of the person by supporting self-determination through client participation in decision-making and respecting differences in each individual. PCP also supports the value of the importance of human relationships. The

PCP circle of support works together with the client to create a plan for enhancing general well being and promoting meaningful relationships with family, friends, and the community.

It is important for social work to ensure that people with DD/ID continue to get adequate services that support the values of the NASW code of ethics. According to Robinson, et al. (2012), it is often the role of the social worker to provide assessment and co-ordination of care for people with DD/ID. Social workers also advocate for and connect people with needed services and resources. These services often include education, housing, day services, health care, transportation, and recreation. They are often closely involved in future planning and goal development as part of an interdisciplinary team.

Funding for continued growth and cost containment in providing adequate services is increasingly supported by empirically based evidence. According to Roberts-DegGennaro (2008), empirically based practice (EBP) has become the trend in social work and similar professions. With the growing trend towards EBP and an increasing need to show outcomes for funding sources, it is essential to do more research on the effectiveness of PCP and other treatment interventions to determine what components produce the most desirable outcomes.

Often times a social worker or other qualified human services professional may take on the role of case manager for individuals with DD/ID. As discussed by Hennepin County, Minnesota (2013), the assigned case manager is responsible for assisting individuals with coordinating services tailored to the individual's needs. These service needs and preferences often include social, educational, vocational, residential, and

medical services. Case Managers also guide the development of an individual service plan (ISP), which addresses client goals and service needs. PCP seems to go hand in hand with the ISP goal development process.

It is the intention of this study to uncover the benefits and barriers to implementing person centered planning for adults with DD/ID. A qualitative exploratory design was used to research the benefits and barriers to implementing the PCP model for adults with DD/ID. Snowball sampling was used to find participants who have been trained in PCP, have at least 1 year of experience working with adults with DD/ID, and have been using PCP in program planning for adults with DD/ID for a duration of 6 months or longer.

Literature Review

Introduction to Person Centered Planning

People with DD/ID have been given a diagnosis of mental retardation (MR) as determined through standardized testing before the age of 18. A person can be diagnosed with MR if they have significantly lower intelligence than the general population determined as having an IQ around 70 or below and some form of impairment in adaptive functioning. Adaptive functioning is how one adjusts to common daily demands and their level of independence as compared with individuals of a similar age, culture, and social background. Individuals may be diagnosed with mild, moderate, severe, or profound MR depending on their level of impairment in intellectual functioning (American Psychiatric Association [APA], 2000). The type or amount of services a person with DD/ID will need is dependent on his/her level of intellectual impairment and adaptive functioning.

Person Centered Planning (PCP) was developed in the 1980's as a way to increase quality of life by promoting choice and enhancing experiences for people with DD/ID. It is also meant to decrease isolation and develop a more comprehensive understanding of the wants and needs of people with DD/ID. There are many approaches to developing and implementing a plan and the process is ongoing. The process involves developing a circle of support consisting of various people in the individual's life, that may include friends, family, residential or day treatment staff, community members, and a facilitator. (Holburn, 2002). The circle of support works with the individual to develop goals based on his/her ambitions and provide supports specific to the individual's needs to work towards accomplishing the goals (Robertson et al. 2007).

Evidence has emerged in the US and the UK showing that PCP can be effective (Robertson et al. 200). PCP is an expansion on the concepts of inclusion and self-determination for people with DD/ID in response to the de-institutionalization movement. A study done by Robertson et al. (2007), introduced PCP to four participating sites in England where external consultants collaborated with organizations to create policies and procedures for the implementation of PCP. Training and support was provided for free to facilitators and managers over the course of 2 years. There were 93 people representative of the full range of DD/ID and between the ages of 16-86 that gave consent to participate in the development and implementation of a PCP plan. The study included ongoing follow up through structured interviews with key informants that knew the client well. Every three months, the key informants were asked open-ended questions to address barriers to the development and implementation of PCP. At the end of the study, the trained facilitators of PCP were asked to complete a final questionnaire aimed at identifying general views of PCP and identifying organizational barriers and barriers for the focus person in the development and implementation process of PCP.

According to Robertson et al. (2007), several barriers were found to hinder the development and implementation of PCP in their study. Main barriers included maintaining trained facilitators, lack of time, staffing issues, limited community support, and limited choice for residential and day treatment services. They also found perceived benefits for individuals who were able to successfully implement a PCP plan. These benefits included more opportunities to participate in preferred activities, and more choice over where they live and work.

Population and treatment responses for people with DD/ID

Prior to the de-institutionalization movement that began in the 1960's, people with DD/ID were excluded from mainstream education, vocational settings, and community residential placement. Life in an institution was often overcrowded, understaffed, and conditions in several institutional settings were described as inhumane (Pollack, 2011). The development of NARC in the 1950's raised awareness about the DD/ID population and many of the challenges they and their families faced in regards to attaining basic services, such as education, social services, medical care, and respite care.

The Education for Mentally Retarded Children Act in 1958 allocated funds to train teachers to work with the DD/ID population in an attempt to increase accessibility for an education. According to Martin, E., Martin R., & Terman (1996), the act was not enforced and schools were able to turn away people that they determined were uneducable. Sometimes individuals were accepted into the mainstream classes, but without any specialized services. The American With Disability Act of 1970 expanded service eligibility for people with DD/ID and helped to further the movement of de-institutionalization by making it possible for more people with DD/ID to move into community residential settings (Pollack, 2011).

In more recent years, services and goals have generally been designed with outcomes in mind that will lead to skill development and increased independence. According to O'brien, C. L., O'brien, J., & Mount (1997), traditional procedures for individual program planning (IPP) often focus on the voice of people that are in a clinical role, while placing less importance on the voice of the client, friends and family of the client, and direct service providers. PCP grew from an ideal of inclusion and self-determination for people with DD/ID to help them achieve their visions and dreams. In

one approach where PCP was first introduced to practice, the circle of support met outside of regular scheduled meetings and consisted of voluntary members of the community, families, and staff who know and care about the client.

According to O'Brien, C. L., O'Brien, J., & Mount (1997), PCP has become more widely accepted and implemented by various organizations and it is sometimes used as a tool to comply with policies and regulations. With wide spread adaptation and implementation of PCP, meetings and outcomes could become regulated and mandated. This may cause people to lose focus of the intention to change service practice and enrich community life through supporting the client's own self-determination.

Benefits to using Person Centered Planning

The concept of Person Centered Planning (PCP) values autonomy, respect, relationships, inclusion, quality of life, and self-determination for people with DD/ID. PCP is in alignment with current cultural practice as we have been shifting from a treatment paradigm that focuses on health and safety to a paradigm that embraces self-determination and choice (Holburn, 2002). PCP can be traced back to the normalization principle that came about in the 1960's, which coincided with the movement of de-institutionalization for individuals with DD/ID. Lakin & Stancliffe (2007) describe how people with DD/ID living in smaller community settings versus large institutions allows for more choice, greater involvement with family and friends, and increased involvement in social activities.

According to Renzaglia, Karvonan, Drasgow, & Stoxen (2003), the philosophy of inclusion, which means creating an environment that meets everyone's needs, also developed from the principle of normalization. Inclusion embraces diversity and creates

an environment for everyone to thrive and maximize their potential. It is meant to encompass all social communities and environments. Inclusion promotes equal opportunities and individualization for people with DD/ID across the lifespan. Because inclusion is not a program or a place, but a philosophy, it can be looked at from the perspective of universal design.

Universal design is an architectural term that means to design structures or buildings to accommodate all people that might potentially use it. If the divergent needs of people are considered during the design process, then it can be beneficial to all users because there won't be the need to make those accommodations or adjustments at a later time. Universal design means to create or develop an environment inclusive to the needs of all potential users. This idea can be expanded to cover learning environments, employment, social, recreational, and various other community environments. PCP is one of the tools that can be used for promoting inclusion. Greater success for achieving goals of PCP may be dependent on universal design because it allows for greater accessibility across a variety of settings (Renzaglia et al., 2003).

Other areas to consider when advocating for inclusion and normalization are positive behavior support, self-determination and ecological inventory. Positive behavior support involves completing a functional assessment to determine an individual's capabilities and needs. It also involves assessing for potential problem behaviors so that a behavior support plan can be put into place as a proactive strategy to provide positive reinforcement to increase adaptive behaviors. Self-determination takes into consideration the client's current skills, interests, and needs. Some self-determination skills may need to be taught to clients so they can have more control over the decision-making in their

lives. Ecological inventory means to prioritize skills, instruction, and support that an individual may need in order to thrive in their current environments and to discover future plans (Renzaglia et al., 2003).

Barriers to the implementation of Person Centered Planning

Cultural practices in the United States tend to reinforce the popularity of PCP because it is individualistic and favorable to adaptation within the culture, however there are also several barriers to the planning and implementation process. In order to implement PCP, co-operation is required between multiple agencies (Holburn, 2002). According to a study by Robertson et al. (2007), the main barriers to PCP development are limited time and difficulty with facilitator implementation. When trained facilitators left or got sick, there weren't any replacements. Lack of time, along with staffing issues were also reported barriers to the plan development.

After a plan has been developed, there are also barriers to goal attainment such as the availability of services. People with DD/ID tend to have limited housing options, day treatment services, and lack of accessible community activities to choose from. There may also be limited community support, with the exception of paid staff (Robertson et al. 2007). There may also be hesitancy to give up control to the individual being served (Holburn, 2002). Limited housing and day service options can be attributed to fiscal restraints because budget cuts have been made in the DD/ID service field during recent years in response to the recession (Pollack, 2011).

It can be more difficult to implement PCP for individuals who have more complex needs, such as limited mobility, behavioral problems, health concerns, and limited communication skills (Robertson et al. 2007). While self-determination develops

with age and maturity levels in the general population, it may develop at different rates or with more controls in place for somebody with DD/ID. The level of disability is also related to the level of self-determination in adulthood. People with moderate to severe disabilities tend to have less choice availability in their lives when they reach adulthood. Self-determination may also decline later in life as an individual ages (Smith et al. 2005). Since PCP is based upon one's ability to use self-determination in gaining control over decision making, more time and creative techniques may be needed to develop and implement a plan for adults with moderate to severe DD/ID or for aging adults with DD/ID.

Trends that may effect cultural adaptation of PCP

PCP is considered to be the law in many states and it can be found in agency policies, government regulations, and procedure manuals. There are various forms and approaches for following PCP guidelines and there has been little comparative research for determining which methods have been most effective. PCP has become popular in the DD/ID subculture and it will be more likely to survive if it is adapted by the larger culture. Trends that may affect adaptation of PCP include managed care, fiscal restraints, privatization, growing waiting lists for residential and day services, regulatory restraints, and labor unions. These trends often impact the funding resources that are used for service provision. Conflicting values within and across cultures may also affect the implementation of PCP (Holburn, 2002).

The trend in the field of social services has shifted towards a paradigm of evidence-based practice (EBP). EBP is a process of gathering evidence through conducting research and integrating effective techniques into practice with clients. The

process involves gathering scientific data to create interventions that are empirically supported to produce desired outcomes (Roberts-DeGennaro, 2008). O'Brien (2002), believes that too much focus on methodological details can distract from the intentions of PCP being a way to promote change by creating more opportunity. Real change comes from a shared interest in supporting people with DD/ID in changing and creating new opportunities so they can live a meaningful life.

According to Pollack (2011), funds for DD/ID services have grown steadily in the United States over the last 40 years and until recently. We are now facing a number of fiscal challenges with the recession. From 2008 to 2009 there was a reduction in state expenditures for DD/ID services across 23 states and federal budget cuts were made across 47 states. Some of the changes in service delivery are related to cuts in Medicaid. These changes include reduced dental services, health care services, and hospice care. Special services at public schools were also cut, making it more difficult for people with DD/ID to get recommended services, such as speech therapy, occupational therapy, and physical therapy. Pollack (2011) also states that reduced spending has led to people with DD/ID not being able to leave their residence as frequently, not seeing friends as often, and not being able to talk to as many people as they had previously. Reduced spending has also led to an ever-increasing waiting list for publicly funded residential services. These fiscal challenges could also effect wide adaptation of PCP because services have become more difficult to access.

Gap in literature

According to Robertson, et al. (2007), there is limited empirical evidence that shows the effectiveness of PCP. Hoburn (2002) states that it would be beneficial to have

a more formal analysis of PCP to achieve a higher success rate and more consistent results. He believes that a scientific approach to analyzing PCP would be beneficial, but it is difficult to operationalise individual components, such as mindful engagement and quality of life.

Summary

PCP is one of the treatment models that developed in response to changing values within the DD/ID subculture, the service delivery system, and within broader society in general. According to Hoburn (2002), the service delivery system for people with DD/ID changed from a medical and custodial model to a model that promotes autonomy, inclusion, and client decision-making. This paradigm shift started in the 1960's prior to the normalization movement. PCP seems to align with the values of the current paradigm, which could prove essential in order for it to survive and thrive. It is also likely that it will continue to change and be revised with emerging research, with changing societal values, or when state and federal regulations mandate the changes.

As discussed by Pollack (2011), we have come a long way in changing the service delivery system for individuals with DD/ID over the past 40 plus years. Strides have been made in moving people into less restrictive community settings and opening the doors to be included in educational and vocational opportunities. There has also been increased access to needed medical, educational, vocational, and social services. At the same time, societal values have shifted towards increasing individuality and choice for individuals with DD/ID. According to Hoburn (2002), cultural practices in the United States tend to support the adaptation of PCP because of its individualistic nature and because it is favorable to adaptation within the culture. PCP is also in alignment with the NASW code

of ethics because it promotes the values of social justice and dignity and the importance of human relationships. It also seems to coincide with the ethical principle of the dignity and worth of the person by promoting individual self-determination with the intention of benefiting the greater society in the process (NASW, 2008).

Conceptual Framework

For the following study, I utilized the concepts of *inclusion and self-determination* along with the *framework from the ecological model* to assess benefits and barriers to Person Centered Planning for adults with developmental disabilities. These concepts were chosen as a way to look at PCP on a broad spectrum and to examine more in depth the effects of PCP for the individual, circle of support, community, organizations and society. The ecological model provides a theoretical framework to analyze the person and environment. As described by Forte (2007), the ecological theoretical framework can be used to better understand the social environment and its influences on human behavior. Individuals are connected to one another in families or groups that make up systems. According to Santrock (2010), Bronfenbrenner's version of ecological theory is based on the influence of several environmental systems, including the *microsystem, mesosystem, and macrosystem*.

The *microsystem* is the setting where the individual lives and in which the individual influences the experiences in this setting. The contexts within the micro system can include the individual's family, peers, school, and neighborhood (Santrock, 2010). In person centered planning for adults with DD/ID, the microsystem might include individual work done with the client and/or their family.

The *mesosystem* consists of interactions between Microsystems and how different contextual connections influence the way in which an individual will behave and adapt in each environment (Santrock, 2010). The mesosystem might include institutional or organizational influences on the environment in which relationships occur (Forte, 2007). This might include an individual's circle of support, family members, peers, and staff.

The individual's interactions within their circle of support, group home, vocational setting, or community environment may influence the outcomes of PCP. The goals of PCP will look differently in a vocational setting than they will in a residential or community setting. Individuals conform to different roles in each environment based on the values, policies, and expectations in the setting.

The *macrosystem* includes the society and subcultures that an individual is part of. Beliefs, behaviors, and societal patterns influence an individual's development throughout the lifespan (Santrock, 2010). *Macrosystem* issues often govern policy and determine legislative agendas. These issues can impact service provision, service eligibility, and how professionals are able to perform their job responsibilities. Cultural trends and beliefs influence policies and affect the availability of resources needed to implement PCP for adults with DD/ID. According to Holburn (2002), cultural practices tend to support PCP because it is individualistic and favorable to adaptation within the environment. Practices that benefit the culture are more likely to be put into place.

In addition to the *ecological model*, it is also relevant to look at the benefits and barriers to PCP using the concepts of *inclusion* and *self-determination* as they relate to the development of the PCP model. Inclusion means there is a place for everyone regardless of abilities. This concept embraces diversity and involves creating an environment that meets everyone's needs. One of the principles of *inclusion* is to make tools available across all social environments for people to attain optimal levels of productivity (Renzaglia, et al., 2003). Without necessary tools or environmental adaptations to gain access to various settings, PCP goals may be limited.

Self-determination is about using one's own values to develop control over decision-making and future goals. The amount of choice a person has is directly related to the setting where one resides and the social influences on the environment. Historically, *self-determination* was limited for individuals with DD/ID living in institutional settings (Smith et al., 2005). There used to be limited staff and opportunities for community integration in large institutional settings, therefore PCP would have been difficult to integrate. As smaller community placements continue to rise for people with DD/ID there is more opportunity for self-determination and PCP.

For the purpose of this study, the researcher used the concepts of *inclusion* and *self-determination* along with the *framework from the ecological model* to guide the development of the interview questions.

Methods

Research Design

For the purpose of this study, a qualitative exploratory design was used to hear from the voices of the experts who are implementing the PCP model. The researcher explored the following research question; what are the benefits and barriers are to the planning and implementation of Person Centered Planning for individuals with Developmental Disabilities/Intellectual Disabilities (DD/ID)? The intention was to hear about first person experiences of developing and implementing PCP from the facilitators and explore more in depth components that are difficult to quantify due to their individualistic nature, such as quality of life, engagement, and self-determination. Thus, a qualitative exploratory design was used in this study.

According to O'brien, C. L., O'brien, J., & Mount (1997), PCP may not be as effective if it is widely implemented without mindful application and consideration of the value of relationships and the agreements necessary for the success of PCP. There are people who seek to evaluate the effectiveness of PCP by counting its outcomes and in essence they are attempting to tally the outcomes of people's life stories. Mindful practice is more involved than counting outcomes. It involves creativity and adaptation while making use of available resources to assist people in moving toward a desirable future where their in the lead of creating their own life story.

Respondents

For the purpose of this study, a qualitative exploratory design was used to research the benefits and barriers to implementing the PCP model for adults with DD/ID, and other populations as applicable. Snowball sampling was used to find participants who

have been trained in PCP, have at least 1 year of experience working with adults with DD/ID, and have been using PCP in program planning for adults with DD/ID for a duration of 6 months or longer.

Instrument

The researcher used a pre-interview questionnaire to collect demographic information from participants prior to the interview. Information covered included gender, age, county of employment, type of setting in which services were provided, type of services provided, and years of experience working with adults who have DD/ID.

The researcher used a set of 10 questions that covered various topics to guide the interview. Topics covered included benefits and challenges to developing and implementing PCP for adults with developmental disabilities, including benefits and challenges for their family, staff, and community. Topics also included client self-determination and inclusion in relationship to implementing PCP.

Data Collection

Data was collected using the following steps:

1. The researcher used snowball sampling to recruit individuals that provide case management and social work services to adults with DD/ID and meet the requirements for the participating in the research. The recruiting process began by contacting 2-3 individuals who have been recommended by one of the researcher's committee members.
2. Initial contact was done via e-mail to find interested parties that meet the research criteria. The e-mail explained how the researcher got the names of potential participants and included an introduction to the study.

3. The introduction was sent via email along with the research questions and the consent form so that the participants could review it prior to making a decision of whether or not to participate.
4. Interested participants scheduled an interview with the researcher.
5. If there was not a response within one week, the researcher made one follow up contact to see if they would like to participate in the research.
6. The interviews lasted approximately 30-60 minutes and took place at the participant's place of employment or a neutral site that was agreed upon by the researcher and the participants.
7. Participants were asked to forward the initial recruitment e-mail as applicable to 2-3 individuals that may have been interested in participating in the study. This process of data collection will be repeated until the researcher has scheduled 8-10 interviews.

Data Analysis

Grounded theory was the analytic strategy used to analyze the data. Grounded theory is a research method used for developing theory by letting the theory originate from, or be grounded in the data (Monette, Sullivan, & Dejong, 2008). Codes and themes developed from analyzing the data. The researcher then used open coding to identify themes from the transcriptions of the interviews.

Researcher Bias

The researcher is familiar with the DD/ID population and embraces the values of self-determination, inclusion and autonomy that are supported by the PCP model. The researcher is also familiar with the traditional process of developing treatment goals and

more recent methods of goal development in which there has been an increased push for client participation and choice in the goal development process. To address these biases, the researcher will have committee members review the clinical paper on an ongoing basis and give feedback.

Findings

Sample

The researcher used snowball sampling to recruit participants. The sample consisted of 4 females and 2 males. Six out of the nine people who were asked to participate in this study met with the researcher in person to partake in interviews. Of the six participants, two individuals worked for the county, one individual worked in a private setting, one individual worked in residential and vocational settings, one individual worked in multiple settings, and one individual worked in a setting marked as other. All of the individuals were based primarily in Minnesota, and a majority of participants work in the metro area. Participants' work experience in the service delivery field ranged from 10-40 years. Out of the 6 participants, one person worked primarily with children.

Themes

This section will present the common themes that were evident and emerged during the data analysis process. To be considered a theme, fifty percent or 3 of 6 participants will have had to discuss the concept in their answers to each question. This section will also include brief summaries of participant responses and direct quotes that were relevant to the themes that were established. Quotations will be italicized.

Understanding of person centered planning?

When asked what their understanding of person centered planning (PCP) is, all of the participants saw person centered planning as an individualized approach that focuses on what the client wants (6 out of 6). Other frequently identified concepts which involved

planning and implementing person centered planning for the focus person, were planning for the future (4 out of 6), and improved quality of life (3 out of 6).

One individual stated: *Person centered planning is a way of planning for people that empowers the choice of the person using services and has it's focus on quality of life, and that tomorrow is better than today* (Case 4, page 1, lines 3 to 5).

Examples of implementing PCP

Participants were asked to give an example of PCP being implemented and all of the examples included the use of a supportive team (6 out of 6). Most often, the examples involved creativity and flexibility to create or implement a plan and find a balance between choice and the risks associated with those choices.

One person gave this example: *he wanted to live on his own and didn't want to work in a sheltered workshop, so the team has figured out a way of having him in an apartment where he gets all of his meals at a very nearby restaurant. They made linkages with the restaurant staff to kind of watch for him and they made linkages with the immediate neighbors in the apartment building and they kind of watch for him, none of whom are paid. We have an arrangement where we pay the restaurant for his food, but he just, he knows to show up. He's very reliable about actually showing up, but if he doesn't, there's somebody from the restaurant who will call and let us know he didn't show up today. Likewise, if the neighbors kind of watch out for him, if they don't hear him or see him they have somebody they call. This somebody that they call is one of our SILS workers..... He also meets with him several times a week, but for relatively short periods of time, but also has agreed to just be a 24-7 available problem solver* (Case 1, page 1-2, lines 41-53).

Benefits of Person Centered Planning

There were several common themes that emerged when asking participants what the benefits are for implementing person centered planning in regards to the client, client's family, staff, and community. The main theme that emerged is that PCP gives the individual authority over decisions and planning in their own life (5 out of 6), and this can empower the person.

PCP also helps create opportunity (4 out of 6), which encompasses greater opportunity for the client and the community. It creates an opportunity to utilize natural or unpaid supports (3 out of 6). The supportive team may consist of both paid supports and natural supports. Holburn (2002), puts emphasis on the supportive team or circle of support being lead by the voices of the focus person, family members, friends, and a facilitator versus members in the service delivery system. As discussed by O'Brien (2002) PCP has greater effectiveness when people are involved that choose to take action that creates opportunities for the individual.

One person stated: *they become a customer, not a commodity. Right now the way our system works, the people who use services are commodities and we fight over them. Which program is going to get how many, and where are they going to go, and where are the empty beds that we are going to let them have, you know, we don't give them life by design, we give them what is left when they show up to participate. So for the client, the consumer or the person who uses services, it shifts them into a role of really being a customer and they get to say, here's my life, here's what I've designed with the people that really care about me, now who out there can help me fulfill that* (Case 4, page 2, lines 66-73).

Another theme that emerged when participants were asked about the benefits to implementing PCP is that the focus becomes more about individual abilities rather than their diagnosis or disabilities (3 out of 6), what's working, which enables them to be engaged and contribute to the community. It's also about empowering the individual.

One of the examples given by a participant was as follows: *and again another story, and this is actually not mine, but from someone who's doing a lot of work with seniors. They had a woman who moved into a nursing home. No one knew her, no one was asking her anything. When they went to do a description and planning with her, they just discovered what was really important, a big thing that was missing for her was church, and so what she was able to get out of these planning meetings was to start knitting some prayer shawls again and start giving back to the community. That was because one person went and said, let's do some planning, let's find out more about you, rather than be content with her sitting in her room, so lot's of wins for every body* (Case 2, page 4, lines 161-167).

Challenges to implementing person centered planning

When asked about the challenges to developing and implementing person centered planning, all participants reported some type of systemic issues in the service delivery system (6 out of 6). These issues included regulatory practices, health and safety concerns, and resources. Participants also talked about challenges that consisted of not having enough time (6 out of 6), inadequate funding (5 out of 6), and problems related to the continuity and commitment of the PCP process (3 out of 6). In this study, one participant stated: *I think that the biggest challenges I've seen are people that have developed really, really great plans and we are stuck in a service system, so staff aren't always in a position to implement them* (case 5, page 2, lines 54-56).

Participants said that person centered planning or thinking is a cultural shift, which creates a challenge because there are people that aren't ready to embrace this different way of thinking (5 out of 6). This different way of thinking includes power sharing and new roles for the client, families, communities, and the people providing services. O'brien (1997), said that traditional methods of planning, such as Individual Program Plans (IPP's) focused more on the voices of individuals in the clinical role and less on the ideas generated by the focus person, family members, friends, and direct care staff. PCP is designed to listen to the voice of the focus person to develop their vision of future planning, with the guidance of their circle of support.

One of the participants said: *I think person centeredness is really a culture, and if you work in a culture where you are used to having control over someone, where you tell them this is what you need to do, this is how you need to do it. This is very, very difficult to make that shift, asking them what would you like me to help you with? So I think unless, if you ask anyone who works in this field, are you person centered, they're going to say yes, but I think there are different levels of person centeredness and giving up that control, weather its the staff, or the family, or the child, giving up that control is very, very difficult, and if you're not in an organization or a culture of person centeredness,*

it's very, very difficult, you know. I know best, I'm the staff, I've been going to school a bazillion years, I've got a lot of experience in this, I know what's best for you. No I don't. I know what's best for me (Case 5, page 3, lines 108-118).

How some challenges with implementing PCP were approached

The most common way participants responded to challenges with planning and implementing PCP was through communication and looking at this new way of thinking as a process of change. People talked about communication as being a key component to working through the challenges, and the responses included communication with service providers, the client, community members, and the client's support system (4 out of 6). Respondents also referred to an understanding that PCP is a change or a shift in thinking which is a process that takes time and planning (4 out of 6). As discussed by Holburn (2002), PCP is a cultural shift and if the larger culture embraces it as the DD subculture has, it will be more likely to survive.

One participant responded: *this is exactly what we are trying to stop, so we're telling workers you're no longer the expert on telling people what to do, your trying to facilitate change. So now managerially we're saying we need to make this change happen without telling people they have to make it, and we're not manipulating them to make it either, but how do we facilitate a process of change rather that dictate a process of change which is largely involved with how do we learn to listen better and talk less* (Case 1, page 8, lines 357-362).

Effect of physical and cognitive abilities on client self-determination and inclusion

Participants were asked if client self-determination and inclusion were affected by their level of physical and cognitive abilities, with four people agreeing that yes it is affected, and two people neither said yes or no. The theme that sticks out the most is support and advocacy being important components of self-determination and inclusion (4 out of 6). People also discussed communication as being an important component contributing to client self-determination and inclusion (3 out of 6).

One of the participants responded: *well they are today, but they don't need to be. We know how to explore and understand people's preferences and desires who are unable to express them. We know how to tell by the way they're behaving what gets them interested and excited, what turns them off and what stops them, but we don't listen to that like communication, we listen to it like there's something wrong* (Case 4, page 5, lines 185-189).

Ways to develop optimal levels of self-determination and inclusion

When discussing optimal levels of self-determination and inclusion across a variety of settings, participants said that strong supports or advocates were essential for achieving optimal levels (4 out of 6). Participants said client choice was important for self-determination (3 out of 6). The researcher was surprised that participants did not mention more environmental factors as creating challenges for people to develop optimal levels of self-determination and inclusion. As discussed by Renzaglia et al. (2003), universal design is a philosophy used to describe ways in which environments adapt to or are created to accommodate all people that may need to access or use them. Increased accessibility creates opportunity to increase self-determination and inclusion for people with developmental disabilities. The variance between participants' answers and the literature may be related to the way in which the researcher's question was worded. Future researchers may want to ask more specifically if environment creates a challenge to inclusion and self-determination. It may also be beneficial to discuss inclusion and self-determination separately instead of lumping them together into one interview question.

One person said: *there's resources, strong access to resources, you know, that we have to have in order for people to have optimal levels of self-determination and inclusion, but I think it really comes down to, where are those advocates, who are those people* (Case 6, page 3, lines 126-129)?

Gaps in current service delivery system

In response to gaps in the current service delivery system, all respondents said yes, there are gaps in the system (6 out of 6). Everyone identified gaps with the process of change in the system, and 4 respondents agreed that the time it takes to implement system change created a gap. Respondents also identified inadequate funding as creating a gap in the service delivery system and four respondents identified gaps related to preparing the focus person and their paid and unpaid supports for the work involved in PCP (5 out of 6). It seems that both fiscal restraints and the process of change in the service delivery system both create gaps in service delivery and are supported by the literature. Pollack (2011), discusses how fiscal restraints, particularly during times of a recession affect service provision, including a decrease in service availability for people with DD/ID.

One individual described the gaps as: *wherever we, at any time when we treat everyone the same way because a rule or a standard or regulation requires us to do that, we are going to be in violation of person centeredness, because the rule is driving what we do and not what works for the individual, so our whole system really doesn't support person centeredness. You can get away with it to a certain extent, but the system doesn't support it, demand it, nurture it, and foster it. The system rides following rule placement. It's a major, major problem* (Case 4, page 7, lines 297-303).

Competence with training received on person centered planning

Overall, participants felt competent with the training they received on person centered planning (4 out of 6). Four people answered yes to feeling competent with the training, one person answered yes and no, and one person didn't give a yes or no answer. When asked this question, two people mentioned the importance of having a mentor or coach, and one person would have liked to have more mentoring when first implementing PCP plans. Participants in this study may have felt increased competence with the training they received because they have several years of experience in the human

services field, have completed extensive training on PCP, and many of the participants train others on how to implement PCP.

When participants were asked if they had anything else that would be helpful to the researcher in the study, there were a variety of answers, however three of the participants talked about unpaid supports and community members playing important roles in the PCP process for plans to be successful.

Discussion

In this section, the researcher will discuss the sample used for this study and how the results may have been influenced by the demographic trends of the participants. The researcher will also examine the themes that emerged and further compare it with the literature. This section will conclude with a brief overview of the purpose of this study and what was gained during the process.

Sample

The sample may have influenced the researcher's results because a majority of the respondents conduct their practice in Minnesota within the metro area. As service providers, the participants are required to comply with federal and state regulations, which may provide similar responses in comparison to the larger population, however answers may vary depending on the rules and regulations of different organizations. Person Centered Planning is not mandated by the state of Minnesota, so this sample may not be representative of other states or rural populations. All of the participants interviewed had extensive training in Person Centered Planning or Person Centered Thinking, had a minimum of 10 years in the field, with a majority of participants conducting training of their own, therefore the answers may have been different if the researcher had interviewed unpaid supports involved in development and implementation of person centered planning.

Overarching Themes

There were several overarching themes that emerged time and time again throughout the interview process. Every participant reflected on person centered planning representing the client as the expert over their own lives, which includes making choices

and planning for the future and also coincides with self-determination (6 out of 6). This also coincides with Holburn's view (2002), that PCP promotes autonomy for the focus person. The focus person's support system was also an essential element that emerged several times when talking about the successes of PCP (6 out of 6). All of these themes were consistent with the literature.

When discussing challenges to implementing PCP and gaps in the service delivery system, participants repeatedly brought up health and safety versus risk and opportunity as being a barrier for the client, more specifically when the client's support system disagrees with client choices or the service system either can't or won't support implementation due to rules and regulations and resources. PCP is viewed as a cultural shift (3 out of 6), which is a process that takes time for society to get accustomed to.

The researcher had various responses to the question about whether or not self-determination and inclusion was effected by a person's level of physical and cognitive abilities. The literature mentions environmental adaptations as being factors as to whether or not an individual can experience enhanced inclusion in the community and various activities, however, mention of environmental factors was limited in participant responses.

Benefits of the PCP model

The benefits of using the PCP model are that it empowers the individual and supports self-determination by giving them control over their own lives (6 out of 6). Having a good support system seems to be the over-riding theme of successful person centered planning (6 out of 6), and the supports can consist of both paid and natural

supports, such as family members, friends, staff, community members, and organizations, which in turn incorporates the micro, mezzo, and macro level of supports.

PCP tends to focus on the individual's abilities versus diagnosis or disabilities (5 out of 6), which promotes inclusion because the focus person has more opportunity to contribute to society and use their abilities to improve their quality of life. Building connections between service and community organizations helps to create more opportunity for the focus person (3 out of 6). This aligns with the discussion by O'Brien, et al. (1997), which looks at shifting the emphasis to what a person is capable of instead of focusing on their diagnosis or disabilities.

Challenges to the PCP model

Although successful use of PCP involves co-operation at multiple levels, challenges become apparent at every level in some instances. Participants all discussed systemic issues that have the potential to create barriers to successful person centered planning (6 out of 6). Participants talked about limited availability of services for where a person with DD/ID lives and works. They also discussed rules and regulations and the need for system change. Holburn (2002), describes PCP as a process that takes longer than other methods and depends on support and collaboration between various organizations for it to be successful.

Power sharing and role shifting were brought up as challenges to planning and implementing PCP several times during the interviews (6 out of 6), which involves shifting power or control to the focus person and his or her circle of support. Traditional service planning generally puts the clinician into the role of expert and PCP shifts the expert role to the focus person.

Another common theme was health and safety versus risk and opportunity (5 out of 6), because to allow for self-determination involves a certain level of risk for the individual. Participants talked about healthy risk taking and allowing for risk in the safest way possible.

Lack of funding and resources and a shortage of time also posed as barriers to planning and implementing PCP (6 out of 6). All participants talked about the need to be creative and flexible to overcome these challenges (6 out of 6). Examples included utilizing unpaid supports and community resources. In a study done by Robertson et al. (2007), one of the main barriers to PCP development and goal attainment had to do with problems with the facilitator. Other challenges included lack of time and limited service availability.

Researcher reaction

The researcher was not surprised by the findings of this study and is in support of many of the themes and issues that emerged as benefits and barriers to person centered planning for adults with developmental disabilities. The researcher believes that traditional service planning is outdated and that new models, such as PCP would be more successful in enhancing quality of life for the individuals receiving services. The researcher was impressed by the amount of tools available for planning and implementing person centered planning/thinking, such as PATHS, MAPS, and essential lifestyles planning amongst others that were mentioned. This coincides with the individualized nature of PCP planning. I was impressed with the various populations of individuals where PCP or components of it have been implemented, such as in mental health, prisons, school systems, and with seniors. The researcher's experience in the field

working with adults with developmental disabilities may have helped sensitize her to the issues discussed in the interviews.

Limitations/Recommendations for future research

The research had limitations related to the small sample size and the limited geographical region where the research was conducted. Snowball sampling was an effective way to recruit participants, however it was an initially slow to begin the process and there was not enough time between approval of the research study and the deadline for completion of the project to interview more participants. It is recommended that future researchers allow more time for scheduling interviews to increase participation. It would also be beneficial to interview participants that are based in rural areas to gain a more comprehensive view of the different challenges presented in implementing PCP, particularly in regards to accessing resources and services. Future researchers may need to specifically request participants to recommend rural colleagues to interview.

Person Centered Planning is individualistic and promotes client choice on goal development to enhance quality of life. Due to the individualistic nature of PCP and varying perceptions on quality of life, it would be difficult to conduct a quantitative study. By taking a qualitative approach, the researcher was able to gain a deeper insight of people's beliefs about PCP and gain an understanding of how people observe the effects of PCP. The researcher heard directly from the voices that develop and implement PCP. The researcher's experience working in the field is also a strength. The researcher has first hand knowledge of service delivery in residential settings designed for adults with DD/ID.

There may have been selection bias because people may have been more likely to volunteer for an interview if they believe that the PCP model is useful in the DD/ID service delivery field. The participants in this study are all professionals in the service delivery system who have had extensive training of PCP. It may be beneficial for future researchers to interview the clients and/or people outside the service delivery system, such as family members, friends, and community members to get different views on the PCP process. It may also be beneficial to send out anonymous surveys to increase participation in the research.

Implications for social work

The implications of this research on social work practice presents a need for systemic change (6 out of 6) in order for PCP to be fully implemented as it was intended, which includes allowing a certain amount of risk taking in client self-determination. This implicates that social workers and other service providers need to work together to advocate for needed resources, systemic changes, and funding.

It also seems apparent that supports and resources outside of the service delivery need to be utilized and that linkages need to be made or reinforced between organizations and community supports. PCP is challenging because it's a process (4 out of 6) and it involves a slow moving cultural shift, which indicates that social workers need to advocate for increased education and awareness for the clients, service professionals, family members, and members of the community in order to move the process forward more smoothly.

Conclusion

The purpose of this study was to explore the benefits and barriers to implementing Person Centered Planning as a replacement for, or in addition to traditional service planning for adults with developmental disabilities. Person Centered Planning was chosen because it's main focus is on enhancing quality of life and putting the "client" into the expert role over their own life. Person centered planning, or as many people call it, "person centered thinking" is not a new concept, however it is only recently that people have become more aware of it and steps have been taken to train people in it.

The strongest theme in this study is that PCP is individualized planning that puts the client into the role of expert over his or her life. This expert role allows for increased self-determination because it increases choices in areas such as types of living arrangements, what kind of work they want to do, and what they like to do during their leisure time. It also makes it possible to follow their vision of what the future should look like. The circle of support may be the most important component of helping the person achieve their future vision.

Challenges to planning and implementing PCP include limited time, funding, and resources, however creativity and flexibility seem essential in overcoming these challenges. System changes also create a challenge because there is a certain level of risk involved in implementing PCP and many service providers are still unwilling or unable to take on this level of risk. Person centered planning or person centered thinking has not been accepted by everyone and there is still the challenge of power sharing or role shifting for many people involved. It is still too soon to know how fully PCP will be adapted for people with DD/ID and whether the larger culture will be able to make the paradigm shift.

As one participant stated, well for all of us, all clients, family, staff, community, it gives us an opportunity to really know the person as a person, beyond their diagnosis. It provides a way for us to get out of our typical thinking, social service thinking, and one of the powerful benefits that I think, that I see happens with people if there truly is a focus about discovering people's capacity, sharing, learning about what people are good at, not just their disability, but their abilities, that is very, very powerful for people (case 3, page 2, lines 63-69).

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Appendix A

Benefits and Barriers to the Implementation of Person Centered Planning for individual with Developmental Disabilities INFORMATION AND CONSENT FORM

Introduction:

You are invited to participate in a research study investigating the benefits and barriers to implementing person centered planning for adults with developmental disabilities/intellectual disabilities (DD/ID). This study is being conducted by Crystal Hughes, a graduate student at St. Catherine University under the supervision of Michael Chovanec, a faculty member in the SCU/UST School of social work. You were selected for potential participation in this research because you have met the requirements of having worked with adults with DD/ID for one year or longer providing case management and/or related social services and you have had some formal training in person centered planning as defined for the purpose of this study. Please read this form and ask questions before you agree to be in the study.

Background Information:

The purpose of this study is to determine what are the benefits and barriers to implementing person centered planning for adults with developmental disabilities living in a group home setting. Approximately 10 people are expected to participate in this research.

Procedures:

If you decide to participate, you will be asked to review the survey and interview questions and read and sign a consent form prior to the interview. Initially, you will be asked to fill out some survey questions with basic demographic information prior to meeting for the interview. The survey information will be assigned a number to keep the information confidential. The survey will be collected in person during the scheduled interview time and after you have signed the consent form. You are expected to and encouraged to contact the researcher with questions, if needed, prior to consent to participate in this research. The questionnaire that will be used during the interview will consist of questions based on the literature review, relationship to the research question, and the professional experience of participants. The interview process will take approximately 30-60 minutes and the audio will be recorded and transcribed by the researcher at a later time.

Risks and Benefits of being in the study:

There are no identified risks or benefits associated with participating in this study.

Confidentiality:

The records from this study will be kept confidential. Any information that is published will not include information that will make it possible to identify you in any way. The types of records the researcher will create include audio recordings and transcriptions based on the audio recordings. Only the researcher will have access to the audio recordings and the survey questions containing demographic information. The audio recordings will be kept in a locked file cabinet in the researcher's home office when not in use. The researcher will personally transcribe all of the audio recordings. The survey information will be collected and assigned numbers to keep the information confidential. The survey information will also be kept in a locked file cabinet in the researcher's home office. The original audio

recordings and written survey will be destroyed upon completion of the researcher or no later than June 1st of 2013.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with the company you work for or with St. Catherine University in any way. If you decide to participate, you are free to stop at any time without affecting these relationships. Should you decide to withdraw data collected about you, I will not include your data in this research study. You may also skip any questions I may ask you during the interview process.

Contacts and questions:

If you have any questions, please feel free to contact me, Crystal Hughes at (612)-214-9062. You may ask questions now, or if you have any additional questions later, the faculty advisor, Michael Chovanec (651)-690-8722, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739.

You may keep a copy of this form for your records.

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time.

I consent to participate in the study. I understand that this agreement also includes my consent to be audio recorded during the interview.

Signature of Participant _____ Date

Signature of Researcher _____ Date

Appendix B

Planning and Implementing Person Centered Planning for adults with Developmental/Intellectual Disabilities

Pre-interview questionnaire to be filled out prior to the interview

Directions: Please check the space or fill in the answers to the following questions prior to the scheduled interview. Please bring this form with you to the interview.

1. What is your gender? _____ Male _____ Female
2. How old are you?
3. What county do you work in?
4. What type of setting do you work in?
_____ Residential _____ County _____ Vocational _____ Private _____ Other
5. What services do you provide for individuals with developmental/intellectual disabilities?
_____ Case Management _____ Administrative _____ Training _____ Other
6. How many years of experience do you have working with adults who have developmental/intellectual disabilities?

Interview Questions on the benefits and barriers to implementing Person Centered Planning for adults with developmental/intellectual disabilities.

Directions: Please review the following questions prior to the interview.

1. Tell me what your understanding of Person Centered Planning is?
2. Can you give an example of Person Centered Planning being implemented for a client?

3. What do you feel are the benefits in implementing the person centered planning model for the following: The client, client's family, staff, and community.
4. What do you feel are the challenges in developing and implementing the person centered planning model for the following: The client, client's family, staff, community.
5. How have you dealt with the challenges you identified above for the client, client's family, staff, and community?
6. Are client's levels of self-determination and inclusion affected by their level of physical and cognitive abilities? Yes / No
If so, please explain.
7. What do you think is necessary for individuals with DD/ID to develop optimal levels of self-determination and inclusion across a variety of settings?
8. Do you feel competent with the training you received to partake in the development and implementation of person centered planning for people with DD/ID?
If so, what did you find most beneficial? If not, what do you think was missing?
9. Can you identify any gaps with developing and implementing Person Centered Planning in the current service delivery system?
10. Do you have any thing else that would be helpful to me in my study?