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EXPECTATIONS AND ANTICIPATIONS OF MIDDLE AND HIGH SCHOOL SPECIAL EDUCATION TEACHERS IN PREPARING THEIR STUDENTS WITH INTELLECTUAL DISABILITY FOR FUTURE ADULT ROLES INCLUDING THOSE AS PARTNER AND PARENT

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EXPECTATIONS AND ANTICIPATIONS OF MIDDLE AND HIGH SCHOOL SPECIAL EDUCATION TEACHERS IN PREPARING THEIR STUDENTS WITH INTELLECTUAL DISABILITY FOR FUTURE ADULT ROLES INCLUDING THOSE AS PARTNER AND PARENT

by

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DISSERTATION

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy
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The University of New Mexico
Albuquerque, New Mexico

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DEDICATION

In memory of my parents, Warren and Marian Holemo Pedersen, who would be so proud, and dedicated to my daughter, Katherine Pedersen Blanchard, of whom I am so proud.

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ABSTRACT

Through a series of individual ethnographic interviews and focus groups, I explored the expectations and anticipations of middle and high school special education teachers as they carry out their professional charge of educating their students with intellectual disability for lives in the least restrictive environment, including possible adult roles as partners and parents. This study examined the choices teachers make, including teaching curriculum and professional responsibility, as they approach their professional duties in educating their students with ID for life beyond the classroom. Teachers were asked to share their expectations of themselves in preparing their students and their anticipation of their students' adult lives once they leave the school system.

Analysis of qualitative data gathered through both recorded individual interviews and focus groups revealed three major domains in which the data clustered including: (a) boundaries; (b) dangers and threats; and (c) responsibility for change. Themes within each domain also emerged to reveal concerns among the teachers for their students' safety, preparation for adult roles, tension with parents, and lack of school leadership.

While this research focused on expectations and anticipations of middle and high school teachers in preparing their students for adult roles, including those of partner and parent, it revealed the need for attention to many aspects of the implementation of an educational program, including utilization of the IEP for individual educational planning and actualization of IDEA as tools to ensure students receive an appropriate education that prepares them for future roles in an inclusive society. Teachers struggled to exercise personal agency and action in making changes and seemed to be unsafe in exploring that possibility within the culture of the school and larger educational systems in which they worked.

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CHAPTER 1 INTRODUCTION

Overview

> The closer the decision-making bodies of society come to understanding retarded [sic] people’s needs, the more likely they will be to develop appropriate and effective programs. The normalization principle does not just affect the lives of retarded people, it has a deep effect on those who work with them, their parents and society itself. (Nirje, 1969, p.195)

The history of people with intellectual disability (ID) in this country is associated with the eugenics movement and represented by three policy decisions related to sexuality. Beginning in the 19th Century, marriage and sexual intercourse were forbidden for women identified with “mental retardation” with the threat of punishment, including criminal penalties (Edgerton, 1999; Sobsey, 1994). When that legislation was not completely successful in eliminating sexual activity and childbearing, forced sterilization became a common practice among people with ID (Kliewer & Drake, 1998; Sullivan, 2001). Eventually, institutionalization and segregation of genders within institutions for the “feebleminded” were also routinely practiced in a continuing effort to control sexual behavior and reproduction (Edgerton; Sobsey; Trent, 1994). Current terminology reflects a change from use of “feebleminded” and “mental retardation” to “intellectual disability”, or “ID” (Schalock, Luckasson, & Shogren, 2007). Therefore, “intellectual disability” and “ID” are used throughout this research to reflect this change and current terminology.

As people with disabilities, and specifically intellectual disability, moved from segregated institutions to more integrated community living, and the “normalization principle” (Nirje, 1969) propelled the move to more typical lives with greater independence in the 1960’s and 1970’s, people with ID began to engage in more typical activities like other citizens. When deinstitutionalization and normalization took hold in North America, Australia, and Europe, this pattern was consistent across continents (Dowdney & Skuse, 1993; Sheerin, 1998). Suddenly, people with developmental disabilities were expected to assume the "same rights, responsibilities and opportunities available to others" (Young & Hawkins, 2006, p.236). As they did, they lived in communities, formed relationships, and established families (Whitman & Accardo, 1990).

While training and education for people with ID focused on interpersonal skills and preparation for transition to work and school environments, little or no attention was given to preparing people identified as having ID for adult lives as partners and parents in society. The modern history of people with ID living in community settings and participating in adult sexual relationships is very short (Griffiths, Quinsey, & Hingsburger, 1989). In addition, training programs and professionals preparing people with ID for adult lives in the community have not prepared them for lives in which intimacy, sexuality and resulting responsibilities are an integral part of their lives (Watson, Griffiths, Richards, & Dykstra, 2002). And while there is increased acceptance for people with ID as co-workers and social acquaintances, there is little acceptance of them as parents or partners (Milligan & Neufeldt, 2001), as evidenced by the fact that before the 1970’s, the professional literature included no references to sexuality and disability. As literature began to emerge, spinal cord injury and sexuality was explored. In their review of the literature in 2001, Milligan and Neufeldt discovered only 158 professional articles addressing sexuality and disability, with 89% of them published since 1990.

The field of study of issues of parents who have intellectual disability is also young (Edgerton, 1999). Booth and Booth (2002), reviewing 253 studies on the topic, found that only 34% of the reference base was published before 1990, and only 21% prior to 1980. The population of parents with intellectual disability is perhaps the last to be empowered and recognized in their right to chart their own course (Espe-Sherwindt & Kerlin, 1990).

Institutionalization and the eugenics movement, however, continue to influence expectations of lives of people with ID (Kliewer & Drake, 1998; Sullivan, 2001), including “scientific” justification for educational segregation and resulting limitations in being fully included in community and work life. Kliewer and Drake argued that special education placements are another means of segregating and controlling people with ID. They maintain that the use of “scientific” testing, teaching methods, and diagnoses help society and practitioners continue eugenic practices of behavioral control, isolation, and segregation.

Although legislation has sought to ensure the full inclusion of students with disabilities in school life, educational practices, curricula, and instruction limit their preparation for success in later life situations (Kliewer & Drake, 1998). The Individuals with Disabilities Education Improvement Act (IDEIA, 2004), Part B, clearly states that “disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society (IDEIA, 601(c)(1)). IDEIA also recognizes the purpose of a free and appropriate public education as that which will ready students "… for further education, employment, and independent living…" (IDEIA 601(d)(1)), and also that students may "lead productive, independent lives to the maximum extent possible" (601(c)(5)(A)).

While public schools are charged with fully including students in school life and activities, the residual power of the eugenics movement and institutional segregation of people with ID, as well as the reliance on pseudo-science to justify segregation, continue to create barriers to the expectation of full inclusion in society, both during schooling years and afterward (Kliewer & Drake, 1998). Not preparing students for adult lives as partners and parents helps justify continued segregation and limited access to the rights and opportunities of other citizens. It also helps assure failure as students are ill prepared for adult roles and responsibilities.

This study focuses on the expectations and anticipations[1] of middle and high school special education teachers as they carry out their professional charge of educating their students with ID for lives in the least restrictive environment. Self-advocacy and self-determination have been identified as important skills in preparing students for successful adult lives in inclusive communities. However, there has been little or no

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[1] Throughout this document, "expectations" of middle and high school special education teachers refers to the professional role they as teachers expect of themselves in preparing students for adulthood and future role(s), including those of partner and parent; "anticipations" of middle and high school special education teachers refers to the life roles they feel their students will assume in the future as adults, including possibly that of partner and parent.

attention given in self-advocacy programs to adult roles of partners and parents (Karvonen, Test, Wood, Browder, & Algozzine, 2004; Test, Fowler, Brewer, & Wood, 2005; Test, Fowler, Wood, Brewer, & Eddy, 2005), where the emphasis is preparation for participation in one's IEP, post-secondary education, and job skills. In curricula, both commercial and constructed by the teacher, there was no evidence of attention to adult roles, or expectation and anticipation of adult roles of partner and parent as students transitioned to life as young adults in community settings (Test, Fowler, Brewer et al.).

This study explored the expectations and anticipations of middle and high school special educators as they pursued their professional teaching careers and influenced the future direction of their students' lives through expectations of themselves in their role as teachers, preparing students for adult roles, and the anticipation of what those future lives will be. This study examined the choices teachers make, including such decisions as teaching curriculum and professional responsibility, as they approach their professional duties in educating their students with ID for life beyond the classroom.

History and Background

When Justice Oliver Wendell Holmes issued his ruling regarding the eugenic sterilization of Carrie Buck in 1927, stating that states may constitutionally prevent individuals with ID from procreation (Buck v. Bell, 1927), he strengthened the belief of contemporary society that people with ID had no right to reproduce. The fact that Carrie Buck may or may not have been a person with ID is irrelevant. Carrie Buck, and an entire class of citizens, were denied reproductive choice, and, as a result of this ruling, were limited in their behavior and prevented from considering choices of adult roles in the future (Hayman, 1990). The Mental Deficiency Act of 1913, which prohibited marriage for people with cognitive disabilities, was already part of English law (Edgerton, 1999) and carried the strong influence of Victorian society to America with policies limiting and controlling the behavior and choices of people with ID (Simmons, 1978; Thompson, 1998). Even though Mickelson (1947) provided some documentation on the capacity of people with cognitive disabilities to parent successfully, involuntary surgical sterilization was still practiced until the 1970's. There was little known about the lives of parents with cognitive disabilities, their struggles or their triumphs.

While the current subject of partnering and parenting with ID may be traced to the mainstream movement of the latter twentieth century, described by Lakin and Turnbull (2005), the Depression Era study of Skeels and Dye (1939), in which institutionalized young children with ID were placed under the care of young female institutional residents, may represent a very early study of parenting by people with ID. Following the Holmes ruling and the widespread practice of institutionalization and sterilization, it is not surprising that Skeels and Dye were met with derision when presenting their research in the 1930's (Schackne, n.d.). It was not until the 1960's, and the Civil Rights Movement, when their classic study was resurrected and reviewed, that there was reconsideration of the rights, and possibilities, in the lives of people with ID (Skeels, 1966). With deinstitutionalization and laws prohibiting the forcible sterilization of people, individuals with ID began to take steps in assuming more typical lives in more inclusive communities.

Issues of women with cognitive disabilities, sexuality, and childbearing are very complex and embedded in a wide range of social beliefs, history, judicial bias, and public policy (Hayman, 1990). With limited exception (Booth & Booth, 2002; Strike & McConnell, 2002), the major body of research in partnering and parenting with cognitive disabilities has been conducted with mothers with ID regarding their ability to parent. Historically, bearing a child without societal permission has been cause to vilify women and make them accountable through shame and withholding resources (Solinger, 1994). A bizarre twist of social construction, this author pointed out, was that White babies born to women out of wedlock prior to the Second World War were frequently diagnosed with moral and mental deficiencies on the basis of their illegitimacy. Later, in order to obtain an abortion, a young unmarried woman was required to present professional documentation that she was psychologically or mentally “impaired”, ensuring that only impaired women would not bear children. Sterilization usually accompanied the abortion. The baby, however, could be adopted into any social class and typically was (Solinger).

In the early 1970’s, Tymchuk was asked to provide initial competency assessments of four mothers who had been raised in the era of institutionalization and who were struggling with educational and social challenges (A. J. Tymchuk, personal communication, October 21, 2006). There had been little inquiry into the parenting of people with cognitive disabilities since the early study by Mickelson (1947). This early 1970’s work of Tymchuk is regarded as a pioneering effort in research and in understanding the issue of parenting with ID (Booth & Booth, 1993; 1994b). Edgerton (1999) recalled that a scholarly conference in 1973 revealed that sexuality and parenthood by people with ID was a topic that was met with strong opposition among the participants. There was concern for the risks of parenting and the lack of systems of support and knowledge base.

With Tymchuk and others pursuing this research and intervention in the United States (Kirschbaum, 2000; Whitman & Accardo, 1990), activity in other English speaking countries also began to develop, including Canada (Feldman, 1994); Australia (Llewellyn, 1995); and the United Kingdom (Booth & Booth, 1993). Today there is increased interest and awareness of this area and a growing population of parents recognized as having ID as evidenced by the creation of the Summit on Supported Parenting. In addition, the Association for Successful Parenting (www.achancetoparaent.net) was formed in 2009 to support parents with ID, and the former president of the American Association for Intellectual and Developmental Disabilities has described "parenting by people with intellectual and developmental disabilities" as a "high priority" for future action by that group (personal communication, S. Eidelman, June 18, 2009). As society has changed over the past 35 years, new supports and challenges have emerged including: an awareness of the interaction of individual characteristics, family, and environmental needs and supports; civil rights legislation, for example the Americans with Disabilities Act; an increasingly complex service system involving many providers and sometimes conflicting regulations; and shifting fiscal and social priorities (Tymchuk, 1999; personal communication, October 21, 2006).

As noted earlier, Booth and Booth (2002) identified only 53 references in the literature regarding parents with ID prior to 1980; they located 86 references published before 1990. Much of this research focused on parent training programs. More recently, research has begun to include input from parents with ID on their strengths, preferences and desires in leading their lives (Ehlers-Flint, 2002; Espe-Sherwindt & Kerlin, 1990; Llewellyn, 1995; McConnell, Llewellyn & Bye, 1997; Strike & McConnell, 2002; Young & Hawkins, 2006).

In contrast, programs teaching self-advocacy in the public education system typically do not address issues of sexuality, partnering and parenting in preparation for adult roles by people with ID, (Karvonen et al., 2004; Test, Fowler, Brewer et al., 2005; Test, Fowler, Wood et al., 2005). The limited access to information and training in preparation for adult roles as partners and parents has continued to keep people with ID behind “new institutional walls” (Lofgren-Martenson, 2004, p. 197), giving the illusion of access to an inclusive society but denying the tools and skills to fully participate with capable, informed, and voluntary choice.

Sexuality Education

An awareness of the need for sexuality education among people with ID has increased (Hingsburger, 1990; Sobsey, 1994; Wehmeyer, Sands & Knowlton, 2006).While research exists in the area of sexuality and disability, much of it is focused on people with sensory and/or physical disabilities (Sobsey et al., 1991). There is belief among self-advocates that there is little current information and little opportunity to learn from medical providers and others (Gill & Hough, 2007; Putnam et al., 2003). Surveys conducted among institutions of higher learning preparing special education teachers revealed that very few offer comprehensive training to prepare special educators to provide sexuality education to their students (Luckasson, Walker-Hirsch, & Park, manuscript in preparation; May, 1980; May & Kundert, 1996). Reports of those working with parents with ID indicate that the education system did not prepare these former students for future roles as partners and parents (Espe-Sherwindt & Kerlin, 1990). As current “abstinence only” education programs in the public schools limit teaching and discussion to prescribed approaches to sexual expression, research indicates that these programs are generally ineffective in reducing pregnancy and sexually transmitted disease among adolescent participants (Santelli et al., 2006; Trenholm et al., 2007). There is no information reported about the participation of students with ID in recent "abstinence only" programs or whether adaptations to the curriculum were made to offer students this or other sexuality education information. The more restrictive discourse results in even greater silence when already limited information is not adapted and made available to the learning needs of students with ID. There is limited research in the area of special education teacher expectations as to their role in preparing students with ID for adult roles in society, and for teacher anticipation of what those roles might include. Previous research by Wolfe (1997) indicated the majority of teachers and school administrators still approved of involuntary sterilization of students with ID,

Adults with intellectual disability were denied the rights of other adults in this country over much of the past century, including the right to be a partner and a parent. Through segregated institutionalization and forced sterilizations, these citizens had little opportunity to develop intimate relationships with others and to make a choice to have families of their own. Public health workers held considerable power over people with ID, as well as other segments of the population that deviated from "middle class ideals for sexuality and reproduction" (Sullivan, 2001, pg. 263), fueling the eugenics movement for many years. Through deinstitutionalization, the normalization principle, and the recognized civil rights of people with ID, the population of people recognized as having intellectual disability who become parents is growing (Whitman & Accardo, 1990). However, the long history of stigmatization of this segment of the population has continued and the influence of the training and practice of public health and other professions has continued to influence our acceptance of the sexuality and reproduction of people with ID (Sullivan). Previous research concluded that adults with ID, while trained in job skills in public schools, are poorly prepared to assume adult roles in society as partners and parents (Espe-Sherwindt & Kerlin, 1990). Previous research has also focused on a wide range of professional disciplines, training, and responses to parents with ID (Booth & Booth, 1993, 1994b; Kelly & Sikka, 1997; McConnell, Llewellyn & Bye, 1997; Sheerin, 1998). I suggest that this body of research raises the awareness that professional expectations continue to bias the opportunities of these citizens for success in adult roles, including opportunities to partner and parent children.

There is little current evidence from the literature, however, as to the expectations and anticipations of the educator who prepares and teaches the student with ID as to how the student will assume adult roles of partner and parent in the future and his or her efforts to understand the expectations held by teachers for their students in the future. Teacher efforts to prepare students with ID for future adult roles are critical as (a) people with ID are living increasingly in inclusive community settings (Feldman, 1997; Lakin, Gardner, Larson, & Wheeler, 2005); (b) the number of adults recognized as having ID who are becoming parents is increasing (Booth, 2003; Whitman & Accardo, 1990); and (c) poor preparation for adult roles can contribute to inappropriate sexual behavior, family disruption, child removal, and denial of the right to parent one’s own children (Booth & Booth, 1994a; Griffiths, Quinsey, & Hingsburger, 1989; Hayman, 1990; Taylor, 1995; Walker-Hirsch, 2007).

The purpose of this study of middle and high school special education teachers working with students with ID is to investigate (a) teachers’ anticipations of the life span opportunities of their students with ID to assume adult roles as partners and parents; and

(b) teachers' expectations for themselves in preparing their students or adult roles. The primary research question in this study was: What are the anticipations of middle and high school special education teachers of their students with ID for future roles as adult partners and parents? Underlying research questions included: What do middle and high school special education teachers expect of their role and responsibility in preparing their students for adult roles as partners and parents?; and What are the anticipations of middle and high school special educators of their students as to future opportunities for adults with ID to marry, to conceive, and to raise children?

Data gathered through this study included extensive interview data of identified participants, collected during individual interviews and focus groups. I expected data to reveal expectations and anticipations that address teaching responsibilities that support post-schooling work-related activities but not those addressing life span roles of partners and parents.

Researcher Positionality and Theoretical Framework

The influences of the researcher's life experiences impact the design and conduct of research and the analysis and interpretation of data (Maxwell, 2005). Recognition of my own life experiences, their relevance for my research, and how my understanding of myself in the world positions me for this research were important steps in developing this research study. In addition, my awareness of these influences on my identity as a researcher helped define the theoretical framework through which this research was developed and interpreted.

Researcher Positionality

My career as an educator has been varied, but focused early on elementary education teaching, both general and special education, with children from culturally diverse and frequently impoverished backgrounds. Seeking to better understand early learning and intervention, I acquired an advanced degree in early childhood special education, working with families of young children in a wide range of settings.

While working in a home visiting program for infants and toddlers with disabilities, I felt ill prepared to address the challenges many of the families I worked with were facing. Poverty, violence, and parental disability, including ID, were common issues. I sought an additional degree in counseling to support my professional skills and to better serve the parents and young children. I soon received increased referrals for families struggling with myriad problems, including ID, and continued to learn more about their lives, their perception of school and measure of success, and their understanding and concern for their children's development. I also began to examine my own expectations and understanding of relationships, of access to support and services, information, and power within institutions.

As a parent and partner, I found strong similarities between these families and myself as a woman who very much wanted to be a parent and valued the relationships I enjoyed in a safe family haven. I also became aware of many differences defined by social class, race, education, and intellect. Of the mothers and fathers with ID with whom I worked, there were many economic and social challenges, including difficulty in reading the directions on a prescription bottle, following a behavior plan, or obtaining help from specific social agencies. As I accompanied many parents to appointments with medical providers, social workers, teachers, and others, I became aware of how "invisible" these parents, and not infrequently their children, were at times to the professionals employed in their care and service.

My own training as a special educator did not prepare me to work with parents with ID. In addition, during my teaching career I do not think that I imagined the possibility of parent and partner roles for students in my care. Education focused on training of skills for later application to jobs and economic self-sufficiency. Recognizing students as future adults with desires for intimate relationships and possibly parenting was not a part of my education or my work. It is also not a part of the literature in teacher preparation.

Theoretical Framework

Just as my positionality as a researcher has been influenced by a variety of life experiences and opportunities, the theoretical framework through which this research was conducted is formed by a variety of perspectives, unified in the overarching belief of the rights of individuals in a democratic society. Central to that is the role of education in not merely preparation for the next steps in life, but rather a support for growing as “a continuous leading into the future” (Dewey, 2004, p.46). The responsibility for education to develop the power for shared membership in society is critical, and moral. Critical disability theory and symbolic interactionism are included in the following discussion.

Critical disability theory

Critical disability theory challenges the existing concept of disability, the expectations of citizenship for people with disabilities that include access to and participation in society, the policies created to address the needs and priorities of people with disabilities, and the role of law for their future (Pothier & Devlin, 2006). Public education and the professions within, represent a response to students with ID from an existing institutional structure that determines the product, or education, its students receive, and therefore the options available to them through their education. Critical disability theory maintains that disability is not fundamentally a medical model of illness versus health, or one of medical treatment needs; nor is critical disability theory the issues of charitable sensitivity and compassion toward people with disabilities manifested in paternalism (Charlton, 2000; Pothier & Devlin). Rather it is a question of politics and the struggle for power over one's own life and self direction. In this struggle, critical disability theory challenges the norms with which ability is measured and valued, to determine how, where and when people with disabilities can engage as full citizens in society. Because this study proposed to explore the expectations and anticipations of middle and high school special education teachers in preparing their students with ID for adult roles, it examined the power relationships between schools and students with ID, a group experiencing new, inclusive life possibilities and challenges, and opportunities previously unaddressed by educational institutions.

The concept of critical theory, described in the work of Jane Mercer (1992) and Peter McLaren (1994), includes critical pedagogy and questioning and rethinking what and why we take social and economic practices for granted, including those affecting the education and life options of people with disabilities. It is succinctly defined as "an array of theoretical and cultural work which exposes and ruptures hidden, reified relationships of power and dominance within society" (Danforth, 1995, p. 139). In addition, critical theory critical disability theory articulates a struggle that is not binary, as in "us" versus "them", but rather a recognition of a continuum of differences, needs, and accommodations that is part of the human presence. This is articulated in IDEIA which states "disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society (IDEIA, 601(c)(1)). Critical disability theorists, however, contend that underfunding in programs such as special education and rigid approaches to categorization, eligibility, and service access have resulted in a social construction of disability that determines people as abnormal or flawed (Pothier and Devlin, 2006). This is not unlike Trent's discussion of the invention of the feeble mind (1994**.** Relative to disability, this contributes to paternalism with concepts of pity and charity deliberately creating a dependency (Oliver, 1996) or infantilizing people with disabilities (Perlin, 1998). Cost-benefit issues are also addressed by critical disability theorists (Charlton, 2000; Porthier & Devlin, 2006) in that there are and will continue to be additional costs to ensure that people with disabilities have equal access to society. It is not a cost savings measure. Schools and educators represent a power structure and privilege of knowledge, resources and access that is embedded in larger social structures at other levels of power and privilege. None of us, at any level, is totally free in our choices, opportunities, or actions. This belief is compatible with the concept of critical theorists who describe the dynamic and dialectical interaction of individual and society (McLaren, 1994), and the power of our professional positions in defining for our students who they are and who they will eventually be (Danforth, 1995).

Access, and citizenship for people with disabilities, according to critical disability theorists, is not merely how people are regarded or invited in. Access requires more than an open door. Social structures and institutions must change to provide access, to rethink and realize what access is, and what it looks like for people with disabilities. Unlike feminism or critical race theory, changing structures and opening doors will not ensure access for people with disabilities. There will never be a level playing field for some people with a disability; some people will never be able to live independently or make decisions and choices without support. While feminism and critical race theory strives to remove barriers and create equal access so that all are afforded equal opportunity to participate, disability will not go away and necessary supports will always be required; it is essential that the way disability is not only perceived but also how it is supported change. The opposite of having a disability is to be “normal”, when one takes a binary stance of: if not this…then this. Critical disability theory, in recognizing that disability is part of life, similarly recognize the on-going need for support. Some people with disabilities, they maintain, will always need this additional support. It is unreasonable to assume that by changing physical access or legislation to recognize that disability is a normal part of life, people with disabilities will be able to participate without support; what that support looks like, and how it ensures full citizenship, however, is very individual. There are some people who will never be able to make complex choices; adaptation to ensure that they may participate to the greatest degree possible helps protect their participation, however.

This stance is in opposition to liberalism which holds disability as a misfortune or bad luck, being less than normal (Pothier & Devlin, 2006). In this way, liberalism seeks to undo the disability to relieve the suffering of the person with a disability. Liberalism seeks equality for race, women, and gay populations; for disability it seeks a “fix” or cure to relieve the condition. Liberalism, Pothier and Devlin maintained, “others” people with disability in this way. A true human rights approach taken on behalf of people with disabilities would not embrace a “hierarchy of disability differences” (p.11) and would value the normal over the abnormal. Disability must not be erased, as one would erase gender bias or racism. It must be recognized and realized as a part of normal existence to ensure acceptance of the individual in society.

Of particular interest to this research, however, is the lack of discourse in the literature about people with ID becoming partners and parents, most especially in the professional education literature. Fine (1988), in her exploration of sexuality education among low income, minority teenage girls, described the “missing discourse”, or the absence of discussion and recognition of sexuality with this group of teens. This is evidenced in the work of May (1980), May and Kundert (1996) and Luckasson, Walker-Hirsch, and Park (in preparation) in surveys of institutions of higher learning and the discovery that very few special education teacher preparation programs offered sexuality education courses for students. Similarly, there appears to be a “missing discourse” about the sexuality and eventual partnering and parenting by people with ID (Tepper 2000), as well as knowledge of and acknowledgement of the need of sexuality education by high school teachers (Brantlinger, 1992; Howard-Barr, Rienzo, Pigg, & James, 2005). Through the absence of discourse, maintained Fine, groups of people are denied full personhood and subjugated as a class; options for their lives are erased or eliminated. Similarly, the missing discussion in education regarding sexuality, intimacy, and preparation for partnering and parenting among people with ID works to define them in ways that deny these aspects of their lives as adults, and separates them from and lessens our expectations of them in adult roles.

Symbolic interactionism

While critical disability theory is appropriate in an investigation of power relationships, symbolic interactionism provides a framework to help the individual interpret, over time, his or her changing relationships with the environment. Described as "both a theory of experience and a theory of social structure" (Denzin, 1992, p. 3), symbolic interactionism maintains that the interaction between the individual and the environment create an understanding of meaning. Interactions have meaning, unique to the individuals within the interaction. Meaning constructs and reconstructs itself across time and experience, and emerges as a result of the reflection of the individual upon the experience. This was first captured in the theory of symbolic interactionism of Mead (Bron, 2002) and has application for inquiry as to how we understand our expectations for our own lives and that of others, including adults with ID. As individuals, we ascribe meaning to people, labels, objects, and events in our lives through our interactions. The theory of symbolic interactionism describes this through four general areas including: 1) use of symbols to define culture and express history; 2) the dynamic nature of a social world and relationships, constantly being created, recreated, and developed; 3) interaction as a key feature of the social world and the need of the individual to understand him or herself in the context of others; and 4) understanding through studying experiences of groups of people, looking beneath the symbols that define their lives, to better understand the common characteristics and meaning groups place on symbols in their lives (Bron, 2002).

Symbolic interactionism requires interpretation of meaning to the symbols of our lives, including actions and words and concepts, which are the processes of human interaction (Blumer, 1966). Meaning is constructed through social interaction. It can also be reconstructed and transformed through interaction; it will change over time. The work of Sullivan (2001) and Nirje (1969) revealed that while legislation may change opportunities for people with ID, our expectations and anticipations in realizing and supporting those opportunities may not follow. The meanings we attribute to the events and individuals, and the meanings attributed to us by others, as well as our experiences in social interaction, will alter, over time, the meanings we place on things and concepts. It requires reflection and the ability of the individual to examine and interpret experiences and his or her social interaction (Blumer). The opportunity to understand the meaning groups assign to symbols and to explore meaning through reflection offers an opportunity to actualize social change as promoted through legislation. By better understanding the expectations and anticipations of special education teachers regarding the future roles of their students as partners and parents, one can begin to understand the barriers to full membership in society for individuals with ID.

This research explores the meaning middle and high school special education teachers working with students with ID ascribe to their professional work, as determined by their expectations for their role in preparing their students for the future and their anticipations of what their students' future roles might be, including the possibility of partner and parent. This will be affected by teachers' previous social interactions, how adults with ID may be represented in their beliefs and experiences, and how their reflections on their own lives and experiences may provide information as to how these expectations and anticipations were developed and maintained. Therefore, symbolic interactionism provides a compatible framework for examining relationships, experiences, and symbolic values that may affect the expectations and anticipations of the middle and high school teacher. Opportunities for people with ID have changed, relative to inclusive communities; how preparation for these opportunities may or may not be addressed through the educational process was explored.

Underlying Assumptions

The underlying assumptions held by the researcher impact the approach taken in conducting research, the research findings and interpretation, and even the initial articulation of the research question (Maxwell, 2005). The research was guided by the following underlying assumptions, developed through an examination of my relationship to individuals with and without disabilities and social institutions that serve us all, including schools, over time. My assumptions include the following:

1. What one knows or feels he or she knows now is never an absolute and is really representing understanding at a point in time;
2. The development of relationships with individuals, institutions, and cultures is constantly changing and is affected by language, behavior, and current awareness of history, law, and science; relationships are interpreted very individually by each of us;
3. As individuals we are never fully aware of what is known and our relationships to what we know, but are part of an on-going process of discovery and rediscovery;
4. Positions of power and privilege, as well as positions of dependency and subservience, are part of a continuum of which we are all a part and of which we may not be aware;
5. In our society, schools and teachers represent a power structure and privilege of knowledge and access that is embedded in larger power structures within our society;

6. People with disabilities have been granted limited access to move and act within social structures in society, both as children and adults;
7. People enter careers in the helping professions, including teaching, with a desire to positively impact lives based on their assumptions developed through prior experiences with individuals and institutions; and
8. Educators continue to grow and change throughout their lifetimes in their expectations and anticipation of the world, students with whom they interact, institutions with which they interact, and understanding of their own “realities” over time.

CHAPTER 2 REVIEW OF RELATED LITERATURE

Overview

The United Nations, in the *Universal Declaration of Human Rights* (1948), stated that “All human beings are born free and equal in dignity and rights”. Through the *Convention on the Rights of Persons with Disabilities*, the United Nations (2006) specifically identified rights to participate fully in society and included language to “eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenting and relationships…” (Article 26-Respect for Home and Family). The right to partner and parent, and to have a sexual identity and express that identity, is not less for people with intellectual disability than other human beings. The *Montreal Declaration on Intellectual Disabilities*, ratified at the Pan-American Health Organization/World Health Organization International Conference on Intellectual Disability, 2004, served to ensure that the rights of people with ID, including the right to partner and parent, be recognized worldwide.

The civil rights movement in the United States helped move disenfranchised people to greater levels of equality, including people with disabilities. The succession of laws that support equal access and participation in society by all people, and resulting self-advocacy by people with disabilities, are examples of that movement in society. Sexuality and the opportunity to partner and parent by people with disabilities, and most especially intellectual disability, however, remain elusive within daily life that denies people with intellectual disability equal rights, and even punishes them for their desires. Watson, Venema, Molloy, and Reich (2002) maintained that this remains the most direct violation of human rights of people with developmental disabilities. Sullivan (2001) reported that current denial of sexuality among people with disabilities is tied directly to historical practices of institutionalization, segregation, and sterilization, and the continuing legacy of the eugenics movement.

In this chapter I explore the literature around the challenges and existing supports for people with intellectual disability in the areas of sexuality, partnering and parenting. I will begin with a summary of current legislation and practices related to permanency planning and adoption through the Adoption and Safe Families Act of 1997 (ASFA), Temporary Assistance to Needy Families (TANF), and the Americans with Disabilities Act as well as the Abstinence-Only-Until-Marriage education program. Next, I will briefly review curricula and general practices for educational preparation among students with disabilities in the public school special education setting as it relates to transition, self-advocacy and future roles as partners and parents.

Following that, I review literature as it relates to sexuality education and the needs of people with ID, including learning considerations. This includes a review of characteristics of parents with ID and parenting programs. Finally, I review the existing research on teacher attitudes and expectations toward sexuality, partnering and parenting in the future among people with ID with implications for student outcomes.

Current Legislation and Implementation

The Individuals with Disabilities Education Improvement Act (IDEIA) (20 U.S.C. ss1400 et seq) mandates a free and appropriate education for all students with disabilities. As discussed earlier, IDEIA includes the provision of education for students with disabilities to the greatest extent possible with children who do not have disabilities. Known as the “least restrictive environment” (CFR 300.615(a)(5)(A)), this section of IDEIA has led to the inclusion of students with disabilities in the larger school culture. It also mandates that students have access to the general curriculum (IDEIA 601 (c) (5)(a)), ensuring that their education will reflect that of other, typically developing students, and that their education will "prepare them for further education, employment, and independent living…" As an example of normalization and the expectation of desegregation of students with disabilities, this is in alignment with other legislation affecting Americans with disabilities in broad aspects of public life, beyond the bounds of public education, as detailed in the Americans with Disabilities Act.

The Americans with Disabilities Act (ADA) (42 U.S.C. ss12101 et seq) is "Federal civil rights legislation that prohibits disability-based discrimination related to employment, public services, public accommodations, and telecommunications" (Perry & Gilliam, 2002, p. 301). Title II of the ADA protects people with disabilities from discrimination in publicly owned and run programs and services. "Reasonable accommodation" must be made, without the "undue burden" of fundamentally altering the program, to ensure that people with disabilities can have access to and use public services. Common to both IDEIA and the ADA is the expectation that people with disabilities be ensured access to participate in American life, be it through access to education, public services, employment, or information.

Temporary Assistance to Needy Families (TANF) is a federal program implemented by states providing access to training and financial support to impoverished parents with dependent children. Poverty is very present in the lives of parents with ID, who may have difficulty connecting with possible supports (Booth, n.d.; Sweeney, 2000). In a 2000 report of welfare recipients, Sweeney stated that a significant number of parents have left the TANF program and that about twenty percent of those who have left have mental impairments. Only two states tested recipients' IQ (Washington and Kansas) where 20-25% of recipients had IQs of less than 80.TANF is a program designed to support the educational, financial and nutritional needs of participating families. The program rules, which were described as “complicated”, were cited as a reason many people with learning disabilities and/or ID leave. Because this is a federal program of services, the provisions of the ADA would apply to making “reasonable accommodation” to allow access to participants who could not read or comprehend the complicated requirements. Sweeney reported that not even minimal accommodation is given to recipients in reading or interpreting the regulations to ensure understanding and compliance. The reluctance of parents with ID to ask for help, and their acquiescence with investigators (Finlay & Lyons, 2002) will likely affect their ability to obtain support or accommodation in a bureaucratic system even if such assistance were offered.

Social and legal systems, established to support citizens, have been less than supportive for parents with ID, providing disjointed services with lags and gaps in service (Tymchuk, 1999), ineffective application of the ADA (Tymchuk, Llewellyn, & Feldman, 1999), failure to support parents with disabilities to maintain their status in the TANF program (Sweeney, 2000), and judicial bias through the courts (Booth, n.d.; Hayman, 1990). Of major concern is the federal Adoption and Safe Families Act of 1997 (ASFA) which was intended to reduce the amount of time a child, removed from his home because of abuse or neglect, is placed in foster care and made available for adoption. The termination of parental rights (TPR) by states can proceed when a child has been in foster care for 15 of 22 months. While parents may work on specific behaviors and skills to regain custody and demonstrate adequacy in parenting, parents with ID will have more difficulty in meeting the criteria and timelines for adequate parenting (Tymchuk, 2001).

In addition, many state laws, including that in New Mexico (NMSA, 1978), indicate parental disability as grounds for removing a child from the home (Lightfoot & LaLiberte, 2006). The language in legislation and statute is outdated and does not reflect current best practice or perception of the needs and rights of people with disabilities (Hayman; Lightfoot & LaLiberte), with New Mexico, for example, relying on the term “mental deficiency” in its State code for TPR. The term “permanency” in child custody cases involving the TPR refers to the permanent adoption of children whose parental rights are being terminated. In complicated legal processes such as these, parents with ID may struggle with written guidance, mastery and demonstration of specific skills, and other measures to regain custody of their children. While parents may work on specific behaviors and skills to regain custody and demonstrate adequacy in parenting, parents with ID will have more difficulty in meeting the criteria and timelines for adequate parenting (Tymchuk, 2001).

As part of the Personal Responsibility and Work Opportunities Reconciliation Act of 1996, also known as “welfare reform”, states were offered funding to promote sexual abstinence before marriage through teen education programs. In the five years following, all states but California accepted the funding and promoted such programs. Evaluation data from only 10 of the participating states is available. Together, those ten states received $45.5 million in federal money, which was matched with an additional $34 million in state dollars, to carry out the program of abstinence only. While the impact of the program, at this point, was measured by evaluation data from very few states, these data reveal very little impact on behavior change and little evidence of sustained impact in the first five years of implementation (Hauser, 2007). Furthermore, some states reported an increase in sexual activity by teens and adolescents, limited knowledge of birth control methods, and unfavorable attitudes toward use of birth control by sexually active teens and adolescents (Hauser). The evaluation reports contained no evidence of adaptations in the program teaching methods or presentation for students with intellectual or cognitive disabilities.

Educational Practices, Preparation and Self-Advocacy

Swain (as cited in Espe-Sherwindt & Kerlin, 1990) maintained that people with intellectual disability have been the last to have a say in their lives and their destinies. This is compounded by the fact that they are frequently ill-prepared through their education and life experiences to build successful lives in the community. Frequently they have been taught few problem solving skills, have had poor role models, and were provided with limited or inappropriate educational opportunities that have not prepared them for successful community membership (Espe-Sherwindt & Kerlin). People with ID are not taught the skills they need to explore their sexuality and become partners and parents either by their own families or educators, said Espe-Sherwindt and Kerlin, because they were never expected to assume adult roles, and “issues of sexuality, parenting, and social role development” have been neglected in their preparation for their place as adults in society (p. 24). In increasing numbers, however, people with ID, as they live in the community, are making the choice to have children of their own and to partner and to become parents. The numbers of people with ID becoming parents is increasing (Andron & Tymchuk, 1987; Feldman, 2002). The number of parents with ID is also overrepresented in the child protective system and the courts as well (Booth, n.d.; Hayman, 1990).

Preparing students with ID for adult roles of partnering and parenting is a complex task and one best not left solely to educators or to the final days of school and transition planning (Walker-Hirsch, 2007). The transition to adulthood for all people is built across a lifetime and not limited to acquisition of literacy or job skills; it also involves self-direction and active pursuit of adult roles. Self-advocacy and self-advocacy teaching programs have been implemented in a variety of educational settings in recent years. It is important to define self-advocacy as used in this review. "Self-advocates speak for themselves" (American Association on Intellectual and Developmental Disabilities, 2007*)*. Self-advocacy "can apply to anyone who speaks up for, defends, or advocates for himself or others", specifically when among people with intellectual disability acting on their own behalf or that of others with disabilities (Shoultz, n.d.., p.1). Pennell (2001) maintained that it is also "speaking loud" (p.223) to ensure that you make others aware that you know your choices and can exercise them, with the expectation that you can and will make mistakes along the way. Self-advocacy has engaged people who are socially excluded, marginalized, and disadvantaged (Rapaport, Manthorpe, Moriarty, Hussein, & Collins, 2005). Self-advocacy is an important component of adult relationships, most especially sexual relationships resulting in partnering and parenting. This is fundamental to citizenship and grounded in the Constitution and the Bill of Rights protecting the right of privacy and "individual choice on issues of family, contraception, procreation, and marriage" (Stavis & Walker-Hirsch, 1999, p. 58) This is reflected in "self-determination," which is defined as

> "…a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one's

> strengths and limitations together with a belief in oneself as capable and effective is essential to self-determination, when acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults.” (Field, Martin, Miller, Ward, & Wehmeyer, 1998, p.101-102).

In previous years, programs to teach self-advocacy, both commercial and teacher designed, have been implemented with students with ID across the country through their special education programs. There has been little consistency and little review of the effectiveness of such programs (Test, Fowler, Wood et al., 2005). These authors reviewed 20 research based self-advocacy studies and 150 position papers to develop a conceptual framework and four key components important to such teaching programs. The curriculum areas addressed in these studies most frequently included financial management and independence and job skills. While practical, and with a recognition of knowledge of self, knowledge of rights, communication and leadership as key components, the curricula reviewed included no approaches to self-advocacy in adult relationships involving sexuality, partnering or parenting.

In a second extensive review of self-advocacy studies, Test, Fowler, Brewer et al., (2005) reviewed 25 self-advocacy studies and concluded that there was evidence that people with disabilities could learn a variety of self-advocacy skills. Current studies, they said, lacked rigor and needed more attention to diverse populations when designing and implementing self-advocacy programs. “Adult roles” of students involved in the programs were elusive in this review as the skills taught prepared students to be self-advocates in their current education settings, most specifically IEP and transition meetings. Areas of personally satisfying adult lives were not addressed in any of the literature reviewed in these studies.

Karvonen et al., (2004) reviewed six programs promoting self-determination among students with disabilities to identify what common factors were consistent with favorable practice. The self-awareness of the teacher, and the leadership necessary to implement such programs was identified as critical to successful teaching in self-determination. While the programs reviewed limited their focus to school based learning and educational transition, students reported that teachers, counselors and administrators were the strongest influences in their developing self-determination skills.

Self-determination and self-advocacy following the school years into adulthood is not well described to include success in achieving typical adult roles. In his critique of the relationship between disability related policy and the self-advocacy movement, Goodley (2005) discussed individual and group resilience and the emergence of resulting social networks among people with ID. His review did not include a discussion of the unique issues and characteristics of parents with ID who, while facing struggles similar to other parents in lower socio-economic strata (Anderson, Byun, Larson & Lakin, 2005; Andron & Tymchuk 1987; Budd & Greenspan 1985; Feldman & Walton-Allen, 1997; Keltner, 1994; Sweeney, 2000) are likely to have to deal with the loss of their children to child protective and legal systems. Firsthand knowledge of these challenges were recounted by Ronai (1987).

Another aspect of parents with ID is the almost universal social isolation they experience as reported by researchers in the UK (Booth &Booth, 2003), Canada (Feldman, 2002), Australia (Llewellyn, 1995), and the United States (Ehlers-Flint, 2002;

Keltner, 1994). Hingsburger (1992) described the isolation and depression of people with ID in North America as a very pervasive characteristic of their social worlds. Their opportunities to be part of a resilient group, with a positive and empowered group identity, are not strong.

Parents with ID are vulnerable to social policy and particularly the child protective system that has great power over their ability to parent. They have few social supports and, as reported by Chen, Brodwin, Cardoso and Chan (2002), there is limited acceptance of their right to form social and marital relationships, let alone become parents. Their relationship with the self-advocacy movement is unique. Their greatest fear, reported Booth and Booth (2003) is the loss of their children. Their self-advocacy may put them in opposition to those that have power over them (Goodley, 2005), in this case threatening their right to parent their own children. In addition, acquiescence of people with ID, in interviewing and problem-solving, is not uncommon (Finlay & Lyons, 2002). When there is so much at risk it is not unreasonable for parents with ID to rely on typical patterns of behavior in order to comply with a caseworker’s expectations and to avoid conflict that the role of a self-advocate might promote.

There has been lack of self-advocacy by parents with ID (Espe-Sherwindt & Kerlin, 1990). Parents in this group have been coerced by social service agencies and have become passive and submissive, they reported. The relationship with social service agencies, and the increased scrutiny of parenting by such agencies, is unique to parents with ID (Andron & Tymchuk, 1987). The educational and social history of people with ID, said these authors, affects their social skills as parents and their ability to interact proactively with such systems of care. This in turn affects their ability to self-advocate, as they are putting themselves in opposition to systems that hold great power over them. As discussed earlier, self-advocacy involves “speaking loud” (Pennell, 2001) to let others know that you have choices and the right to exercise your choices. There is also the expectation that you, as a self-advocate, will make mistakes in the process. Meanwhile, a power differential exists between parents with ID and social systems which is not easily resolved. Parents with ID are at extreme disadvantage when approaching such systems as self-advocates (Booth & Booth, 2006). There is sometimes little room for mistakes and little time to learn and apply new skills with child removal and adoption laws forcing termination of parental rights with timelines parents with ID may not be able to meet (Lightfoot & LaLiberte, 2006).

Self-advocacy among parents with ID is not represented by extensive research in the literature. Limitations of literacy (Booth & Booth, 1993; 1994b), resulting limitations in knowledge of one’s rights, a limited or non-existent political base, and daily struggle for survival (Tymchuk et al., 1999) all contribute to the lack of self-advocacy in this area. The concept of people with ID becoming parents remains a social reality facing strong social opposition in itself (Edgerton, 1999), beginning with the passage of the British Mental Deficiency Act of 1913 banning marriage for people with ID, and the memory of forced sterilizations for this population in the fairly recent past (Edgerton, 1993). There are some ways, however, that the voices of parents and others with ID are beginning to emerge. This is being actualized in the UK following publication in 2001 of the White Paper, *Valuing People* (Rapaport et al., 2005). Alternate, non-traditional ways of engaging people with ID in advocacy and self-advocacy are being explored here and abroad as well (Ehlers-Flint, 2002; Llewellyn, 1995; Young & Chesson, 2006).

Goodley (2005) warned of co-opting self-advocates, and the leverage they may have, when they become too close to systems of care and organized efforts charged with their well-being and services. Self-advocacy, and the necessary tension between the self advocate and the “helping institution” is especially difficult to achieve with vulnerable populations dependent upon the institution and also susceptible to institutional disapproval and power. Williams and Simons (2005) approached this delicate balance, articulating the need for honesty by the researcher, in entering the research setting, and inviting the participation of people with ID at any level, especially as individuals who are advocating for themselves while in a very dependent position. Booth and Booth (2003) described personal triumphs and experiences of participants feeling “vindicated” when they put newly learned self-advocacy skills into practice and confronted service providers. With this vulnerable population, frequently at the mercy of child protective services and other helping institutions, self-advocacy at that level may be risky and one that might negatively affect outcomes for parents with ID. The risk of losing their children, through alienation of systems of care and the court system, for an already marginalized population, may seem an unreasonable trade off.

There is considerable room for education, especially on-going education throughout the school years, that prepares students with ID for adult roles with a strong sense of self. There is also considerable room for reconfiguration of social systems and services that are designed to meet the myriad needs of this group of citizens.

Sexuality Education

As noted, none of the reviews of self-advocacy and self-determination teaching programs in the public schools identified sexuality, partnering or parenting as areas of preparation for students. In addition, the nationwide initiative of teaching abstinence-only before marriage did not report adaptations or accommodations for the unique needs of students with intellectual disability. Sexuality is an important part of normal development and preparation for integration into community living. While there is considerable controversy about sex education for a wide range of students, Watson, Griffiths et al., (2002), noted four factors that have influenced the acceptance of sexuality education programs for people with disabilities in recent years including: deinstitutionalization, awareness of sexual abuse of people with ID, the prevalence of AIDS, and the self-advocacy by people with ID to know more about their social and sexual development. Because of the complexity of sexuality and sex education, which must span a life-time, Brantlinger (1992) recommends a "family life education" approach, embedding a broad range of personal expression and self-advocacy skills in a holistic philosophy of learning, which may include intimacy and sexuality, parenting, and family life.

Information for people with disabilities regarding sexuality has been difficult to obtain. While the literature reports little direct information from people with ID as to their needs relative to knowledge of their sexuality and sex education, people with physical disabilities have reported frustration and anger at medical and educational systems that provide little or no information to them in this area (Gill & Hough, 2007; Putnam et al., 2003). The successful supports that provide social sexual education require self-aware teachers and healthcare providers that can deliver information at an appropriate level of understanding to each individual. Among people with ID, this must be broad to accommodate a variety of learning styles and abilities. As noted earlier, the self-awareness of the teacher is critical in supporting self-advocacy and self-knowledge of students. This is an essential element of the educational process that prepares students for lives as adults who may choose to partner and parent in the future.

In their review of curricula of sexuality education for people with intellectual disabilities, Blanchett and Wolfe (2002) identified specific content areas and concepts for learning and instruction including (a) biological and reproductive information, (b) health and hygiene, (c) relationships, and (d) self-protection and self-advocacy. In addition, Blanchett and Wolfe reported that very few of the twelve curricula reviewed had an evaluation component, making a determination of the success or limitations of the instructional program difficult. In addition, they noted the limited emphasis on home, school and community partnerships in teaching and reinforcing sexuality education and appropriate and safe sexual practices. They also emphasized the need for stronger professional awareness and education in preparing educators to support students' sexuality education through their own knowledge and comfort with the subject area, clarification of their own values and self-awareness, and release of their own biases toward students who are entitled to make their own choices in sexual expression.

Blanchett and Wolfe (2002) also emphasized the need for specific, instructional approaches that accommodated the students' difficulty in transferring or generalizing information from the learning environment to real life settings. While inclusion offers greater opportunity for students with ID to interact with and learn from typically developing peers, the "incidental learning" available through inclusive, casual, and social interaction is not sufficient to meet the specialized learning needs of students with ID in sexuality education (Hingsburger, 1990; Walker-Hirsch, 2007). Walker-Hirsch recommended specific modeling, scripting, and rehearsal in preparation for generalization to real life situations. This approach, she said, reduces the novelty of situations as they arise, preparing students, in advance, for encounters they can anticipate.

In addition, Blanchett and Wolfe (2002) suggested the following in selecting and implementing sexuality curricula: (a) match curricula with student needs for a comprehensive of specialized approach; (b) select curricula based on content needed; (c) combine curricula if one does not meet student needs; (d) select and utilize curricula to address IEP needs and priorities; (e) begin with available and commercial curricula, adapting and creating tailored approaches for generalization; (f) modify curricula based on review of goals and objectives; (g) modify activities as needed (p. 56). These suggestions parallel those from the National Information Center for Children and Youth with Disabilities (1992) in individualizing approaches and making instructional adaptations relative to a child’s needs, learning style and developmental level.

Supporting Parents with Intellectual Disabilities

Prominent researchers in the field assert that an accurate prediction of prevalence of parents with ID will never be known (Booth & Booth, 1999; Tymchuk 2006; Accardo & Whitman, 1990). The families identified and included in prevalence figures are ones involved with service agencies or the court system. They have either sought help or have been referred for help from a variety of entities. Tymchuk and Booth and Booth asserted that there are many successful families we may never know about who are coping adequately as parents with ID. They are invisible to traditional service systems. Similarly, individuals reported in research studies and legal proceedings are not representative of the entire population of existing parents with ID (Andron & Tymchuk, 1987). The prevalence of parents with ID will always be unknown, they said. Booth and Booth (1999) suggested that the complexity of modern life and the increased scrutiny and surveillance of the population, however, may result in more parents being unable to cope with stress and therefore brought to the attention of social welfare and judicial systems. Tymchuk (personal communication, October 21, 2006) suggested that only by tracking students who leave special education settings would we be able to ascertain prevalence of parents with ID. The general aversion to public registries makes this highly unlikely (Accardo & Whitman, 1990).

Much of the research in the area of parents with disabilities has focused on parents with physical disabilities (Kirshbaum, 2000; Olsen & Clarke, 2003; Barker & Maralani, 1997; Wates, 2002). In the national survey completed in the United States on behalf of Through the Looking Glass (Barker & Maralani), a disability advocacy organization in California, parents with ID were not well represented in that or previous efforts to identify parents with disabilities. The authors reported that the survey itself might have prevented some parents, especially those with ID or deafness, from responding in the ways surveyors made available (written surveys, questionnaires, and phone interviews). Citing supporting data from the 1993 Survey of Income and Program Participation of the U.S. Census Bureau, Barker and Maralani reported that 7 million parents in the United States had some disability and were parenting children less than 18 years of age. Thirty percent of people with disabilities become parents, as opposed to 40 per cent of people without disabilities, they reported. Of the 30% of people with disabilities who become parents, one in five was a parent with ID. Of all parent groups, however, they are the most likely to lose custody of their children through legal proceedings. The broader literature bore this out reflecting on the heightened level of scrutiny to which parents with ID are subjected (Booth & Booth, 1994a; Dowdney &

Skuse, 1993; Edgerton, 1999; Wates, 1997), not uncommonly resulting in the loss of their children. Olsen and Clarke (2003) reported that in the UK, parents with ID represent two thirds of all cases involved with child protective services. Similarly, as Booth (n.d.) reported, this treatment is not unique to the UK; in the United States and Canada up to 80% of parents with ID lose custody of their children. In Belgium it is estimated that 40% of children born to parents with ID are removed from their parents' care; in Australia one third of children of parents with ID were in child protective custody. In another study reported by Booth (n.d**),** 7 of 16 infants born to mothers with ID were in process of being removed from their parent(s) within one week of birth, with six of those removals having been originated before birth. Hayman (1990), in his review of the legal and political history of parenting by people with ID, likened widespread child removal and the presumption of incompetence and inadequacy to another form of eugenics: while parents with ID may reproduce, they will not raise their children to be like them. This was also articulated by Chen, Brodwin, Cardoso, and Chan (2002) who maintained that while societal attitudes toward social and educational inclusion for people with disabilities have improved, areas of personal and social inclusion, including dating, sex, and marriage, have been slower to change.

It is widely accepted that the number of parents with ID is increasing and will continue to increase with individuals exercising access to inclusive communities and relationships in those communities (Whitman & Accardo, 1990). Knowing the high rate of child removal from parents with ID, increasing numbers have implications for social systems and the role of education in preparing students with ID for adult roles and choices. What was thought of in the past as lower fertility rates for people with disabilities was most probably the limited opportunities to reproduce due to segregation of the sexes in institutional settings and sterilizations (Whitman & Accardo). What is uncertain today is the total number of existing families in which one or both parents has ID. What is also unknown is the number of people with ID who will become parents in the future. Parents with ID were also underrepresented in the National Health Interview Survey conducted by the U.S. Bureau of the Census, National Center on Health Statistics in 1994 and 1995. Of the 202,560 mothers surveyed, 140 were women with ID or developmental disabilities (DD). Anderson et al. (2005), estimated that there are 49,719 mothers with ID nationwide; and 80,638 with both ID and DD, living with their children. Because of the small sample size, the authors stress caution in any interpretation of the population estimates. Needs of mothers with ID and DD were combined for analysis as the data for mothers in these groups were so limited. When one considers the number of women with ID who lose custody of their children (Booth, n.d.; Tymchuk, 2006; Accardo & Whitman, 1990), it seems that many women who may be parents with ID were not included in this survey as all respondents currently lived with one or more children.

Implications for Children, Parents, Families, Society

Children are the most vulnerable people in the issue of parents with intellectual disability, an issue that brings out strong emotional responses among professionals (Edgerton, 1999). Children of mothers with ID are at increased risk for developmental delay (Feldman & Walton-Allen, 1996; Keltner, 1994). The juxtaposition of child welfare and safety and adult self-determination has made the issue of parents who have ID an especially complex subject. In promoting the concept of dignity of risk (Perske, 1972), it is a balance of who is at risk and to what degree, resulting in a dilemma of protecting children and protecting parent rights at the same time (Feldman, 1997). Following is a review of six studies that reflected inquiry in the area of parents with ID and their children. These studies were selected because they examined the nature of risk factors within families when parents have ID, were conducted by well-known researchers in the field with a history of scholarly publications, and report possible supports and strengths among parents with ID.

Frequency of involvement with child protective services (Feldman, 2004; Feldman & Walton-Allen, 1997) and concern for safety, health, and general wellbeing of children within these families (Budd & Greenspan, 1985; Llewellyn, 1995; Lewellyn, McConnell, Honey, Mayes, & Russo, 2003; Tymchuk, Andron & Rahbar, 1988) were characteristics reported by the researchers. Therefore, it is not surprising that four of the articles reported on direct parent training in areas of health, safety, child developmental and behavior management.

One of these studies was the research published by Budd and Greenspan (1985). The authors reported the results of a survey conducted with 16 parent training programs serving parents with ID through behavioral therapy approaches. Fifty-two parent questionnaires were returned in the survey, representing information about parents taking part in services offered through these programs.

Budd and Greenspan (1985) adapted the Parent Training Questionnaire, a 56-item survey, from previously developed and published tools identified by the authors. The survey asked respondents, the therapists, to estimate intellectual functioning for the parents with ID, describe the type of treatment provided, rate the level of each parent’s participation in training offered through attendance and interaction, and rate the degree of each parent's competence and resources. The questionnaires were sent to 20 professionals involved in parent training programs serving parents with ID and other high risk characteristics. Sixteen programs, principally community mental health centers and university based clinics, responded. Respondents were asked to conduct the survey over as many as five family meetings with families who met the criteria of (a) mother had ID, (b) behavioral or educational parenting skill intervention was provided, and (c) the therapist had on-going contact with the family sufficient to anticipate outcome of the therapy. The results of the surveys were coded with appropriate reliability.

Results indicated that the most frequent training provided addressed behavior management, basic childcare, and child development. No relationship was revealed between characteristics of parent age, history of institutionalization, income, number of children in the family, functional level of the children, presence of a father in the family, and outcomes for success through the training. Only seven percent of the therapists attributed parents' cognitive levels as a reason for questioning their competence. Training programs described through the returned surveys indicated that the services provided to parents with ID were more involved and intense than that typically available through other community parent training programs. Less than one half of the participating parents with ID made substantial improvement according to the therapists. In one third of the cases therapists were optimistic about parent outcomes. There was limited generalization of skills reported. The authors do state that "Some…made considerable improvement," p 27, but do not indicate how many are "Some" and what "considerable improvement" means. Parents who entered the various programs with higher abilities initially, not measured by IQ but rather capacity to care for their children, showed the most progress.

Few of the reporting therapists identified cognitive function as the measure of competence in parenting. In addition, parents with initial ability to parent, who perhaps had greater levels of socialization, empathy and compassion, demonstrated greatest progress in the course of the program. A behavioral therapy approach may not be the most appropriate fit for teaching those characteristics if those are the qualities successful parents demonstrate (Budd & Greenspan, 1985).

The second study reporting research on direct parent training was conducted by Tymchuk et al. (1988). The authors reported the results of problem-solving training with nine mothers who had ID and were caregivers for their young children living with them. The mothers ranged in age from 21 to 38 years of age and all had children between 1 and 4 years old. Several had older children as well. The mothers were all participants in Project Parenting, a university and community program providing assessment and treatment for mothers with ID and their families.

With Project Parenting staffers, Tymchuk et al. (1988) generated 50 child rearing decision making situations, ranked them by importance with the mothers, and created a sequence of decision making steps. Vignettes were created for the most important of the situations and two scores were identified: problem identification (that there is a problem); and application of the steps (what to do about the problem). The mothers were trained through the vignettes over a series of sessions conducted for six weeks. They received some prizes and encouragement by the staff. They did not receive punishment or admonishment for not responding correctly to the decision-making vignettes.

The results reported indicted an increased ability of the participating mothers in decision making, by identifying the problem and the necessary steps, as demonstrated through the vignettes. They also maintained this ability after one month. They had considerable difficulty, however, in generating alternative decisions when asked. This skill was not apparent. While the study did not address generalization to real life situations, the authors reported two concrete examples given by mothers in applying the problem identification and application of steps to practice in novel situations in their lives.

Health and safety promotion was a theme carried out in further research (Llewellyn, et al., 2003). In addition, methods and approaches developed or influenced by Tymchuk at UCLA (Tymchuk et al., 1988) were continued or adapted for this study. The participants in this study (Llewellyn et al.) were English speakers who had a diagnosis of intellectual disability, a history of receiving special education services, or who had been identified by the referring social service agency as a person with an intellectual disability. There is no report of administration of standardized test(s) of cognitive ability to determine level of intellectual disability. All 45 parents, from 40 separate families, were primary caregivers of their young children, under the age of five. They all resided in Sydney, Australia. None had been diagnosed with mental illness, substance abuse, or living in situations of domestic violence. Informed, signed consent was obtained for all participants through the consent process described as typical in this community in Australia and not unlike the process in the United States.

Employing a randomized controlled trial, Llewellyn et al. (2003) adapted the Home Living Profile (HLP), which had been developed at UCLA in the United States, to reflect the Australian language and customs as well as the learning preferences of the advisory group which represented the intellectual level of the participating subjects. Following a baseline assessment, home based intervention focused on parent decision making for health and safety and was conducted through ten-week lessons, averaging 11.5 visits per participant. Participants were separated into four groups with staggered visit schedules and intervention approaches including home visits only, current services only, lesson booklets only, or a combination. All groups eventually received the complete home visit and booklet intervention. However, comparison of groups, both those currently receiving total intervention and those not, was made throughout the study through direct interview of the participations. In addition, a three-month follow-up was conducted to determine if participants had maintained anticipated improvement in knowledge of lesson content. The outcome measures identified through the HLP included "Health" (comprehension, illness and symptoms, emergencies, going to the doctor, and medicine safety) and "Safety" (home dangers, home illness precautions, and home precautions). Again, the participants were interviewed, using the materials adapted for the lessons, to determine retention of skill.

Results of the study revealed that this specially designed parent education program for parents with intellectual disability was effective in increasing knowledge of health and safety issues and maintenance of this knowledge and application of it over a three month period. Parents who received the home visits in combination with their current services and used the lesson books had improved knowledge of precautions as measured on the adapted HLP at a greater rate than those receiving only current services or booklets. Of note is the positive correlation between reading accuracy and scores on health comprehension. Llewellyn et al. (2003) speculated that parents with higher reading levels may have had greater knowledge to begin with regarding health, safety and related vocabulary. However, it is also notable that the authors did not measure intelligence or intellectual functioning at the onset of the study.

Research with parents with ID has also been active in Canada. In his 2004 report of research conducted with 33 families with parents with ID, Feldman (2004) explored the cost effective means of increasing caregiver ability and reducing child neglect through independent, self-study of child-care, health and safety skills. All of the 33 parent participants had been recently assessed for eligibility for services for people with ID in Ontario, Canada, and all met the DSM-IV definition of ID. All of the families were living independently and below the poverty line, and most were receiving some form of subsidy. Child protective services was supervising 79% of the families. The mean age was 26.3 years. The mean reading grade level was 4.1 as measured by the Wide Range Achievement Test. The mean age of the target children was 9.9 months, ranging from 2 to 51 months.

Feldman (2004) designed a child-care checklist and accompanying task analysis, manuals and audiotapes about childcare practices. Manuals included line drawn illustrations and were inexpensively easily reproduced. Questions such as “When to call the doctor?” and “When to call 911?” were addressed. After several visits by home visiting staff who recorded observations and assessments of home safety, an oral checklist was administered and scored to determine parent skill level. Baseline of parent knowledge of skills was monitored over several more home visits. The manual was then read to the parent and parents listened to audiotapes were demonstrated for in home self-study. Parents were then called to check on the use of the manuals. If there was no increase in skill within 3-4 weeks as measured by the home visitor through observation and checklist, prompting was employed by the home visitor. Parent skill was monitored until there was 80 per cent success. Observation was faded out eventually to once every 6 months. If a parent was not successful, direct, full training of the lessons was offered.

Feldman (2004) reported that there was no difference in response to a variety of variables including (a) responses of mothers versus fathers, (b) frequency of visits such as weekly versus monthly, (c) materials used by another agency rather than staff directly supervised in the study. Across all participants, 96% met criteria through the self-study materials and 80% maintained the skill or knowledge in follow-up. The author reported that the results were the same for those using the self-study materials as those receiving direct instruction by a specially trained parent educator delivering the lessons.

Other studies reviewed explored social systems and supports for parents with intellectual disability. In her inquiry into viewpoints of parents who have ID, Llewellyn (1995) reported on her two year exploration with six married couples, 4 of which included both members who had ID, or ID. The participants were identified through various agencies in Australia where the study was conducted. They all were parenting young children and were approached by agency staff regarding participation in the study. They were then contacted by the author and included in the study with their consent.

Llewellyn's (1995) inquiry was an in-depth series of contacts, interviews, and observations conducted over two years. Home visits, family outings, phone calls, and other activities, including formal interviews conducted every month, were carried out. Mean number of contacts with each couple over the two-year period was 25. Field notes and observations were recorded and data analyzed to determine the type of supports the participants received and their satisfaction with those supports.

Results of Llewellyn’s study (1995) were reported in a cluster of ways, but overall, some basic assumptions about support for parents with intellectual disability were challenged. These include the fact that not all adults in this group have family support, not all family support is desired, that friendships with anyone other than family or caregivers are very rare, and family members, benefactors and professionals provide the core of support for parents with ID. Couple partnerships were active decision-making relationships among the participants. Everyday management was of critical importance in their lives. Family support was given, but typically with very negative messages about the decision to become parents. The participants expressed a willingness to accept information and support that both recognized their self-worth and fit their ability to understand. They did not like judgments or coercion. They did value family, especially family that was geographically close. Friendship ties were non-existent among the parent participants. They experienced severe social isolation with reliance on family and professionals for social encounters. Support from professionals was not always welcome. Again, fear of judgment and lack of confidence about one’s ability affected the relationships (Llewellyn).

Similarly, Feldman and Walton-Allen’s (1997) research study investigated the effects of mothers’ ID and poverty on several areas of child development through a comparison of performance of children raised in poverty by mothers who did not have and intellectual disability with those who did. The comparison involved two groups of families with school-aged children, 6-12 years old. All mothers with ID were living in Ontario, Canada, where they had been referred from 10 social service agencies. Maternal level of cognitive ability was measured on a battery of standardized intelligence, academic and behavioral adjustment tests. Seven families were eliminated from the study because maternal IQ was greater than 70 on this battery of tests, resulting in a total of 27 families where the mother was identified as having ID. All of the eligible families who contacted the authors agreed to participate; none dropped out. In obtaining informed consent for participation, the mothers with ID were accompanied by their "workers." The comparison group was recruited through community flyers in low income neighborhoods where the target population of mothers with ID lived. The first 25 mothers who responded participated throughout the study; none dropped out. Mothers in the comparison group were also tested as described above, with seven mothers refusing. These women were included as their work history indicated that they did not have ID. Mothers in both groups were between 30 and 35 years of age, half were married or partnering with another, all were poor, and most were receiving welfare. None of the children in either group had known disabilities or neuro-biological impairments.

Feldman and Walton-Allen (1997) assessed academic achievement and intelligence, behavior disorders, and quality of the home environment as well as maternal social isolation and support, using standardized tools. In comparing the school aged children in the two groups, Feldman and Walton-Allen determined that there was greater history of involvement with child protective services in the group with maternal intellectual disability. In addition, there was greater incidence of intellectual disability reported among the fathers of children in this group. The home environment also received lower rating scores in the group with maternal ID and increased social isolation was found among this group of mothers. Through review of school records, the authors found that child IQ was lower among the group with mothers with ID as was school achievement. Behavior disorders were identified more frequently among children of mothers with ID, especially among boys. Children with IQ’s greater than 85 who had mothers with ID had more behavior difficulties than others in either group. Higher maternal social isolation and lower home environment scores correlated with increased child conduct concerns and hyperactivity. Maternal isolation also correlated with increased behavior problems in children.

No children of women with ID in this study were without problems (Feldman & Walton-Allen, 1997), and these children had more difficulties all around than children of mothers without ID. Maternal ID appeared to affect boys and girls differently, with boys having statistically significantly lower academic achievement and increased behavior problems. The social isolation of mothers in this group appeared to be a critical factor in how they might support their children. One family in the group had received early intervention for a son when he was an infant. This child had an IQ of 97 at the time of the study, suggesting that early intervention with mothers who had ID may affect outcomes for children through improved cognitive ability. This is also reflective of the early research of Skeels and Dye (1939).

The results of the Feldman and Walton-Allen (1997) study are not unlike that of Anderson et al. (2005). Anderson et al. made a distinction between people who had ID only and those who had a cluster of developmental disabilities (DD), including ID and/or physical disabilities in their study. They reported that almost 30% of children whose mothers had ID in their sample, or both ID and DD, also had intellectual and/or developmental disabilities, and were more likely to have learning difficulties and to be enrolled in special education. Children in this group whose mothers were not married were also enrolled in special education at an increased rate and reported learning and behavioral problems at school. In his review of 20 early intervention studies with children of mothers with ID, Feldman (1994) reported that 40% of children enrolled had an IQ of less than 70 with delayed language development. In addition, they were considered high risk for behavior and psychiatric disorders. Feldman stated that parenting skills were needed to support intellectual and psychological development. He also recognized the limited research in evaluating the effectiveness of programs such as those he reviewed.

Similar to Llewellyn (1995), Ehlers-Flint (2002), in her research with parents with ID, discovered that her participants led very socially isolated lives, characterized by poverty and relatively devoid of friendships. Similarly, Koese, Hussein, Clifford, and Ahmed (2002) examined social support networks of mothers with ID and reported that while those with stronger networks had better psychological well-being, few had strong family relationships with extended family members. Few could identify a friend. While Tymchuk (1992) recognized the importance of familial support for adequate parenting, several researchers reported that participants described difficulty in relationships with family members who may have been negative about the parent status of the person with ID and interfered (Llewellyn; Ehlers-Flint), or were not supportive of the parent with ID (Whitman, Graves, & Accardo, 1990).

Parents with ID have been perceived as incompetent and held to higher levels of scrutiny not experienced by other groups (Andron & Tymchuk, 1987; Booth & Booth, 1993; 1994b; Edgerton, 1993; Feldman, 2002)). This has affected the ways in which they interact with social services or other governmental agencies, and in their fear in asking for help and assistance (Taylor, 1995). There is also a lack of consistency in how parents are treated and in decision making around parenting and their ability to remain actively parenting their own children (Booth & Booth, 1993; 1994b; Taylor). There has been no clear definition of what adequacy of parenting is, expectations, or training by the professionals who make life changing decisions (Hayman, 1990), resulting in a nebulous, shifting, and undefined standard to which parents with ID are held.

Depression among mothers with ID has been identified as another factor negatively affecting the quality of parenting (Booth & Booth, 2003; Feldman & Walton-Allen, 1997). Poverty, social isolation, and domestic violence have been shown to affect the parent’s level of depression and ability to care for his or her child (The New Mexico Infant Mental Health Collaborative Committee, 2003; Shonkoff & Phillips, 2000). While the extent of maternal depression, and direct impact on one’s parenting has not been fully identified or researched with this population, the effects of maternal depression on early childhood development in general is well documented in the literature (Shonkoff & Phillips). This remains an important area for further study and investigation. Within families in which the mother had ID, maternal depression has been shown to affect the quality of the home life (Keltner, 1994).

Teacher/Provider Expectations Regarding Sexuality, Partnering and Parenting Among Students with Intellectual Disabilities

The broader literature assessing the life satisfaction among adults with ID who are parenting is rife with examples of social isolation (Llewellyn, 1995), poverty (Booth & Booth, 1993; 1994a; Feldman & Walton-Allen, 1997), and legal action affecting their families (Booth, n.d.). Preparing students with ID for future participation and contribution to society is a critical role of educators in a democracy (Goodlad, Mantle-

Bromley, & Goodlad, 2004). The complexity of adult life for people with ID, especially should they choose to parent, is an instructional challenge.

Teacher expectations in the academic setting have been considered a powerful influence on IQ (Rosenthal & Jacobson, 1968). Academic expectations of special education students have also been affected by previous student performance (Rolison & Medway, 1985), as well as by teacher biases based on social and ethnic differences (Obiakor, 1999). Teacher expectations and resulting self-fulfilling prophecy, while not strongly affecting all academic sectors, did seem to exist for stigmatized, at-risk students, such as students in special education classes (Jussim & Harber, 2005). Thus, the power of teacher expectations in affecting academic outcomes for students, especially those in special education, appears to impact student achievement. Darling-Hammond, French, and Garcia-Lopez (2002), in reporting student teacher experiences with marginalized, multi-cultural students, addressed the importance of creating a teacher corps prepared to address complex issues flexibly and directly in order to achieve a measure of social justice. While pre-service teacher expectations for partnering and parenting were not directly a part of this report, the themes of self-advocacy, equal access to society and preparing students for full citizenship apply.

Separate from academic achievement is the influence of educator values regarding sexuality among students with disabilities (Bemish, 1987). Because of the limited research in this area, a variety of related studies will be considered.

Brantlinger (1992) found no previously published literature about special education teachers' perceptions and concerns regarding including sexuality education in the secondary curriculum. In her qualitative study of 22 secondary special education teachers, Brantlinger reported that most of the responding teachers strongly acknowledged a need for sexuality education in the school and that such education would reduce problems associated with sexuality among their students. Very few, however, had any experience with teaching sexuality content, and those who did provided no focus on relationship, self-understanding, or decision-making. Two teachers reported that their special education students were excluded from general education sexuality instruction because it was “above their heads” (pg. 36).

Male teachers expressed vulnerability and discomfort with teaching sexuality education, fearing parent responses and being identified as sexually aggressive. There was general fear among teachers who were concerned that the content would lead to inquiry or actions beyond their level of knowledge and control. The greatest obstacle for pursuing and carrying out sexuality education was lack of administrative support, however. Additionally, lack of training and competence in the content and as a sexuality educator was a major barrier to providing sexuality instruction. None of the teachers had received training in their teacher preparation programs regarding sexuality education. Two home economics teachers in that study stated they had some preparation. While the existing power structure in the educational setting and administrative barriers were recognized as ways sexuality education is limited to students with intellectual disability, Brantlinger (1992) stated that teacher preservice and inservice training programs can be effective ways to ensure that students are prepared for future life roles.

Wolfe (1997) surveyed administrators and both general education and special education teachers about their values around sexuality issues of mid- and high school students with ID. With 98 people completing and returning a mailed survey, and a return rate of 24%, Wolfe was able to organize responses of administrators and teachers to determine that, similar to other groups surveyed, the respondents typically had a negative reaction to consideration of the opportunity for people with ID to become parents, with administrators holding the more negative reaction. The degree of negativity of reaction by both groups (administrators and teachers) seemed related to the degree of disability of the student with the student with more severe disability receiving the most negative responses. The reasons given included concern for the individual(s) to care for their children and the possibility of heritable intellectual disability with offspring. In addition, the absence of family support or financial stability influenced their responses, reported the respondents. This is similar to Tymchuk's (1992) identification of predictors of adequate and inadequate parenting.

Although legal protections now prohibit involuntary sterilization of people with ID without a court order, the majority of respondents to Wolfe's (1997) survey approved of sterilization of people with ID. Prevention of “unnecessary menstrual cycles” (p. 79) was one rationale for sterilization respondents noted. In addition, “protection from rape and assault” was another (p. 79). How sterilization would protect against rape and assault was not reported by Wolfe, however. In addition, the surveyed teachers and administrators expressed concern that child bearing by individuals with ID would cause undue tax burden to the public. Wolfe advised professionals to examine their own values, gaining self-awareness, in preparation for their work with individuals with disabilities.

Aunos and Feldman (2002) reviewed articles reporting attitudes toward issues of sexuality, sterilization, childbearing and parenting by people with intellectual disability. Parents, direct service workers, teachers, university students, and students with ID were among the groups included in a wide range of studies reviewed here. While several of the studies were published more than 20 years ago, teachers were reported to have among the more positive attitudes toward sexuality, partnering and parenting by people with ID than the other groups reported in the literature. Of the teachers, women had more favorable reactions than male teachers, with Aunos and Feldman speculating that men may have been sensitive to possible questioned motives if teaching sexuality education.

Parents of children with ID and direct care staff had the most negative reactions to issues of sexuality, partnering and parenting by people with disabilities. Parents expressed ambivalence about talking to their children about sexuality, limiting their children's access to knowledge in some cases. Parents were more forthcoming with daughters than with sons regarding sexuality information (Aunos & Feldman, 2002). Similarly, Llewellyn (1995), in a study with couples parenting with ID, discovered that parents of these individuals were very uncomfortable with their children's choice to become parents. They had concern for their well-being, ability to manage their own lives and to care for their children.

Research with direct care staff and attitudes about sexuality was the most abundant in the review by Aunos and Feldman (2002). While the individuals included in the cluster of studies in this category represented a wide range of roles and professions, in general direct care staff felt that sexual relations among people with ID should be discouraged. This reaction did not extend to people with physical disabilities, however. As noted earlier, there is more information available (Sobsey et al.,1991) and more self-advocacy among people with physical and sensory disabilities (Kirshbaum, 2000; Olsen

& Clarke, 2003; Barker & Maralani, 1997; Wates, 2002), perhaps making partnering, sexuality, and parenting more acceptable.

As Aunos and Feldman (2002) reported, most of the literature reviewed was at least 20 years old at the time of publication of their review. Current reflections of the social and political climate are not known. For example the current abstinence-only initiative had not yet been introduced to American education when the reported studies were published. Also, the presence of AIDS was not as well known as today, which may also affect the responses of respondents.

As more current research emerged, however, there appeared to be little change in acceptance of professional staff in supporting sexuality and sexual expression by people with ID, including preparation for roles as partners and parents. Milligan and Neufeldt (2001) reviewed personal narratives, cultural images, and the attention to sexuality within rehabilitation settings serving people with disabilities, including ID. The assignation of "asexuality" was common regarding people with disabilities although websites developed by people with disabilities and first person narratives revealed the contrary. In their review of research on attitudes toward people with disabilities, the authors identified common beliefs among professional rehabilitation staffers that people with disabilities bring less social worth to social situations and that society treats people with disabilities as asexual and of lesser social value, resulting in rejection and further isolation. This was considered a "self-fulfilling prophesy" (p.92) in that some people with disabilities would withdraw from social interaction and therefore present an asexual presence. The interaction of society and cultural images and practices has been slow to change attitudes about the sexuality of people with disabilities while physical access may be a reality.

Christian, Stinson , and Dotson (2002) surveyed staff working with adult women with developmental disabilities to determine the staff acceptance of sexual expression of these women and the influence this acceptance had on their approach to serving these women. Of the 75 surveys distributed to staff, 43 were completed and returned, which represented about 20 percent of the employees of the organization. Staff responding included 20 with bachelor’s degrees and 5 with master’s degrees. Less than half of the staff responding stated that women with disabilities were not regarded as sexual beings, but while women with disabilities might enter into intimate relationships, there were more important priorities for their lives and for the organization. Most reported that women with disabilities could have children but that sterilization was an acceptable form of birth control and was supported by the degree of disability a woman had. In addition, the majority of staff surveyed stated that with adequate support and training women with disabilities could be successful mothers.

The majority of respondents in this study reported that women with disabilities should receive sexuality education and that they, as support staff, were comfortable providing that education (Christian et al., 2002). Only 7.1% of those responding, however, said that they themselves had received any training in delivering a sexuality education program. While the agency had developed policies regarding sexuality education for the women served, the personal views of the staff, they reported, would guide their actions in determining sexual boundaries, intervening in intimate situations, and in providing information and education to the women in their care. The authors concluded that the personal beliefs and acceptance of staff, separate from agency policies and protocol, influenced actions and what and how education would be provided to the women with developmental disabilities. Establishing policies, the authors stated, was not enough. Supporting the work of employees on a regular basis and providing education and training to staff, as well as examining staff attitudes in implementing agency policies was essential.

Lofgren-Martenson (2004) explored changing beliefs and expectations regarding sexuality and disability in Sweden, observing behaviors and interviewing staff members and parents who worked with adolescents with ID. The author explored three themes and situations in which issues of sexuality among adolescents with ID would be examined, including social situations where they might meet and socialize with potential partners, the opportunities for self-determination and independence in areas of sexuality and sexual expression among youth with ID, and opportunities for sexual expression and eventual parenthood for youth with ID. While Swedish attitudes toward sexuality and sexual expression among the general population have changed over several years, the author found that there was little opportunity for youth with ID to socialize and develop intimate relationships with others. Social situations were limited to group functions heavily supervised by staff. While the lives of staffers had changed in terms of their opportunities for more social freedom, this same freedom had not been extended to the youth under their supervision. Similarly, staff and family reported being uncomfortable with sexual expression by youth with ID and these behaviors were described as “abnormal” (p. 204) and therefore discouraged. They feared exploitation of the youth in sexual relationships and described limiting information and opportunity as a way of reducing risk of exploitation. Friendships, rather than love, were encouraged, with youth “protected” from forming more physical relationships and staff avoiding discussion of sexuality. There was little privacy provided youth, again for presumed protection, and staff and family assumed a double standard for expression of sexuality and loving relationships for youth with ID. Sexual expression among the youth observed, Lofgren-Martenson reported, was typically heterosexual and not unlike that of other adolescents. The goal was not typically intercourse but rather focused on flirting, hugging and other brief physical contact, and kissing and petting. Youth with stronger verbal abilities sought more intimate sexual relationships and voiced a desire to be parents and partners.

In another study, Chen et al. (2002) reported that attitudes about dating and marriage for people with cognitive disabilities were not well understood. In their study comparing attitudes about people with disabilities and dating and marriage, the authors analyzed responses of college psychology students in California, Singapore, and Taiwan to questions about social behaviors of people with disabilities. American students had the more positive attitude toward dating and marriage by people with cognitive disabilities than students from either Taiwan or Singapore. However, the large number of American women expressing positive attitudes, as opposed to American men expressing less positive attitudes, skewed the results. This may reflect a similar gender difference reported by Wolfe (1997) above. Among Chen et al.'s findings was that attitude was correlated with the amount of prior contact respondents had with people with disabilities. If a student did not have previous experience with people with cognitive disabilities, his or her attitude was typically less positive. Those who had experience held less negative attitudes.

Chen et al. (2002), in exploring attitudes in the emerging economic communities of the Pacific Rim, suspected that not only individual exposure but government leadership was responsible for attitude. Setting government policy to ensure membership of people with disabilities not only in employment settings but in social choices that may include marriage and family will, they predict, affect attitude.

While recognizing the need for sexuality education for students with intellectual disability, and seeing education as a way to help students develop healthy adult relationships and safe behaviors, Howard-Barr et al. (2005) reported that parents and special education teachers often felt unprepared to provide instruction. In order to ascertain the needs of teachers in teaching a sexuality curriculum, 494 Florida special education teachers were mailed an instrument constructed from 36 sexuality concepts and asked to respond to 94 questions regarding sexuality education. With 42% of the teachers responding, results indicated that except for abstinence, less than 10 per cent of the respondents addressed topics of “sexual behavior”. While most respondents indicated that they had some education in sexuality, their training was not adequate and most received no training in teaching sexuality education to special education students.

With less than one half of respondents teaching sexuality education, the topics they chose to teach or felt comfortable teaching were limited. Teachers did not see their students as typically engaging in sexual behavior in the future and therefore reported that sexuality education would lead to inappropriate behavior or exploitation. Nonetheless, teachers reported the need for some sexuality education among their students.

The authors concluded that teacher preparation should include a methods course in sexuality education. This aligned with respondents’ recommendations that professional preparation should include training in sexuality education.

The Discourse of Disability, Sexuality, Partnering, and Parenting

In his discussion about ID, Bogdan (1980) compared and contrasted perceptions of ID over time. Using Edgerton's classic study of former residents of a state institution for people with ID as a starting point, Bogdan maintained that the system of classification delivers more than just a mere label. Historically, the category of "ID" comes with a complete set of pre-conceived expectations of the individual's abilities and disabilities, and resulting expectations of life decisions made for him or her.

An example of this is "Barry's" story, an account of a man institutionalized for 35 years (Dimity, 2000). Barry's institutional life was chronicled through his case file. Meticulous records, emphasizing medical history and his many deficits, failed to recognize his strengths and his misdiagnosis of ID many years earlier. The tragedy is less the misdiagnosis than the institutional assumptions made for and about Barry and the resulting treatment, whether he had ID or not. The documentation, professional record keeping, and resulting "absolutes" about Barry's existence represent what McLaren described as "dominant discourse" (1994, p. 189): that which is spoken out loud, carries weight of the prevailing professional and scientific judgment of the time, and therefore becomes "truth".

Adults and children with disabilities, their parents, and teachers may lack the social and political power, as well as the reflective opportunity, to challenge the "dominant discourse" (McLaren, 1994, p. 189), or "discourse of category membership" described by Danforth and Navarro (1998, p.4) in research of themes in language about people with disabilities. The poignant result may be one quoted by Danforth (1995), from a child who had been moved from a segregated class for children with emotional disturbance to a general education setting: "Does this mean that I'm not EH anymore?" (p. 136).

Expectations of ability and disability held by schools and those who work in them are also powerful. The application of a dominant perspective, often driven by a medical/deficit model, limits the way one conceptualizes disability, supports full membership in a social context such as a school, and provides educational access (Danforth, 1995). The way disability is discussed, or not, also telegraphs what is valued and expected (Peter, 2000).

The absence of discourse regarding sexuality and future adult roles of people with ID is very noticeable in the educational literature, where self-advocacy (Test, Fowler, Brewer et al., 2005; Test, Fowler, Wood et al., 2005) and self-determination (Karvonen, et al., 2004) programs for high school students do not include even minor mention of these concepts. This omission is not unique to educational programs for students with ID as Fine (1988) noted a missing discourse of desire relative to adolescent girls, which contributed to their lack of knowledge and continued vulnerability in sexual situations. Similarly, Tepper (2000) described the "missing discourse of pleasure" in supports and services designed for people with disabilities. He stated that the continued denial of sexuality among people with disabilities creates a system to juvenilize, protect, and isolate. Priestley (1998) maintained that by denying sexuality and eliminating discourse about roles of partners and parents of people with ID, we are able to avoid an examination of social systems and political and social change. By "othering" people with ID, and characterizing their sexuality as deviant, said Priestley, we can continue to control their sexuality and reproduction and achieve what the eugenics movement set out to do. First person accounts bear this out (Putnam et al, 2003) as adults with physical disabilities reported little or no information about sexuality, sexual pleasure, and adult relationships through medical providers.

Summary and Conclusion

People with ID are entitled to the same freedoms and choices enjoyed by other citizens and described in law, court decisions, and legislation. However, successful transition to adult roles of partner and parent is fraught with difficulties. The absence of discourse in transition curricula (Test, Fowler, Brewer et al., 2005; Test, Fowler, Wood, et al., 2005) has failed to provide people with ID adequate knowledge and support in decision making in adult roles. The majority belief of service providers in sterilization of people with disabilities (Aunos & Feldman, 2002), the failure of social systems to support and protect their welfare, safety, and families (Booth, n.d.; Finlay, & Lyons, 2002; Hayman, 1990; Tymchuk, 1999; Tymchuk et al., 1999; Sweeney, 2000), the difficulty and sometimes absence of teachers and providers in supporting sexuality education (Christian et al., 2001; Lofgren-Martenson, 2004), and the more recent approach to sexuality education that promotes abstinence-only, provides a narrowing context in which people with ID can grow in their own self-knowledge to actualize choices.

Child wellbeing and safety must remain the first priority in all families, including families parented by people with ID. The frequency with which parents with ID lose their children, and the ambiguity of expectations, however, does not take into account their learning needs, need for accommodation, or cultural and social bias of service systems designed to support them. Early and on-going developmentally appropriate education by the school, family and community can help prepare them to interact socially and enjoy the liberties of society. The lack of clear roles, support and information, coupled with inflexible service systems in addressing issues of child removal and permanency does not serve them well.

While people with ID continue to express themselves sexually and become partners and parents, the lack of discourse within teacher preparation programs, schools, educational curricula, and the educational literature is stunning. The vision and expectations for the lives of people with ID, beyond school transition and work place social skills, are not articulated; the missing discourse among those preparing to teach students with ID is an area for further exploration.

CHAPTER 3 METHODOLOGY

Overview

The purpose of this study was the investigation of the expectations and anticipations of in-service special educators on life span opportunities of their students to assume roles as partners and parents with ID. In the following chapter I describe the research design and methods used to investigate (a) the expectations of middle and high school teachers of their roles, as professional educators, in preparing their students for future roles beyond the classroom; and (b) their anticipations of the lives their students will live beyond the classroom, especially possible adult roles of partners and parents. The description of research design includes a rationale for the selection of ethnography as well as a description of the ethnographic interview selected for this study. The research site, selection of participants, approaches to data collection and analysis of data are discussed. In addition, approaches assuring trustworthiness are reviewed.

Research Design

Through ethnographic interviewing, this study created a cultural picture or ethnography to investigate the expectations and anticipations of in-service special educators on life span opportunities of their students to assume roles as partners and parents with ID. The study specifically focused on (a) the expectations of middle and high school special education teachers of their roles, as professional educators, in preparing their students for future roles beyond the classroom; and (b) their anticipations of the lives their students will live beyond the classroom, especially possible adult roles of partner and parent.

Data gathered through this study included extensive interview data of identified participants. I collected and analyzed data to reveal expectations and anticipations that address teaching responsibilities that support post-schooling work-related activities of their students but also those addressing life span roles of partners and parents. In addition, I expected data to reveal the expectations for the role of the educator as well in preparing students with ID for adult roles.

The primary research question in this study was: What are the anticipations of middle and high school special education teachers for their students with ID for future roles as adult partners and parents? Underlying research questions included: what do middle and high school special education teachers expect of their role and responsibility in preparing their students for adult roles as adult partners and parents?; and what are the anticipations of middle and high school special educators of their students as to future opportunities for adults with ID to marry, to conceive, and to raise children?

I chose ethnographic interviewing as the means through which information was gathered in addressing these questions. The inquiry into the personal response of the participant educators and the need for open-ended “humanly implemented inquiry” (Lincoln & Guba, 1985, p. 187) in gathering and analyzing information requires a naturalistic approach.

Ethnographic Research

Because ethnographic research seeks to understand “the cultural meanings people are using to organize their behavior and interpret their experiences…” (Spradley, 1979, p. 93), it provided an appropriate vehicle for exploring the expectations and anticipations of in-service special educators as to the future of their students and their role in preparing students for future roles including possibly partnering and parenting. All of us, Spradley wrote, create meaning of our own daily lives without thinking about it. Our understanding becomes automatic as we are part of that culture, know what to expect and know what the meaning of observations, relationships, and language in that culture are. It is the pursuit of meaning, examined through the meaning of behavior, language, and interactions of a group (Creswell, 1998), that opens the researcher up to understanding the culture. And it is culture that is the focus of ethnographic research.

Agar (1996) contrasted ethnographic research with that of more traditional, positivist hypothesis testing, describing the ethnographic process as just that, a process that produces changes over the time of the research. This change may be realized through the questions asked as well as through the relationship between researcher and informants. He described the researcher at times like the student of the informant, one learning from the informant. This is not unlike Spradley's (1979) description of the researcher entering into a new culture, learning from every encounter, interaction, and artifact in that environment; a novice immersed in an environment from which he/she will learn.

Ethnographic research also seeks to tell the story of a culture and the understanding gleaned through informants. It is "discourse" (Bruner, 1997) and also a translation of research information from the studied culture to the researcher's culture and audience unfamiliar with the informants' and the cultural meanings (Spradley, 1979).

Ethnographic research strives to better understand culture and the meaning we attribute to relationships, words, and products of that culture, through direct and intimate involvement with members through observation, interview and interaction. There are expectations of respect for the research site and informants as well as for transparency in collection, interpretation and dissemination of the information gathered. Philosophically, there are basic assumptions that guide qualitative research and that which is conducted through ethnographic study. Creswell (1998), has described this through: *ontological* considerations, those of differing and multiple realities for the researcher and those engaged in the research setting; *epistemological* assumptions, affecting the distance of researcher from research setting, and minimizing this by increased time in the setting; *axiological* assumptions, or role and understanding of values in the study; *rhetorical* assumptions as to the language used in reporting the narrative and the differences in terminology and meaning from quantitative research; and *methodological* assumptions, and the anticipation that the researcher will use an inductive approach to the research, employing specific methods to gather information for understanding. Ultimately, the question posed by Spradley (1979), must remain prominent in the ethnographic researcher's mind:

> Ethnography for what? For understanding the human species,
> but also for serving the needs of human kind. One of the great challenges
> facing every ethnographer is to synchronize these two uses of research. (p. 16)

The background and rationale for the study was developed through a variety of sources and includes (a) the awareness of the currently limited role educators play in preparing students with ID for adult roles as partners and parents (Espe-Sherwindt & Kerlin, 1990); (b) the absence of curricula in self-advocacy programs that prepare students for these roles (Karvonen et al., 2004; Test, Fowler, Brewer et al., 2005; Test, Fowler, Wood et al., 2005); and (c) the absence of discourse about sexuality, partnering and parenting in preparation for life roles (Fine, 1988; Putnam et al., 2003; Tepper, 2000). There has been little direct inquiry as to what expectations and anticipations educators, including in-service special educators, have for themselves and how they have formed their expectations in affecting students' adult roles and their anticipations of what those adult roles will be. Previous limited inquiry among teachers was published more than twenty years ago (Aunos & Feldman, 2002); there has been no inquiry as to the expectations of teachers for themselves and anticipations of assumption of adult roles in the future for students with ID.

Ethnographic research sets a means for examining this topic, and extracting an understanding of how expectations and anticipations are formed within the life context and culture of in-service special educators. How and what we expect for and of people with ID is affected by the cultural underpinnings of our lives and those that form our professional roles. Educational institutions are charged with preparing students for life roles; what life roles are students with ID prepared for and how do in-service teachers anticipate their part in providing that education? Because ethnography "is a description and interpretation of a cultural or social group or system" (Creswell, 1998, p.58) it was well suited to the research. Ethnography examines the themes present within culture, in this case that of in-service special educators, to gain understanding of that culture. It also provides a way in which the "missing discourse" (Tepper, 2002) of disability can be addressed. It is an effort to begin to "fill in" the missing or absent discourse in the areas of sexuality, partnering and parenting among people with ID by those charged with preparing them for their futures.

Methods

While methodology is determined by the researcher's assumptions, the purpose of the research, the approach taken and the perceived role of the researcher, specific methods are the tools by which the research is carried out. It is a dynamic concept, and one that involves the active participation of the researcher and acknowledgement by the researcher of his or her influence on decisions throughout the process. It is strongly affected by the researcher's expectations and anticipations and is reflected in the language the researcher uses to discuss and describe the research site, data sources and data collection approaches, data analysis and approaches to ensure trustworthiness

Research Site

This study was conducted between Spring 2010 and Fall 2010. Following approval by the Institutional Review Board (IRB), I asked university special education instructors to be permitted to present a brief 10-15 minute introduction to the study in their graduate level classes, in an effort to recruit in-service middle and high school special education teachers as participants. During those presentations I provided all students with a brief overview of the project, both verbally and in writing, with my contact information should they wish to participate. This information was provided on a flyer approved by the IRB (Appendix A – Recruitment Flyer). In addition, I posted the recruitment flyers in the Special Education Program at the university and disseminated them to other colleagues who had contact with special education teachers. Contact with me was independent on the part of the individuals and I provided a variety of means by which they could contact me. These included cell phone number and email, through a private email account create for and dedicated solely to communication about this study.

Once interested individuals self-identified as possible participants and contacted me for more information through the means described above, I explained the study to them in greater detail, including eligibility as participants and criteria for inclusion in the study: middle or high school special education teacher who works with students with ID within 40 miles of the university; who have at least a bachelor’s degree; and are over 21 years of age. I offered to meet individuals in person before giving more information, but all requested that I explain the study to them over the phone. After that, a mutually agreed upon time and place to meet and obtain written consent was arranged. Consent was obtained using the IRB approved form (Appendix B - Consent to Participate in Research). While opportunity to allow more time to consider consent was always offered, all participants requested that interviews be conducted immediately after having given consent. These initial meetings and interviews were held in a location and time convenient to the teachers, but ones that assured privacy and safety for all. Locations included vacant university classroom, meeting room, and office, located on university property. One participant requested that I meet her at a coffee shop adjacent to her school where the interview was conducted outdoors but at a distance from any other patrons. At this location, recording equipment did not function and written notes of the interview were developed. Notes and quotations were read back to the participant during the interview for her approval. All other participant interviews were audio recorded with the agreement of the consenting teachers.

At the initial meeting, background information about the inception of the research, the expected outcomes, and the research process was shared with the participants as part of the informed consent procedures approved in advance by the IRB. I also shared expectations of participation in an individual interview and a later focus group which would include other participants in the study as well. The consent for participation was obtained in order for the research to begin.

Following the guidance of my dissertation committee, I sought the participation of a minimum of eight individual participants but attempted to recruit 12, allowing for possible attrition. Once participants consented to participate, general demographic information was obtained from them individually on forms submitted to and approved by the IRB (Appendix C – Demographic Information). Because the location for face-to-face meetings and interviews and focus groups was individually negotiated, settings varied by participant, but were all mutually agreed upon settings offering privacy and safety for all participants at mutually convenient times, which included evening and weekend hours. The format and the interview questions followed Spradley’s approach to descriptive questions (1979) including the grand tour, mini-tour, example, experience, and native-language questions (pp. 86-91), gathering and revisiting areas of information through a conversational approach which continues to check in with the participant as to the researcher’s understanding. The tools used to gather information through interview and focus group mirrored the process Spradley described. First general, demographic information was gathered, requesting information about the participants’ educational history and teaching experience (Appendix C – Demographic Information). This was followed by a request for information unique to the individual’s understanding of the influences of his/her life that affected career decisions as well as expectations for future roles of students, including partnering and parenting (Appendix D – Interview Questions) with mini-tour questions emerging to better understand initial details shared through the demographic and interview questions. Finally, focus group questions (Appendix E – Focus Group Questions) served to engage all participants in deeper conversation about their work, their expectations for themselves, and their anticipations of their students’ future lives as scenarios were discussed. Hypothetical –interactive questions were utilized to draw out participant’s thoughts about dating, intimacy and pregnancy of students they might know. Native language questions throughout interview and focus group activities helped the researcher ensure that there was understanding of intent and use of language and descriptors of the participants.

Field notes were made prior to, during, and following the face-to-face meetings and interviews with the students. These notes included my impressions and general thoughts throughout the research process.

Participants

Unlike quantitative sampling techniques, which are based on gathering a representative sample from a population to be studied, sampling methods in this qualitative study were based on selection of participants who could provide information to best answer the research questions. This purposeful sampling approach is framed by four basic goals. These are: (a) achieving a representative or typical sample through deliberate selection, with resulting confidence that the results will be representative of the larger population; (b) capturing the total range of the population, or “maximum variation” (Guba & Lincoln, 1989, p. 178) in sampling; (c) examining specific cases through which your theories can be examined; and (d) establishing opportunities for comparison of individuals or settings (Maxwell, 2005, pp. 89-90). Selection of participants and related decisions throughout the research process, however, are affected by the realistic possibilities and opportunities of access, data collection, relationship with participants, ethical considerations, and attention to validity.

As described earlier, participants in the research were in-service middle and high school special education teachers working with students with ID. Because recruitment was initiated through university special education teacher preparation programs, some participants were currently enrollment in coursework. Participants were informed about the purpose and anticipated value of the study and the cultural norms as well as the acceptable research practices of this academic setting. Participants were also assured of confidentiality in their participation and contribution to this research. Because of closeness between the teaching and university communities, and the fact that several of the participants are known to both, I have elected to not describe the participants individually by age, gender, experience, or teaching assignment. Rather, they are described collectively to honor the commitment to confidentiality.

While the minimum number of participants for this study was eight, I sought the continued participation of between eight and 12 in-service teacher participants, because of possible attrition by participants during the course of the study. After several months of recruiting I had obtained consent for eight teachers meeting the criteria for the study and who committed to both an interview and participation in a focus group of peers. Several other individuals, including three pre-service teachers, two elementary special education teachers, and one teaching assistant, expressed interest in participation but did not meet the requirement of a middle or high school in-service special education teacher working with students with ID, licensed with a minimum of a bachelor’s degree and teaching within a forty mile radius of the university from which this study originated. Of eight initially consenting to participate, all completed both an interview and participation in a focus group.

Basic demographic information was sought from the participants following their agreed consent to participate (see Appendix C – Demographic Information). This information included age, gender, educational history, teaching background, general knowledge of IDEIA, presence of people with disabilities in their families and among social groups and contacts, contact information, and preferred interview times. Participants were informed that information would be gathered throughout the research process to include direct interviews and focus group, through audio recording and/or written notes should the participants prefer and from data gathered through the demographic information forms. All participants were assigned a pseudonym for identification in reporting the data.

The eight participants who committed to the study all taught within a 40 mile radius of the university. The 40 mile radius was chosen to include the possible participation of individuals from several school districts surrounding the university. A mid-year online survey of job openings for special education teachers among five school districts within this 40 mile radius revealed a wide range of vacancies. One smaller district reported two vacancies in general education and none in special education. All other districts reported vacancies in special education teacher positions, including: 11 teacher vacancies, two of which were in special education, or 18% of open positions; three teacher vacancies, one of which was in special education, or 33.3% of open positions; two teacher vacancies, one of which was in special education, or 50% of open positions; and 69 teacher vacancies, 46 of which were in special education, or 66% of open positions. The number of special education vacancies at mid-year among four of the five school districts surveyed reflects current challenges recruiting and retaining qualified staff to carry out the day-to-day teaching of students with special education needs within the research study area.

One male and seven female participants were included, with a mean age of 45 years. The age range of the participants was 31 years to 69 years. Three had master's degrees in special education; two currently held bachelor's degrees in different areas of study but were enrolled in special education classes in a master's program; two held bachelor's degrees and were currently enrolled in an alternative licensure non-degree program; and one held a bachelor's degree with no additional post-graduate coursework. All participants currently taught special education and worked with students with intellectual disability. Their classrooms were typically self-contained meaning that their students were not in inclusive settings throughout the day. While several had teaching and substitute teaching experiences with students in general education as well, current assignments were exclusively special education with little involvement with students in general education.

Professional teaching experience ranged from one half year by one participant, following several years of working as a substitute teacher in special education, to 18 years of employment as a high school special education teacher by another. The mean years of special education teaching experience at the middle and/or high school level was 5.6 years. This did not include several years of substitute teaching by two participants and ten years of preschool teaching by one other participant.

In describing coursework which addressed preparation of their special education students for adult roles, including dating, partnering and parenting, responses included: four participants who had been or were currently enrolled in a university course dealing with sexuality of people with intellectual disabilities; one who had completed a workshop on sexuality and people with ID; one who had received in-service professional development training on transition from high school; one whose undergraduate program included health, science and biology as well as home economics; and one who identified training in child development, communication disorders, psychology, and behavior disorders as an undergraduate.

Knowledge of IDEIA, (or “IDEA”, Individuals with Disabilities Education Act, as it is commonly referred to) and important elements of the legislation varied among the participants broadly. The five participants who had either completed master’s degrees or who were currently enrolled in master’s programs all cited coursework that focused on IDEIA. However, the important elements affecting their work identified by these five participants ranged from transition planning to the Developmental Disabilities Waiver (DD Waiver) program. Of the three who had not studied for a master’s degree, one identified transition and physical accommodation for students who may need assistance such as a ramp or preferential seating, one questioned legality of her guidance to sign as the principal on IEPs, and the third indicated little knowledge of IDEIA as it related to her daily work.

All participants identified at least one family member who had ID, including a sibling (1), nephews (2), a former in-law (1), adopted children (1), aunt (1), and distant cousin (1). Identification also included a family member who had a stroke in her 60’s (1), as well as one’s self and one’s children and grandchildren (1). Among friends identified with ID, participants identified a fellow church member or child of a church member (2); the grandson of friends (1); and former clients served through the DD Waiver (1). Three identified no friends with DD and one stated that friends “don’t let me know” if they have ID. None of the participants indicated a requirement for special accommodation in order to participate in the interview or the focus group.

Data Sources and Collection Strategies

Recruitment was initiated shortly after IRB approval of this study by the university, and data collection commenced six weeks later with the first participant. However, difficulty in engaging eligible participants and recruiting a minimum of eight for the study delayed completion of enrollment and data collection through both the interview and focus group portions of the study. Data were collected throughout the spring, summer and fall semesters, 2010, providing an opportunity to conduct extended interviews with participants to gather sufficient data through comfortable rapport. All eight initial participants continued in the study to its completion. Specific timelines were not rigidly sought, but rather attention to time and relationships for the collection of sufficient data to answer the research question(s) and to develop understanding of the information addressing the research problem. When little or no new data were emerging, it was considered that there has been saturation (Creswell, 1998). While interview and focus group discussions were primary approaches to data collection, Maxwell (2005) cautioned that prescribed questions and rote observation inhibit and limit the amount and type of data gathered. Rather, he suggested a willingness to maintain an open mind and creative thinking as collection strategies are implemented. This was the approach I pursued, including accepting timelines I could not influence as the eligible participants identified themselves and committed to being part of the study.

Interviews and Focus Groups

With the exception of one individual interview that was not recorded because of equipment malfunction in the interview setting, the approach to data collection was through audio recordings, supplemented by notes made by the researcher prior to, during, and following the interviews and focus groups. Interviews were conducted using a series of open-ended questions approved in advance by the university IRB (see Appendix C - Interview Questions). Timing of interviews was dependent on the teacher participants' schedules and availability, negotiated with the researcher. The role of the researcher and listening techniques employed were critical to the way in which data emerged, as expressed by Maxwell (2005) earlier. Careful listening informs careful questioning, and elicits critical information. Spradley (1979) lists three basic principles to strengthen the rapport between participant and interviewer in the early stage of exploration (p. 81). These include (a) repeated explanations throughout the interview, from beginning to middle to end by the interviewer to ensure the participant is informed of the interviewer's intention and expectation; (b) restatement of what the participant says, reinforcing what has been said and checking in with the participant as to whether what you heard had been intended; and (c) seeking an understanding of use of language rather than an expectation of meaning or explanation.

One individual interview was conducted with each participant, followed by participation in one of two focus groups which included three to four participants each. Focus group questions were also pre-approved by the IRB (see Appendix D - Focus Group Questions)**.** One to two focus groups had been anticipated, but one participant was unable to attend either due to a family emergency. Through consultation with the dissertation committee chair, it was determined that a follow up individual interview would be conducted to include only one individual. While beginning questions, previously approved by the IRB, were used to guide each interview, I pursued probe questions, examples of which were approved by the IRB, to expand understanding and to develop rapport between the participants and myself. This was done to elicit information that deepened the conversation and yielded more information to address the research questions. Through thoughtful questioning and listening, the interviews provided opportunities to develop rapport and a relationship, in the manner of the "friendly conversation" nature of the ethnographic interview (Spradley, 1979). As Spradley indicated, however, specific interview elements also involve (a) an explicit purpose – which is a shared expectation of both interviewer and participant, but one of which the interviewer has more awareness of the purpose and gradually more control over the direction; (b) ethnographic explanations – ranging from general project explanations, recording explanations, native language explanations, interview explanations related to specific tasks, to clarify explanations about a specific question; (c) and ethnographic questions, which can include descriptive, structural and contrast questions, for example (Spradley, pp.55-68).

The focus group engaged a cluster of participants in discussing an issue or problem through interaction. It is an especially effective means of examining "not only what people think but how they think and why they think that way" (Kitzinger, 1995, p 299). Participants were engaged in a less formal discussion with the opportunity to agree with or counter the ideas and experiences of others. It was an interactive process, and while the researcher was prepared with a guide and specific questions and purpose, the focus group was not solely dependent upon the researcher's questions and direction. In this way the focus group served to draw out information that did not emerge in the more formal individual interview setting. However, participation in a focus group can also compromise confidentiality; while all participants were asked to maintain confidentiality regarding the discussion and other participants, there is no guarantee that such commitment will be respected (Gibbs, 1997; Kitzinger). Participants were made aware of this limitation in the consent form as well as in the introduction to each focus group.

As in any successful friendly conversation, timing and pace were important. Spradley (1979) stressed the need for pacing and patience in developing rapport and relationship, overtime, and at the same time reminding the interviewer to maintain control over the interview. The researcher as an instrument of the research is critical in being the listener, and by managing the interview. This is accomplished through utilizing good listening skills, remembering what was said, and anticipating next steps in the interview which will facilitate understanding of the data eventually (Glesne, 2006).

Observation was limited to the interview setting and carried out only during the ethnographic interviews, with notes recorded immediately following the interview. Participants were not observed in their classroom teaching settings. How they physically interact with their students in the classroom, as teachers, and observation of their interactions in the classroom or with their peers, colleagues, supervisors, and parents of their students was not the focus of this study. Their interactions with the researcher the interview setting, however, was observed and noted.

Observation notes included both a description of what was observed as well as reflections of the observation. Creswell (1998) suggested these include what the researcher might be feeling or thinking about what has been observed. In addition, researcher's drawings accompanied the observation notes and included representations of the setting and other physical recollections of the experience. This also assisted researcher recollection of the interactions with the participants.

As anticipated, rapport grew with each interviewee as the observation developed. Gaze was affected by a number of factors including anticipated comfort of the interviewee in the setting, body language of the interviewee, gender, and choice of position of the interviewee in the interview setting. The observation is certainly affected by the researcher's perspective developed through culture, age, education, and experience, among other factors. Typically, in following Spradley's (1979) description of the ethnographic interview as a friendly conversation, the researcher sought to weave observation into the interview experience, seeking first a comfort level with the interviewee, finding common ground and understanding, reflecting Glesne's (2006) guidance of listening carefully and remembering what was said. The researcher strived to ensure that observation was unobtrusive and that gaze sought to find a comfort level with the interviewee rather than serve the convenience or curiosity of the interviewer.

Documentation

Specific but basic information was solicited from participants as to age, gender, educational history, employment background, family make-up, including presence of people with disabilities in the family, contact information, need for accommodation, and preferred interview times and locations. These data were collected on paper forms which had been submitted in advance to the IRB for approval (see Appendix C – Demographic Information)**.** Participants provided information requested on the forms soon after giving consent for participation; the researcher confirmed information with them and recorded additional information should the participant offer more. This type of documentation is typical of naturalistic inquiry in that it is (a) stable; (b) non-obtrusive; (c) exact in containing specific information; and (d) of broad coverage, which includes participant background and demographics (Yin, 2003).

Reflective Journal

More a personal reflection on the research experience, and not as specific to the research setting as the field notes described earlier, a reflective journal was maintained that includes recordings of reflections beyond the research site and memos, autobiographical notes, and other thoughts and ideas that surrounded the research experience. Categories of reflection included elements of the research design, methodology, theory, and other information. The reflective journal entries continued throughout the data analysis. It required researcher discipline in maintaining, but provided an additional information source.

Peer Mentor

Peer mentorship provided a means to refine data analysis and interpretation. A colleague with extensive experience in qualitative research volunteered to be a peer mentor, interacting as themes emerged from the research data and discussing possible ways data might be interpreted. In addition, guidance was given as to development of memos and personal, autobiographical elements impacting data analysis.

Data Analysis

The nature of qualitative research is the on-going analysis of data, beginning with early analysis in the initial stages of data collection. This includes keeping a regular journal of reflections providing a way to capture information not readily apparent from the direct interviews or observations. Maxwell (2005) recommended the regular review of taped interviews, prior to transcription, and then a review of written transcriptions as well. During this time, I wrote notes and memos to document what I was seeing or hearing in preparation for categorizing and connecting analyses. Spradley (1979) reiterated the need to begin the analysis as data are being collected, in the search for cultural symbols and relationships between the symbols emerging from the data analysis. I transcribed the recorded interviews myself, which Davidson (2009) recognized as a method of initial analysis, influence, and interpretation of the data.

Domain Analysis

I utilized Spradley's (1979) approach to domain analysis, clustering interview and observational data and concepts into categories as they began to form and emerge. This, too, was an on-going process and helped inform the next round of interviews as the analysis progressed. I predicted that the phenomena I was researching would reveal a variety of themes, with relationships emerging between the various themes across domains to form a whole. Strauss and Corbin (1998) reminded that not all concepts fit into structures or categories created by this analysis, and must be shifted from "concept" to a dimension of another, emerging property. The use of Spradley's domain analysis is dynamic and allows the researcher to look at information in an organized hierarchy within a domain. The researcher's creativity and personal experience and background helped form the organization of information with the domains identified.

Analytic strategies included finding relationships between statements and events, and linking the interview transcripts to the focus group discussions. I looked for relationships between themes, categories and domains, finding similarities, but also differences and the missing pieces. A final sort of the data was developed and organized in domain analysis displays (see Appendix F – Domain Analysis Displays). Because of the absence of information about the discourse of adult roles of people with ID in the educational literature as well as the self-advocacy literature, I predicted this process would begin to explore that.

Member Checking

Participants were invited to review summaries of both individual interviews and individual contributions to the focus groups. Their input was intended to be incorporated into the report, with a reciprocating effort to involve the participants and accommodate their input. Only one participant offered a correction to the summary submitted to her, which was a correction in the chronology of her previous employment. Multiple efforts were made to engage participants in providing additional input and/or corrections. This effort at clarification and understanding during the analysis of the data parallels that of Spradley's (1979) basic principles for guidance for conducting interviews including repeated explanations throughout the process, restating what a participant says to ensure accurate understanding, and seeking understanding of use of language rather than judgment of meaning. Member checking was conducted continually throughout the research, consulting participants as to the accuracy of the interpretation and understanding of their intent. This was done through verbally checking in with participants throughout the interviews and focus groups, through review of written summaries of interview and focus group participation, and follow up email and phone calls to participants to identify any inaccuracies in the data representation.

The Role of Theory

Critical disability theory examines the power relationships between institutions and social structures and people with disabilities. It recognizes the ongoing need to adapt systems of supports for the needs of the individual with a disability, which may be a lifelong need (Charlton, 2000; Pothier & Devlin, 2006). There is not the expectation of fixing or curing the disability in an approach typical of the medical model, but rather recognizing it as a normal part of life and providing appropriate supports so that the individual may participate in society to the greatest degree possible. Schools and educators represent a power structure and privilege of knowledge, resources and access that is embedded in larger social structures at other levels of power and privilege. As a group, adolescents and young adults with ID will be experiencing new, inclusive life opportunities and challenges historically unaddressed by educational institutions. How students with ID are prepared to engage in opportunities of the larger society will determine, in part, their success. Schools, and the people who work in them, wield much power in determining what that preparation will entail. Recognizing opportunities for adult roles, including those of partner and parent, is one step in determining what educational preparation for the future will look like. None of us, at any level, is totally free in our choices, opportunities, or actions. However, for a group experiencing new, inclusive life opportunities, challenges and opportunities previously unaddressed by educational institutions, language influences the power relationships. The missing discourse in areas to be explored, adult roles of partnering and parenting by people with ID, in the ideas, words and articulations of middle and high school teachers can inform the training of future teachers who, as members of school teams, wield power in making teaching decisions.

The importance of life experience and how that is reflected through relationships and language was articulated in symbolic interactionism, another theoretical lens through which this study was undertaken. The use of language beyond communication, but also for constructing reality, said Spradley (1979) is central to how we interpret the world. The combination of critical disability theory and symbolic interactionism, in exploring the expectations and anticipations of in-service teachers in preparing their students with ID for adult citizenship in a democratic society seems a good match for this study.

Symbolic interaction requires interpretation of meaning to the symbols of our lives, including actions and words and concepts, which are the processes of human interaction (Blumer, 1966). Meaning is constructed through social interaction. It can also be reconstructed and transformed through interaction; it will change over time. The work of Sullivan (2001) and Nirje (1969) revealed that while legislation may change opportunities for people with ID, our expectations and anticipations in realizing and supporting those opportunities may not follow. The meanings we attribute to the events and individuals, and the meanings attributed to us by others, as well as our experiences in social interaction, will alter, over time, the meanings we place on things and concepts. It requires reflection and the ability of the individual to examine and interpret experiences and his or her social interaction (Blumer). The opportunity to understand the meaning groups assign to symbols and to explore meanings through reflection offers an opportunity to actualize social change as promoted through legislation. By better understanding the expectations and anticipations of in-service teachers regarding the future roles of their students as partners and parents, one who is one can begin to understand the barriers to full membership in society for individuals with ID.

As I undertook this research, I remained open minded, however, with an interest in seeing what emerged rather than superimposing expected outcomes on the proposed work. The selection of ethnographic interviewing is an appropriate method of exploring the use of language in describing expectations and anticipations of adult roles by in-service teachers within the culture of public education and special education and the existing power relationships between institutions and people with ID.

Ethical Considerations and Techniques for Assuring Trustworthiness

As the researcher, I adhered to the need for trustworthiness, as described by Lincoln and Guba (1985), by pursuing four specific aspects, including: 1) *credibility,* by negotiating the outcomes and checking in with the participants as to what I am observing and my interpretations. This does not preclude a possible difference in opinion as to what is observed, but it served to keep me aware of the participant's perspective, and required that I acknowledge a different perspective if it emerged; 2) *transferability*, by recording "thick description" of the setting and documenting observations in rich detail, with a consideration that other's qualitative work may have relevance for my observation and that there may be transferability of knowledge, but that can only be approached by recording minute detail; 3) *dependability,* by looking at a variety of data from a variety of sources in order to get the best picture of what I was observing and what I was a part of. Through triangulation, the process I expected to employ by reviewing demographic information, considering field notes developed at different times and with different participants, and interviews and focus groups, I attempted to ensure dependability in this process and the final product; and 4) *confirmability*, by keeping a journal, field notes, and other documentation of my process and involvement in this study, helping to ensure that the interpretations I drew from the experience, was evidenced by the data and not from a personal perspective or assumption not based on data.

Summary

Over the previous year and a half I developed and conducted ethnographic interviews and focus groups to explore the expectations and anticipations of in-service middle and high school special educations teachers as to their expectations of themselves in preparing their students with ID for future roles, including those of partner and parent, and their anticipations of what students' future lives and roles will be. The research was carried out at the University of New Mexico and included interviews, focus groups, the collection of demographic information, as well as researcher reflective journal and field notes and memos. All University practices for informed consent and research protocol approval were observed and no research was initiated without approval of the IRB. Member check was conducted throughout with participants invited to provide clarification of information gathered, assuring credibility of the research.

CHAPTER 4 FINDINGS

Overview

This chapter summarizes the findings of a series of ethnographic interviews, both individual interviews and those from small focus groups following individual interviews, conducted between Spring 2010 and Fall 2010. The eight participants were all middle and high school special education teachers working with students with intellectual disability. Data sources included interviews and focus group discussions. The purpose of this study was to investigate the anticipations of middle and high school special education teachers as to life span opportunities of their students in assuming adult roles as partners and parents with intellectual disability, and their expectations for themselves in preparing their students for adult roles. The primary research question in this study was: What are the anticipations of middle and high school special education teachers for their students with ID for future roles as adult partners and parents. Underlying research questions included: what do middle and high school special educators expect of their role and responsibility in preparing their students for adult roles as adult partners and parents? and what are the anticipations of middle and high school special educators of their students as to future opportunities for adults with ID to marry, to conceive, and to raise children?

Data collection resulted in transcripts and notes of recorded and unrecorded interviews and focus group discussions conducted over a seven month period, from March 2010 through September 2010, with eight middle and high school special education teachers currently working with students with ID. A semi-structured interview process for both individual interviews and focus groups was utilized, following guided questions developed in advance and approved by the IRB. While interview questions focused on the individual participant’s decision to become a special education teacher and his/her preparation for guiding students to adult roles, including those of partner and parent (see Appendix D – Interview Questions), focus group discussions elicited responses to a series of scenarios about “Mary” and “John”, a hypothetical young couple, both 18 years of age, with ID, who were engaged in a romantic relationship progressing from dating to intimacy to pregnancy (see Appendix E – Focus Group Questions).

Participant responses to both individual interview questions and to focus group scenarios, however, took a broader approach to not only questions of preparing students with ID for adult roles, but also the relationship of the participant teachers to their work in general, and expectations of them in their teaching roles. Relationships with parents and school hierarchy, the possibilities and limitations of IDEIA, and their own life experiences all figured prominently in the conversations conducted with the eight participants.

I begin this chapter with a description of data that fall into three major domains for analysis. The domains that emerged from sorting and resorting data were (a) *Boundaries*; (b) *Dangers and Threats* ; and (c) *Responsibility for Change*. Each of these domains includes a number of themes that were revealed through the data analysis. The themes are grouped and analyzed within the major domains identified above. The analysis is illustrated in a visual display, including the domains, themes, and supporting data (See Appendix F – Domain Analysis Displays). Linkages and connections within the three are identified to provide a unifying picture of the data. Excerpts from transcripts of individual interviews and focus groups are used extensively, and at times repeated, to demonstrate the linkages and connections between the domains. Information in parentheses is provided by the researcher for clarification unless otherwise indicated.

Individual participants are identified with pseudonyms throughout the findings. In addition, information as to where the excerpt is located within the transcripted data is provided in parenthesis to indicate the individual interview or focus group and page on which that information is located. For instance, participant “Lin” is identified in interview number “one” on page six of that interview as “Lin, I, p. 6”, or in focus group number “two” on page three as “Lin, FG II, p.3”. One participant, “Toni”, did not participate in one of the two focus groups but rather a follow up interview, and her participation in the follow up is identified as “Follow up interview”.

Boundaries

A recurrent theme emerging from the data was that of understanding the tension of where one, as an individual, began and ended relative to one’s work; one’s relationships to others; one’s responsibility to others through work and personal relationships; one’s interaction in a larger society; and society’s interaction with individuals. Five themes in the domain of boundaries are presented from the data: *tension between personal/professional boundaries; paternalism; students’ own boundaries in social and social-sexual interactions; societal boundaries; and parental boundaries.*

Tension between personal/professional boundaries. If a teacher does not have good personal and professional boundaries it will limit how he or she can identify breach of boundaries for himself and strongly affect how he can teach students with ID about appropriate boundaries. Some past personal experiences of participants aligned to parallel identification with their students’ lives today, or that of caregivers, as boundaries between self and others blurred. One example was Lin, who shared the story of an early personal history fraught with disorganization, abandonment, and stigmatization. As a teacher, she similarly described her students’ trauma in being “ostracized” and “downgraded”.

> I felt that like last year our kids’ lives got ripped apart by how (the school district) changed the inclusion settings in our middle schools. And I wholeheartedly disagreed, with that happening at our schools, and other schools, too, not just ours. I don’t think, I think we are almost going backwards in middle school, I don’t know about elementary school, but our kids were back into small segregated classrooms. I had, um, where kids were like, “Ms. __, I am not wanting to be in a special class. Everybody knows I’m a special ed student, I don’t have to be ostracized…”. I think your life could fall apart as easily as mine, and if someone had an accident and became disabled today, how would their life change? It doesn’t matter what you have, it is just hard to see how people judge people so much. I’ve been judged all my life….(Lin, I, p.16)

The participant, Lin, went on to share some of her own, personal history, juxtaposed with her report of her students’ feelings and motivation observed during the current school year:

> I did have difficulties, but not disabilities, or intellectual disabilities. And so many people just saying you won’t make it, you don’t belong. They labeled me “foster” and because I was a foster kid, and it really drove me to want to make these labels go away. (Lin, I, p.16)

One’s approach to being a special education teacher can be influenced by personal, early experiences as well. Lin reported the following:

> And some of my kids don't have that pride, I think that they have been labeled and, and I had one, one comes to mind, last year, he said "Ms. _______, I have been put down all my life. And you tell me I can make it, but I have been put down all my life. What do I do?" I don't think there is that self-support. I think you have to reach down younger to elementary school to do that. Because sometimes they have been so traumatized that by the time they get to middle school they don't know how to change that around, so sometimes I think that there just needs to be a little bit…I don't know.
>
> *Researcher: So how do you think their adult lives will be like?*
>
> If you don't reach that, if you're told you are, not to bring my personal life in it, but if you are told you are stupid and you cannot make it in life, you may not make it in life. Unless you have that self determination to say "You know what? See ya!" And move on. And I think that a lot of our guys, if they need that boost and they don't have it, that that sticks in their mind. If they don't get it, they might not do well, they might be living off the system, they might be committing crime. I don't know. It's hard to say, but, but I would say that some of my guys have had a strong family foundation. (Lin, I, p.8)

Perhaps identifying with caregivers, or potential caregivers, Dot shared information about a sibling, one year younger than herself, who required surgery immediately after birth, the same surgery she, herself, required as an infant. Her sibling's post-operative recovery did not go well, however, resulting in intellectual disability. "It could have happened to any of us", she said, referring to her brother's resulting disability. As a sibling raised in a family that cared for a child with a disability, Dot knew first hand challenges of caregiving for a person with ID. Dot's perspective and family experience influenced her contribution to the discussion of a potential romantic relationship between two young adults with ID, "Mary" and "John", who were central to the series of scenarios about dating, intimacy and pregnancy. Dot said "I have a brother who is mentally handicapped. My mother is close-minded about that type of relationship." As the focus was guided to discuss the romantic relationship evolving to one of intimacy between the couple in the scenario, Dot went on to say:

> If there are guardianship issues, there have got to be a ton of players involved, to raise that child, care for that child, pay for that child. I teach special education and I have a lot of grandparents and they do not have the energy. They are tired out. ...and we all agree, someone has to step in, whether it is the grandmother or whatever. I feel for the grandparents. I don't think it is fair that those kids get dumped on them because their own children didn't step up to the plate. I don't think that is exactly fair to the parent, either. (Dot, FG I, p.5)

One discussion that spontaneously emerged in each of the three focus groups, and a discussion that was not prompted or even anticipated, was that of abortion and/or adoption of a baby conceived by two young adults with ID. Individual feelings regarding abortion and adoption emerged immediately from most participants, prior to their asking for more information about "Mary" and "John's" relationship, family support, decision making, or choice to begin a family or raise a child. Upon hearing, in the scenario, that "Mary" was pregnant, participants in all three focus groups reacted:

> "Yikes! That's a tough one. My personal thoughts, depending on how bad her disability is, I would be a proponent for abortion." (Dot, FG I, p.4)

"I would adopt the kid. I wouldn't want her to go for an abortion."(Pat, FG I, p.4)

"I am glad neither of you said abortion, because I am strongly opposed to abortion."(Jane, FG II, p.18)

"No, I don't believe in abortion." (Cal, FG I, p.4)

"I think that creates other psychological problems."(Jane, FG II, p.18)

Beyond individual feelings of abortion, one participant, Toni, shared that she thought "…adoption or abortion would be the choice" (Follow up interview, p.2). While she felt knowing the degree of disability "Mary" experienced would help with that choice, there was no discussion or inquiry into "Mary" and "John's" relationship, support, or active participation in making a choice to parent or not. Personal feelings cannot be avoided in reacting to personal decisions. However, the reaction by these participants did not reflect, as professionals, an emotional distance from their personal feelings to the professional perspective in the situation "Mary" and "John" were facing.

Paternalism. This theme represents a means of denying people with disabilities equality (Charlton, 1998) and surfaced as a theme through charity, assistance, and ultimately control within the domain of *Boundaries.* In this way *paternalism* denies recognition for respect and responsibility to which other citizens are entitled (Charlton). It is an over-reaching control of a class or group of people. Shame and pity, he maintained, are "two sides of paternalism" (p 55). One participant discussed her decision to become a teacher as follows:

> I became a special ed teacher and wanted to work with special ed students because it is a forgotten group of people. There are a lot of people who do not want to touch it. And those kids have every right. Yes, it's important to reach

> them in elementary school, but it is also important to reach them in middle school. And to get them to be individuals outside the classroom, and working with students, and to me it is very touching, because they respond to you.(Lin, I, p.6)

Another participant (Jane) described one of her reasons for becoming a teacher as "the desire to be needed". In addition, in describing her students she shared the following:

> So, I think their life could be one of maybe probably being institutionalized. I think a lot of them have gone into their own world and are happy where they are. There are others who want to be more than what they are. They want to be considered "normal". So, I would like to say most of them would have kind of a middle of the road life. (Jane, II, p.2)

Future roles for students and quality of life in those roles, for Jane, ranged from institutionalization to isolation to marginalization, for a mediocre future. She did not mention establishing goals to educate students to be able to access other options or that that was a responsibility in her role as a teacher or the school's role in its mission. Jane went on to describe her understanding of pregnancy among students with ID in the following:

> What I've observed with kids with disabilities is that they want a baby; they want something that they will love. They feel that that is really missing in their lives. A lot of them want a baby. They know what they are doing and they know what they want. But they don't know what they want. (Jane, FG II, p.19)

Another participant put difficult discussions with students in perspective of the classroom and the teacher’s role. These discussions would be complicated with any students, but with students with disabilities, she felt, even more so:

> One of the things I have dealt with is students who are homosexual. It is a very difficult thing to deal with. But we dealt with it in the classroom and openly. I would be very concerned about teachers who would put their own personal judgment in it. To where a kid comes to you and says “ I have a crush on a guy who sits next to me,” and the teacher says “AAAA! That is wrong, that is just wrong.” Or the girl who comes in and says “You know, I think I am pregnant,” who suddenly comes in and says “I think I am pregnant,” and to not be judgmental. On top of their disability, they deal with all the same emotions everybody else does. There are elements of shame, and guilt, etc., and the teacher that does not deal with that is my concern. This teacher is going to tell “Mary” “ Mary, you’re not supposed to get pregnant” and to “John” “John, no, no, no!” (Lee, FG II, p.23)

Language chosen to describe possible futures for students with ID relative to intimacy and reproduction reflected emotional reactions among the teacher participants and descriptors that project concerns beyond the question asked, which was “How do you think others, including the broader society, will react to this information?**”** The following exchange with Lin illustrates this:

> …and I think that it is still again lack of education, training, community support and building an understanding.
>
> *Researcher: Lack of education for whom?*

> The general population for being able to address it. We went from institutions to the general population and there was no in between as to how do we look at this group of people as a society and how we can help them. We went to "They shouldn't do this and they shouldn't do this", instead of saying "They are going to do this and how do we help?" How do we make this a positive thing? It to me is like a society of alcoholics or drug addicts or anybody else. You have got to figure out how to work together rather than ostracizing them and saying you stay on your side of the creek and I will stay on mine. You have to come together. We all belong here. We have to accept it. (Lin, FG II, p.11)

Another participant, Lee, offered a counterbalance to the historic beliefs and practices associated with *paternalism*:

> I think that we are continually progressing with our ideas about people with ID. We are moving from when we thought they were insane, putting them away in institutions, because they had a disability. So I think this is the next steps of broadening our ideas of society of what people with disabilities can and cannot do, what their rights are, what their human rights are, and what their relationships are. So I think that as a society, people are probably not ready for that. Or some people might look at it from a pity standpoint, you know, "Ooh!" They wouldn't quite take it seriously. I do not know how many people actually take couples with disabilities seriously, or rather "How cute is that?" Growing a relationship:
>
> I think that is where the problem is. I think once it goes beyond dating, once it moves beyond that, I think that is where a lot of society will start to

> struggle because we do not have the model for that. We, as a society do not know what that looks like. And what would that involve? And what if they have kids, what would that look like? And would the kids be a burden to our society? How are WE *(emphasis of participant)* going to have to deal with that? We don't say that with everyone else, we don't have that perspective. We don't know what the model is. (Lee, FG II, p.5)

The power of language and the enduring legacy of the eugenics movement also emerged in these research data. One participant shared her belief, off the recorded interview, that sterilization would be a preferred course for some people with ID (She agreed to allow me to report her comment during that unrecorded exchange). In addition she offered the following comments in the recorded interview in response to the question of whether her students might eventually form intimate relationships:

> Yes, and sometimes they could breed. Multiply. And you also wonder about their parenting skills and how good a parent they would make and would their children suffer. There are all these things. And then there are others. I am so gratified when I see them having those types of relationships. They found happiness. They are really, truly happy. (Jane, IV, p.5)

This concern carried over to the participant's contribution to the focus group, of which she was a part, with the following:

> Teaching special ed, and particularly where I am teaching now, that is why I say they are going to breed, because we have generations upon generations of these types of people just coming into our midst and the parenting is terrible and kids aren't interested in their education; people aren't interested in doing their best, so

> we have this cycle of them, just, being very demanding of our society. They, when you say they don’t form relationships, they are not particular where they are acting out their relationships. (Jane, FG II, p.2)

Another participant in the same focus group used the term “breeding” in a follow up response to Jane’s earlier comment:

> I think it is still taboo….I see the difficulties teaching inclusion, the trouble they have with the general ed populations’ parents even allowing anyone with any type of disability into my classroom I have more struggles that way, that even the general society says “No, no, no! We are not going to do that. We are not going to allow that. We are going to put our foot down because we do not want them breeding”. (Lin, FG II, p.10)

Participants shared candidly their sense of self in the work and their personal relationship to the work. Boundaries were blurred at times with some participants, as personal experiences and close identification with their students and perceived struggles of students, influenced decisions they might make for students, including options for grandparents as caregivers, impressions of administrative decisions, and parents’ roles.

Students’ own boundaries in social and social-sexual interactions. This theme reflected the absence of awareness and observation of typical social boundaries by students. These were issues raised by all of the participants who recounted concerns they had for students relative to sexuality and sexually charged interactions with others. These concerns included harassment of other students, potential stalking, not knowing appropriate behavior in public settings, and unintended pregnancies.

The combination of sexual maturation and socially inappropriate behavior was reported by one female teacher, who worked with the social worker to develop students' sense of boundaries. These concerns were discussed in the classroom, where the social worker utilized a scaled system of gauging boundaries. The teacher went on to describe classroom interaction and professional challenges she faced without understanding what the school "protocol" was for addressing these challenges:

> All of the students in my class were boys, just boys, and boys, and thinking about boy stuff, and I knew because I heard them talking in class and they were very interested in having a relationship. So, I think they will. I just hope that whoever takes over the class next year will spend some time focusing on relationship. I was just concerned about one kid who I thought could be a stalker. He just didn't get the reciprocity of a relationship. He thought "I like you and you have to like me." …And another kid, Ooh, and he was saying things to the boys like "Let's go in the bathroom…and hook up", and we had to have really serious conversations with him. And the social worker talked to him about the inappropriateness of that as well as the consequences of that if you say that to someone who doesn't know you are joking around. And we assumed that he was joking, but …the male social worker told him "these are the connotations behind this and this is what this means." We had a lot of conversations about this. (Lee, VII, p.13)

While there was no reference of the IEP as a tool to guide instruction or to identify goals related to sexuality education, Lee did describe a situation and indicated a specific curriculum she and the school counselor and social worker were using to address communication issues with students. She also referenced training in sexuality she had received in a graduate course as good preparation for dealing with an incident that arose:

> We had an incident last year with two students with disabilities. I was the sponsor teacher and it was a big deal and the security came and got me. So I was brought into it immediately. An incident. I was asked to intervene. I called mom and dad, the nurse was called, and they all came in and we sat down and talked about it, and the expectation was that I was going to be the one staying on top of what this student was experiencing, was going through. I don't know what the normal protocol is, and we have dealt with dating and sexuality in the classroom.
>
> *Researcher: So you talked openly with your students about this?*
>
> Lee: It was always prescribed as part of the lesson plan and the social worker was going to be there and the counselor and we addressed it together as a group. It was part of our curriculum. I think in terms of preparation of teachers, I don't know how prepared teachers are. I feel more prepared because I took a sexuality class. I feel quite prepared to deal with something like that. (Lee, FG II, p.21)

Personal boundaries and protection of personal boundaries appeared to be breached with this vulnerable population, vulnerable by age and vulnerable by disability. This lack of boundaries feeds the potential for victimization and exploitation of individuals with ID as well as the possibility of them acting as, or being perceived as, aggressors. Concerns about boundaries may be seen in the frequency of pregnancy and parenthood among the students in special education classes taught by the participants and reported spontaneously by three teachers. One teacher estimated that about 5% of her female high school students become pregnant each year. Another teacher participant described how students spoke openly of sexual encounters, with reports of several of her male students having fathered children. A third teacher reported a middle school student coming to her last year stating she was pregnant. The teacher contacted the school nurse; the student left school and the teacher, who was working as a substitute, received no more information about the student or her future. However, throughout the interviews and focus groups there was no indication of an adopted sexuality curriculum used by the teachers, or their colleagues, in the classroom, or any systematic sexuality education made available to students with ID. Another teacher appealed for approaches to training and awareness for developing student boundaries in Focus Group II:

> If you don’t give them a good way to communicate, they will find a bad way to communicate. And it’s funny. I don’t mean really funny. But most of the time it is guys. Two weeks ago one of my students was cooling down, and there he was with his pants pulled down. It happens a lot. And we have EAs (Educational Assistants) in there and some are guys and some are not. I don’t want some parent saying “Why is my daughter seeing a penis in the classroom?” I am used to it. It is unsettling, but you get used to it. But, it is fine, just not in school. (Chris)
>
> *Another participant comments:* Just do it in the bathroom. (Cal)
>
> Yes, go in the bathroom. If they do not have a good way to do it, they are going to do it anyway. We take for granted that we don’t do it in public. As teachers and parents and advocates, we have to focus on any possible way we can get that information out. (Chris) (FG I, p.12)

While Chris and classroom staff may become “used to it” in the classroom, and they may not recognize the need for direct guidance and teaching of boundaries to students, inappropriate student behaviors remain inappropriate and will not be tolerated in social settings we expect students to have access to in inclusive communities, including inclusive school settings. This is especially important as they pursue adult roles and opportunities. Direct instruction for students with ID is provided for subjects such as reading, math and job skills. With the exception of Lee’s report of co-teaching with a social worker, direct, systematic instruction was not provided to address social-sexual behaviors that can limit a student’s ability to participate in an inclusive community, shop for his own needs, associate with neighbors, develop long term relationships, or support himself. In fact, there was general abdication of the responsibility of providing direct guidance to students, and, if intervention or instruction was provided, it was most frequently provided by ancillary staff such as counselors, social workers, and nurses exclusively, usually in reaction to problems as they arose. Boundaries, or lack of boundaries, put the student at risk as well as those with whom he or she may come in contact. Lack of social-sexual boundaries among students may result in victimization of students, or in student aggression, or perceived aggression, against others. The participants’ statements of pregnancies and sexual activity among their adolescent students, and sexually aggressive comments and behaviors in the classroom are examples of this. One participant expressed a desire for ways to reinforce appropriate behavior with appropriate information.

Societal boundaries. This reflects the constraints or limits set by society on individuals or groups and was a fourth area within the domain of *Boundaries* around which data clustered. *Societal boundaries* included the belief among the participants that society makes, or will make, decisions for people with disability. In addition, they indicated there is the lack of awareness about people with intellectual disability by the larger society, beyond that of families and teachers who know people with disabilities. One exchange between participants was: "Society does not know about people with disabilities except for the greeter at Wal-Mart" (Dot). "Or, the cart boy at Albertson's" (Chris) (FG I, p.3)

Following the discussion of "Mary's" pregnancy, every participant in one of the focus groups joined in with an opinion, and came to the same conclusion (FG I, pp. 6-7):

> Participant 1: There is a segment of society where you have to include every group, and there are people out there that would make sure that this girl did not have another child by tying her tubes. A good 20 to 30 percent of society. (Dot)
>
> Participant 2: It would be a political issue (Pat)
>
> Participant 3: Even guardians cannot make that decision. (Cal)
>
> *Researcher: This side of the table feels that if that were the case, there would be strong pressure that "Mary" did not become pregnant again.*
>
> Participant 2: Abortion is a very political issue. (Pat)
>
> Participant 1: Most of society would not want "Mary" to have another child. (Dot)
>
> Participant 3: True. (Cal)
>
> Participant 4: Yes. That's the truth, but there are people every day without a disability who are having children and shouldn't, but people with disabilities are treated differently. I think Dot is right:. "Oh my god!" There are people who say this can never happen again, regardless of the care taker of the child. (Chris)

The societal reach is strong, they agreed, and "Mary's" sexual activity and pregnancy would be regarded differently because she had a disability. This difference was reflected in another comment:

> Their body did not stop at four, five or six or whatever age; their body continued to grow just like ours. So physically there are things that happen with these people, regardless of whether they have a disability or not. I think society forgets that. That whatever they feel in their lifetime, this individual is going to feel it too. It becomes this real big judgment factor. When we say these people deserve to have sexual relationships in their lifetimes. This person doesn't because mentally they do not know what to do and I think many people think that. (Lee, FG II, p.12)

Conversation in another focus group evolved from characterizing reproduction by people with disabilities as "breeding" and a "problem" to a comparison with the Civil Rights movement, seeking equality for a race or class of people. Three participants weighed in on this contrast.

> They do not want them to breed. They are afraid they will have children just like them or worse, or the children will not have proper care. Or love. They believe honestly that there will be another burden on society. (Jane, FG II, p.14)

> They will probably be asking mom and dad why didn't they abort, or why didn't they take care of this problem. Why aren't you handling this problem? (Lin, FG II, p.20)

> There are some people who are interested in people with disabilities moving forward. There might be one group of people who are almost unrealistically thinking “How are we going to help?” And then other people saying “Oh no, this is a nightmare!” and protesting in front of their house. It would definitely make the news for sure….I think the other thing, too, it is outside our comfort zone. We need time to get used to this. Like we talked in one of our special ed classes, how similar education and disabilities is like to when they were trying to desegregate schools. For blacks and whites to go to school together, no, it is this big drawn out thing. Part of normal society, but how long has it taken to get here? And now with people with disabilities, we are seeing the same thing. We are getting there. But it is taking us so long to get there. People are being included now. Change and acceptance in society takes a long time. (Lee, FG II. p.20)

When asked about society’s reaction to “Mary’s” pregnancy, participants agreed that there would be a negative response, characterized by people who did not have experience with people with disabilities. To some, this was in reaction to the perceived burden such a pregnancy and birth would place on society. To others it was a double standard placed on people who are different, people with disabilities. The spectrum of rejection to acceptance, that mirrors the history of people with ID in this country from eugenics to a parallel with the Civil Rights movement, was described by Lee who compared it to desegregation of schools and the long process of social change. She recognized this comparison as one she had first learned of in a special education class. The belief that boundaries for people with ID are separate and different than those for people without ID was consistent among participants: there is a double standard. This speaks to the need for direct, effective and systematic teaching of social-sexual boundaries and understanding of the importance of adherence to personal boundaries for a safe and successful independent, adult life.

Parental boundaries. This was a final theme that emerged in the domain of *Boundaries*. Almost every participant commented on the involvement, or lack of involvement, with parents of students in their classes. One concern expressed by several participants was the limitations parents put on their children with ID and the limited expectations for them:

> I have some students that I think, because of the support they have from family and friends that they will do very well. I have other students that I am concerned about because I think that their families are not prepared to give them the help they need, and that their lives will be like my aunt's, locked up in the house, because their families are not quite ready for them to attack the world. They think that they can't. There are some students with challenges, they have autism, on some level either Asperger's or more affected, and these two students, their challenges are more. Their families say "They will always live with me, they don't have to worry." I had a kiddo in my class, he had a cell phone and he would text with his mother, all the time. I told him we don't text in class, you know, all the time, and his mother insisted he text her and that he could go to the principal whenever, and just insisted that this is what we are doing. And there was one day when he texted her, and she had gone to the bathroom and didn't text him back right away and he had a complete meltdown. I don't know what happened but she left her phone on the table that day and did not text him right back. So there was a

> meltdown. And he was totally dependent on her. And I told her “If anything ever happens to you, your son is totally dependent on you. There has to be something else.” They become so dependent on their parents. And it is not only the child that becomes dependent; it is the parent that has become dependent in their role as well. I definitely see that as an issue for most of these parents. (Lee, VII, pp.5-6)

With discussion spontaneously evolving from preparation of students for future adult roles to day-to-day challenges teachers faced, participants offered their thoughts regarding the limited expectations they felt parents had for their children:

> I know a lot of parents come into an IEP with real negative “My kid’s not able to do this, he can’t do this…” And I think “Why are you saying this?” So I think a lot of parents don’t even go that avenue, to even think about it, but some yes, and some of them no….One particular parent, always came into meetings, she was very involved in her son’s life, but she was very negative about it. And that he couldn’t be reached in certain aspects of his learning; and I feel that she, she didn’t have a dream that he would reach those types of goals, that he was minimized in his abilities, and that she’s stopping at that minimized level instead of letting him try to grow. (Lin, I, p.6)

Another participant offered the following:

> Most parents say you can’t do this, you are not going to do this, and that leads to lack of quality of life and most parents do that. And I think that most will not feel invited…that transition will not be good, that we have not offered alternatives. Expectations are very limited. When I ask what is going to happen next, they say “What do you mean? This is it? There is no next.”(Lee, VII, p.7)

The conversation continued in both interviews and focus groups, with parents identified as setting limiting expectations for their children with boundaries that would affect their futures.

> Parents need more involvement in everything. Kids can do better. Mexican parents might want the kid in home with them. They have low expectations. Other parents want kids in nursing home, and have no expectations. Kids with Down syndrome can have more development. Parents limit their children's opportunities. Middle school parents think "Whatever. Four more years of school and then I will see." They think it is (the school district) responsibility. No expectations of their kids. (Pat, VIII, p.3)

Puberty, sexuality and burgeoning adulthood were other discussion topics that elicited thoughts about parent boundaries, formed from their expectations and anticipations of what their children's lives would be like as adults.

> And as far as intimate relationships, I think it is one of those things that parents are just not wanting brought up around their students with disabilities. It is complex, not something you can just answer with one simple response and the child is going to stop with the questions. (Chris, II, p.6)

Teachers of middle and high school students with ID deal with complex issues and boundaries every day as they negotiate relationships with parents of their students. Toni reported "One mom put her daughter on birth control. She condoned it. I don't know if it was right or wrong." (Toni, VI, p.5)

The sense of parents' limited expectations for their children, and the boundaries set for their futures, were countered by one participant's sense of respecting parents' boundaries and knowledge of their own children:

> I had a student and I told that mom that she could have competitive employment and the mom just looked at me like "You need to get to know my daughter". Not condescending. And I can now kind of see where the mom was coming from. Ok, she can talk, but the girl pretty much said the same thing all year. And if you ask her questions she does not respond with logical responses, and mom knew this and she was real nice and let me figure this out on my own. And maybe she could still (have competitive employment). She is 16, so maybe she could be a greeter and just say "Hi". And you have to recognize that the parent knows the child. They have been raising this child for fifteen to twenty two years. They know that child. Better than anybody. And you have to respect what they chose for that child. Last year I was teaching a class, and one child was near proficiency on the state test, and mom would not allow him to take the SBAs anymore because she said they stressed him out. I was all for it. The kid was an outstanding artist. To let me know they comprehended the story I would have them draw a picture and it was Halloween and he drew an incredible picture, incredible detail, and I wanted to get him in art, but mom wouldn't have it. Said it would stress him out. And I don't know, maybe when he went home he just lost it. I have to respect the parent. I know it probably sounds bad whether I like it or not, but the parent is dealing with their child and it is their child and I am just the teacher, and it may not be

> what I want but that is it. I have to respect what the parents' wishes are for their student. (Chris, II, p.4)

The above discussions reflect the complexity teachers deal with on a daily basis in positioning themselves in the complicated relationships between parents and students in school, as well as their complex relationship, at times, between the parent and the child; their role and responsibility as a teacher preparing students with ID for future roles; and the parents' expectations, knowledge of their own children, and priorities for their own children, grounded in their values and beliefs, and their children's education. There was neither discussion of, nor voiced desire for, organized support for parents and caregivers to help prepare families for the physical and sexual transitions the students were making.

Dangers and Threats

Dangers and Threats was the second domain that emerged from the data analysis and fell into five themes. The themes within dangers and threats include: *exploitation and students as victims, students as aggressors, threats to parents and grandparents, threats to society,* and *professional dangers.* As participants shared their ideas and experiences, elements of boundaries, professional and personal as well as those of students, their parents, and society, were also reflected. Following are findings relative to dangers and threats reflected in the data.

Exploitation and students as victims. This theme emerged within the domain of *Dangers and Threats* as a concern developed from real-life observations and experiences of the participants. When the scenario of "Mary" and "John" expecting a child was first presented, two participants stated that the first question would be that of possible exploitation and abuse of "Mary" resulting in a pregnancy. An example of the vulnerability of students with ID, especially in the context of adolescent contact with peers in the social environment of school that heightens curiosity and the need for acceptance, was well described by Lee:

> I had one student who got in trouble kissing a girl underneath the stairway while someone else was taping it. And he was like, “Miss___, what did I do wrong?” He totally didn’t get this. These were two regular ed students and two special ed kiddos and he did not get the context of this.
>
> *Researcher: That this was exploitation?*
>
> Lee: Right. He didn’t get that. And he was a senior, 18 years old, and the girl was 18 also, and she said, “Oh, here is my boyfriend”, and these other girls had their little iPhones and they said “Well if he’s your boyfriend why don’t you kiss him. You can’t really have a boyfriend because aren’t you in the ISP (Intensive Supports Program) program and you can’t have a boyfriend.” And she said, “No, really, he is my boyfriend.” And they said “Well, if he is your boyfriend, kiss him.” And she said “Kiss me,” and then they were telling them to do this and do that and this. And the security guard caught them and took the iPhone and it was a big deal, and I was talking to him and he said “But she’s a girl, she’s my girlfriend.” And I said, “But that’s not how this works. No one should ever be taking pictures of you guys privately.” And that it is not for anyone else’s benefit. And he was like, “Oh, wow, who knew?” So I had concerns that they did not know how to have these relationships. Obviously they were curious because they all wrote it down, but they had no clue. (Lee, VII, pp. 8-9)

Others shared their concern about their students' lack of knowledge and awareness, including their lack of access to information about sexuality, socially appropriate behavior, and opportunities to learn what is appropriate. One teacher who has had a number of students with ID who are also parents reported the following:

> A lot of my young moms never have been taught about sex; never had a sex ed class. I tell them to take care of themselves. You do not know if they will be ready to take care of themselves. A lot of their parents say "once they turn 18 they're out"… They don't know about having sex and they don't even know about the diseases. We had to go over the diseases. I say "Do you know? Don't you guys realize that there are, there are pockets like this? I show them pictures on the computer, not graphic, graphic, "Do you guys know you can get these and transfer them person to person?" I am a science teacher. If this is what they are going to take out of science, I would rather have them educated. I consider myself to be (in a special position). (Toni, VI, p.8)

This was echoed by another participant, who offered information about a curriculum addressing sexuality and relationship among people with ID:

> I mean these days there is a huge risk of disease; it is one of those things. And un, unfortunately I do not think they get into that a whole bunch and it is necessary for anybody who is going to be sexually active, but as far as the *Circles* (curriculum), and you shake hands at this level, mom and dad are here. I think it is outstanding. (Chris, II, p.7)

Issues of safe sex and appropriate education and preparation, and the unique learning needs of students with ID, including their relationship with their parents, was cited by one participant as follows:

> Sometimes the education is lacking, either their parents haven't prepared them somehow, because most of the time, parents of 18 year old kids, their parents have talked to them about the birds and the bees. "Ok, and this is what sex is." But with kids with disabilities, chances are their parents haven't talked to them about this. "Just say no. You have to stop." Does she know that? Chances are no one has had that conversation with her. So, my concerns are more on that level: How prepared are they and at what level do you step in to make sure nobody gets hurt or there is no negative fallout? (Lee, FG II, p.7)

While concern, and fear, was shared by several of the participants regarding their students' vulnerability and lack of awareness, only Chris offered knowledge of a specific curriculum or approach designed for people with ID. Two participants specifically spoke of the limited information made available to them to teach sexuality to their students. Cal said "There is **no** (emphasis of speaker) sexual curriculum available through (the school district) unless we make it up ourselves. It is not there. There is nothing. They barely give us the notebooks for our classes" (FG I, p.9). Pat echoed these thoughts with the reflection on the unique developmental period of adolescence and the role the school district could play: "I think because they're in puberty, they have a different type of development at different times. Special ed should have some kind of talk about self-concept and their interest in relationships." (Pat, FG I, p.9)

Others expressed concern about dangers of sexual behavior among their students, coupled with responsibility for financial issues and consequences as well. Toni offered the following regarding the students she works with: “The kids in the class talk about having kids, get married and have kids, which is part of life, but not the relationship aspects, or the money part.” (Toni, VI, p.4) Similarly, Jane shared her concern for broad issues of personal knowledge related to adult roles:

> They need to be taught health and they need to know about STDs (sexually transmitted diseases) and they need to know about their responsibility to a partner, financially, how to balance a checkbook. (Jane, IV, p.7)

Issues and concerns raised by the participants through interviews and focus groups demonstrated their awareness of the vulnerability of their students. Some, such as Lee, above, described this in the context of exploitation of students with ID by other general education students in a high school setting. General concerns, which would seem to be a concern for the entire student body at the schools where these teachers worked, also focused on the danger of sexually transmitted diseases and the lack of knowledge, or opportunity to gain knowledge, about the dangers and consequences. Except for Chris’s reference to the *Circles* curriculum, the education offered was not systematic, but offered by what the teacher may have at hand, and in Toni’s case, pictures from the internet.

Students, more than one participant stated, can also be victimized by the legal system he or she does not understand, should they act aggressively toward others or should their actions be misunderstood. In this way, being an aggressor, or acting in a way perceived as aggressive, may lead to becoming a victim, and possibly exploited by the legal system.

Students as aggressors. This second theme emerged within the domain of *Dangers and Threats*. Participants recounted specific examples of this in both the individual interviews and focus group discussions. Some events happened in class, and some in the larger school community. Issues of knowing, understanding, and respecting boundaries were prominent in the concerning interactions between students and others in their environment:

> We did sexual harassment training in our class. And we talked about the technology piece; they all have cell phones and are texting, and, for instance, if a boy sent 37 texts to this girl, and she didn't respond to any of them, then this is someone who you do not want to text. If Officer (school police officer) gets you and this girl files a complaint, and guess what, you are in trouble. (Lee, VII, p.12)

Cal shared a similar experience:

> This brings up a good point about a student who **looked normal** (emphasis by speaker) and had an intellectual disability, a couple times made inappropriate advances to girls and got in trouble by it. I can see where there is that need for education at that age about what is appropriate and not appropriate because the girls were very offended, but he saw nothing wrong. He had not been brought up in a structured home, then was, but had a lot of baggage from his previous life. Something to consider is their background and then how to teach them the

> appropriateness of how to treat women or be with boys, and suddenly there is a legal charge against the boy, to a boy who does not realize he is doing something wrong and he is in serious trouble.(Cal, FG I, p.9)

Specific examples from participants' teaching experiences regarding students' lack of understanding of social rules and interactions with others as well as impulse control were brought up during interviews and focus group discussions. Again, boundaries were crossed in ways that were not only construed as aggressive but were threatening to other people. The behavior of students with disabilities being perceived as violent or aggressive, and evaluated by a different standard than that of students without disabilities, raised concerns for participants as well:

> The only difference might have been that a 15 or 16 year old might not have made the mistake in front of the parent, but how often do boys do something inappropriate in middle school and high school, and when they're out of school…and sometimes purposefully, but just as an accident or a lack of education…. We go to the extreme with people with disabilities. "Oh, they are out of control and nobody is going to be able to control them," when really, it is probably very far and few between. (Lee, FG II, p.13)

Sexually perceived behavior that may be aggressive, or construed as aggressive, is emotionally charged, sometimes resulting in strong reactions that affect a student's education and further opportunities. Another participant shared the history of one of his students whose life was changed by circumstances: early abuse, he felt, transformed him from a victim to an aggressor:

> I do have a student now who is higher functioning, and I do see his life being more open, but I still see that as being far off.
>
> *Researcher: How so?*
>
> Well, he has had a history of abuse, and I don't know the statistic, but the statistic for being abused to abuse (becoming an abuser) is very high, so he cannot be alone with people who are in a wheelchair. I just don't see him really getting out anywhere because it will be such a risk for other people in that situation. Overall that's that part, of them growing up when they get out of high school. (Chris, FG I, p.4)

Complications with responsibility for actions and what students face as they approach legal adulthood was also discussed. This was juxtaposed with a teacher's feeling of limited influence in affecting outcomes:

> Once they are eighteen they have to abide by the law as everyone else. Not everyone will say "I am sorry, you have a disability. That's why you did that." There were countless stories in the (sexuality) class about this. And they got arrested. Because it's the law. We owe them that information. It is a fine line, you want to help but you know your hands are tied. I just wanted to say that. (Chris, FG I, p.6)

The complexity of the teacher's role in supporting middle and high school students as they move toward adulthood and adult responsibilities is evidenced by the previous reports. Students with ID, participants stated, are very vulnerable to abuse and exploitation, including abuse by other students, with and without disabilities. In addition, students with ID may also exhibit aggressive and dangerous behavior toward others, or their behavior may be interpreted as aggressive. No matter what the intention, the consequences for behavior can be very great and can have lifelong implications as they move toward adulthood and are recognized as adults by society and the legal system. Aggressive students with ID can be victimized and exploited as well, by others in their environment or a legal system under which their behavior will be scrutinized and judged. While these risks were openly shared by all participants, there was no mention of development of IEP goals that addressed sexual behaviors or sexuality education for students with ID whom they taught.

Threats to parents and grandparents. This theme within *Dangers and Threats* resurfaced in the data analysis. As recounted earlier, *parent boundaries* was an issue almost all participants identified as a factor in students' lives. In addition, students with ID also represented, to these participants, a danger or threat in the everyday and future lives of the parents and grandparents who cared for them. Lack of future planning, lack of opportunities for students beyond the school years and the school day, and limited or no vision for the future of middle and high school students with ID were interpreted by a number of participants as threats to parents' and grandparents' wellbeing. The sense of grandparents raising grandchildren with ID as wearing them down was reported earlier, in the description of parents or grandparents getting "dumped on" with the baby conceived by "Mary" and "John". In addition, the following was shared regarding future planning:

> Parents have no idea of how they are going to subsidize their (the students') care needs. So, I haven't seen a program yet that prepares our kids, either middle school to high school or high school to post-secondary. It would be interesting to

> figure out what we can do better, in middle school and in high school, to prepare our students for the next segment of their lives. And I always go back to if we are going to prepare the students we have to prepare the parents or whoever their caregiver is as well. I think that is big. (Lee, VII, p.15)

The concept of sexuality among people with ID, including adolescents growing into adulthood, has been difficult for the general society, but also for parents who may expect to see their children as "eternal children" as one participant suggested. In this way, parents' perceptions of their children, and the potentially threatening thoughts about their future and sexuality, can be present in the teacher-parent relationship:

> And as far as intimate relationships, I think it is one of those things that parents are just not wanting brought up around their students with disabilities. It is complex, not something you can just answer with one simple response and the child is not going to stop with the questions. (Chris, II, p.7)

Other participants shared similar feelings:

> A lot of people don't realize that they actually go into puberty, that that comes no matter what. That realization is shocking even to the parents. I have to talk to them. Parents are surprised that things like that are going to happen. Adolescence and puberty changes everything. Everything changes: meds, growing, changing, hair growing. They are shocked. People not around disabilities are even more shocked.(Cal, FG I, p.3)

And:

> I think even for a typical kid, parents in mid school think they are little kids. Parents with kids with disabilities think that they are forever kids. They cannot

> understand that development. No one is trained to be a parent so when you have a kid with disabilities, and they are waking up to their sexuality…Kids are already beyond the parents' imagining. That happened to me with my kids. Puberty? No kidding! (Pat, FG I, p.3)

Life changes in students will alter the parent-child relationship, and, as described above, change the stability of the dynamic between the parent and the child. This can threaten that relationship. This is not unique to parents of children with disabilities, as Pat stated, but it may be more pronounced as the child's intellectual development does not mirror the physical development. The vulnerabilities of students with intellectual disabilities come into play as well, as parents' roles and responsibilities change along with their children's development.

Threats to society. This theme emerged within the domain of *Dangers and Threats*. It revealed concerns among some participants that extended far beyond the classroom and their professional experiences and responsibilities as teachers. It reflected issues of personal and professional boundaries, as well as fears about the current economic climate. Economic concerns regarding care and support for people with disabilities is not a new issue, reported Charlton (2000), but is one which is repeatedly revisited when the interrelationship of people with disabilities and responsibilities of society are explored. One participant's thoughts, when asked about the broader society's response to news that "Mary" and "John" were expecting a child, included a comparison with a recent, sensational news story about a woman living with public assistance who gave birth to octuplets through in-vitro fertilization provided by a well known fertility specialist:

> The thing that keeps popping into my head is that Nadia Suleman who had eight children, and now the state of California is paying for it, and people are just furious. They just see it as a huge financial burden at so many different levels. When you say complex support system, it is a financial support system. (Dot, FG I, p.5)

Concern for use of public funds to support people with disabilities in general was raised by other participants. One said, as a follow up to Dot's comment above. "I don't know about your students, but mine are on the DD (Developmental Disability) Waiver. That is all about how much money they can get. That is huge how much money you get" (Chris, FG I, p.5). Another participant followed with: "Nor does the DD waiver cover for maternity or the medical aspects of that" (Cal, FG I, p.6)

The perceived economic burden was not the only expressed threat to society as eugenics, and sterilization, discussed earlier, was raised by one participant. Repeated here are Jane's comments:

> Yes, and sometimes I think they could breed, multiply, and you also wonder about their parenting skills and how good a parent they would make and would their children suffer. (Jane, IV, p.5)

And:

> They do not want them to breed. They are afraid they will have children just like them or worse, or the children will not have proper care. Or love. They believe honestly that there will be another burden on society. (Jane, FG II, p.14)

The sentiments above were countered by Chris who reflected on his own experiences with a need for support from social systems and identified with possible needs of “Mary” and “John”:

> It goes back to the financial piece. I am always defending, or feel like I am defending, my students. “Mary” and “John” are going to be a burden on society, but that happens whether or not you have a disability or not, especially in this economy. There are a lot of people who are getting state assistance. There were times when I didn’t have health insurance and I had to go to the state hospital, but nobody is going to say anything else to me, because you can’t look at me and make a snap judgment. So much of the time they say because they have a disability that they are a burden. Well, somebody loses a job. We all go through those hard times, and that is why those systems are in place. (Chris, FG I, p.6)

And society’s perception juxtaposed with society’s responsibility:

> Most people don’t realize. Society does not give them credit. How many relationships of people without disabilities get divorced? We see it one way. We are advocates for our students; we want them to have companionship. We still live in a society that still thinks the eugenic route. How can we get rid of these disabilities, rather than how can we integrate them…and it will be a state program that does that. (Chris, FG I, p.2)

Similarly, another participant offered this perspective relative to how people with disabilities are automatically perceived by society from her own teaching experience:

> I think there is this misconception that people with disabilities or the poor do not know how to manage their lives. I work at a school with very wealthy families and I see a lot of dysfunctionality among the parents that are very affluent, very well off, educated, without disabilities. Normal parents can have a child with disability, and people with disability can have a child without disabilities, and raise that child. (Lee, FG II, p.3)

The perceived threats to society, while expressed mostly in concern for the financial burden society would have to shoulder for parents with ID, extended beyond the boundaries of the classroom and people with disabilities to include the poor. Social systems, such as the DD Waiver, were also discussed. Underlying feelings of inadequacy of people with disabilities to reproduce and raise children, reflective of the Eugenics movement, also surfaced in this cluster of interviews and focus groups.

Professional danger. This is the final theme to be explored in the domain of *Dangers and Threats*. In *professional danger,* I found a consistent theme voiced by the participants as they discussed challenges to them in their work and their work place. It is also the most robust in terms of how many times it emerged in conversation and how fraught teachers' daily lives were in trying to discern their own boundaries, rights, and responsibilities in the school setting. Guidance they received from school leadership was also particularly convoluted and put them in situations that were confusing and sometimes professionally compromising. This led to some uneasiness which they seemed to repeatedly "check out" with each other or with me throughout the research.

One of the discussions affecting one's sense of safety as a professional in the school was that of knowing and adhering to legal boundaries. This related typically to

IDEIA and school practices relative to enforcement of that legislation. One participant eloquently described disability education legislation. “It was created to be a backbone for people with disabilities so they can be protected, like their skin,” said Toni who went on to talk about how teachers’ boundaries and responsibilities are dictated by IDEIA:

> (As teachers) it makes us aware and doesn’t let us take advantage of the kids, what is right and what you can do and can’t do. It makes the teacher responsible. What you can and can’t do. (Toni, VI, p.6)

The intent of the law, and the teacher’s responsibility for carrying out that intent, however, was frequently complicated for participants; they shared experiences that were confusing and unclear as they conducted their work. Lee expressed that by saying “I think it is that our laws are actually set in place, I know that they are there to protect the individual, but sometimes I think it is just because we are a very litigious society.” Minimal knowledge of the law was expressed by another participant who said “Basically, I know enough to CYA, to cover myself.” Another participant recalled that she is directed to sign off as the “principal” on IEPs and questioned the legality of that. In addition, the IEP process as carried out in her school, she reported, is one inconsistent with both the intent and the requirements of the law:

> Every kid needs to be on an IEP. I am a small group teacher and have 18 in my history class. It is no small group. I just wham bam it out. No way can I even modify for that kind of curriculum much less teach individuals. …I am thinking about the IEP, and we just write these blanket statements in transition plans and call it a day. I don’t think it is because we don’t care. I think we care, but based on (the school district) system and the government system and all these

> bureaucracies that control all this paperwork, I am not allowed to write down that this kid could use some help, one-on-one, on sexuality. That is what this student needs. I think we all know what these students need, but we know what reality is. (Speaking to other participants in the group) Sounds like you get to have more one-to-one help with kids. We are just told to send them to the right people. At a high school level we are told "Don't talk, don't touch, get them out." Parents know their kid is going to leave public education and what is going to happen next and they are more litigious. It is not really an IEP, really. (Dot, FG I, p.10)

Funding for IDEIA, some participants felt, impeded their ability to make special education viable and reflected disrespect for their work. One participant shared her belief that "A lot comes down to money. We don't write too much in the IEP so we don't have to pay for it. We have kids who need one-on-one, with an EA (educational assistant). We are told never to put that on an IEP". Another participant went into greater detail describing the lack of financial support for special education and the resulting stresses and threats to the profession:

> I have my issues with IDEA, not with the principle of the law, but to my understanding, IDEA has never been properly funded. It is the same as walking up to a general contractor and saying "I want an addition on my house", and the contractor saying it would cost you 20K, and you agree, and then you pull out 15K and say "Do it for this." And that is what happens in the classroom And not all EAs (educational assistants) are like this, but you cannot find people who want to change diapers on adolescents for eight to 10 dollars an hour. Quality people. And when you are working with five to eight students with

> severe disabilities, you do not need somebody who is in your classroom who is fighting with you. And they do not think about this when they are writing the law, when they say "a few less million". I do not think special ed teachers have a long career life span. It is a stressful job. And then you don't get to see huge improvements in students and you feel, "Oh, I am a crappy teacher, that's why they do not pay me so much" and that's the part that bothers me. They really didn't fund it properly and I believe the kids deserve the funding. It sounds crass and greedy, but money is what makes it happen. Like we still have a sub, since September, because no one wants to fill the spot. It is a really tough job. And I think teachers across the board need money, and the special education programs in general need a lot of money. Adaptive bikes, standers, 17 to 18 thousand. I do not want to sound crass; you have to have the money to outfit rooms. I needed a break room for one of my students in my classroom this year. It wasn't cheap. It makes me mad. (Chris, II, p.9)

Participants, all of whom worked daily and directly with adolescents with ID, discussed confusion and lack of guidance from school administration in dealing with issues of sexuality. Lin was unsure of expectations but said "I don't think there is anything we are allowed to do in middle school in regard to sexuality. I know we had a student last year who got pregnant and it was just hushed up, shut down." Pat described approaching parents of a student she had who was acting out sexually. She wanted to include the student in a health education class she was adapting for her students with another, general education teacher, to address issues of sexuality. Parents told her they would teach their own child, and her principal told her it was not her business even though she felt it was her job. Cal shared that “there is no sexuality curriculum available through (the school district)”. Several participants reported that any curriculum in use for general education was not appropriate for their students who needed alternative approaches to understanding relationship and sexuality. Pat stated “Regarding sexuality curriculum (for our students) I think we have little resources.” School nurses, social workers, and counselors were frequently relied upon for support with sensitive issues with students, including sexuality and sexuality education. In regard to knowledge of students’ intimacy, Dot said she would not “touch that with a ten foot pole”, but rather refer to the nurse, counselor, or parents if she discovered her students, like 18 year old “Mary” and “John”, were dating. Who the social worker was and the skill level of that individual was a consideration for Cal in making a referral. Two other participants in the focus group who were familiar with the school Cal taught at concurred that the individual social worker’s skill would affect the decision to make a referral. While there seemed to be, in general, a belief that ancillary staff had superior knowledge and skill, there was no discussion or information shared about the training of such ancillary staff in addressing sensitive issues with students with ID, such as adapting information for students with cognitive differences, an expertise of special education teachers. One participant was interested in getting the same education these professionals received, however. Another stated “We would get in trouble if we tried to teach sexuality” and the others in the focus group voiced their agreement. One participant assessed the risks to teaching his students about sexuality and appropriate relational behavior as follows:

> And you take a child without disabilities, it is a lot of questions and people get very uncomfortable with those questions, and then you take a child with

> disabilities and people are going to say “I am not going to put myself at risk here by talking with kids with disabilities.” But, it is one of those things that has to happen so kids understand what is right and what is wrong. It struck me with (sexuality course instructor) because if you don’t tell them, they will not know. And it is important because of the high percentage of people with disabilities who do get assaulted sexually. (Chris, II, p.8)

While confusion existed regarding how to ensure students received information and guidance they needed relative to relationship and sexuality, Chris summarized the conflicting needs and voices in his work environment and reflected on his graduate coursework which included specific training in sexuality of people with ID. He juxtaposed that with needed decision making and guidance from school leadership:

> That is the only guidance I ever got, from (sexuality course instructor), and her class. It’s a topic that makes a lot of people uncomfortable. A guy talking about this? As a male teacher, it is strange enough; I just keep my mouth shut. People are going to think “Who is this guy and why is he interested in sexuality?” I mean, they are going to have some questions, “Who is this guy and who is he talking to about this?” (sexuality course instructor) told us this isn’t something you just jump into. People do not realize their kid is 13, 14, they think he is still seven or eight. But he has hormones. In high school, if they start doing that stuff, we do the same thing, we just get them in separate classes ‘cuz it’s easier. Parents say “Do not talk to my kid about this. Do not talk to him. Do not allow him to go to the *Circles* program” …. I just went to training for a reading program. Now we are all working in the same ISP reading program, yet we do not have a program

> for this, for a subject so sensitive. I want the district to tell me what to teach, and how to teach it. I know a lot of teachers don’t want that. They want their own autonomy, or whatever, but I want them to lay it out for me, so our kids know it from junior high: here are some activities. This could rile some people up, if you go home and start talking about private parts and whatever else. It can get misconstrued right away. (Chris, FG I, p.11)

Limited guidance from leadership and conflicting practices within the school settings, relative to IDEIA, represented *professional danger* to the participants. This sense of danger was especially present in issues of sexuality as the participants reported that the school district offered no guidance. However, *professional danger* permeated many aspects of their teaching, including implementation of IDEIA. Participants indicated that all issues of sexuality are not embedded in the curriculum but rather referred to someone else in the school.

Responsibility for Change

The final domain that emerged from the data analysis was *Responsibility for Change.* It encompasses two themes that reveal where responsibility lies for affecting change in the school community in which the participants worked, and ultimately in the lives of their students as they prepared them for future roles, including partner and parent. These themes include: *affecting students’ futures for community life* and *affecting professional standards in professional settings*

Change, itself, is inevitable, as that which dramatically occurs in human maturation. Change in the student has been reported from the data relative to the physical, mental and social changes exhibited by adolescents as they grow into adulthood. Puberty, all participants reported, brought change to the students' lives, and the lives of those around them. These changes also challenged the perception and understanding of parents and the broader society that did not expect the child with ID to grow, physically, into an adult with ID who would have the same sexual desires and drives as others. Elements of change are linked to dangers and threats students might experience as victims of exploitation and/or abuse, as well as being aggressors, or perceived as aggressors, and perhaps victimized by the legal system as adults. The teacher's role is myriad as he or she manages multiple priorities in educating students.

The inevitability of physical development is something over which neither parent nor teacher has control. Similarly, the knowledge and perspective the parent, school colleagues and administrators come with, as well as social and economic events, are ones over which the middle and high school special education teacher does not have responsibility. The domain of *Responsibility for Change* and related themes address those aspects of teaching and professional behavior over which one does have responsibility and a measure of control. It also assumes personal agency, as an agent of change, in affecting the outcomes for students and responsibility for one's actions.

Affecting students' futures for community life. This theme represents one important and powerful role teachers play as agents of change. Through this, the teacher can help students actualize full inclusion as adults with ID, impacting the acceptance and opportunities they will have in the future. One participant reflected on the role he sees for himself in affecting change not only for his students but for a class of people who have disabilities:

> And then when I started getting into special ed, or teaching special ed, I saw a facet of American society that was the last vestige of a fight. I am a pot stirrer, too. Although civil rights and women's rights aren't exactly where they need to be, they have plenty of people who are trying to make it better for minorities and women so I saw people with disabilities as a group that was underrepresented. As a teacher I can show through my career choice that I can make a difference, that people with disabilities may not be able to do everything we can do or as fast as other people, but they are still people, they contribute and they make my world better, my life happier. I always talk about the kids I work with, even though they cannot talk, they still make me laugh. (Chris, II, p.2)

Very frequently responsibility was assigned to others by the participants. An example of this was the relationship the participants had with parents of students in their classes. Parents' understanding and awareness of the students' needs and abilities as they transition to adulthood was most commonly described as unwillingness by parents to accept changes in their maturing children with ID and denial of responsibility. Several participants recounted interactions with parents that concerned them regarding support for their children. In these instances participants did not identify ways in which they used their professional status and knowledge to help redirect that dynamic:

> "Their families say 'They will always live with me, they don't have to worry'." (Lee, VII, p.5).
>
> "I know a lot of parents come into an IEP with real negative 'My kid's not able to do this, he can't do this…' And I think 'Why are you saying this?'" (Lin, I, p.11)

> “Most parents limit their child’s opportunities. In middle school they say ‘four more years, then I’ll see’” (Pat, VIII, p.3)
>
> “And as far as intimate relationships, I think it is one of those things that parents are just not wanting brought up around their students with disabilities.” (Chris, II, p.7)

In these instances, participants did not indicate that they approached parents about their expectations for the students or any dialogue with parents to move forward a mutual understanding of student needs during this period of maturation toward adulthood. However, some participants did recount examples of taking responsibility to address inappropriate parent expectations and also to recognize parents’ unique knowledge of their children. Lee recalled intervening in a parent-child relationship and taking responsibility for informing the parent of dangers of her son’s dependence upon her. This resulted when the parent, who maintained a frequent cell phone relationship with her son throughout his school day, was not available one day when he called her: “So there was a meltdown. And he was totally dependent on her. And I told her ‘If anything ever happens to you, your son is totally dependent on you. There has to be something else’”(Lee, VII, p. 6). Another participant reflected on his growing awareness of a parent’s understanding of her child and his growing respect for that: “They have been raising this child for fifteen to twenty two years. They know that child. Better than anybody. And you have to respect what they chose for that child” (Chris, II, p.5). Similarly, Pat assumed a proactive approach by informing parents that they were the “boss” of her and the principal and that they had a right and responsibility to let her know what they thought was important. However, she felt that for the most part parents were passive or expected the school district to be responsible for all choices and direction in educating their children (Pat, VIII, p.5).

There was a range of responses to how participants deal with concern for parent involvement with students' progress toward adulthood. This varied from acknowledging concerns without addressing them with parents, and, in a limited way taking responsibility to identify concerns directly with parents. In between, there was recognition of need for parents to make changes along with their students in accommodating the next stage of human development. There was no identification of the need of a systematic approach to preparing parents for change or for incorporating information about sexuality and maturation in IEP goals, however. There was also no identification of new skills to develop, as a special education teacher, to better interface with parents during this challenging stage of their children's development.

Participants were asked, during individual interviews, what they thought their students' adult lives would be like. None of the participants identified current educational activities and purposes as being pertinent in connecting to the future settings and opportunities their students could access. Most responses ranged from students remaining at home with their parents to living in group homes, nursing homes, or other institutional settings. Many of those responses have been reported earlier, identifying nursing homes or institutions as locations in which students will find themselves after their school years. Personal life satisfaction will be affected by future, limited opportunities for students:

> I feel like it could not possibly be as exciting or fulfilling as what they are in now: school versus home. Not quite as much fun. Not as much contact with general education people, people with normal intelligence. I wonder about that. I

> think they will stay at home and not get as much contact except with family members, unless they go into a home, a group home like ____________. But the same thing every day, not like school. The same job every day, having a set schedule on a daily basis. (Cal, III, p.1)

Another participant shared the following reflection on what that future life will most likely be like:

> But a lot of them will end up with their parents. Their parents know that. I don't know…it definitely will not be a typical adult life. It is kinda sad. I sit around and think about it all the time. (Chris, II, p.3)

Stating that the ability to live independently and the potential for a future role as a partner and parent, Chris reflected on his teaching experiences and the ability of students with ID who he had worked with in the past. The degree of disability would be a factor in determining what opportunities students will have as adults.

> Probably more my CRL, community reference learning, students…I don't see my ISP students really understanding, comprehending those types of matters, really understanding the consequences of intercourse and what might happen. It is really one of those things, complex, even for people without disabilities. The ISP students, I would say no. The CRL students I could see that. Some of those guys, finding a wife somewhere, having a real nice family, a job they have. Coming home. (Chris, II, p.6)

A vision for the future for students was also expressed by Lee who saw parallels in the desires and wishes of people with ID with herself. She also challenged the societal perception that people with ID would not grow to want or need relationship with others, including friendships and more intimate relationships.

> I just thought that working with our students, in my circle, people are under the impression that people with ID don't have the inclination for sexuality or relationships, and that is not true. They want the same things that we want and they may want to be in relationships with other people because they are frequently excluded or singled out so if there is that opportunity for them to meet somebody to establish a friendship or even a relationship I always think that is wonderful because I always know that is the heart of what everyone wants, with or without disability.(Lee, FG II, p.1)

Responsibility for students would rest most frequently with families most participants stated. The school's ability to affect change in that future was limited or non-existent as described in the following:

> I am worried about them. They need more help planning their lives after high school. Public education isn't helping them fill out applications; get into trade school, etc. Public education is more interested in the college bound student. Not our kids. They can do janitorial work. We don't do good on-the-job training. A lot of students make more money, but they have to figure that out on their own. Families help more than the public education system. More kids probably would qualify for SSI, but no one knows how to get linked into those agencies. I don't know either. (Dot, V, p.3)

School, and its mission and charge through IDEIA, seemed almost superfluous to the question of what future lives will be like. The connection seemed remote with school not impacting students' lives for future opportunities. Similarly, school priorities and opportunities seemed non-responsive to student needs as described in the following:

> AHHH (audible sigh) a lot of my students get in trouble. If they haven't been incarcerated yet, they will be incarcerated…. You do not know if they will be ready to take care of themselves. A lot of their parents say once they turn 18, they are out. I don't know if they can take care of themselves. Sometimes I think of Job Corps (as a post high school setting). They get to live there for three years. (Toni, VI, p.5)

Participants' responses to the question of what they thought their students' future lives would be like all indicated a future with limited access to community opportunities. While there was desire voiced for different approaches and priorities of the school, no participant identified himself or herself as an agent of change with responsibility to help students realize a different future.

Affecting professional standards in professional settings. This second and final theme within *Responsibility for Change* is defined here as the process in which teachers reinforce the principles of their profession and the legislation that has created a protective framework for students with disabilities. The purpose of that legislation and the role of special education teachers are to help students learn and grow so that they may achieve equal membership in an inclusive society. While many advocated for stronger opportunities for their students, the data reveal that this was not always a clear path for the participants in this study. Sometimes participants felt that educational hierarchy and economic pressures on the school district limited their power to change outcomes, or even give students access to a free and appropriate education. Sometimes participants expressed a lack of knowledge of how to pursue next steps for their students. At other times, participants seemed unaware of how they might become an instrument of change as teachers, in such things as identifying IEP goals and in selecting and implementing a curriculum. They also expressed a lack of support in their work environments should there be a desire to make change from the current status quo. When asked what support she as a middle school teacher got in preparing students for adult roles, Jane responded: "Absolutely none." (Jane, FG II, p.24)

Of note was the passivity some demonstrated in allowing practices they felt were inappropriate or unethical, and perhaps illegal, to continue in daily school activities and in school culture. Educational hierarchy, ranging, in one participant's perspective, from school principals to the "government system" and "bureaucracies", limited the role she felt she, as a teacher, could take in affecting change for her students. A veteran special education teacher of 18 years, she had many questions about how she was directed to carry out her work, including signing for the school principal at IEP meetings.

> I don't think it is because we don't care. I think we care, but based on the (school district) system and the government system and all these bureaucracies that control all this paperwork, I am not allowed to write down that this kid could use some help, one-on-one, on sexuality. That is what this student needs. I think we all know what these students need, but we know what reality is. (Dot, FG I, p.10)

This participant went on to state:

> A lot comes down to money. We don’t write too much in the IEP so we don’t have to pay for it. We have kids who need one-to-one, with an EA. We are told never to put that on the IEP. (Dot, V, p.4)

Disappointment in financial support for special education and full implementation of IDEIA was described by another participant:

> I have my issues with IDEA, not with the principle of the law, but to my understanding, IDEA has never been properly funded… They really didn’t fund it properly and I believe the kids deserve the funding. (Chris, II, p.9)

Chris also offered the following relative to desiring guidance from the school administrators in addressing sexuality education with students:

> I want the district to tell me what to teach, and how to teach it. I know a lot of teachers don’t want that, they want their own autonomy or whatever, but I want them to lay it out for me: our kids know it from junior high, here are some activities. This could rile some people up, if you go home and start talking about private parts and whatever else. It can get misconstrued right away. (Chris, FG I, p.11)

While sexuality education was not the direct focus of interview or focus group questions, all focus group discussions evolved to include this topic. Several participants reported limited or nonexistent school supports for their students relative to sexuality education and complicating social factors; while there was an identified need for students and parents to better understand the physical and sexual transition to adulthood, these priorities were not recognized as part of their classroom responsibilities or teaching expectations for most. Toni used her position as a science teacher to inform students of

STDs and other dangers of sexual activity, but she did not identify a curriculum or a systematic means of doing this. She did use pictures from the internet to give them information. Most participants did not address this issue in their classes and they felt unsafe doing so: “I don’t teach sexuality classes and I don’t even know when they get that.” stated Lin, a science teacher (I, p.10). “We would get in trouble if we taught human sexuality” (Dot, FG I, p.11). No one in the focus group disagreed with her. One participant expressed the following: “I know that even in middle school there is interest (in sexuality),” (Cal, III, p.2). While the priority of preparing students for adult roles of partner and parent were recognized, there was frequently an absence of achieving a means of imparting that information to the students. In response to the interview question “How do you think your students are prepared for adult roles?” one participant who teaches middle school responded: “Not at all.” Another participant answered the same question similarly: “They aren’t. In high school, no. We protect kids with disabilities and don’t make them responsible for their own lives. Also teachers need expectations, high expectations. Parents and teachers need high expectations,” (Pat, VIII, p.4). While Pat indicated an attempt to engage the school counselor in including her students in sexuality education, neither of these participants identified a personal responsibility or personal empowerment for affecting change in school practice and in curriculum for their students. Fellow teachers were identified as having limited knowledge, too, and of not taking responsibility in their professional roles:

> I see teachers talk to parents. They choose not to share information with parents. (I have) assumptions that there is bad communication. We need training on how to socialize (for students), parents’ rights, and teach kids. Once a

> year we need an in-service for the DD Waiver. Teacher doesn't know…We need more expectations. Parents need training in IDEA. Teachers don't know." (Pat, VIII, p.6)

Ancillary staff was most frequently identified as taking responsibility when crises arose around inappropriate behavior, especially sexual behavior. Two participants shared that ancillary staff (counselor and social worker) provided regular lessons to the class on relationship and appropriate contact with others. The social worker was identified by one participant as being part of the classroom "team" in this regard. Ancillary staff was recognized as the most appropriate to intervene in crisis situations as well as to teach sensitive subjects, such as sexuality. Such ancillary personnel were identified as having responsibility for teaching and responding to students' needs when issues of sexuality emerged. The teacher was generally not involved or engaged in issues once they were referred to the ancillary staff: "In middle school if something like that comes up it goes right to the counselor. I don't think there is anything we are allowed to do in middle school in regard to sexuality," (Lin, FG II, p.21). When discussing "Mary" and "John's" beginning relationship, dating, most participants shared that they would refer to the nurse, counselor or social worker immediately. One participant stated that it "depends on who the social worker is", however. Another participant stated: "I need some training. I do not know what kind of training they even offer, like what the counselors get." (Lin, FG II, p.25)

With the exception of the two participants who worked directly with ancillary staff in their classrooms, no other participants indicated a teaching relationship between themselves and the nurse, counselor or social worker. Nor did they indicate how their knowledge of their students and learning abilities may have been utilized in supporting ancillary staff in addressing topics of sensitivity with their students. In addition, none of the participants specifically indicated use of a Functional Behavioral Assessment (FBA) or a Behavioral Intervention Plan (BIP) with their students, including students with inappropriate social-sexual behaviors.

While the training that counselors, nurses, and social workers received was regarded as most appropriate, and in some cases superior, to deal with issues of sexuality and sexuality education for students with ID, one participant shared the following as she described her own needs and responsibilities as a teacher:

> One of the things that came up for our folks with ID is they are very easy targets and they are very vulnerable. And it is up to us, as educators, to know what to look for and how to deal with it. As teachers we need to know what the protocol is and what the expectations are from our school. I think most of the teachers don’t get that training. It is absolutely critical. It should be like all the other required training. (Lee, FG II, p.25)

One participant reflected on a career choice that has helped him achieve more than a livelihood. He also uses himself as an instrument of change in daily interaction with others.

> And then when I started getting into special ed, or teaching special ed, I saw a facet of American society that was the last vestige of a fight. I am a pot stirrer, too. Although civil rights and women’s rights aren’t exactly where they need to be, they have plenty of people who are trying to make it better for minorities and women so I saw people with disabilities as a group that was underrepresented. As

> a teacher I can show through my career choice that I can make a difference, that people with disabilities may not be able to do everything we can do or as fast as other people, but they are still people, they contribute and they make my world better, my life happier. I always talk about the kids I work with. (Chris, II, p.2)

Frustration with colleagues and the general public in their understanding of people with disabilities has motivated this participant to speak out to colleagues, friends, and others to help address misconceptions of and bias toward people with ID:

> Ya, even now I have to talk to people about, you know, the retarded thing. I still have to talk to people about that. I mean adults. Teachers. The pot stirrer thing, I mean I love it. I always wanted to be a teacher after my junior year in high school. (Chris, II, p.3)

Professional responsibility was pursued by one participant as she chose to study special education and make it her career. This grew out of concern for parents and general confusion about the field while she was working as an EA:

> I think that is why, when I got the opportunity to study special ed, I was concerned about the disparities, and much of it from a lack of knowledge. They didn’t know what laws were in place and how to use them and parents didn’t know how the laws could benefit their child. So that is a role I have played, to educate our parents, especially at the high school level. By that time they have battled their whole life in special ed, and they hate the schools and they hate the teachers and they are so exhausted. They hate the school and they are so disconcerted. So one of the things I tried to do last year was to work with the parents, and especially with autism, how to work with them and how to give them

> a better quality of life. So that became just a primary focus of my work. (Lee, VII, p.4)

This participant went on to describe her responsibility to advocate for people with disabilities, not just her students and not only in the school community: “Yes, that is what I teach. Even as part of community, our circle of influence is whoever is around us. Whoever is around us has a stake in how we interact with other people.”

While the above participants expressed concerns for their students and biases toward them and other people with disabilities, they also expressed approaches they have taken, either directly with colleagues, friends, and parents of students, or generally by gaining knowledge and information about the entitlements promised through special education. This resulted in advocacy, on their part, for their students with ID. Another participant expressed concern about the conduct of colleagues but with a much different approach in responsibility to address concerns. The presence of school leadership was not identified as present in the setting. Describing behavior of colleagues at the school in which she works, she shared the following:

> We have a meeting every Wednesday. And at that meeting I hear some pretty inappropriate things by the teachers about kids and what kids are doing. Laughing, snickering, and I just sit there and take it in and think they should not be discussing it in the manner in which they are discussing it, because what they are doing is making fun. And I really don’t know what help they are getting. I really don’t know. I am in my own little isolated world. (Jane, FG II, p.25)

Responsibility for awareness of student needs and the professional role in addressing those needs was another area that emerged in the theme of *Affecting* *professional standards in professional settings.* Several participants expressed surprise by the questions asked during the focus group discussions. Change in thinking by some individuals took place in the course of the interviews and focus groups conducted through this research as well. While participants recounted classroom experiences that demonstrated challenges of maturing students, there was not a consistent awareness of professional responsibility of addressing issues of adult roles of partner and parent with students in their care. Very frequently responsibility for stronger direction in addressing student needs was assigned to others by the participants. This assignation clustered around the factors listed above: parents, school system capacity and desire, social systems and supports, and the students themselves.

Some participants spontaneously shared their reflections during or at the conclusion of the interviews and focus group discussions. Cal, who had concern for beginning sexual behaviors of her middle school students ("A lot of times it is the boys not knowing boundaries and girls not understanding that") said, at the conclusion of the focus group: "I didn't expect this, Mette. I was blindsided. This surprised me. This was surprising." Similarly, a participant who estimated that 5% of her female students became pregnant each year also expressed surprise at the scenarios and questions at the end of the focus group. Another participant, in the course of discussion of the scenarios, shared the following:

> I was just picturing a girl with Down syndrome with a belly, you know what I mean? That would set funny with me. I never expect it. I never expect one of them to get pregnant. And that goes against the way I talk: "They deserve this, or that." No, I never expect it to go that far… That's why I am more open to them

> going ahead and having a relationship because I don't think it ever would get there. (Chris, FG I, p.6)
>
> *Researcher: How so?*
>
> I never thought about it, I never really took it that far out. (Chris, FG I, p.6)

Later, at the conclusion of the focus group, this participant spontaneously described the interaction as "thought provoking." This participant's interview was closed with the following comments:

> The relationship class (sexuality and people with ID), that is something that will stay with me for the rest of my life. It bought up a lot of good points. Why don't people with disabilities deserve a relationship? I was always so focused on education, math, read this, read that. I was never focused on relationship. If I ever worked in an adult agency, that would be the place for it. In a high school, people are really scared of it. It is something that needs more attention. (Chris, II, p.12)

Summary

This chapter reported the findings of individual ethnographic interviews and subsequent focus groups conducted with middle and high school special education teachers working with students with ID. The purpose of this study was to investigate the anticipations of middle and high school special education teachers as to life span opportunities of their students in assuming adult roles as partners and parents with intellectual disabilities, and their expectations for themselves in preparing their students for adult roles.

The domain analysis of data obtained from the interviews and focus groups yielded information from the teachers as to the expectations for themselves in preparing their students for adult roles, including those of partner and parent, and also their anticipation of what their students' adult lives will be like. Three major domains emerged from the domain analysis and those were: (a) *Boundaries*; (b) *Dangers and Threats*; and (c) *Responsibility for Change*. Within those major domains, multiple themes were identified and discussed relative to the data as well.

Boundaries for teachers, parents, students, and the greater society were reviewed. Teacher boundaries were not always well defined and, among some participants, revealed eroded boundaries between self and their students. The importance of teaching students good boundaries was illustrated by student behaviors that have made students both aggressor and victim. The participants' responsibility in maintaining and modeling good boundaries with students is non-negotiable and requires careful attention. Parents were frequently mentioned as a support to students, but one that also presented challenges with boundaries as students matured to take on adult roles. Teachers were challenged to navigate these complex relationships and expressed concern that parent boundaries frequently inhibited the students' opportunity to grow into adulthood. There was neither request nor discussion of needed support in systematically discussing difficult issues with parents and with mediating sometimes conflicting expectations. Societal boundaries were described as setting a double standard for people with ID as participation in society appears more restricted by economics and social expectations.

Dangers and Threats represented the second domain analyzed. The themes within dangers and threats include: *Exploitation and students as victims, Students as aggressors, Threats to parents and grandparents, Threats to society,* and *Professional dangers*. As discussed above, inappropriate student behavior can result in both aggression and victimization by a marginalized adolescent population. Students with ID are especially vulnerable to such dangers. Several participants identified potential threats to parents and grandparents as they were challenged with lifelong support of a child, or grandchild, with ID. As students approached adulthood, and physical and sexual maturity was occurring, more concerns were exposed. The toll of raising a child with ID, and sustaining that child through adulthood was discussed. The effect of this on a caregiver’s financial resources was also an issue that emerged.

Society, the participants discussed, was also threatened by people with disabilities, due, in part, to limited, firsthand knowledge of this group of people by the larger population. Economic strain, because of additional support people with disability may require, was a concern, and was both a direct and indirect element of the discussion. References to the eugenics movement and historical practices regarding people with disabilities were also present in the discussion. A variety of social issues, including multiple births due to in-vitro fertilization, parents’ behavior, and the current economic crisis were discussed relative to opportunities for people with ID to engage in adult relationships and to become parents and partners. Choice for parenthood, however, was not strongly voiced as options of abortion or adoption were discussed and implied as preferences by the participants.

Professional dangers voiced by the participants included their challenges in dealing with school culture and practices. Limited guidance from leadership and conflicting practices within the school settings, relative to IDEIA, represented professional dangers to the participants. This sense of danger was especially present in issues of sexuality as the school district offered no guidance or curricular expectations.

The final domain *Responsibility for Change,* included two themes that reveal where participants believed responsibility lies for affecting change in the school community in which they worked, and ultimately in the lives of their students as they prepared them for future roles, including partner and parent. These themes included: *Affecting students' futures for community life* and *Affecting professional standards in professional settings.*

A*ffecting students' futures for community life* and *Affecting professional standards in professional settings* both identified where responsibility lies, according the participants, for leading students with ID to adulthood. All of the students taught by the participants were middle and high school age and will be exiting public school soon or within a few years. There was little sense of connection between actions in the classroom today for success in the future. Rather, there seemed to be parallel paths within a student's life, one leading to day to day school activities and the other, separate, leading to a life that is, at best, disappointing. There seemed to be a missing connection with what is taught in school, how parents and community are engaged, and what skills students need for the future. In addition, there was limited knowledge of or connection with agencies and supports for the next phase of the students' lives when they exit high school.

The participant teachers most frequently saw themselves as reacting to factors which impacted their teaching, often confusing direction and results. Lack of guidance from school hierarchy in both implementation of IDEIA and in decision making about curriculum presented dilemmas for the participants at many levels. No participants described support they received from school leadership. Expertise of ancillary staff was utilized to support teaching in two classrooms, when crises arose, and, in a number of cases, when perceived crises were possible. As participant teachers were not engaged in decisions as to funding, school practices in setting IEP protocol, and systematically addressing both student social-educational needs and parent concerns, the results were confusing. Participant teachers did not identify a connection between the work they were doing currently with students and what life the students would be assuming once they left the public school system. Participants did not indicate support for themselves as they pursued their work. While issues of sexuality and puberty were introduced through scenarios in the focus groups, they permeated the responses of most participants in both the interviews and focus groups. Complex issues of puberty and students' burgeoning adulthood were not addressed systematically through classroom planning and goal setting, and participants identified few if any school supports to assist them or guide them in this aspect of their professional work. In addition, participants' own beliefs, biases, life experience, and education impacted their professional presence and their actions as they described their expectations for themselves and anticipations of future roles of their students, including those of partner and parent.

CHAPTER 5 DISCUSSION

Overview

This qualitative research study utilized individual ethnographic interviews and subsequent focus groups conducted with eight middle and high school special education teachers working with students with ID. A semi-structured interview process was employed to gather information from these eight teachers. The purpose of this study was to investigate the anticipations of middle and high school special education teachers as to life span opportunities for their students in assuming adult roles as partners and parents with intellectual disabilities, and their expectations for themselves in preparing their students for adult roles. The primary research question in this study was: What are the anticipations of middle and high school special education teachers for their students with ID for future roles as adult partners and parents? Underlying research questions included: what do middle and high school special education teachers expect of their role and responsibility in preparing their students for adult roles as adult partners and parents?; and what are the anticipations of middle and high school special educators of their students as to future opportunities for adults with ID to marry, to conceive, and to raise children?

The study was developed out of an interest about the preparation for students, adolescents and young adults with ID, who will soon be assuming adult roles in society. Issues of partnering and parenting were of particular interest because of the change in opportunities for people with ID as they have entered a more inclusive society. While parenthood among people with ID is now more common, parents with ID typically face loss of custody of children who may be born to them (Budd and Greenspan, 1985; Llewellyn et al., 2003). A review of curricula used by middle and high school teachers revealed little if any attention to issues of adult roles as partner and parent in society (Test, Fowler, Brewer et al., 2005; Test, Fowler, Wood et al., 2005). Almost a decade ago, education preparing students with ID for adult roles, especially sexuality education, was reported as a critical need for these students (Watson, Griffiths et al., 2002) but educational practices, curricula, and instruction have provided little support for actualizing later life opportunities (Kliewer & Drake, 1998). Ironically, IDEIA, which recognizes disability as “a natural part of the human experience and in no way diminishes the right of individuals to participate or contribute to society” ((IDEIA, 601(c)(1)), also identified the purpose of a free and appropriate education as that which will prepare students “… for further education, employment, and independent living…” (IDEIA 601(d)(1)), and also that students may “lead productive, independent lives to the maximum extent possible” (601(c)(5)(A)).

While this study was proposed with the specific research question identified, the qualitative research approach carried the inquiry and subsequent findings to unexpected areas, broadening the discussions and information revealed through the process. This is consistent with Agar’s (1996) guidance to the qualitative researcher, describing it as a process that produces change over time. Similarly, Spradley (1979) described qualitative inquiry as one in which the researcher is changed as she enters into and learns from a new culture. In this chapter I will discuss the research, its limitations, explanation of findings, and the implications for next steps as well as conclusions.

Limitations

As the primary instrument in qualitative research, the researcher influences the process from start to finish, including interpretation of the data (Wolcott, 2001). This results, in part, from the direct and intimate involvement of the participants as they share their experiences and opinions with the researcher.

First, I came to this research through some shared experiences with the participants: I am a special education teacher. However, my career path and training have been different. I have master's degrees in early childhood special education and counseling and have never taught in a high school or middle school. The participants generously shared information about their lives, their work, their opinions, and motivations that were very important to this research. My instincts and training urged me to look more deeply into personal background and motivation which contributed to attitudes held by and behaviors of the participants, most particularly that of awareness of boundaries with students and the professional responsibility of the teacher. However, I resisted and worked to create distance from the participants. This may have resulted in limitations to the data that were ultimately produced: I did not pursue follow up questions I might otherwise have asked, erring on the side of caution and trying very hard to adhere carefully to the research protocol. I concluded that it was my commitment to the IRB as to what I would be requesting of the participants. However, I have asked myself if I perceived the IRB as a convenient barrier which limited my follow up questions and probes. Some of the information I obtained from the participants was clearly concerning to me; I may have been uncomfortable and chose not to pursue further questioning. I also suspect it was my training and instincts as a counselor that provided a venue in which the participants generously shared the information they did about expectations for themselves and anticipations of their students' adult lives. This is central to qualitative research in which the researcher’s influence is necessary and a resource to the research itself (Holliday, 2002).

Second, while I have taught special education students as old as 12 years in my career, I have never worked as a middle or high school special education teacher. My experiences and training have been much different from the teacher participants interviewed in the course of this research. Also, I have not worked in a classroom for several years but rather pursued a career in disability and special education through administrative and training activities for the most part. However, my limitations of recent classroom work and no middle or high school teaching experience may have allowed me to listen to better understand what these eight teachers were currently experiencing in the world in which they work. It was a new culture for me and one from which I recognized I had a lot to learn.

Third, the study was limited both by the number of participants and the experiences and contributions of the participants themselves. Also, ethnographic research is not easily generalizable to other settings. The eight teachers who participated in this research were sought from a wide range of sources, including university programs, colleagues and others who had relationships with middle and high school teachers working with students with ID. There is no way to determine how exactly their experiences and responses mirror the entire population of teachers. That is not possible. The number of teachers included matched the number or participants proposed for this study. They also represent a range of ages, teaching, and educational experiences. And while there were considerable differences in their responses, there were also considerable similarities.

Fourth, the study was limited by the limited methods of data collection which included a formal interview and focus group, or, in the case of one participant, a follow-up interview. While a limiting factor, the data do contribute to an otherwise unexplored and unreported question: what are the expectations and anticipations of middle and high school special education teachers in preparing their students for adult roles, including those of partner and parent.

Fifth, closeness of the university and teaching communities, and the personal reflections and thoughts expressed by the eight teacher participants, make reporting more specific information about each one difficult. It was tempting to provide a personal profile of each teacher, including age, years of teaching, number of years each taught, education level, and teaching assignment. While pseudonyms were given each participant in reporting the data, revealing information about each one as described above would risk identification of individuals with information shared. It would also compromise the commitment to confidentiality ensured by the consent form approved by the IRB and the professional integrity of the researcher. Therefore, it was essential to limit individual assignment of specific, personal details which might, in any way, reveal the identity of any of the participants for future readers of this document. As reported earlier, the focus group itself can limit confidentiality in that, while participants are asked to not divulge identification of others, there is no way to ensure participants keep all discussion and identification of each other confidential. I feel that risking identification of any of the participants is inconsistent with my commitment to the IRB.

Sixth, the participants demonstrated strength, both personal and professional, and were very generous in sharing their experiences as middle and high school teachers working with students with ID. I value the contribution they have made to this research. In reviewing and interpreting the data, several concerning statements and themes emerged, many of which are reported here. It was my intention to interpret the data as I saw them, relying on the tacit knowledge revealed by the participants (Spradley, 1979) and to report that interpretation. It is through the frank and generous participation of the eight teachers that I am able to report these data and their contribution to this research. However, interpretation of the data was challenging for a number of reasons. As themes emerged, it was clear the focus of the research had expanded, in part, to day-to-day challenges and limitations of the participants' work life and the lack of direct connection to the anticipation of students' future roles as their work was carried out. Member checking went on throughout the interview and focus group process, as I checked back with participants to ensure I understood what they were intending and to determine that they understood the questions. Notes made during the process, and immediately following the interaction with participants helped confirm the information gathered during the face to face meetings. All but one of the interviews was recorded. In that one interview recording was not possible because of the setting, but extensive notes were taken with quotes recorded by hand. These were read back to the participant several times during the interview and a summary was sent as well to ensure accurate representation of her participation. That participant responded by email to the written summary that "I would say tat (sic) is accurate of my thoughts and feelings." Summaries of the interviews and focus group participation were sent all other teachers as well and followed up with additional requests for feedback. In total, I received four responses as to the accuracy of the summaries. Only one minor correction, the chronology of work experience, was offered by any of those responding. This is a limitation to the trustworthiness of the data: only half of the participants provided acknowledgement of or feedback to the summaries sent them. However, multiple efforts were made to obtain feedback including the ongoing member checking, summaries, and follow up email/text messages. Several expressed pleasure in the research process upon completion of participation in the interviews and focus groups. I received no other corrections to the summaries and how the interview and focus group participation was represented in the summaries.

Seventh, one participant could not participate in either focus group because of a family emergency. An individual follow-up interview was conducted with this participant in lieu of the focus group participation. Predictably, this interview was limited by less data and less discussion than the others. While it is recognized that there would not be interaction with other participants during the follow-up, the participant was very engaged and freely shared her experiences and opinions. She did express a desire to have interacted with others around the questions as she found the discussion interesting and would have liked to have heard what others said.

Finally, critical disability theory was selected as one theoretical approach best reflecting the research undertaken in this study. I recognize the limitations possible with selection of any theory, but critical disability theory was, in some ways, incongruent with my own disability work over many years. This work has included the promotion of strong developmental practices in early childhood and prevention of later disability through a range of early interventions and treatments. As disability theory recognizes the importance of societal acceptance of the individual where he or she is, not seeking to fix or cure the disability, it is a good fit for this study and the interpretation presented here; in some ways it also appeared to be in conflict with my work with young children and families. I have come to resolve this conflict in recognizing that disability theory also recognizes the ongoing need for support of people with disabilities, frequently throughout the life span. Early intervention with young children is a support similarly, to both families and children. It may reduce the need for later support as the individual grows and matures, but it does not devalue the status of the individual and what that individual brings by attempting to remedy the disability, making the individual “whole”. Rather, it strongly recognizes the individual child and works from that child and family’s strengths, recognizing needs and accommodations. In this way, I feel critical disability theory is not alien to disability work undertaken with young children and families. Rather, it reflects the support families may need as they address the challenges of raising a child with disabilities. It seeks to ensure that those supports are available, individualized for each child and family. This is precisely what early intervention and special education, both created by IDEA, envision.

Comparison of Findings to Theoretical Framework

Through both symbolic interactionism and critical disability theory, findings were reviewed, compared and analyzed relative to the frame of how teachers carried out their work, how they functioned as members of a system of power and privilege in the public schools, and how they reacted to and interacted with other elements of the system of power affecting the day to day educational opportunities and eventually the adult life opportunities of the students they taught. Teachers, school hierarchy, and the larger society emerged as systems of power and privilege affecting the education and future of students with ID. These systems interacted with each other with the teachers identifying both school hierarchy and the larger society as powers that affected and, in many ways, dictated what they did in their professional lives. Elements of language, thought, and action representing that interaction helped create the frame by which data were analyzed and the resulting domains.

The purpose of this study of middle and high school special education teachers working with students with ID was to investigate (a) teachers' anticipations of the life span opportunities of their students with ID to assume adult roles as partners and parents; and (b) teachers' expectations for themselves in preparing their students for adult roles. The primary research question in this study was: What are the anticipations of middle and high school special education teachers of their students with ID for future roles as adult partners and parents? Underlying research questions included: What do middle and high school special education teachers expect of their role and responsibility in preparing their students for adult roles as partners and parents?; and What are the anticipations of middle and high school special educators of their students as to future opportunities for adults with ID to marry, to conceive, and to raise children?

Critical disability theory challenges the prevailing or existing beliefs around disability and what life for people with disabilities will be. It engages the voice of the disability community that speaks out on its own behalf and expects recognition and opportunity. It also recognizes the ongoing need for support, through the life span. An understanding of the role of parents and other key family members in supporting and promoting the self-advocacy of people with ID and other disabilities is essential; while family presence is especially important in the early years of a child's life, the family support and investment frequently continues well into adulthood. It is in contrast to those prevailing beliefs that have been promoted through a variety of traditional means, including the medical model requiring “fixing” the ill or faulty human; charity, pity and shame historically associated with disability; and reaching back to the eugenics movement which sought to eliminate elements of society which were less than perfect, including “the disabled”. All of these facets were present within the data collected through this research and emerged side-by-side with descriptions and passions that reflected the desire to bring critical disability theory into the practice by some of the participants. There appeared to be tension, at times, between what *is* in the daily lives of the teachers and their students, the shackles of historical thought and practice expressed by some of the participants and present in their daily work settings, and what *might be* as a society moves forward to recognize the value as well as the ongoing needs of people with disabilities and their right to full membership in society. Table 1. illustrates this tension with solid arrows between power and privilege and elements either ensuring or obstructing future opportunities for students with ID, including possible future roles of partnering and parenting. In this way the data and their analysis represents a crossroads where both thought and practice, heavy with bias and prejudice, are juxtaposed with an awareness of what can be and what must be put into practice to ensure the rights of people with disabilities. It is a complex map and one that the participants seemed to grapple with in reflecting the reality of their day-to-day practice within systems of power and privilege, including teachers themselves, school systems and the larger society, and a desire to affect change at some level. There was not consistency, except for the continued tension between reality and hope. There was also, at times, a social blindness to the role

Table 1. Power and privilege relationship in obstructing and/or ensuring future opportunities.

ENSURING FUTURE OPPORTUNITIES, INCUDING PARTNERING AND PARENTING	RELATIONSHIPS OF POWER AND PRIVILEGE	OBSTRUCTING FUTURE OPPORTUNITIES, INCLUDING PARTNERING AND PARENTING
Students prepared for adult life Teacher well trained and implementing IDEIA Ongoing discussion and partnership with parents Positive vision of student future Recognition of own power (Darling-Hammond, French, & Garcia-Lopez, 2002; Rosenthal & Jacobson, 1968)	**Professional Special Education Teacher** Tools of Power and Privilege: knowledge, specialized/advanced education, authority, power to change, leadership	Expression of pity/flaws (they want to be normal) Paternalism Scapegoating parents Use of language symbolizing less than human status Little/No personal agency for change Grim vision for the future Eroded boundaries Inability to address sexuality
Schools are inclusive Ongoing supports and resources to teachers Advocacy for all students Engage parents in lifespan planning Positive vision of student future (Charlton, 1998;)	**School Hierarchy** Tools of Power and Privilege: knowledge, IDEIA and its implementation, authority, leadership, power to change, economic decision making	Failure to provide leadership and implement IDEIA; Failure to engage parents in positive future planning; Limited role of teacher as agent of change; Failure to provide adequate fiscal resources; Failure to provide guidance (i.e. curriculum); Limited vision for future.
IDEIA and ADA implemented, including supports to limit TPR Inclusive society Physical and social access Lifelong individualized supports (Charlton, 1998; Lightfoot & LaLiberte, 2006)	**Larger Society** Tools of Power and Privilege: authority, legislation, economic decision making, expectations for culture, history (eugenics)	Underfunding services for less privileged, including people with ID; Creating dependency through no employment or housing; Vision for future not inclusive; Failure to implement legislation.

and power teachers can wield in affecting social change yet a recognition of limitations of the work environment. There was also an acceptance of the system of power in which the teacher participants worked and in which they did not feel valued, supported, or recognized for their work. The future lives of students were described as grim and limiting, and the expectations of teachers for themselves were not ones of action in changing the present or the future.

As indicated in Table 1., the relationships of power and privilege sit between the ability to obstruct future opportunities and the ability to ensure future opportunities. People with disabilities will always need the support of those systems of power. Through the lens of critical disability theory, those systems must change, however, to share power and ensure equality. The professional special education teacher, school hierarchy, the larger society are positioned to affect change or to preserve the status quo. This research explored those relationships.

Explanation of Findings

Employing Spradley's (1979) Domain Analysis, qualitative data were gathered through individual interviews and focus groups conducted with eight teacher participants; the data were then analyzed. Using the theoretical lens described above, this analysis resulted in sorting the data into three domains eventually, which were: (a) *Boundaries*; (b) *Dangers and Threats*; and (c) *Responsibility for Change.* Within these domains multiple themes emerged. The domain analysis of data obtained from the interviews and focus groups yielded information from the teachers as to the expectations for themselves in preparing their students for adult roles, including those of partner and parent, and also their anticipation of what their students' adult lives will be like. The final analysis of data is represented in a Domain Analysis Displays (see Appendix F – Domain Analysis

Display) and illustrates the organization of the data as they were finally sorted and analyzed.

Boundaries for teachers, parents, students, and the greater society were reviewed. Teacher boundaries were not always clear and resulted in *Tension between personal/professional boundaries*. Among some participants, this revealed eroded boundaries between self and their students. Such erosion results in blurred distinction between self and others, and in this case between teacher and student history and challenges; failure to see the students with ID as an individual is a critique of critical disability theory. One participant's early experience as a foster child was reflected in her recounting conversations with her students. In that Lin identified very directly with her special education students, labeling their isolation and stigmatization along with her own in childhood. Another participant, Dot, a sibling of a person with ID, framed her position regarding sexuality and disability for potential students in the context of her own family. The challenge of maintaining professional boundaries is not new or unique in ethical discussions of special education teaching (Howe & Miramontes, 1992). It is one, however, that requires attention to protect students as well as the emotional well-being of the teacher. The ability to teach good boundaries to students with ID begins with setting strong personal boundaries (Schwier & Hingsburger, 2000), and is a basis for understanding relationships throughout life.

Paternalism, described as a means of denying people with disabilities equality (Charlton, 1998) emerged as a theme through examples of charity, shame and pity, as some participants recounted professional choices and resulting teacher-student relationships that incorporated these elements. Jane's comments reflected this as she spoke of students wanting to be more than what they were, with the assumption that being a special education student with ID was “less than”. Paternalism results in control of one group over another, and devaluation of one by another.

Inappropriate *Student boundaries in social-sexual interactions* were illustrated by accounts of student behaviors that resulted in both students as victim and student as aggressor. The participants’ responsibility in maintaining and modeling good boundaries with students requires vigilance. People with ID frequently have a lesser ability to understand the more subtle relationships reflected in personal boundaries, putting the student with ID at a disadvantage (Joseph & Barisa, 2007). Inappropriate sexual behavior can develop through lack of social guidance and supports (Griffiths et al. 1989). Teachers are in a position of responsibility for this, linking their personal boundaries to the ability to identify and model appropriate boundaries for students. Students with ID require specific interventions and instruction to gain skill in understanding subtle social nuances; the findings reveal that there was little systematic instruction in this area.

The theme of *Parent boundaries* emerged, with parents frequently mentioned as a support to students, but one that also presented challenges to boundaries as students matured to take on adult roles. Participants reported that many parents avoided discussion of their child’s maturation and transition to adulthood, and many assumed their child with ID would be dependent on them for life. Participants also reported some parents taking no responsibility for supporting their children in the future, waiting for their school years and resulting parental responsibility to end. Teachers were challenged to navigate these complex relationships and expressed concern that parent boundaries frequently inhibited the students’ opportunity to grow into adulthood. Pownall, Jahoda, Hastings, and Kerr

(2011) reported the challenges of mothers of adolescents with ID relative to sexuality and sexuality education, including much different approaches to sexuality education for their children without ID. Fear and confusion on the part of parents is common. While students with ID require more direct information and instruction regarding sexuality and relationships in general, parents of children with ID express anxiety and distress in addressing issues of sexuality with their children (Kingsley & Walker-Hirsch, 2007). This was similarly reflected in the accounts of participants in this research.

Themes emerging in the domain of *Boundaries* reflect direct control of eventual opportunities for students through practices that ultimately represent the power structure of the school. While paternalism may be most closely aligned with a power differential in the school, resulting power inequity is not unique to paternalism. The denial of access to skills, including lack of social-sexual education, results from modeling inappropriate boundaries, paternalistic approaches, lack of guidance and leadership, and inability to engage parents in awareness. It also gives absolute power to the institution, and subsequent institutions in which the individual will function (Goldman & Morrison, 2002). It forces an overflow of inequity to the broader society which participants identified as holding a double standard for people with ID. The student is not prepared for adult roles and society reinforces those expectations. *Societal boundaries*, identified by participants, were perhaps the most powerful, including expectations of society to judge and make decisions for people with ID, including the right to procreate.

Dangers and Threats represented the second domain analyzed. The themes within *Dangers and Threats* include: *Exploitation and students as victims*, *Students as aggressors*, *Threats to parents and grandparents*, *Threats to society*, and *Professional* *dangers*. As discussed above, dangerous student behavior can result in both aggression toward and victimization by a marginalized adolescent population. Students with ID are especially vulnerable to aggressors (Cox-Lindenbaum & Watson, 2002). In addition, their behavior may be aggressive or perceived as aggressive by others (Goldman & Morrison, 2002). One or both of these situations were identified by all participants as concerns they had for their students. Some participants identified potential *Threats to parents and grandparents* as they were challenged with lifelong support of a child with ID, or support of a grandchild of parents with ID. As students approach adulthood, and physical and sexual maturity occurs, more concerns were exposed for the caregivers, participants reported. The effect of this on a caregiver's financial resources was also an issue that emerged, with one participant who grew up with a sibling with ID being most vocal.

Threats to society were discussed as a threat by people with disabilities, attributed by participants, in part, to limited first-hand knowledge of this group of people by the larger population. The cart boy at Albertson's grocery store was an example provided by a participant of the limited interaction the greater society has with people with ID. Economic strain, because of additional support people with disability may require, was a concern, and was both a direct and indirect element of the discussion. Reference to the eugenics movement and historical practices of institutionalization and sterilization for people with disabilities were also present in the discussion. This was promoted by one participant in both interview and focus group. A broad range of social issues were lumped together in the discussion of the broader society's reaction to dating, intimacy and pregnancy by young adults with ID. The current economic crisis was discussed relative to concern for people with ID who might engage in adult relationships and become parents and partners. Recognition of choice for parenthood and raising one’s own child, however, were not strongly voiced; rather, options of abortion or adoption were the focus of discussions which spontaneously emerged in each focus group. One participant, however, described a possible scenario in which students he had worked with previously might establish a relationship, a home and a family. This was unique, single example in the discussions.

To one participant, the plight of students with ID and their impact on society was compared to that of alcoholics and drug addicts, with future incarceration being an inevitability expressed by another. In addition, the burden of people with ID “breeding” was raised by one participant. Subjugation of human beings to an inhuman status through the term “breeding” reflects a perspective of total control promoted at the turn of the previous century by The American Breeders Association and through its publication, *The American Breeders Magazine,* a professional periodical that advocated the study of human eugenics (Davenport, 1910). The symbolism of such terms and labels, in the context of social interactionism, assigns meaning to people and their lives. It also reflects a value held for people described in these terms by the participants. While the participant using the term “breeding” initially asked to speak off the recorded interview about this belief, she was very open and forthcoming about using the term in the focus group discussion. The use of terms referring to alcoholics, drug abusers and incarceration, however, were not filtered by the participants. One teacher, Toni, explained that she felt her students would end up incarcerated and shared that several of them already had been. It was part of the accepted progression of their lives and part of the school and community cultures in which they were enrolled.

Professional dangers voiced by the participants included their challenges in dealing with school culture and practices. Limited guidance from leadership and conflicting practices within the school settings, relative to IDEIA, represented professional dangers to the participants and left them unsure of how to proceed. This sense of danger was especially present in issues of sexuality as they reported that the school district offered no curricular leadership. Some participants stated that they had no guidance, they did not know where students received sexuality education, and that addressing issues of sexuality with students would not be something they would do. Several teachers reported that pregnancy was not uncommon in their classrooms, with one stating that about 5% of her female students became pregnant every year. Nonetheless, teaching about sexuality was perceived as forbidden in their school settings and in their school culture. When crises occurred they were referred to ancillary staff. Only two participants reported engagement with other school supports, social worker or counselor, that was proactive in developing relationship skills and boundaries. One participant utilized pictures from the internet to show her students the dangers of STDs. She indicated she had no other guidance and resource, but felt compelled to give her students some information about this health danger.

The final domain *Responsibility for Change*, included two themes that identified where participants believed responsibility lay for affecting change in the school community in which they worked, and ultimately in the lives of their students as they prepared them for future roles, including partner and parent. These themes included: *Affecting students' futures for community life* and *Affecting professional standards in professional settings.*

Affecting students' futures for community life and *Affecting professional standards in professional settings* both identified where responsibility lies, according the participants, for leading students with ID to adulthood. All of the students taught by the participants were middle and high school age and would be exiting public school soon or within a few years. There was little sense of connection between actions in the classroom today for success in the future. Rather, there seemed to be parallel paths within a student's life, one which the teacher pursued, leading to day-to-day school activities in the classroom, and the other, separate and external to the classroom, leading to an adult life that is, at best, disappointing as described by the participants. There seemed to be no connection with what is taught in school, how parents and community are engaged, and what skills students need for the future. Discussion of parents as a challenge to the participants permeated all focus groups. This emerged through analysis of the data and was present in all domains: *Boundaries, Dangers and Threats*, and *Responsibility for Change*. However, there was neither a request for nor discussion of needed support in systematically discussing difficult issues with parents or in mediating sometimes conflicting expectations. In addition, there was limited knowledge of or connection to agencies and supports for the next phase of the students' lives when they exited high school. Participants with several years of teaching experience wanted information about SSI and the DD Waiver but had not yet obtained it and did not indicate a desire or awareness of how to seek it out. Rather, there was an implied expectation that information would come to them, with regret that it had not yet. Thus, the responsibility for change in affecting student access to support was assigned to someone or something else: the school should provide needed training for teachers and it did not do so. No indication of personal agency to gather the desired information or expertise was recognized. Nor did the school culture appear to empower teachers to exercise personal initiative or grant permission to seek out other resources.

Affecting professional standards in professional settings, the final theme in the domain of *Responsibility for Change* was one in which participants revealed little personal agency for themselves in actualizing future opportunities for students. Missing from all interviews and focus groups was a discussion of the use of the IEP to set goals and identify strategies for student skills in developing relationships and in sexuality education. While the topic of sexuality was prominent in participants' discussion and in their challenges with parents, there was no organized way in which they identified an approach, such as using the IEP process, to address these important issues. Similarly, there was no indication of use of FBAs or BIPs to address sexuality issues, some of which were very blatant.

Aunos and Feldman (2002) identified many aspects of teacher perception of sexuality education among students with ID that mirrored research results here. Their review of research conducted 20 years ago included teachers not having appropriate knowledge, and the reluctance of male teachers to address issues of sexuality. The current research of this study revealed other aspects of special education teachers' reports as to how they did, or did not, address issues of sexuality with their students, either as individual teachers or as part of a team. There were reports of working with other school staff, such as the social worker, counselor, or nurse to address issues as they arose. This ancillary staff was perceived as having superior knowledge and training to address student learning needs, especially in sensitive subjects. There were few if any proactive, systematic measures taken to support healthy sexual development and sexuality education among their students. Rather, the involvement with other school staff was usually in reaction to an issue of inappropriate social and sexual behavior that arose with a student. No participant spoke of an IEP team addressing issues of sexuality by developing individual goals for students; no participant mentioned the IEP process as being one to engage in creating goals to address maturation and sexuality. No participant described the IEP meeting as an opportunity to discuss puberty, maturation, and entry into adult roles with parents of their middle and high school students. In this way, current practices serve to keep people with ID behind "new institutional walls" (Lofgren-Martenson, 2004, p. 197), giving the illusion of access to an inclusive society but denying the tools and skills to fully participate with capable, informed, and voluntary choice.

Implications of Findings

The interactive process, through interviews and focus groups utilized in this research, revealed that there is an identified need and desire by middle and high school special education teachers to impact student learning for adult roles, including those of partner and parent. Similarly, the need for school leadership and hierarchy to set direction for teachers and a culture of preparing students for future lives was revealed. The failure of the educational hierarchy to affect change reflects the struggle with power and privilege identified in critical disability theory as people with disabilities are denied access to inclusive societies through limited education, training, and experience. Also apparent were gaps in the process of actualizing practice to address needs and realize the promise of IDEIA in preparing students for adult lives. Howe and Miramontes (1992) described the special education teacher as a "broker" who must "negotiate 'deals'" (p.66) within the school culture to obtain the best opportunities for students. In order to do this, the authors maintained, teachers must have a solid understanding of their role in negotiating these opportunities for their students as well as an understanding of and commitment to special education legislation. Several of the participants in this study acknowledged a lack of understanding of IDEIA. While there was desire to help their students, among most participants there was a lack of understanding of their role in preparing students for future lives. Envisioning students' future lives and seeing the purpose of their daily work with students was limiting. There was also helplessness in affecting change in the school culture. Administrative support was missing, or even obstructive, in providing guidance to teachers serving students.

Currently, teacher participants described a culture in which they were reacting to a range of factors (Figure 1.). The student, while present, was not identified as central to interaction in these relationships.

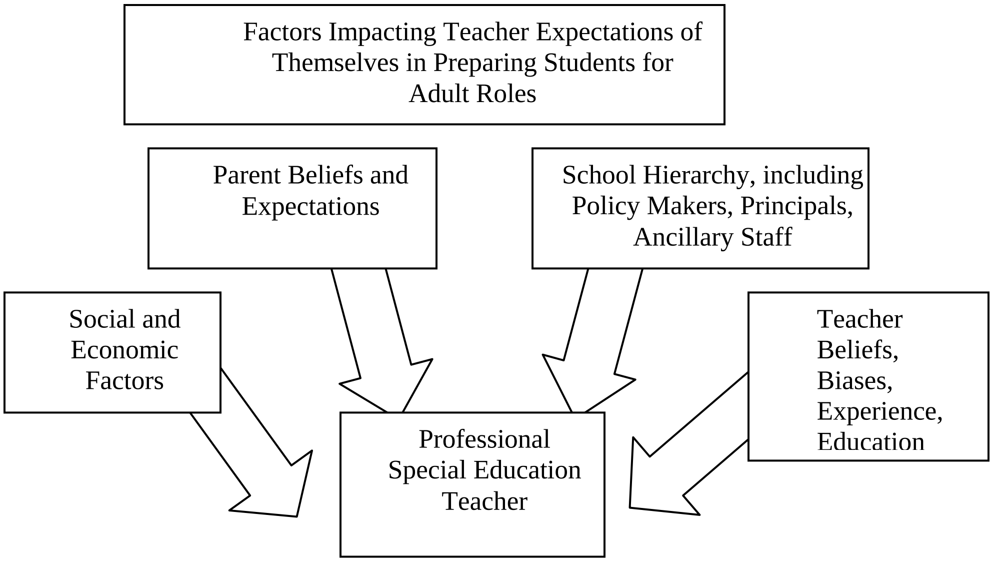


Figure 1. Factors impacting middle and high school special education teacher expectations for themselves in preparing students with ID for adult roles, including partner and parent.

Implications for Practice

Day-to-day interaction with students, as reported by the participants, did not reflect skills that would be important to future opportunities for their students. Student opportunities envisioned by the teachers were mediocre, at best, and included placement in institutions, nursing homes, home with parents, and even future incarceration. The teachers participating in this research did not identify ways in which they, and their use of the IEP, were utilized to prepare students for fuller lives.

Participants all expressed a concern for lack of support and direction in addressing issues of sexuality with their students. They all identified a need for their students in this area, however, and cited examples of student victimization, aggression, pregnancy, and other boundaries that were concerning. While school ancillary staff provided some support, other than identifying school leadership as responsible for setting guidelines, the participant teachers identified few, if any, suggestions as to how to create change. While student pregnancy was identified by almost all participants, there was no identified curriculum, and the IEP was not identified as a vehicle for either naming or addressing needed support in the area of relationships and sexuality education.

As Figure 1. illustrates, the participant teachers in this study most frequently saw themselves as reacting to factors which impacted their teaching. This led to confusion as to direction and results. Social and economic factors, parent beliefs and expectations, and school hierarchy all impacted them and how they carried out their work. Their role was reactive, rather than proactive in serving the needs of their students. They also identified gaps in their own understanding, but did not acknowledge this as a contributing factor to their situations. Participants described a lack of knowledge of IDEIA and difficulty in garnering support of school leadership to carry out their work.

Participants demonstrated little understanding of self in reflecting on how their actions ultimately affected their students and their relationships with others, including parents and school leadership. Reflective practice, with ongoing teacher support, is one way in which practice may be positively impacted. This practice is common in the birth-to-three field with infants and toddlers, where it has been utilized for many years (Siegel & Shahmoon-Shanok, 2010). While “reflective teaching” and its role in teacher education may not yet be fully understood, Calderhead (1989) described reflection in this practice as “a process of becoming aware of one’s context, or the influence of societal and ideological constraints on previously taken-for-granted practices, and gaining control over the direction of these influences” (p. 44). Because participants in this study did not articulate the connection between what they do now in the classroom and how that impacts student outcomes with learning and skill, reflection on one’s work, expectations, and processes is an important place to begin.

In addition, awareness of one’s context, such as with the participant Lin, whose early experiences invaded her perception of her students’ place in school and life, must be explored in terms of personal and professional boundaries. This would serve both the teacher and the student well. Knowing the sometimes disruptive lives of special education students, Lin’s early life could provide understanding and support for her students.

However, appropriate personal and professional boundaries are needed. The opportunity to work professionally with a skilled supervisor to provide reflection and exploration of how the professional functions in her work, beyond adhering to administrative requirements, will help develop better plans for achieving well identified goals (van Woerkom, 2010). This is also congruent with Dewey's (2004) concept of reflective thinking and critical thinking in teaching.

As Figure 2. illustrates, a more interactive relationship with key entities can engage these factors for a less reactive and more pro-active teaching relationship. Changing teacher interaction with parents, school hierarchy, and societal influences, with

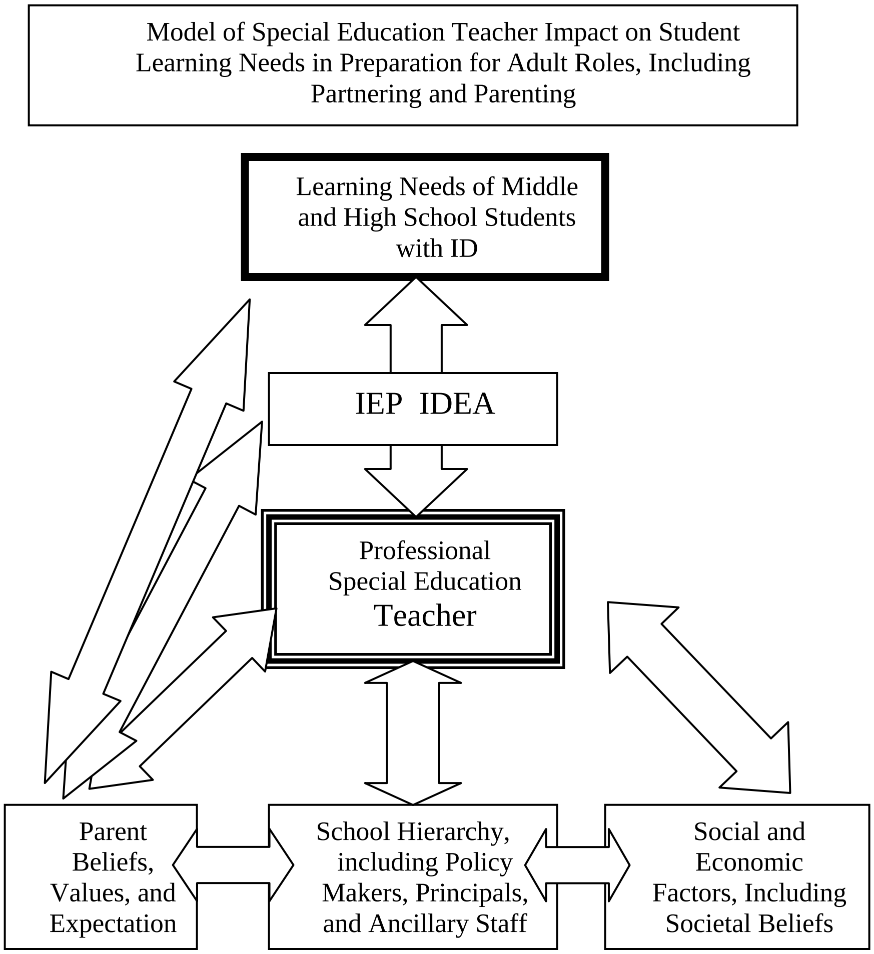


Figure 2. Model of interaction of professional special education teacher with other factors in preparing students for future adult roles, including partner and parent.

a recognition of the IEP as a vehicle to identify and address appropriate goals and strategies, can impact student learning.

Creating a culture of reflective practice would support the teacher and school hierarchy in developing an interactive relationship to affect student outcomes. One participant described a school culture in which students were openly discussed among teachers with derisive and mocking comments. When professionals engage in gossip and belittling of others, it is most frequently a result of fear and lack of skill and leadership. (V. Bernstein, personal communication, September 8, 2011). Changing that dynamic requires change in practice at all levels of the educational culture in which such behaviors occur. It also requires leadership that is informed and persistent in actualizing that change

The need and responsibility of educators to adequately prepare all students for community membership is described by Goodlad et al. (2004), as follows:

> The liberal function of teachers in a democratic society is to develop the abilities of their students to choose and cultivate visions of the good life while simultaneously preparing them for full participation in adult society. Central to such preparation is the ability to exercise one’s basic freedoms responsibly and without unjustly preventing others from doing the same. This requires that individual students develop a degree of healthy autonomy, independence of judgment, strength of character, and a measure of self-understanding. (p. 51-52)

Understanding the expectations and anticipations of special education teachers, as they prepare their students to cope with life as adults, including possible roles as partners and parents, are important issues for our time. They are ones, however, which teachers alone cannot resolve. School administrators, principals, ancillary staff, and others who represent the power structure within the institutions of public education must be engaged to provide leadership to the school community, including students with ID and those who teach them.

Implication for Policy

Legislation and changing institutions, and resulting social change through legislation, helped create inclusive opportunities for people with ID. The limited access to information and training in preparation for adult roles as partners and parents has continued to keep people with ID behind “new institutional walls” (Lofgren-Martenson, 2004, p. 197), continuing an illusion of access to an inclusive society but denying the tools and skills to fully participate with capable, informed, and voluntary choice.

Dewey (2004) recognized the challenge of individuals existing side by side with each other yet in isolation, without being part of a shared community or society. Sheltering and isolating individuals, he felt, does not promote growth or qualify as education. While Dewey was reflecting on issues of class and race in society and public education of his time, the challenges continue today as we have broadened our understanding of diversity in society to include people with disabilities. Dewey also reflected upon the presence of power differential in educational and other social systems, with the danger of individuals or groups overpowering others in ways similar to those described by McLaren (1994) and Rappaport (1995).

Dewey (2004) understood the importance of interaction with the environment and the influence the quality of the interaction has on development. That quality was enhanced by diversity rather than limited interaction and resulting limited growth. In this way, Dewey’s beliefs are not unlike those of social interactionism where meaning is constructed from experience and interaction (Blumer, 1966). The process results in growth, which Dewey felt was on-going and the purpose of education, which must “progressively realize present possibilities, and thus make individuals better fit to cope with later requirements” (Dewey, p.46).

Understanding the vision and purpose of IDEIA is one critical factor in being able to implement it. Understanding one’s place in the social and cultural fabric of education and providing leadership for teachers and parents within that is the role of the school hierarchy and leadership. van Woerkom (2010) reported that the unconscious actions of educators, including leadership, can affect, and derail, the best intentions if they are not examined and understood. Teachers in this research study reported little support from administrative supervisors. They were confused and angry about mysteries of funding, lack of responsiveness and direction, and even access to basic supplies. The lack of transparency in leadership was felt in the classroom and resulted in lost opportunities for students. Clear and consistent oversight, with clear direction and accurate interpretation of IDEIA is essential. Legislation (IDEIA) and resulting regulations are in place. According to participants in this study, regulation is not being adhered to or enforced and policy is negated, leaving students without the supports they need and to which they are entitled.

Policy implications include the adoption of curriculum that helps guide students through relational transitions, including sexuality education. Such curriculum must engage parents, from the early years of their children’s lives, in preparation for transition, not merely as an exit from school, but as an entry into adult roles, including possibly those of partner and parent. In order for such curriculum to be effective, there must be open dialogue and discussion about relationships and sexuality with appropriate accommodations for people with ID to benefit and learn from that dialogue.

Most importantly, implications for policy require courage from leadership to implement IDEIA, to bring parents into the discussion that prepares them for the future, and provides safeguards for students who are otherwise left with little preparation for or protection in an adult world to which they have been promised access.

Implication for Future Research

Teachers who participated in this research shared information that was both alarming and inspiring. They also revealed that they had not thought about future implications for students' lives. Reflective practice may be effective in addressing professional development needs of middle and high school special education teachers and their administrators relative to issues that emerged through this research. Developing a model for reflective practice and ensuring engagement of administrators and teachers would be a future research step to undertake. Questions to consider might include improvement in understanding and implementation of IDEIA, identification of personal agency in affecting change, and personal/professional boundaries as they affect interaction with students.

Understanding roles of those who affect students' education is another area of research to consider. What do administrators, parents, and teachers expect of their roles and responsibilities in preparing students for adult life? There seemed a missing connection between teacher activities and goals in the classroom and what students' future lives and exit from the public schools ultimately will bring. Future research as to effectiveness of preparation of students for adulthood and the expectations of parents and administrators as to their responsibilities in this is a research direction to consider and pursue.

Because ancillary staff (social workers, counselors and nurses) played important roles in responding to crises, future research on comparison of the training and preparation for teachers and ancillary staff may reveal future training directions, so that there is cross training to ensure adequate preparation for a wide range of classroom staff. Similarly, it may reveal gaps in training in a range of professions and the need to rethink teacher and ancillary staff preparation for the future.

Issues of human sexuality and our relationships with others in our lives do not emerge mysteriously in puberty. Research on preparation of students and their parents, from early elementary school years, for personal and social changes seems appropriate to explore. There is limited research in this area and one that may help better understand the transition to adulthood, with a life-span perspective.

Summary and Conclusion

Good educational practices are not unique to the needs of students with disabilities. While this research focused on expectations and anticipations of middle and high school teachers in preparing their students for adult roles, including those of partner and parent, it revealed the need for attention to many aspects of implementation of an educational program. Does special education need to be rethought and reconstructed? The promise of IDEIA envisioned students gaining skill and opportunity for full inclusion to the greatest degree possible for people with disabilities. The results of this research reveal that that is not happening. The lack of connection between what schools are teaching and what awaits students when they exit from public education creates a bleak picture.

There are diligent efforts by teachers taking place every day. There is also a distance to go in actualizing change in the lives of students for the best possible outcome and future adult roles. While this research set out to explore expectations of teachers in preparing their students for adult roles and anticipations of what those adult roles would be, including partnering and parenting, much more was revealed: there are gaps in understanding IDEIA, in working closely with parents throughout a student’s school career to prepare for adulthood and greater independence, in leadership within schools, and connections with future systems of care and support. Teachers seemed unable to exercise personal agency and action in making changes, and seemed to be unsafe in exploring that possibility within the culture of the school and larger educational systems in which they worked. There was no acknowledgement of strength in school leadership in offering support and guidance. One must ask why the system exists. It does not appear to hold the student as central to its purpose.

LIST OF APPENDIXES

APPENDIX A – RECRUITMENT FLYER

APPENDIX B – CONSENT TO PARTICIPATE IN RESEARCH

APPENDIX C – DEMOGRAPHIC INFORMATION

APPENDIX D – INTERVIEW QUESTIONS

APPENDIX E – FOCUS GROUP QUESTIONS

APPENDIX F – DOMAIN ANALYSIS DISPLAYS

APPENDIX A - RECRUITMENT FLYER

RESEARCH PARTICIPANTS SOUGHT

WHO?

Middle and High School Special Education Teachers working with
Students who have intellectual disability

WHAT?

To participate in one individual, taped interview, approximately one hour in length,
and
one taped focus group discussion of one to two hours in length

WHERE?

All interviews and the focus group will be held in a mutually convenient
location

WILL THIS AFFECT MY GRADE AS A SPECIAL EDUCATION STUDENT?

No.
Your decision to participate or not will have no effect on your grade or any other
services to which you are otherwise entitled. Your information and participation will
remain confidential

WHAT IS THE PURPOSE OF THIS STUDY?

To learn more about the expectations and anticipations of middle and high school
teachers in preparing their students with intellectual disabilities for adult roles.
This study is conducted as partial fulfillment and requirements for a doctorate in special
education at the University of New Mexico

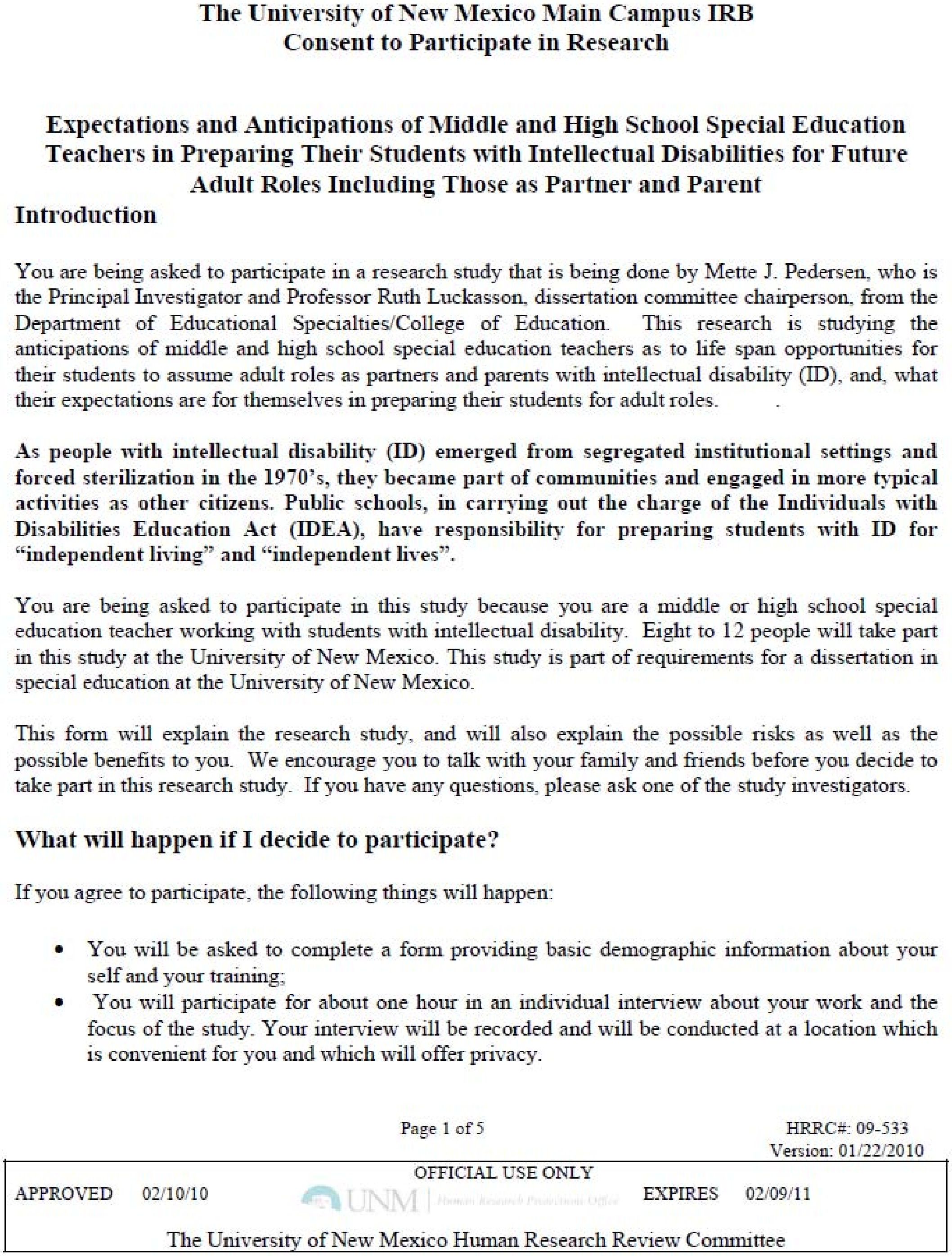
WILL I GET PAID TO PARTICIPATE?

No. There is no payment for your participation

HOW CAN I LEARN MORE?

Contact Mette Pedersen
Phone: 505-206-0120
Or
Email:
Spec.ed.research@gmail.com

APPENDIX B - CONSENT TO PARTICIPATE IN RESEARCH



The University of New Mexico Main Campus IRB
Consent to Participate in Research

Expectations and Anticipations of Middle and High School Special Education Teachers in Preparing Their Students with Intellectual Disabilities for Future Adult Roles Including Those as Partner and Parent

Introduction

You are being asked to participate in a research study that is being done by Mette J. Pedersen, who is the Principal Investigator and Professor Ruth Luckasson, dissertation committee chairperson, from the Department of Educational Specialties/College of Education. This research is studying the anticipations of middle and high school special education teachers as to life span opportunities for their students to assume adult roles as partners and parents with intellectual disability (ID), and, what their expectations are for themselves in preparing their students for adult roles.

As people with intellectual disability (ID) emerged from segregated institutional settings and forced sterilization in the 1970's, they became part of communities and engaged in more typical activities as other citizens. Public schools, in carrying out the charge of the Individuals with Disabilities Education Act (IDEA), have responsibility for preparing students with ID for "independent living" and "independent lives".

You are being asked to participate in this study because you are a middle or high school special education teacher working with students with intellectual disability. Eight to 12 people will take part in this study at the University of New Mexico. This study is part of requirements for a dissertation in special education at the University of New Mexico.

This form will explain the research study, and will also explain the possible risks as well as the possible benefits to you. We encourage you to talk with your family and friends before you decide to take part in this research study. If you have any questions, please ask one of the study investigators.

What will happen if I decide to participate?

If you agree to participate, the following things will happen:

- You will be asked to complete a form providing basic demographic information about your self and your training;
- You will participate for about one hour in an individual interview about your work and the focus of the study. Your interview will be recorded and will be conducted at a location which is convenient for you and which will offer privacy.

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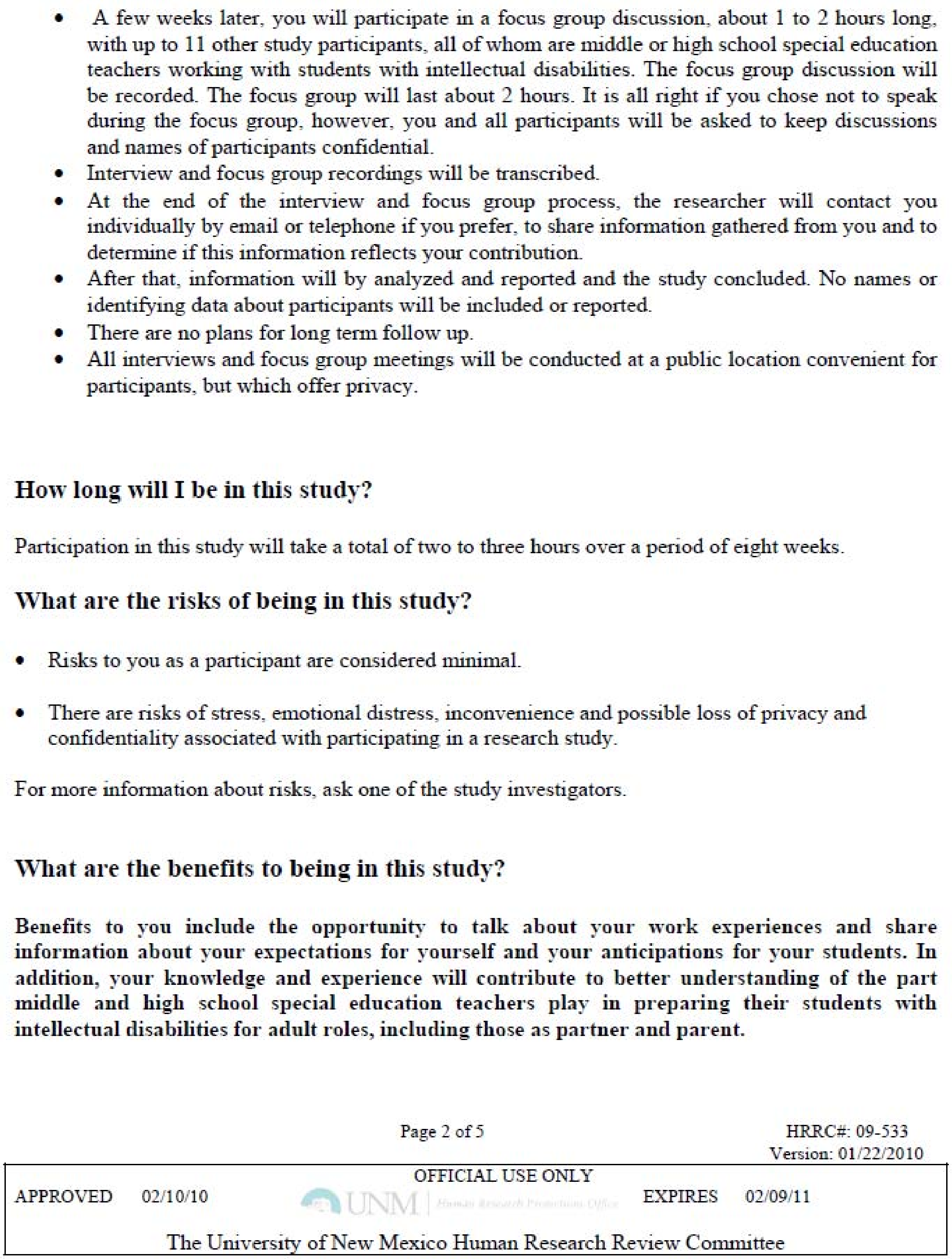

- A few weeks later, you will participate in a focus group discussion, about 1 to 2 hours long, with up to 11 other study participants, all of whom are middle or high school special education teachers working with students with intellectual disabilities. The focus group discussion will be recorded. The focus group will last about 2 hours. It is all right if you chose not to speak during the focus group, however, you and all participants will be asked to keep discussions and names of participants confidential.
- Interview and focus group recordings will be transcribed.
- At the end of the interview and focus group process, the researcher will contact you individually by email or telephone if you prefer, to share information gathered from you and to determine if this information reflects your contribution.
- After that, information will by analyzed and reported and the study concluded. No names or identifying data about participants will be included or reported.
- There are no plans for long term follow up.
- All interviews and focus group meetings will be conducted at a public location convenient for participants, but which offer privacy.

How long will I be in this study?

Participation in this study will take a total of two to three hours over a period of eight weeks.

What are the risks of being in this study?

- Risks to you as a participant are considered minimal.

- There are risks of stress, emotional distress, inconvenience and possible loss of privacy and confidentiality associated with participating in a research study.

For more information about risks, ask one of the study investigators.

What are the benefits to being in this study?

Benefits to you include the opportunity to talk about your work experiences and share information about your expectations for yourself and your anticipations for your students. In addition, your knowledge and experience will contribute to better understanding of the part middle and high school special education teachers play in preparing their students with intellectual disabilities for adult roles, including those as partner and parent.

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What other choices do I have if I do not want to be in this study?

Your participation in the study is completely voluntary and you may choose to discontinue involvement at any time. However, participation in taped interview and focus group are the only ways in which you can be included.

How will my information be kept confidential?

We will take measures to protect your privacy and the security of all your personal information, but we cannot guarantee confidentiality of all study data.

Information contained in your study records is used by the researcher. The University of New Mexico IRB that oversees human subject research, will be permitted to access your records. There may be times when we are required by law to share your information. However, your name will not be used in any published reports about this study.

What are the costs of taking part in this study?

There is no cost to participants taking part of this study, other than costs incurred through driving to community location for interview and focus group meetings and loss of time after school.

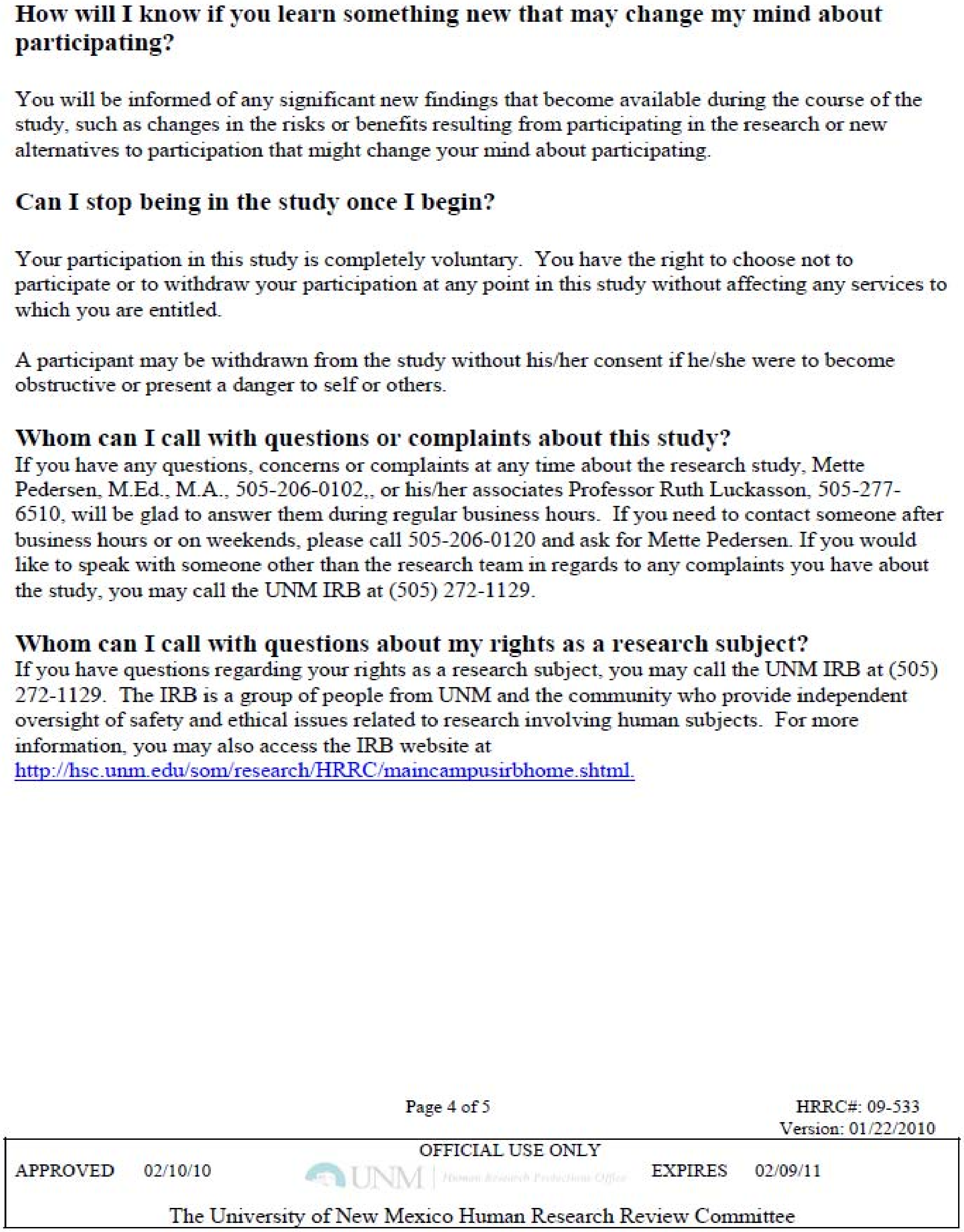
What will happen if I am injured or become sick because I took part in this study?

No commitment is made by the University of New Mexico (UNM) to provide free medical care or money for injuries to participants in this study. If you are injured or become sick as a result of this study, UNM will provide you with emergency treatment, at your cost. It is important for you to tell one of the study investigators immediately if you have been injured or become sick because of taking part in this study. If you have any questions about these issues, or believe that you have been treated carelessly in the study, please contact the Main Campus IRB Office at the University of New Mexico, Albuquerque, New Mexico 87131, (505) 272-1129 for more information.

Will I be paid for taking part in this study?

No. There is no payment for participation in this study.

APPENDIX B - CONSENT TO PARTICIPATE IN RESEARCH



How will I know if you learn something new that may change my mind about participating?

You will be informed of any significant new findings that become available during the course of the study, such as changes in the risks or benefits resulting from participating in the research or new alternatives to participation that might change your mind about participating.

Can I stop being in the study once I begin?

Your participation in this study is completely voluntary. You have the right to choose not to participate or to withdraw your participation at any point in this study without affecting any services to which you are entitled.

A participant may be withdrawn from the study without his/her consent if he/she were to become obstructive or present a danger to self or others.

Whom can I call with questions or complaints about this study?

If you have any questions, concerns or complaints at any time about the research study, Mette Pedersen, M.Ed., M.A., 505-206-0102,, or his/her associates Professor Ruth Luckasson, 505-277-6510, will be glad to answer them during regular business hours. If you need to contact someone after business hours or on weekends, please call 505-206-0120 and ask for Mette Pedersen. If you would like to speak with someone other than the research team in regards to any complaints you have about the study, you may call the UNM IRB at (505) 272-1129.

Whom can I call with questions about my rights as a research subject?

If you have questions regarding your rights as a research subject, you may call the UNM IRB at (505) 272-1129. The IRB is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human subjects. For more information, you may also access the IRB website at http://hsc.unm.edu/som/research/HRRC/maincampusirbhome.shtml.

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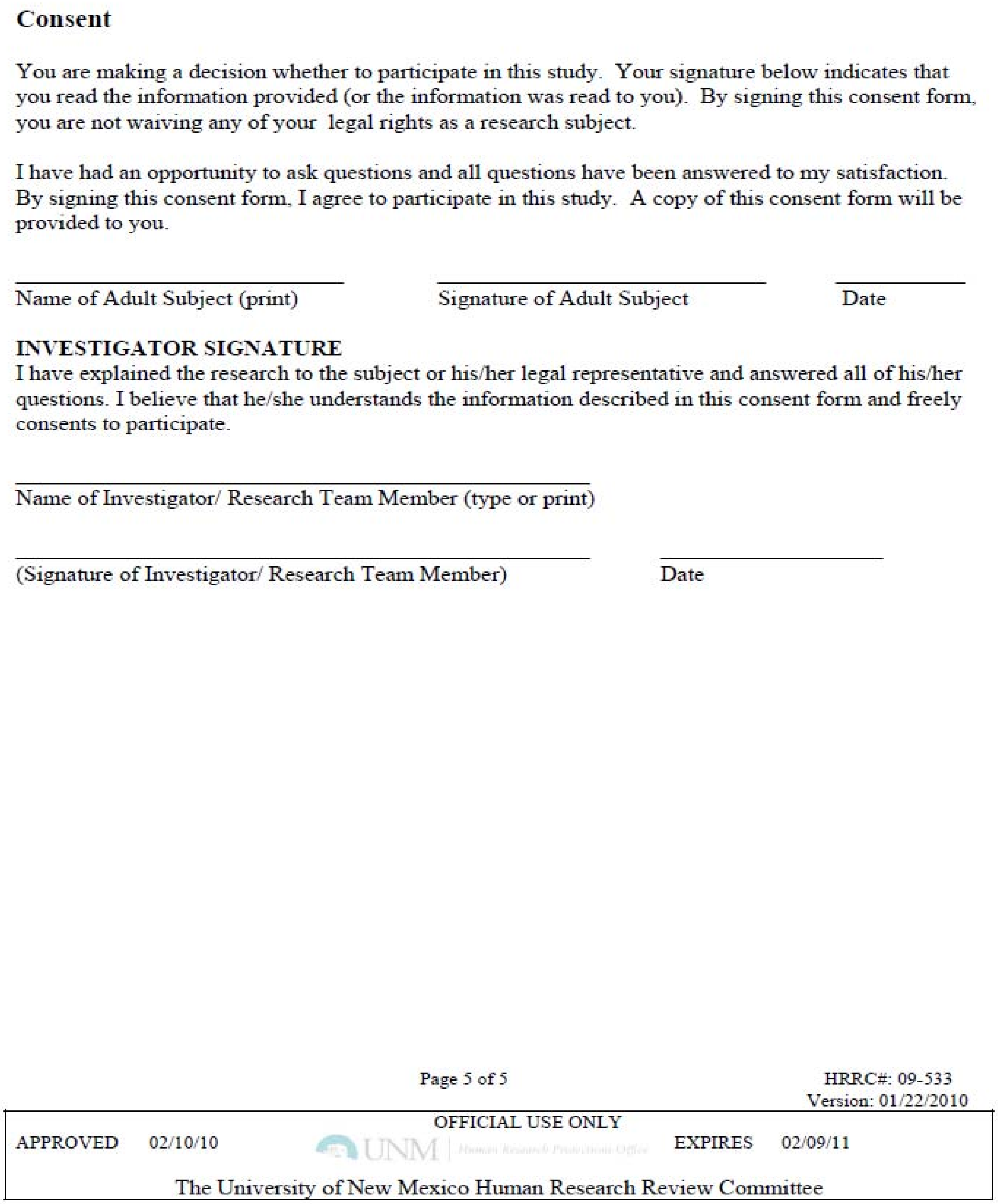
APPENDIX B - CONSENT TO PARTICIPATE IN RESEARCH



Consent

You are making a decision whether to participate in this study. Your signature below indicates that you read the information provided (or the information was read to you). By signing this consent form, you are not waiving any of your legal rights as a research subject.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate in this study. A copy of this consent form will be provided to you.

Name of Adult Subject (print) Signature of Adult Subject Date

INVESTIGATOR SIGNATURE

I have explained the research to the subject or his/her legal representative and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.

Name of Investigator/ Research Team Member (type or print)

(Signature of Investigator/ Research Team Member) Date

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APPENDIX C - DEMOGRAPHIC INFORMATION

Demographic Information

Date: _____________________

Name: ____________________

Age: ______________________

Educational History

Institutions attended: __________________

Degrees obtained: _____________________

Current course of study (if student): ______________________

Teaching experience: ____

____

Please describe any coursework you have had which addressed preparing students for adult roles as people with disabilities, including dating, partnering, and parenting:
____

____

Please describe your training and knowledge of IDEA: _______________________

____

What are the important elements of IDEA as they affect your
Students? ____
____

What is your experience with people with intellectual disabilities (ID):

Family member(s): ____

Friend(s): ____

Student(s): ____
____

Other: ____

APPENDIX C - DEMOGRAPHIC INFORMATION

Do you have need for special accommodation in order to participate in the interview or focus group? If so, please describe ____
____

Days of week and times most convenient for you:________________________________

Days of week and/or times you are not
available: ____

APPENDIX D - INTERVIEW QUESTIONS

Interview

1. How did you decide to become a special education teacher working with middle/high school students with ID?

2. What aspects of your life do you feel have most influenced your career decisions?

3. You work with students who will soon be adults. What do you feel your students' adult lives will be like?

4. Do you think your students might have intimate relationships as adults, marry and/or have children?

5. How do you think your students have been prepared for adult roles?

6. What do you know about IDEA and the ADA?

   How does this affect you as a teacher?

APPENDIX E - FOCUS GROUP QUESTIONS

Focus Group Questions

In our previous interview opportunity, you each have shared information about your teaching experiences and preparation. I am going to read some scenarios to you and ask for your reactions, thoughts, and ideas regarding these situations:

1. Two young students you know, Mary and John, both have intellectual disability. They are now both 18 years of age and are dating each other.
    a) What are your thoughts about this?
    b) How do you think others, including the broader society, will respond to this information?
2. Two young students you know, Mary and John, both have intellectual disability. They are now both 18 years old. You have been informed that they are having a sexual relationship.
    a) What are your thoughts about this?
    b) How do you think others, including the broader society, will respond to this information?
    c) Why do you think society will have this response?
3. While you have known Mary and John, both over 18 and with ID, are dating and had a sexual relationship, you have just found out that Mary is pregnant.
    a) What are your thoughts about this?
    b) How do you think others, including the broader society, will respond to this information?
4. What guidance do you as a teacher have in dealing with situations such as Mary and John's?
5. What additional guidance do you feel you need, if any?

Domain Analysis Displays

Domain Analysis of Boundaries

Boundaries	Tension between personal and professional boundaries	Early experience of trauma; identification with students	Students ostracized; “judged my whole life”; foster child label; told you are stupid
		Identification with caregivers	I feel for the grandparents; not fair to the parents
		Personal views negating choice for individual with ID (degree of disability would affect decision)	Proponent of abortion
			Adopt the kid
			Opposed to abortion
			Don’t believe in abortion
			Creates other psychological problems
			Adoption or abortion
	Paternalism	Pity	Forgotten group of people
			People who do not want to touch it
			Touching because they respond to you
			Desire to be needed
			In their own world
			People might look at it from pity
		Shame	Want to be more than what they are
			Concern about teacher who shames student
			Like society of alcoholics or drug addicts
			They could breed

Domain Analysis of Boundaries

Boundaries	Student boundaries in social-sexual interactions	Inappropriate toward others	Sexually aggressive comments
		Consequences	Pregnancies
			Legal issues
		Communication skills	Harassment, use of electronic devices, perseveration
	Societal boundaries	Society makes decisions for people with ID	Tying her tubes
			Not having another child
		Judgment of people with ID	Because of lack of knowledge of ID
	Parental boundaries	Parents put limitations on students with ID	Make dependent on the parent
			Negative parent attitudes
			Low expectations
		Parents limit students’ knowledge	Avoidance of issue bounds student options and access
		Respecting parent position	Parent knows student best
			Respecting parent boundaries

Domain Analysis of Dangers and Threats

Dangers and Threats	Exploitation and Students as Victims	Lack of student knowledge	Don’t know how to have an appropriate relationship
			Don’t know about sex
			Don’t know about risks of pregnancy and diseases
		Exploitation by responsible power structure(s)	No special education guidance given
			Potential student victimization by the legal system
	Students as aggressors	Aggressive behavior by student	Sexual Harassment
			Harm
		Lack of knowledge	Can result in victimization by legal system
		Inappropriate behavior	Interpreted as aggressive/double standard
	Threats to parents and grandparents	Present and future life of caregivers	Wearing parents down
			Financial burden
		Avoidance of planning for future	Lack of planning
	Threats to society	Economic burden	Need for public assistance, such as DDWaiver
		Resulting pregnancies	They will breed
		Inability to manage their own lives	Society will have to take responsibility and assume costs
	Professional Danger	Professional Role	Challenges discerning boundaries, rights and responsibilities
			Danger of discussing/teaching sexuality to students (especially by male); get in trouble; wouldn’t touch with 10 foot pole
			Unsure of legal responsibilities under IDEA (sign for principal? What is put on IEP)
	Professional danger	Professional supports	Desire for more information and training, like social workers have
			Refer questions to social worker, counselor, nurse, etc., when issues/crises arise.

Domain Analysis of Responsibility for Change

Responsibility for change	Affecting student futures for community life	Advocacy	Interested in disability rights; pot stirrer
		Barriers	Parents avoiding or negating future opportunities/maturation
			School not connecting students to future opportunities
		Future life of students	At home, group home, institutions; not a very interesting life; I think about it all the time; I worry
		Change in self	Better understanding of parents
	Affecting professional standards in professional settings	Barriers	School/educational hierarchy
			Lack of adequate funding in school district
			Lack of personal/professional knowledge of how to change
			Lack of action/passivity/collusion
		Direction	Want to be told what to teach; want direction
		Vacuum	Priorities voiced, but no discussion of actualization to practice
		Teaching practice	Fear: pictures from internet; school police officer will be involved
			Not preparing students for adult life
			Lack of personal responsibility in fellow teachers and self
			Refer to ancillary staff; some interaction by two participants
		Self as agent of change	Pleasure in being pot stirrer
			Righting societal wrongs
			Educate parents
			Advocacy
			Abdication of responsibility for change – in my own little isolated world
		Awareness of/responsiveness to student needs	Surprised by research questions; hadn’t thought about before
			Assign responsibility to others: parents, school, social systems and supports, students
			Not to be addressed in school: fear, belongs in adult agency

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