

Disability Studies Quarterly
Fall 2002, Volume 22, No. 4
pages 9-27 <www.cds.hawaii.edu/dsq>
Copyright 2002 by the Society
for Disability Studies

Discrimination, Sexuality and People with Significant
Disabilities: Issues of Access and The Right to Sexual
Expression in the United States

Holly Anne Wade, M.A.
University of California, Berkeley and
San Francisco State University

Abstract

A review of legislation, policy and practice was conducted to outline the conflicting issues that contribute to the currently widespread discrimination of people with significant disabilities in the United States and their access to sexuality education and expression. Although many individuals with significant disabilities face discrimination on multiple levels, barriers to sexuality seem pervasive in most environments that people encounter. While some individuals with significant disabilities have been successful in establishing and maintaining intimate relationships, many continue to face isolation in the communities in which they live. This paper will outline the issues that surround and contribute to the discrimination of people with significant disabilities in the United States with regard to their right to sexuality and discuss the need for new policies that will serve as potential remedies for this national problem.

Introduction

Persons with a broad range of disabilities - cognitive, motor, sensory and psychiatric - have been victims of intentional and irrational state-sponsored discrimination and exclusion from the basic rights and citizenship in every aspect of public and private life including employment, housing, the judicial system, marriage, parenting and education. Congress was aware of the centuries of discrimination when it enacted the Americans with Disabilities Act (ADA) in 1990. (Brief of Amici Historians and Scholars at 1, Bd. Of Trustees of the Univ. of Ala. V. Garrett, 531 U.S. 356 (2001))

This statement illustrates the acknowledgement of discrimination towards people regarded as disabled. This recognition led to the enactment of the Americans with Disabilities Act in 1990 which became the most visible, culminating law to address discrimination on multiple levels as it exists for individuals with disabilities in our country. This process of recognition, understanding and revealing the history of pervasive and intentional discrimination led to a broad law that attempts to mediate the numerous levels of mistreatment and violations of human rights for individuals with significant disabilities.

In the last ten years, many individuals with significant disabilities have realized greater opportunities and access to both public and private life domains which has increased the participation of such individuals in meaningful and integrated work, education, community, and housing. With education and support some individuals with significant disabilities have been successful in initiating and maintaining intimate relationships with others and have found ways to realize healthy social and sexual relationships. It is the lives of such individuals that we must learn from. How have they been able to establish relationships with others and successfully maneuver in a system in which access to their most fundamental right, sexuality, has been historically denied? Hingsburger (1991) asserts that "people with disabilities can develop sexual relationships if they live in healthy environments surrounded by people with appropriate attitudes." While positive accounts of relationships among people with disabilities do exist (Shakespeare, Gillespie-Sells & Davies, 1996; Melberg-Schwier, 1994) there is still a great discrepancy in desire and opportunity among individuals with significant disabilities in our communities.

To this end, we find laws that have done little to increase the likelihood that individuals with significant disabilities will realize the same opportunities and access to sexual expression and relationships that their non-disabled peers have. Specifically, individuals with significant disabilities continue to encounter discrimination with regard to their right to participate in both education that will lead to an understanding of their sexuality and opportunities to engage in sexual activity and expression. This analysis will focus on the issues of sexuality in the lives of individuals with significant disabilities. For the purpose of this analysis individuals with significant disabilities will be defined as people who experience moderate to profound intellectual disabilities and may experience a secondary sensory or physical disability.

While a token acknowledgement of the need for opportunity and education with regard to sexuality and individuals with significant disabilities does exist (Kempton & Kahn, 1991; McCabe, 1993; Hingsburger & Melberg-Schwier, 2000; Gordon, 1974; Ludwig, 2000; Abramson, Parker & Weisberg, 1988; Wolfe & Blanchett, 2001), little has been accomplished to end the discriminatory attitudes and practices that remain a part of

both policy development and implementation. Such acknowledgement has led to the development of specific curricula (Wolfe & Blanchett, 2000; Ames, 1991; McCabe, 1993) that meets the needs of individuals with significant disabilities, but has failed to implement a standard policy (Wolfe & Blanchett, 2000) that will ensure such individuals have access to sexuality education in schools or community settings. Without guiding policies, little can be done to ensure that an individual's rights to education and training in sexuality will be realized.

Further, while the movement towards normalization and inclusion in the community has moved many individuals from segregated settings to more integrated options, little has been done to increase the likelihood that in such settings people with significant disabilities will move beyond being physically present and become emotionally connected (Sapon-Shevin, Dobbelaere, Corrigan, Goodman & Master, 1998; Meyer, 1991; Stainback & Stainback, 1990; Strully & Strully, 1996; Van der Klift & Kunc, 1994). The efforts of Congress to protect the rights of individuals with significant disabilities and increase their access to public life has succeeded, but continues to fail in addressing policies that would support the end to discriminatory practices in their private lives.

This dichotomy between private and public lives continues to be at the core of discriminatory practices in disabled people's lives. As disability activist Crow (1991) suggests, without the recognition of sexuality we have very clearly missed the point. She claims that we have categorically failed to recognize the importance of sexuality as the core to the ultimate realization of access to education, housing and work. Without the recognition of private lives for individuals with significant disabilities, the fight for access and integration may continue, but people with significant disabilities will remain in a separate and unequal status among the non-disabled population. The failure to include sexuality education and expression in the lives of people with significant disabilities leads to further discriminatory policies and stifles efforts to wrong the human rights violations of the past.

Current failures in our educational and support practices have their roots in the history of segregation and discrimination of this population. Decades of rampant disregard for the humanness of individuals with significant disabilities has led to policies that illustrate how states continue to interfere with an individuals rights to pursue consensual relationships and realize a private life (Field & Sanchez, 2001). Like current practices, history illustrates a denial of both the desires and needs of individuals with significant disabilities and their right to opportunities for sexual expression.

History of Legislation, Policy and Services
Related to the Sexuality of People with Disabilities

The 1600s to the 1880s: The Beginning of Misperception and Discrimination

Sexuality has always been an area fraught with misunderstanding and moral debate. The presence of disability provides an added twist. History has shown us that the area of people with significant disabilities and sexuality is one built on misconceptions and discrimination (Abramson, Parker & Weisberg, 1988). In 1614, the first medical diagnosis of mental retardation was recorded, the cause of the condition was given as "overindulgence in sexual pleasure." These attitudes and the "total disregard for the sexual rights" (Kempton & Kahn, 1991) of individuals with significant disabilities lasted well into the 1940s (Reed, 1997). There were advances in educating individuals with significant disabilities in the late 1700s and early 1800s, but these efforts were thwarted from 1880 to 1940 due to the eugenics movement (Kempton & Kahn, 1991).

The Eugenics Movement: 1880-1940

The first sterilization laws were passed by Indiana in 1907 and by 1948 forty-two states had enacted such laws (Abramson, et al., 1988). This movement was an attempt to breed out individuals with disabilities who were characterized as "sexual perverts" or "habitual criminals" and were considered to be prone to criminal behavior and sexual promiscuity (Kempton & Kahn, 1991). Between 1907 and 1957 it is estimated that approximately 60,000 individuals were sterilized without their consent and/or knowledge (Kempton & Kahn, 1991). In 1927 the Supreme Court, in an opinion written by Justice Oliver Wendell Holmes, upheld the constitutionality of the Virginia sterilization law in *Buck v. Bell* and endorsed the involuntary sterilization of a 17 year-old young woman. "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind...Three generations of imbeciles is enough" (*Buck v. Bell*, 1927: 205-207). This public discrimination led to perpetuating the misconceptions of people with significant disabilities and furthered the discrimination and inhumane practices against this population.

The 1940s and 1950s: Shifting Attitudes with Little to No Improvement in Widespread Discrimination

Progress was slow in improving both the educational and housing prospects for individuals with significant disabilities. However, public attitudes began to shift as a result of the Nazi's version of eugenics and sterilization which were questioned by Americans in a post World War II era (Reed, 1997). Despite this understanding involuntary sterilization laws remained in many states until the 1970s

(Kempton & Kahn, 1991).

During the 1940s people with disabilities were housed primarily in institutions. This practice began in an effort to "care" for individuals with significant disabilities who could not be cared for at home (Kempton & Kahn, 1991). Typically, these environments consisted of large, congregate living arrangements that lacked all opportunities for privacy. Such living situations provided no dignity and/or support to treat people in a humane and respectful manner. In these settings sexuality was misinterpreted and punished (Kempton & Kahn, 1991). Sexuality for individuals with significant disabilities was not identified as an issue, no education was given and no formalized support was provided.

In the 1950s parent groups began to form and they demanded research and services be available to their children. The discrimination of the past was beginning to change and parent advocacy was born. While most parents believed their children to be eternally innocent and having no sexual rights (Nolley, 2001; Abramson, et al., 1988), the movement toward advocacy did open the doors to potential opportunities in housing and education that had previously been unavailable to them.

The 1960s: The Sexual Revolution

The period from 1960-1970 was a decade of great change in supports and services to people with significant disabilities and a general sexual awakening for the society. Basic human rights for individuals with mental retardation were still not recognized as evidenced by 18 states still not permitting such individuals the right to marry. However, the period does reflect movement toward growth. President Kennedy (who had a sibling with mental retardation) established the President's Committee on Mental Retardation which advocated for community-based services to meet the needs of people with mental retardation labels. Also during the 1960s the sexual revolution was born. This notion of sexual freedoms was extended to only a select number of members of the disabled population. Members who were allowed this right to sexual freedom were believed to be higher functioning and more capable of making decisions (Wolfe, 1997). This form of decision-making continued to perpetuate the mass exclusion of people with more significant disabilities from sexual expression. It furthered the discrimination against individuals by allowing others to make decisions on perceived notions of competence rather than individualizing support to meet the needs of each person.

The 1960s also brought the movement toward normalization that led to deinstitutionalization. Many individuals with significant disabilities were moved from large institutions to smaller group living situations in the community and advances were made to understand and appreciate the sexuality of individuals with significant disabilities (Gordon, 1974).

The 1970s: An Era of Legislative Growth

The Family Planning Services and Population Research Act of 1970 (PL 91-572) was passed. Title X of this act authorized grants to establish voluntary family planning services, conduct research and provide information. Within this act, services for people with disabilities were not explicitly cited but efforts to include this population were made.

The Rehabilitation Act of 1973 (29 U.S.C. 701, et seq.) was passed and for the first time all individuals were entitled to equal access to all federally funded programs regardless of the nature or severity of their disability. 1973 also brought a heightened awareness to reproductive rights with the landmark Supreme Court decision (Roe v. Wade, 1973) that guaranteed a constitutional right to abortion. In this environment the reproductive rights of individuals with significant disabilities also were championed. However, as of 1973, 23 states still had laws permitting involuntary sterilizations and the courts repeatedly endorsed the involuntary sterilization of people with significant disabilities.

Although people with disabilities continued to face discrimination in the 1970s significant gains had been made to improve the quality of life and improve educational opportunities for young people. In 1975, Congress passed Public Law 94-142, the Education for All Handicapped Children Act (subsequently reauthorized and amended as the Individuals with Disabilities Education Act [IDEA], PL 101-476, 1990; PL 105-17, 1997) requiring that schools provide a "free and appropriate public education" for all children regardless of perceived ability. This legislation led to important gains in both the integration and education of children with significant disabilities. While advances in such legislation were noteworthy, the sexuality of individuals with significant disabilities was still far from being acknowledged or recognized. No policy recommendations for sexuality education were made and discrimination with regard to sexual freedoms was still rampant (Wolfe & Blanchett, 2000).

The 1980s: Sexuality Acknowledged, Abuse Measured

With the deinstitutionalization and normalization movements of the late 1960s and early 1970s the sexual rights of individuals with significant disabilities began to be recognized (Kempton & Kahn, 1991; McCabe, 1993). These movements provided an impetus for an increase of access to information by people with disabilities, but still work was needed. As people came out of the institutions and moved back into the community during the 1980s, it became clear that people with significant disabilities needed more training as they frequently were more susceptible to exploitation (Sobsey, 1994). Abuse data from 1988 to 1998 revealed that individuals with significant disabilities were more likely to be victimized than their non-disabled peers (Stiggall, 1988; Mitchell & Buchele-Ash, 2000; Lumley & Miltenberger, 1997; Sullivan & Knutson, 1998). It has been suggested that such individuals with significant disabilities are at least twice

as likely to be abused sexually and may be five or more times more likely to face all forms of abuse than the general population (Sobsey & Calder, 1999; Sobsey, 1994). Some suggest that abuse is not a question of "if," but "when" for most individuals with significant disabilities (Prada, personal communication, 2000).

Additionally, at this time, the 1984 amendments to the Developmental Disabilities Act [Developmental Disabilities Assistance and Bill of Rights Act of 1975, PL 98-527, 1984 Amendments, 42 U.S.C.] became law. The new amendments emphasized independence, productivity, and integration into the community. This act also specifically mandated the creation of state protection and advocacy systems designed to protect persons with developmental disabilities from discrimination and abuse (Mitchell & Buchele-Ash, 2000).

The 1990s: Equal Access

During the 1990s there was movement towards securing typical lifestyles for people with disabilities. Efforts in the disability movement since the 1970s to enact non discrimination laws bore considerable fruit in the 1990s and people with disabilities moved forward in attaining access to transportation and independent living services (Crow, 1991). Advocates fought for equal access in education with the inclusion movement of the 1980s. Deinstitutionalization offered opportunities for people with significant disabilities to live alongside their non-disabled peers in the community and be included in the communities in which they lived. In addition other legislation, such as supported employment which for the first time placed value in including individuals with significant disabilities in the community to work, was recognized and embraced (Certo, Pumpian, Fisher, Storey & Smalley, 1997). Also the passing of The Americans with Disabilities Act of 1990 (ADA), 42 U.S.C. 12101, et seq.) allowed many professionals and advocates to see positive growth in the disability rights arena. The most recent movement involves recognizing the struggle to free monies from its bureaucratic chains and allow individuals with developmental disabilities access to their funding in order to both identify and purchase the services they desire (Bradley, 2000). These battles to attain the quality of life outcomes that people with significant disabilities desire enabled many to begin to realize their hopes and dreams.

The Millennium and Beyond

At the turn of the century, many individuals with significant disabilities began to realize their dreams and have their rights recognized. During the past two decades the quality of life for individuals with significant disabilities has improved. As a result of groundbreaking litigation, disability rights legislation, advocacy on the part of persons with disabilities and their family members, people with disabilities can no longer be subjected to

institutionalization, involuntary sterilization, over medication, over restraint, aversive interventions, and denial of health and other care (Mitchell, et al., 2000). However, history continues to perpetuate misconceptions about sexuality and disability. Even though the right to sexual expression has been recognized by many, as evidenced by this statement by the National Information Center for Children and Youth with Disabilities:

American society is acknowledging that people with disabilities have the same rights as other citizens to contribute to and benefit from our society. This includes the right to education, employment, self-determination, and independence. We are also coming to recognize - albeit more slowly - that persons with disabilities have the right to experience and fulfill an important aspect of their individuality, namely, their sexuality (NICHCY, 1992, p. 1).

While the basic rights of all individuals to realize their full potential has been embraced, the policy and practical considerations have not been addressed. The isolation and segregation of the past have taken on new faces in inclusive settings and without formalized sexuality education and recognition of basic human rights these discriminatory practices will continue well into the 21st century for individuals with significant disabilities.

Beyond History: The Right to a Relationship in the United States

The mentally retarded person has a right...to such education, training, rehabilitation and guidance as will enable him [her] to develop his [her] ability and maximum potential. (United Nations Declaration on the Rights of the Mentally Retarded, 1983)

This statement recognizes the rights of individuals to attain their maximum potential. The process of moving toward this goal continues to have many benefits for people with significant disabilities and has led to increased opportunities for relationships (Reed, 1997).

Unfortunately, while the move to integrated settings has had some benefits, many remain socially isolated in inclusive settings (Sapon-Shevin, Dobbelaere, Corrigan, Goodman & Master, 1998; Meyer, 1991; Stainback & Stainback, 1990; Strully & Strully, 1996; Van der Kluft & Kunc, 1994). The isolation that individuals face has not been adequately impacted because of the lack of attention to sexuality education. The inherent conflict among educators, service providers and parents about what to teach, how to teach and when leaves many individuals without any formalized sexuality education. Many parents believe that information on sexuality will make their child more likely to engage in sexual

behaviors (Fegen, Rauch & McCarthy, 1993). Agencies that provide services to individuals rarely provide training to their staff on sexuality issues and rarely have someone on staff that is responsible for such education (Huntley & Benner, 1993). This lack of instruction and support has definite consequences for individuals with significant disabilities. Whether cloaked as protective practices or just ignored, the lack of appropriate information given to people with significant disabilities about their sexuality underscores the failings of existing legislation and policy to stop discriminatory practices.

This protection can have many forms and is intended to keep individuals with significant disabilities from being a risk to themselves or others. However, within these protective practices the intentional discrimination of the past can be found. While the sexual needs of people with even the most significant disabilities has been acknowledged (Reed, 1997; Mitchell & Buchele-Ash, 2000) the implementation of policies and support practices have been slow to develop. It seems that the level of disability one experiences can in some way dictate how much knowledge they will have available to them. Again the historical roots of discrimination can be found even today as an attempt is made to determine who is competent enough to have access to information about sexuality and the right to express themselves sexually.

Issues of Competence and Consent

The right to have sexual relationships, marry, bear children and other basic human sexual freedoms have been categorically denied to individuals with disabilities throughout history (Brief of Amici Historians and Scholars, 2001; Field & Sanchez, 2001). While efforts have been made to right the wrongs of the past, still little has been done to individually protect the rights of people across the country with regard to sexual freedoms that non-disabled people have. The right to a consensual relationship is a freedom that most people have, however if you have a disability label in the United States your ability to consent to a relationship with another person is questioned (Sundram & Stavis, 1994; Field & Sanchez, 2001; Stavis, 1991).

It could be argued that sexual expression for an individual with disabilities requires that each party is deemed competent and has the ability to consent to such expression before any activity can take place. Generally, there are three components that must be present to establish competency to provide legal consent: (a) knowledge of the important aspects of a decision and its risks and attendant benefits; (b) intelligence, reason or understanding which shows that the knowledge is comprehended and/or it is applied in a manner consistent with a person's values or beliefs; and (c) voluntariness, meaning that the person is not subjected to coercion and understands that there is a choice and he or she has the ability to say "yes" or "no" to it (Stavis, 1991).

There are two methods of determining capacity of an individual to make a decision. First, a clinician who is recognized by the courts, statute or professional training as qualified to do so can make a determination. Medical doctors also are generally recognized as qualified individuals that can make either "clinical determination" or "clinical competency" decisions (Stavis & Sundram, 1993). The second method of determination is judicial and is usually based on evidence and expert opinion (Stavis, 1991). The clinical method is more widely used due to both its lower cost and availability.

Establishing competence to provide legal capacity regardless of the method is an arduous task, one that most Americans do not have to encounter in order to have a sexual relationship. Inherent in consent determination measures is both an effort to protect and ensure reciprocity as individuals enter into a relationship. Ironically inherent in such determination decisions there is a presupposition that individuals with significant disabilities have had the access or right to the information or education that would allow them to be deemed competent in such situations. An effort must be made to balance the interests of all parties and allow for the voices of individuals with significant disabilities to be heard and validated (Field & Sanchez, 2001). The right to the information with regard to sexuality must be recognized and may be the only manner in which to ensure that individuals with significant disabilities will have the necessary tools to understand and conquer the arduous process of capacity determinations in our country (Reed, 1997).

The Right to Sexuality Education in the United States

Widespread acknowledgment that sexuality education continues to fail youths and society has been documented in the literature (Levesque, 2000; Moran, 2000; Elia, 2000; McKay, 1998; Sears, 1992). The continued conflict between content and morals has led to a generation of youth given only information to comprehend "abstinence only" sexuality education while rates of pregnancy, disease and abuse continue to rise. For individuals with significant disabilities the situation is far more complicated.

For all students, with and without disabilities, sexuality education remains highly controversial and value-laden (Wolfe, 1997; Elia, 2000). Most people think of sexuality education as providing information solely about physically how to have sex (McCabe, 1993; Elia, 2000; Gordon, 1974; NICHCY, 1992) as opposed to illustrating how to develop relationships, communication skills, values and identity. For the purpose of this paper, the definition as presented by the Sexuality Information and Education Council of the United States (SIECUS) will be used. It states:

Sexuality education is a lifelong process of acquiring information and forming attitudes, beliefs and values

about identity, relationships, and intimacy. It encompasses sexual development, reproductive health, interpersonal relationships, affection, intimacy, body image, and gender roles. Sexuality education addresses the biological, sociocultural, psychological, and spiritual dimensions of sexuality from the cognitive domain (information); the affective domain (feelings, values, and attitudes); and the behavioral domain (communication and decision-making skills). (SIECUS, 1996, p.3)

However, this definition is not widely known and the misunderstanding, as mentioned above, made by many families and educators is more common. Unfortunately, the current educational trend serves to restrict access to information about sexuality by youth which subsequently serves to increase the likelihood of abuse and sexually transmitted disease and it limits access to education about what constitutes a meaningful relationship (McCabe, 1999; Kempton & Kahn, 1991; Muccigrosso, 2000).

In the case of school-based education, this misunderstanding about sexuality education is of great significance to individuals with significant disabilities in particular as they may have even more limited access to sexuality education than their peers without disabilities. It is interesting to ask why social and sexual intimacy evades the lives of youth and young adults with significant disabilities when it plays such a central role in the lives of their peers without disabilities.

Research indicates that in the frequent absence of comprehensive school-based sexuality and relationship education, individuals without disabilities learn about sexuality from their families, their peers and the media (Ludwig, 2000). When a young adult with a significant disability seeks to gain information regarding sexuality, their peers may be able to provide little to no assistance. This is compounded by the fact that few individuals with significant disabilities have access to situations that provide opportunities to learn from typical social contexts due to isolation in special classes or schools that exclusively serve students with disabilities (Shuttleworth, 2000). In addition, even when sexuality education is offered in general education, many individuals with significant disabilities are denied access to these school programs (Sobsey & Calder, 1999).

Families of students with significant disabilities also tend to serve as points of restriction of sexuality education (Koller, 2000; Shuttleworth, 2000). It has been suggested that parents are the primary source of sexuality information for their children (SIECUS, 1999). However, for individuals with significant disabilities, information regarding sexuality may or may not be given which will increase both vulnerability to abuse and further their inability to understand their sexual needs and desires. Parents of children with significant

disabilities are confronted with many day-to-day challenges that may interfere with their ability to recognize the need to provide sexuality information to their disabled child (Mason, 1995).

This basic right to information and education is not given to individuals with significant disabilities in regard to sexuality (Reed, 1997; Muccigrosso, 2000). However, in the efforts to protect them (e.g. consent determinations) we ask that they have knowledge of information that was never made available to them. Levesque (2000) suggests that how schools prepare youths for responsible citizenship, including the manner in which youths treat others and themselves in their intimate relationships, is a fundamental starting point for a successful future and social participation. Mitchell et al., (2000) suggests that education systems continue to fail youth with disabilities by (a) providing sexuality education that is less than adequate for preparing a child with significant disabilities for adult life, (b) encouraging programs of isolation and separation, and (c) not including families as members of their child's educational programs. Should not individuals with disability labels have the right to an education that they will be held accountable for and will further their capacity to reach their maximum potential?

Moving Forward: Potential Remedies for Change

Needed a New Policy that Focuses on the Potential of All People to Engage in Meaningful, Reciprocal Relationships

The fundamental right to sexual expression for individuals with significant disabilities has been well documented in the literature (Muccigrosso 1991; Fegan, Rauch, & McCarthy, 1993; Kempton & Kahn, 1991; Wolfe & Blanchett, 2001; Ludwig, 2000; NICHCY, 1992; Gordon, 1974; Field & Sanchez, 2001). Experts also agree that individuals with significant disabilities have the right to relationships with people they choose to be with (Hingsburger & Schwier, 2000). Given these acknowledgements it seems archaic that our system still struggles with how to support both the access to information as well as the right to a relationship for individuals with disabilities. However, while an understanding of need may be present, methods of delivery and ongoing support remain the most critical aspects of policy development that need to be addressed.

Reed (1997) suggests that the reason for the lack of policy development is a result of the conflict between protection of people considered to be vulnerable and their rights to sexual expression. Given this, the conflict in the law poses many challenges to those who love and care for and about people with significant disabilities. The law must protect those who are most vulnerable and unable to give their consent while it continues to ensure that disabled persons be protected from harm (Reed, 1997). For some individuals the interest of their parents and guardians cannot be avoided because of the perception that the individual is vulnerable

with regard to relationships, privacy and sexual expression. However, these interests of parents and care providers should not nullify the interests and desires of their child to have fulfilling reciprocal relationships, the right to privacy and sexual expression (Ames, 1991).

What is needed is a policy that reflects the needs of all constituencies, one that balances the rights of individuals with disabilities and those who care for them. This balance would encompass recognition of the individual's freedom of sexual expression while still addressing the concerns, and at times competing interests, of care providers and family members. Inherent in such a policy would be the notion of "dignity of risk," allowing individuals the right to pursue relationships, while recognizing potential risks. When we balance appropriate ongoing supports and access to information the conflicting tension of rights and protection will shift and allow individuals with disabilities the dignity to make critical decisions that effect their lives.

Policy makers need to focus on the basic rights of individuals with significant disabilities and allow for these rights to play an integral role in the development of policies that will reflect the needs and desires of people with such disabilities. Legislation must take into account the fundamental need of all humans to express themselves sexually and their right to love and be loved. The historical perception that individuals with significant disabilities are not capable of feeling must be dispelled (Kempton & Kahn, 1991). Blanket legislation that mandates individual treatment of this constituency must be reflected in practices that mandate individualized assessments. Policies must reflect the values and desires of the people they ultimately benefit. No longer should clinical views of what is best for one be applied to all. Provisions in legislation and policy must call for the individual to be central to the decision-making that directly effects their life and relationships.

Needed: Policies that Enable the Accurate and Individualized Assessment of Competency and Consent for Individuals with Severe Disabilities to Explore Sexual Expression

Standards have been set by states that call for an assessment that measures the capacity of individuals with significant disabilities to engage in relationships and explore their sexual expression. This assessment can take many forms, rarely however do the rights of individuals play a role in these capacity decisions. States discriminate based on disability and rights to sexual expression are questioned. A disabled person must prove their competency before being allowed to engage in any sexual activity. If deemed competent by means of clinical tools, instruments and the like, then the person may engage in a sexual relationship. If found incompetent by such means as mentioned above, the person will not be allowed to be sexual with a person. The presumption of incompetence for individuals with significant disabilities must be lifted.

Again, legislation that calls for a standard form of assessment to be used will not meet the needs of individuals. Research suggests that it is unwise for legislation to declare those who function at a certain level of mental retardation to be categorically unable to consent to sexual relations (Abramson, et al., 1988). Assessment tools that are flexible and inclusive in their ability to determine the range of abilities a person with significant disabilities may have are necessary. Also the tool must allow for each person to establish the parameters of their relationship and have all the information available to understand reciprocity and consent. Reed (1997) suggests that assessment tools should make the following considerations before being adopted by the legislature: (a) the evaluation should only require the minimal levels of knowledge, intelligence and voluntariness be demonstrated in finding informed consent; (b) "consideration of how the general population's actual decision-making processes frequently fail to match ...[existing] legal standards" (Sundram & Stavis, 1994); (c) a person's ability to consent is not static and should be reevaluated over time; (d) standards must be in place to make evaluations based on specific situations, not universal determinations for all; (e) all assessment instruments used in determining the capacity of an individual to engage in sexual relations must be accompanied by systematic and comprehensive sexuality education.

Within these boundaries, legislators can attempt to formulate policy that reflects the needs and rights of individuals with disabilities and their right to sexual expression. Policies must reflect the potential of all human beings to reach their maximum potential and support strategies to that end. The historical discrimination of people with disabilities in this light once again illustrates that our society has held people with disabilities to a different standard. This standard has not prepared them to reach their maximum potential but rather set them up for a no win situation, one where they are accountable for information that was never made available to them. A comprehensive sexuality education will begin to right the wrongs of the past and give individuals access to information that will finally allow them to reach their maximum potential in public and private domains.

Needed: A Comprehensive Sexuality Education Program that Will Prepare Youth with Severe Disabilities for Informed and Successful Relationships

Sexuality education in the United States is plagued by debate and controversy (Elia, 2000). Many individuals with disabilities do not have access to such education regardless of legislation that calls for instruction that is based on individual student's needs taking into account the student's preferences and interests (IDEA, 1997). Such education should do much more than prepare youth with disabilities for sexual relationships with others. It allows for the information that

can lead to active and productive lives filled with relationships and opportunities for participation in both public and private domains.

The SIECUS Report (1999) outlines the four main objectives of a comprehensive school-based sexuality education program: information, values clarification, relationships, and responsibility. Thus, sexuality education will allow individuals meaningful relationships and the right to sexual expression if they choose rather than face the multiple layers of discrimination without the necessary tools and information. Sexuality education for individuals with significant disabilities is a daunting task, one worth the challenge. If nothing else, this education could begin to inherently change the perceptions of individuals with significant disabilities in the public eye and further the efforts of many to right the wrongs of the past.

Needed: A Fundamental Appreciation of the Spirit of Self-Determination

The final piece of needed policy addresses the need of individuals with disabilities to become stakeholders in the decisions and policies that directly affect their lives. The movement toward self-determination and its ability to increase the likelihood of quality of life outcomes has been well documented in the literature (Wehmeyer & Schwartz, 1998). These researchers found that self-determination was the essential element that predicted quality of life. With specific legislation in place that ensures the right of individuals to have a voice with regard to decisions about their lives (Developmental Disabilities Assistance and Bill of Rights Act of 1975, PL 98-527, 1984; IDEA) and the self-determination movement, it is likely that people with disabilities may finally be heard with regard to their human sexuality needs. Policy must be developed that can inform service providers, families and educators how to better create environments where self-determination can be fostered and embraced.

Summary

The history of legislation, policy and practice regarding the sexuality of people with severe disabilities has been one of great challenges. The fact that the vast majority of persons with significant disabilities still remain isolated from relationships and are deemed incompetent to explore their basic human rights is a national issue that cannot be ignored. The government has both made great strides toward and added to the barriers that prevent people with significant disabilities having relationships with others. Continuing issues include: the lack of access to sexuality education; the need for ongoing intensive support; the systems requirement for competence and consent; minimal support for the individual's interest in sexual expression; and the interests of parents and society to protect people with disabilities from their

fundamental right to sexual expression.

Suggestions for addressing these issues include: instituting policy that undeniably supports sexuality education for all people with disabilities regardless of severity; providing opportunities for learning and support in real life settings; placing limits on the states ability to determine someone's ability to explore their sexual expression; and continuing support of individuals as they embark on relationships with others. Additionally, and most importantly, the national misperception that people with disabilities are not capable of feeling or loving must be clearly dispelled by policies and practice so that progress toward ending the discrimination and isolation of individuals with severe disabilities can be made.

Over the 30 year history of the disability rights movement laws have become more inclusive and many individuals have realized access to basic human rights and relationships that had been historically denied to them in both their public and private lives. In this struggle individual's with significant disabilities still face competing interests between themselves and those who "care" for them. Revising the law on capacity and providing sexuality education will allow for a dialogue that has been missing in the debate. If basic rights of all people are to be considered the evaluations of courts, legislature, caregivers and parents must be heard in light of the desires, hopes and dreams of the individual with significant disabilities. As Charlton (1998) says, "nothing about us without us." Our nation must serve individuals first and protect them second and not until then will people with significant disabilities realize or have access to their maximum potential.

References

Abramson, P., Parker, T. & Weisberg, S. (1988). Sexual expression of the mentally retarded people: Educational and legal implications. *American Journal on Mental Retardation*, 328.

Americans with Disabilities Act of 1990; PL 101-336, 42 U.S.C, 12101.

Ames, T.R. (1991). Guidelines for providing sexuality-related services to severely and profoundly retarded individuals: The challenge for the nineteen-nineties. *Sexuality and Disability*, 9, 113.

Bradley, V. (2000). Changes in services and supports for people with developmental disabilities: New challenges to established practice. *Health & Social Work*, 25, (3), 191-200.

Buck v. Bell, 274 U.S. 200 (1927).

Brief of Amici Historians and Scholars at 1, 15-19, Bd. of Trustees of the Univ. of Ala. v. Garrett, 531 U.S. 356 (2001).

Certo, N., Pumpian, I., Fisher, D., Storey, K. & Smalley,

K. (1997). Focusing on the point of transition: A service integration model. *Education and Treatment of Children*, 20, (1), 68-84.

Charlton, J.I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.

Crow, L. (1991). *Rippling raspberries: Disabled women and sexuality*, unpublished MSc dissertation, South Bank Polytechnic.

Developmental Disabilities Assistance and Bill of Rights Act of 1975, PL 98-527, 1984 Amendments, 42 U.S.C.

Education for All Handicapped Children Act of 1975, PL 94-142, 20 U.S.C. 1400 et seq.

Elia, J. (2000). The necessity of comprehensive sexuality education in the schools. *The Educational Forum*, 64, (4), Summer, 340-347.

Family Planning Services and Population Act of 1970, PL 91-572.

Fegen, L., Rauch, A. & McCarthy, W. (1993). *Sexuality and people with intellectual disability*. Baltimore: Paul H. Brookes Publishing.

Field, M.A. & Sanchez, V.A. (2001). *Equal treatment for people with mental retardation: Having and raising children*. Cambridge: Harvard University Press.

Gordon, S. (1974). *Sexual rights for the people...Who happen to be handicapped*. Syracuse: Center on Human Policy, Syracuse University.

Hingsburger, D. (1991). *I witness: History and a person with a developmental disability*. Mountville, PA: Vida Publishing.

Hingsburger, D. & Melberg-Schwier, K. (2000). *Sexuality. Your sons and daughters with intellectual disabilities*. Baltimore: Paul Brookes Publishing.

Huntley, C. & Benner, S. (1993). Reducing barriers to sex education for adults with mental retardation. *Mental Retardation*, 31, 377-381.

Individuals with Disabilities Education Act (IDEA) Amendments of 1990, PL 101-476, 20 U.S.C. 1400 et seq.

Individuals with Disabilities Education Act (IDEA) Amendments of 1997, PL 105-17, 20 U.S.C. 1400 et seq.

Kempton, W. & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability*, 9(2), 93-110.

Koller, R. (2000). Sexuality and adolescents with autism. *Sexuality and Disability*, 18 (2), 125-135.

Levesque, R. (2000). Sexuality education. *Psychology, Public Policy, and Law*, December.

Ludwig, S. (2000). *On sexuality and developmental disabilities*, available on line: <www.sexual/health.com/susan_ludwig.htm>.

Lumley, V. & Miltenberger, R. (1887). Sexual abuse prevention for persons with mental retardation. *American*

Journal on Mental Retardation, 101, (5), 459-472.

Mason, M. (1995). The breaking of relationships. *Present Time*, January, 3-8.

McCabe, M.P. (1993). Sex education programs for people with mental retardation. *Mental Retardation*, 31, (6), 377-387.

McKay, A. (1998). *Sexual ideology and schooling: Towards democratic sexuality education*. Albany: State University of New York Press.

Melberg-Schwier, K. (1994). *Couples with intellectual disabilities talk about living and loving*. Rockville, MD: Woodbine House.

Meyer, L. (1991). Advocacy, research, and typical practices: A call for the reduction of discrepancies between what is and what ought to be and how to get there. In L.H. Meyer, C.A. Peck, & L. Brown (Eds.), *Critical issues in the lives of people with severe disabilities* (pp. 629-649). Baltimore: Paul H. Brookes Publishing Co.

Mitchell, L. & Buchele-Ash, A. (2000). Abuse and neglect of individuals with disabilities: Building protective supports through public policy. *Journal of Disability Policy Studies*, 10, (2), 225-243.

Moran, J.P. (2000). *Teaching sex: The shaping of adolescence in the 20th century*. Cambridge: Harvard University Press.

Muccigrosso, L. . (2000). Personal communication.

National Information Center for Children with Disabilities (NICHCY). Sexuality education for children and youth with disabilities. *NICHCY News Digest*, 17, 1992. Available at <www.nichcy.org>.

Nolley, D. (2001). Personal communication.

Prada, V. (2000). Personal communication.

Reed, V. (1997). Criminal law and the capacity of mentally retarded persons to consent to sexual activity. *Virginia Law Review*, 83, 799.

Roe v. Wade, 410 U.S. 113 (1973).

Sapon-Shevin, M., Dobbelaere, A., Corrigan, C., Goodman, K., & Mastin, M. (1998). Promoting inclusive behavior in inclusive classrooms: "You can't say we can't play." In L.H. Meyer, H.S. Park, M. Grenot-Scheyer, I. Schwartz & B. Harry (Eds.), *Making Friends: The influences of culture and development*, (pp. 105-132). Baltimore: Paul H. Brookes Publishing.

Sears, J.T. (1992). *Sexuality and the curriculum: The politics and practices of sexuality education*. New York: Teachers College Press.

Shakespeare, T., Gillespie-Sell, K., & Davies D. (1996). *The sexual politics of disability: Untold stories*. London: Cassell.

Shuttleworth, R. (2000). The search for sexual intimacy for men with cerebral palsy. *Sexuality and Disability*, 18, (4), 263-282.

SIECUS. (1996). *National guidelines task force*.

Guidelines for comprehensive sexuality education: Kindergarten-12th grade. New York: Sexuality Information and Education Council of the United States.

SIECUS. (1999). *Issues and answers fact sheet on sexuality education.* New York: Sexuality Information and Education Council of the United States, August/September, 29-33.

Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* Baltimore: Paul H. Brookes Publishing Co.

Sobsey, D. & Calder, P. (1999). *Violence against people with disabilities: A conceptual analysis.* Presented at the U.S. National Research Council's Committee on Law and Justice Meeting, Irvine, CA.

Stainback, W. & Stainback, S. (1990). Facilitating peer supports and friendships. In W. Stainback & S. Stainback (Eds.), *Support networks for inclusive schooling: Interdependent integrated education* (pp. 51-63). Baltimore: Paul H. Brookes Publishing.

Stavis, P. (1991). Harmonizing the right to sexual expression and the right to protection from harm for persons with mental disability. *Sexuality and Disability*, 9, 131-137.

Stavis, P., & Sundram, J. (1993). Sexual behavior and mental retardation. *Mental and Physical Disability Law Reporter*, 17, July/August, 448.

Stiggall, L. (1988). AIDS education for individuals with developmental, learning or mental disabilities. In M. Quackenbush & M. Nelson (Eds.), *The AIDS challenge: Prevention education for young people* (pp.405-418). Santa Cruz: Network Publications.

Strully, J., & Strully, C. (1996). Friendships as an educational goal: What we have learned and where we are headed. In S. Stainback & W. Stainback (Eds.), *Inclusion: A guide for educators* (pp. 141-154). Baltimore: Paul H. Brookes Publishing.

Sullivan, P. & Knutson, J. (1998). Maltreatment and behavioral characteristics deaf and hard-of-hearing youth. *Sexuality and Disability*, 16, 295-319.

Sundram, C.J. & Stavis, P.F. (1994). Sexuality and mental retardation: Unmet challenges. *Mental Retardation*, 32, 255-258.

United Nations. (1983). *Human Rights: A compilation of international instruments.* New York: United Nations.

Van der Klift, E., & Kunc, N. (1994). Beyond benevolence: Friendship and the politics of help. In J.S. Thousand, R.A. Villa, & A.I. Nevin (Eds.), *Creativity and collaborative learning: A practical guide to empowering students and teachers* (pp. 391-401). Baltimore: Paul H. Brookes Publishing.

Wehmeyer, M.L. & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 38, (1).

Wolfe, P. (1997). The influence of personal values on issues of sexuality and disability. *Sexuality and Disability*, 15, (2), 69-89.

Wolfe, P. & Blanchett, W. (2000). Moving beyond denial, suppression and fear to embracing the sexuality of people with disabilities. *TASH Newsletter*, 26, (5), 5-7.

Wolfe, P. & Blanchett, W. (2001). *Preparing students with significant disabilities for healthy sexual lives*. Paper presented at the annual meeting of TASH, Anaheim, CA.