Sexuality and related social skills training: Meeting the challenge for adults with developmental disabilities

Caroline Mary Adkison

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SEXUALITY AND RELATED SOCIAL SKILLS TRAINING: MEETING THE CHALLENGE FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Rehabilitation Counseling

by
Caroline Mary Adkison

September 1997
SEXUALITY AND RELATED SOCIAL SKILLS TRAINING: MEETING THE CHALLENGE FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

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September 1997

Approved by:

Dr. Joseph Turpin, First Reader 9/9/97

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ABSTRACT

Historically, people with developmental disabilities were denied the right to live in and integrate with the society of individuals without disabilities. Landmark legislation and a societal shift over the past two decades, however, have made it possible for people with developmental disabilities to live and work in the communities in which they live. This has increased opportunities for persons with developmental challenges to establish social and interpersonal relationships. However, the risks for abuse and health hazards have increased for this population as well. A survey of 38 adult day and supported work programs in a two-county area of Southern California assessed the current status of sexuality and related social skills training offered to adults with developmental disabilities participating in pre-vocational and work programs. Results indicated a lack of sexuality or related social skills training as part of regular programming for adults with developmental disabilities. Future research on sexuality and related social skills for individuals with developmental disabilities is discussed. A resource list of
available training materials on sexuality education for persons with developmental disabilities is included in the appendix.
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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>iii</td>
</tr>
<tr>
<td>ACKNOWLEDGMENTS</td>
<td>v</td>
</tr>
<tr>
<td>CHAPTER ONE: INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>LITERATURE REVIEW</td>
<td>4</td>
</tr>
<tr>
<td>Historical Background</td>
<td>4</td>
</tr>
<tr>
<td>Disability Legislation</td>
<td>7</td>
</tr>
<tr>
<td>Implications of Inclusion</td>
<td>9</td>
</tr>
<tr>
<td>CHAPTER TWO: METHOD</td>
<td>21</td>
</tr>
<tr>
<td>Sample</td>
<td>21</td>
</tr>
<tr>
<td>Instrument and Procedure</td>
<td>22</td>
</tr>
<tr>
<td>CHAPTER THREE: RESULTS</td>
<td>24</td>
</tr>
<tr>
<td>CHAPTER FOUR: DISCUSSION</td>
<td>26</td>
</tr>
<tr>
<td>CHAPTER FIVE: CONCLUSION</td>
<td>35</td>
</tr>
<tr>
<td>APPENDIX A: Resource List</td>
<td>37</td>
</tr>
<tr>
<td>APPENDIX B: Samples</td>
<td>45</td>
</tr>
<tr>
<td>APPENDIX C: Sample Participants</td>
<td>47</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>50</td>
</tr>
</tbody>
</table>
CHAPTER ONE: INTRODUCTION

In American society there are a multitude of social reforms, one of which is the emerging civil rights of people with disabilities. Since the early 1970's, concepts such as normalization have increasing made it possible for people with developmental disabilities to live in and interact in the community along side those individuals without disabilities (Mesibov, 1990). In our current decade, landmark legislation such as the 1990 Americans With Disabilities Act and the Rehabilitation Act Amendments of 1992, have promoted new political movements and social attitudes towards people with developmental disabilities (e.g., mental retardation, cerebral palsy, epilepsy, and autism). Such notable acts resulted in improvement in equality, integration, and inclusion, in school, community and employment settings (Schroner, 1992). Will's study, reported by Morgan, Salzberg, Moore, and McSweyn (1995), revealed that a quarter of a million individuals, each year, with developmental disabilities, between 16-22 years of age, transition from school settings into vocational training and employment programs. Although rehabilitation
professionals are increasingly turning their attention to vocational training and employment programs for individuals with developmental disabilities, there are many areas of vocational and employment programming that have not received adequate attention (Hingsburger & Pendler, 1990; Muccigrosso, 1991). One such area is sexuality and related social skills training. A focus on sexuality and related social skills training for adults with developmental disabilities is salient to the study of vocational and employment programs in general, and individuals with developmental disabilities in particular. This is an imperative training component in light of the societal issues which must be dealt with concerning sexual abuse and exploitation, HIV and other sexually transmitted diseases, pregnancy, and contraception, both within and outside the workplace. For example, people with developmental disabilities have been identified as a high-risk population for sexual abuse and exploitation (Muccigrosso, 1991; Sobsey & Mansell; 1990; Tharinger, Burrows-Horton, & Millea, 1990). It has been suggested that lingering societal myths about disability and the sexuality of
individuals with disabilities, may have prevented people with disabilities from receiving sexuality instruction. It has been further suggested that our society is reluctant to confront sexuality issues in general (Mesibov, 1984).

Accordingly, this paper examines the current status of sexuality and related social skills training programs for individuals with developmental disabilities who are participating in work activity and supported employment programs. Myths and misconceptions regarding disability related to sexuality will be identified. Current legislation and rights of people with developmental disabilities related to sexuality issues will be discussed. Implications of full integration into the community, such as increased social experiences, added risks, and inappropriate sexual behaviors will be addressed. A resource list featuring a selection of available books and training materials for developing sexuality and related social skills training for persons with developmental disabilities is included in Appendix A.
Literature Review

Historical Background

According to Buscaglia (1994), negative connotations of disability and deviance were firmly in place as early as 384 B.C. and continue to have a strong and deep-rooted tradition in our society. Moreover, researchers have identified the existence of prejudice toward and segregation of people with physical and mental disabilities in virtually every part of the world. There are several myths about sexuality and people with developmental challenges (Hingsburger, 1987; Kaeser, 1992; Sobsey & Mansell, 1990). The term myth is defined as a false belief (American Heritage Dictionary, 1988), unsubstantiated story (Random House Thesaurus, 1984), or a recurring theme which represents the world view of a culture (Campbell, 1988). One such disability myth is related to the causation of disability, a myth which may have been propagated by the human need to explain inexplicable phenomena such as physical and mental disability (Buscaglia, 1994). A second myth is related to the idea that people with disabilities are not sexual (Muccigrosso, 1991) or should not be sexual
(Hingsburger, 1987). Each will be discussed in turn.

**Myth number one: Disability as Punishment.**

This myth is based on cultural superstition about and attitudes toward persons with mental and physical disabilities. Historically, any type of unexplained physical or mental deviance was considered to be the result of supernatural forces. The ancient Greek culture, for example, considered disability or disfigurement to be the work of evil spirits. Persons with crippling conditions or mental deficiencies were often killed, and defective infants were put out in the wilderness to die in early Greek societies. The ancient Hebrews believed disability was a punishment from God, often for the transgressions of the parents of a person with a disability (Buscaglia, 1994). In the middle ages, people with physical and mental abnormalities were seen as possessed by the devil and were sometimes burned at the stake. Individuals with developmental disabilities, in particular, were considered to be idiots or imbeciles. Persons with cognitive disabilities were generally social rejects and in many instances were hidden away by their families, locked up in
asylums or institutions, and even killed, because they were thought to be dangerous, mentally ill, or sub-human (Buscaglia, 1994; Sobsey & Mansell, 1990; Association for Retarded Citizens [Arc], 1980).

**Myth number two:** Persons with disabilities are not sexual.

The second myth revolves around the issue of sexuality and disability. This myth is based on cultural standards and expectations about the sexual needs or behaviors of persons with disabilities and the perceived consequences of sexual activity in this population. Specifically, the myth mandates that persons with developmental delays are limited in sexual capacity because of their physical or mental limitations (Buscaglia, 1994), or they are non-sexual (Muccigrosso, 1991). Further, this was the approved of or the expected state for individuals with developmental disabilities (Hingsburger, 1987). The general society was often uncomfortable with the normal sexual desires and impulses of people with disabilities (Buscaglia, 1994), and little recognition was given to the subject of sex where adults with developmental challenges were involved (Ayrault, 1971). As recently as two decades ago, the
concept of providing counseling or sex education to people with developmental disabilities was considered dangerous (Hingsburger, 1991), because of the fear that people with developmental delays were oversexed (Kaeser, 1992), or because sexual knowledge was thought to increase undesirable sexual behaviors in people with disabilities (Buscaglia, 1994; Hingsburger, 1988; Mesibov, 1986). People with developmental delays were deprived of their reproductive rights and often were not permitted to marry because of the belief system that people with developmental disabilities were more likely to have a child with a disability (Buscaglia, 1994; Hingsburger, 1988; Kaeser, 1992)).

Disability Legislation

The end of the 19th Century brought about a shift of public attitudes about disability, resulting in a more enlightened approach to providing services for persons with developmental and other disabilities. In the 1950s, special educational opportunities were established for all students with disabilities under the Individuals with Disabilities Education Act (IDEA). The 1965, 1967, and 1968 Vocational
Rehabilitation Act Amendments further improved and expanded services to people with physical and mental handicaps. Over the past two decades, decisive state and federal legislation has enabled people with developmental and other disabilities to take their lawful place as equal members in society (Sexuality Information and Education Council of the United States {SIECUS}, 1995). Under California’s Welfare and Institutions Code, 4502 (j), the rights of people with developmental disabilities are specifically recognized in that they have all of the same rights and responsibilities guaranteed to all Americans by our Constitution and the laws of the State of California. In addition, under the Lanterman Act, people with developmental disabilities share the same rights to privacy and sexual expression as persons without disabilities. Further, sexual relationships mutually consented to by adults are protected by governmental guarantees of privacy, which includes the right to make decisions about birth control and reproduction. In addition, under Lanterman persons with developmental disabilities have: a right to make choices in their own lives, including, but not limited to, where and with whom they
live, their relationships with people in their community, the way they spend their time, including education, employment, and leisure, the pursuit of their personal future, and program planning and implementation.

According to Schriner (1996), the 1992 Rehabilitation Act Amendments, in particular, made disability legislation more congruent with the civil rights legislation originally addressed by the Americans With Disabilities Act. This contributed to increased opportunity for persons with developmental disabilities to make autonomous decisions about where and with whom to live, and made training and employment opportunities a reality for people with developmental disabilities (Harper, 1996).

As a direct result of the movement toward integration and inclusion, vocational training programs and supported employment agencies have begun to serve a large number of individuals with developmental challenges. The implications of this trend will be discussed more fully in the following section.

Implications of Inclusion

The trend towards full community inclusion has given people with developmental disabilities new experiences,
more risks, and increased opportunities to make choices (Arc, 1990), to socialize, date, and even marry (Buscaglia, 1994). Over the past few decades, American society has been confronted with an alarming array of statistics that document the many risks related to interpersonal relationships and sexuality, that people in our society, including those with developmental disabilities face. Those risk include, sexual abuse and exploitation, HIV/AIDS and other sexually transmitted diseases (STDs), as well as unplanned pregnancy.

The most alarming statistics are related to sexual abuse and exploitation of individuals with developmental disabilities. Sexual abuse can be defined as unwanted touch, visual or verbal aggression perceived as unwanted sexual activity, and/or nonconsensual intercourse including penetration. Sexual abuse involving people with disabilities usually occurs in the form of exploitation of someone who lacks knowledge of or the means to recognize a potential abusive situation and/or make a conscious choice not to engage willingly (Cole, 1986). Children and adults with developmental delays represent a disproportionate
number of the total reported sexual abuse victims (Muccigrosso, 1991), and they are often the targets of violence, perversion and assault (Tharinger, Burroughs-Horton, & Millea, 1990). Persons with developmental disabilities are more at risk for sexual abuse than people without disabilities and it is estimated that sexual abuse in this population is four times as high as in the population of non-disabled individuals (Muccigrosso, 1991; Sobsey and Mansell, 1990; Tharinger, Burroughs-Horton, & Millea, 1990). An alarming study on sexual abuse by Finklehor (1984), revealed that up to 25 percent of all female children and adolescents with developmental disabilities, one out of eleven male children with developmental disabilities, and as high as 90-99 percent of people with developmental disabilities over age 18 are victims of sexual abuse. Furthermore, it has been discussed that when people with developmental disabilities are sexually abused or exploited, it is usually by a family member, care provider, or other acquaintance (Muccigrosso, 1991), and abuse is commonly repeated and chronic (Sobsey & Doe, 1991). Educating people with developmental delays
about how to protect themselves from being sexually abused or exploited is viewed by Muccigrosso, (1991), Sobsey and Mansell (1990), and other researchers, as a viable tool that should be used in the fight against sexual abuse and exploitation.

The seriousness of sexual abuse is exacerbated by the risk of contracting the HIV virus, AIDS, or other STDs. Thus, any individual who has been sexually active whether consentually or non-consentually, must be informed of such risks (Hingsburger, 1994; Kaeser, 1992; Muccigrosso, 1991), as the HIV virus and AIDS are at epidemic proportions in this country (National Center for Health Statistics, 1985). Thus, sexuality education should be a central component of programs designed to reduce the prevalence of sexually-related medical problems.

The need for sexuality instruction and training in related social skills for people with developmental disabilities has been documented for more than a decade of study (Graff, 1983). According to SIECUS, there is a need for:

greater access to information and educational material that affirms the sexuality of people of all
abilities including those with early-and late-onset disabilities; physical, sensory, and mental disabilities; and disabilities that hinder learning.

It has been discussed by Hingsburger and Moore (1991), Muccigrosso (1991), and others, that many adults with developmental disabilities are participating in employment programs completely ignorant of what kind of social and/or sexual behavior is expected of them or what constitutes responsible sexual behavior (Hingsburger, 1987). Statistics indicate that a deficit in social skills is one of the leading factors in increasing the percentages of sexual abuse and exploitation (Muccigrosso, 1991) as well as serious health hazards or unwanted pregnancy for people with developmental disabilities (Buscaglia, 1994). Although debates thus far have failed to resolve questions regarding who should become responsible for informing people with developmental disabilities about appropriate social and sexual behaviors, as more and more persons with developmental disabilities become involved in community-based work, there are increased risks for abuse and exposure to the sexual misbehaviors of others in the workplace. The challenge of providing information and
instruction on sexuality and appropriate social interaction may thus lie with employment services providers, to ensure that desirable and appropriate social interaction is increased (Hingsburger, 1989).

Over the years there has been considerable discussion about social skills training for individuals in the population with developmental disabilities. Psychological tests indicate that persons with developmental disabilities are often weak in reasoning and judgement. Society is not realistic when it expects individuals with developmental disabilities to display socially appropriate behaviors if they have had little training or instruction (Ayrault, 1971). Castles and Glass, in their 1986 study of social and problem-solving skills, found that social skills training and interpersonal problem-solving skills training improves social competencies in people with developmental disabilities. Social skills training has also been found to be effective in helping individuals with developmental disabilities with adjustment problems and self-confidence building (Mellard & Hazel, 1992), and vocational success is more likely for people with developmental disabilities when
emotional and behavioral problems have been addressed (Etu, Thompson, and Strohmer, 1993). Knowing how to express affection appropriately, indicate preferences, and make choices, are important social skills (Foxx, Faw, Taylor, Davis, & Fulria, 1993), and are skills that can be taught to people with developmental challenges (Castles & Glass, 1986; Muccigrosso, 1991). Social skills and the ability to problem-solve empowers individuals with developmental disabilities to make appropriate decisions or act in a pro-active manner in social situations which may put them at risk (Castles & Glass, 1986).

As previously discussed in regards to social skills training, people with developmental disabilities who participate in sheltered and supported work programs are also dependent on the agency personnel who run the programs to ensure they are informed of appropriate sexual behaviors (Hingsburger & Moore, 1991). As persons with developmental challenges become adolescents and adults, and work services providers learn more about the social problems of this population, concerns about sexuality become unavoidable (Mesibov, 1984).
Sexuality issues include physical, ethical, social, spiritual-psychological, and emotional dimensions (SIECUS, 1996). Professionals providing services to persons with developmental disabilities and the parents of individuals in this population, must realize that all persons are sexual (SIECUS, 1996), the sex drive is basic in all human beings (Ayrault, 1971), and sexuality is a natural and healthy part of living (Buscaglia, 1994). Sexuality education ideally, strives to help people understand a positive view of sexuality, provide information and skill to take care of sexual health, and acquire decision making skills. Comprehensive sexuality education appropriate to an individual’s age and developmental level should ideally be an important part of the education of every individual, and should respect the diversity of values and beliefs of families and cultures (Arc, 1995; SIECUS, 1996). According to Hingsburger (1989), people with developmental disabilities often live in environments bereft of peers and have had little exposure to and experience with interpersonal relationships. Thus, one of the objectives of providing relationship training to persons with
developmental disabilities who have entered the workplace, is to teach the differences between types of relationships, such as friendship, love, sexual love, and staff/working relationships, according to Hingsburger.

Dealing with the sexual misbehaviors of clients with developmental disabilities is a critical issue encountered by service providers (Kaeser, 1994), and must be addressed by employment professionals (Hingsburger 1987). According to Hingsburger the major problem areas when working with inappropriate sexual behaviors in the workplace are, confused self-concept, isolation from peers, lack of sexual knowledge, lack of personal power, and/or a history of negative or furtive sexual experiences. For sexuality training to be effective, these problems must first be addressed by the trainer or counselor, according to Hingsburger. Demetral (1993), in his study on assessing counterfeit deviance in persons with developmental disabilities, stated that it is critical that professionals working with individuals with developmental disabilities be aware of the danger of diagnosing sexual misbehavior as deviance. An inappropriate sexual behavior or incident may
be related to lack of information, poor social skills, or a history of being a sexual victim, according to Demetral.

A number of researchers have focused on factors which may contribute to the increased percentages for sexual abuse and serious hazards to health and well-being in the population of people with developmental disabilities. For example, persons with developmental challenges are generally uninformed about their own sexuality and are naive about what constitutes risky sexual behavior (e.g., unprotected sexual intercourse); they have in many cases been excluded from sex education programs in school; and parents of sons and daughters with developmental challenges are often uncomfortable about discussing sexuality with their adult children who have disabilities (Ayrault, 1971; Buscaglia, 1994; Muccigrosso, 1991). Moreover, persons with disabilities are often sheltered by family or care providers; in many cases have lived in restrictive social environments, are dependent on others for decision making, are more trusting of others, and have been taught to be compliant and passive (Hingsburger & Griffiths, 1986). Further, individuals with developmental delays often lack
cognitive and communication skills, may be confused about appropriate physical (or sexual) contact (Muccigrosso, 1991), may be frightened to report abuse or sexual activity for fear of reprisal from family or trainers, or may not know who to go to in regards to questions about sex or for advice when it is needed (Hingsburger, 1989).

The information discussed in the above sections highlight the importance of developing training and educational programs addressing sexuality and related social issues, as well as the need to give people with developmental disabilities information on all aspects of life, including those aspects non-disabled adults expect, such as an intimate relationships (Kaeser, 1992). Moreover, it has been clearly shown that people with developmental disabilities have the right to be informed about their own sexuality (Buscaglia, 1994), to be educated about pregnancy, contraception, and serious health hazards, and it is crucial that persons with developmental disabilities be cautioned against sexual abuse and exploitation (Muccigrosso, 1991). This study surveyed Program Directors and Managers of sheltered and supported work programs.
specifically designed to provide either pre-vocational training or on-the-job training for adults with developmental disabilities, to assess the current status of sexuality and related social skills training in these programs.
CHAPTER TWO: METHOD

Sample

In April of 1997, a list of all programs accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) in a two-county regional area of Southern California were identified from the CARF directory. These programs were accredited by CARF to provide work adjustment, work services, or supported employment to consumers with developmental disabilities, funded by the California State Department of Rehabilitation/Habilitation Services. A second list of all pre-vocational and vocational training programs funded by a private, State of California vendored-agency in the same two-county area were identified from a resource directory provided by one of the pre-vocational programs within the survey area. Seventy-three adult day programs were identified in all. Ten of the programs had multiple locations within the two county area, thus, were counted as only one program. Those programs which offered more than one type of programming (i.e., both a supported work program and a vocational training program), were counted one time for each program. Thirty-
eight different programs were thus identified from the list of seventy-three adult day programs, which included twenty adult developmental centers, eleven work activity/workshop programs, and seven supported work programs (See Appendix C). Adult developmental centers were those programs providing pre-vocational and socialization programming for persons not yet ready for work activity centers (work shops). Work activity/workshop programs were those programs providing on-the-job vocational training in a sheltered setting. Supported employment programs, were those programs providing on-the-job training for individual workers at various job sites within the community. The Program Directors and/or Managers of the participating employment programs provided the data for this study.

Instrument and Procedure

On 15, April 1997, a cover letter and questionnaire, reduced in size and printed on one side of an over-sized, pre-addressed, postage-paid postcard, were sent to the Program Directors/Managers of each work program in the sample. The cover letter explained that the purpose of the study was to assess the extent to which sexuality and
social skills training is provided to adults with developmental disabilities in sheltered and supported work programs and if such training was offered, whether it was provided by agency staff or from an outside source. (See Appendix B.) The Program Directors or Managers were asked to complete the questionnaire which asked what percentage of consumers they perceived could benefit from sexuality and social skills training and whether their program offered formalized training. To further examine the available sexuality and social skills training provided to adults with developmental disabilities, those respondents indicating that sexuality education was included as part of regular programming were requested to indicate if training was provided by regular staff or by an outside agency. (See Appendix B). Respondents were asked to circle the appropriate response and/or write in the necessary information and return the postcard to the investigator. Six weeks after the initial mailing, the researcher made a follow-up phone call to those programs who had not responded to the mailing. The responses were numbered to assist with tracking responses.
CHAPTER THREE: RESULTS

Twenty-four questionnaires were returned to the researcher via U.S. Mail, resulting in a 63 percent (63%) return rate. The remaining fourteen programs (37%) were contacted via telephone. Twenty (53%) of the total responses were from adult developmental centers. The twenty adult developmental centers participating in this survey served 2,354 clients. Eleven (29%) of the responses were from sheltered work programs. The eleven work activity programs participating in this survey served 862 clients. Seven (18%) of the responses were from supported employment programs. The seven supported employment programs participating in this survey served 616 clients. The total number of clients served in the 38 programs participating in the survey was 3,832.

Program directors and managers from the surveyed programs indicated on an average, that they perceived 55 percent (55%) of the consumers in adult day programing would benefit from sexuality and social skills training. Only one adult developmental center currently serving 33 clients indicated that sexuality and social skills training
was a service offered as part of regular day programming, and that service was provided to the one client in the program who had requested such a service. The remaining programs (nineteen adult developmental programs serving the remaining 2,353 ADC clients, eleven sheltered programs serving 862 WAC clients, and seven supported programs serving 616 SE clients), indicated they did not cover the areas of sexuality and related social skills training as part of regular work services programming for their participants with developmental disabilities.

**Sexuality Training in Adult Day Programs**

<table>
<thead>
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<th>No</th>
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<td></td>
</tr>
<tr>
<td>SE</td>
<td>0</td>
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</tr>
<tr>
<td>WAC</td>
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<td>Served</td>
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<tr>
<td>ADC</td>
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<td>2353</td>
</tr>
<tr>
<td>Total:</td>
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<td>3831</td>
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</table>

The respondent who indicated that programming covered sex education was asked to provide more specific information by responding to two additional questions (Refer to items 2A and 2B in appendix B). That respondent indicated sexuality and social skills instruction was provided by regular program staff.
CHAPTER FOUR: DISCUSSION

The integration of the physical, emotional, social and intellectual aspects of being in ways that are positively enriching, and that enhance personality, communication, and love...every person has a right to receive sexual information and to consider accepting sexual relationships for pleasure as well as for procreation.

SIECUS, 1996

This study assessed the current status of sexuality and related social skills training in adult developmental centers, work activity, and supported employment programs for persons with developmental disabilities in a large two-county area of Southern California. Results indicate that out of thirty-eight different programs currently serving 3,832 clients with developmental disabilities, only one adult developmental center is currently providing sexuality and social skills training as part of regular programming. Thirty-seven programs participating in the survey indicated that no training is currently being offered to workers with developmental disabilities participating in their programs. The Program Director of the developmental center which indicated the presence of sexuality training discussed via a telephone conversation with the researcher that
instruction on sexuality and related social skills is provided to one client out of thirty-two clients, purely due to the request of one client in their program.

A total of 3,832 clients with developmental disabilities are currently participating in work activity and vocational training programs in the thirty-eight surveyed programs in this area of Southern California. One client out of this group is being provided training in sexuality and related social skills, while 3,831 clients are not provided any type of training or instruction in this subject matter. It is evident by these results that individuals with developmental disabilities in this part of Southern California, are not widely exposed to sexuality education or related social issues that may put them at risk when participating with others in social or employment settings. These results are congruent with the research of Hingsburger and Pendler (1990), Muccigrosso (1991), and others, who have written extensively that the sexuality issues of adults with developmental disabilities are not widely addressed.

These results are remarkable due to state legislation
which requires access to developmentally appropriate materials on sexuality and reproduction for persons with developmental disabilities, as well as equal opportunities to experience all of the amenities in life to which a non-disabled person would be entitled (Lanterman Developmental Services Act 1993, cited in Muccigrosso & Marion, 1995). Furthermore, relevant Federal legislation such as The Developmental Disabilities Assistance and Bill of Rights Act (DDA) of 1976 mandates State/Federal grant programs to provide "improved care and training" for people with developmental disabilities (Rubin & Roessler, 1995 p89).

The fact that sexuality training is not being provided to such a large number of adult clients with developmental challenges, would appear to indicate that knowledge about and attitudes toward sexuality in regards to this population have not changed much from the past. As a group, individuals with disabilities in our society have been one of the most discriminated against (Buscaglia, 1994). As discussed above, people with developmental disabilities were deprived of their basic human rights in the past, and it was not considered appropriate to allow them
opportunities to mingle in society, establish intimate relationships, marry, or have families. People with developmental disabilities were not viewed as sexual beings, and most of society believed sex education increased sexual misbehavior or would contribute to the birth of children with disabilities. In reality, studies indicate that sex education actually increases adaptive sexual behaviors in clients with developmental disabilities (Buscaglia, 1994; Hingsburger, 1989; Mesibov, 1986). Studies do not indicate that parents with developmental disabilities will necessarily have a child with a disability (Buscaglia, 1994), however, many segments of society continue to deprive people with developmental challenges from participating in sexuality education programs while they are in school and continue to segregate people with developmental disabilities from the non-disabled population today. These continuing practices of segregation have made it very difficult for people with developmental disabilities to experience the pursuit of happiness in our society (Arc, 1990), or to make choices that would allow them to develop their full potential
Erroneous beliefs about sexuality in relation to individuals with disabilities discourages the provision of sex education to people with developmental disabilities (Sobsey & Mansell, 1990).

Furthermore, these disturbing results are inconsistent with more than a decade of compelling studies clearly indicating that persons with developmental disabilities are particularly vulnerable to sexual abuse, exploitation, and serious health hazards (Graff, 1993; Muccigrosso, 1991; Tharinger, Burroughs-Horton, & Millea, 1990). Even more disconcerting is the fact that only one out of 3,832 clients in programs surveyed in this study is currently participating in a sexuality training component as a part of a vocational or pre-vocational training program, although all of the surveyed programs include components of self-care management, behavioral intervention, and community integration. The implementation of self-care management, behavioral intervention, and community integration components allows persons with developmental disabilities to prepare for employment and appropriate interaction with others within their community. Since these
programs acknowledge that it is important to manage self-care, and interact with others appropriately, one would assume that the provision of sexuality training would assist individuals with disabilities to integrate into their community safely and appropriately. As the basic premise of the provision of the work training programs is to provide training to persons with developmental disabilities to become as independent as possible, it would seem necessary to provide services and training that encompasses other important areas of life, such as sexuality. Social interaction is an integral part of most of our lives, with or without the presence of a developmental disability, and without proper instruction on appropriate interaction with others, persons with developmental disabilities may not be successful in their goal to become as independent as possible.

It has been clearly shown that people with developmental challenges lack education on how to utilize interpersonal skills, have little self-esteem, and rarely do they possess the ability to advocate for themselves (Ayrault, 1971; Hingsburger & Griffiths, 1986; Hingsburger,
Professionals who work with individuals with developmental disabilities were identified as the persons responsible for assisting people with developmental challenges to overcome such social deficits (Hingsburger, 1986). Specifically, developmentally appropriate and proactive training programs for self-protection against abuse and exploitation must be developed (Muccigrosso, 1991). Further, information on each individual’s right to choose, for example, that people can and should make choices about sexuality, and whether or not to be sexually active, must become integral components when addressing sexuality and related social skills with this population.

Unfortunately, this survey was not designed to gather information directly on the relative interest in or requests for sexuality training as part of vocational programming, on the part of the participants. Future research could explore the reason why the program directors and managers who participated in this study indicated that they thought only 55 percent (55%) of their program participants with developmental challenges would benefit
from sexuality or social skills training. One respondent indicated that sex education in work programs are limited due to parental influence. This is congruent with Hingsburger and Pendler’s 1990 discussion on parental opposition to sexuality instruction. According to Hingsburger and Pendler, a concern of some parents is that sexuality education may increase interest in becoming sexually active, which may in turn, create more problems. According to a study by Mesibov (1986), studies do not validate such a concern. Future research could focus on these issues.

Results of the present study should be interpreted with caution for several reasons. First of all, the postcard survey format used in this study does facilitate a good return rate, however, the amount of information that can be gained is restricted. Although the format is appropriate for exploring the status of sexuality and related social skills training programs, as in this study, the required brevity of the questionnaire restricts gathering more detailed information. Secondly, the sample size is relatively small and restricted to one geographical
area. Thus, more information from other areas and from a larger sample is needed to determine the generalizability of the current findings. Third, no differentiation was made comparing respondents working with individuals having mild versus severe disabilities. These are additional factors to consider in future research.
CHAPTER FIVE: CONCLUSION

Clearly, a myriad of challenges exist for day program and employment services professionals providing training in sexuality and related social skills to participants with developmental disabilities. For example, the concept of offering comprehensive, on-going programming and training on the subject of sexual and social behaviors goes beyond teaching biology (Muccigrosso, 1992). The subject requires advocating for clients in terms of sexual equality, as well as for health and safety issues.

Moreover, professionals who commit to providing sexuality training may need to take on the attitudes and viewpoints of the public in regards to persons with developmental disabilities, as well as accept the disapproval and/or challenges of parents who do not support such training.

Ultimately, the greatest challenge to implementing sexuality and social skills training programs for people with developmental disabilities may lie in the attempt to alter societal attitudes and increasing society’s awareness of the merit of sexuality and social skills education. Many
persons with developmental disabilities have the same interest in and capabilities for sexual relationships as non-disabled people do (Ayrault, 1971) and as Hingsburger and Pendler (1990), pointed out, it could be exciting to be part of a process that educates others on the fact that a adult with a developmental challenge is a person who is capable of and has the potential for a full, productive, and loving life.
Appendix A

Resource List

The following reference materials were contributed by:
The Committee On Sexuality
C/O Jennifer Marion
146 S. Morrison Ave.
San Jose, CA 95126

BOOKS:
An Easy Guide to Loving Carefully
Kempton, McKee & Stiggall (1987)
Network Publishing, P.O. Box 1830
Santa Cruz, CA 95061

Building Self Esteem in Persons with Developmental Disabilities
Frank R., & Edwards, J.(1988). P.O. Box 3612,
Portland, OR 97028

Changing Inappropriate Sexual Behavior
Griffiths, Quinsey & Hingsburger (1989).
Paul Brooks Publishing, P.O. Box 10624
Baltimore, MD 21285

Double Jeopardy: Pregnant and Parenting Youth in Special Education.
Muccigrosso, L., & Scavarda, M.L.
Counsel for Exceptional Children,
1920 Association Dr., Reston, VA 22091 ($10.00)

Family Life and Sexual Health: Special Education
Seattle-King County Public Health, Family Planning Publications, 110 Prefontaine Ave. # 500, Seattle, WA 98104

Human Sexuality Handbook.
A comprehensive guide to positive expressions of sexuality developed specifically to meet the needs of adults who have
developmental disabilities.
The Association for Community Living
One Colorado Dr., Springfield, MA 01104

I Contact, Sexuality & People with Developmental Disabilities
PO Box 587, Mountville, PA 17544. ($13.00).

I to I, Self Concept and People with Developmental Disabilities
PO Box 587, Mountville, PA 17544. (13.00).

Making Love, Etc.: a booklet for young people with disabilities. Bloorville Children’s Hospital. $10.00
25 Buchan Ct., Willowdale, Ont. M2J 439

Sex Education and Counseling of Special Groups
Chas. Thomas, 2600 So. 1st. St., Springfield, IL 62717

Sexual Assault: A Survivor’s Handbook for People with Developmental Disabilities. Books I-III
Baladerian, N. (1986). Mental Health Consultants,
PO Box T, Culver City, CA 90230. ($20.00 ea).

Sexuality and the Developmentally Handicapped
Rowe & Savage (1987). Edwin Mellen Press,
Box 450, Lewiston, NY 14092.

Shared Feelings: A Parent Guide to Sexuality Education

Stigall and Associates: 21450 Bear Creek Rd.,
Las Gatos, Ca. 95030
Understanding and Expressing Sexuality: Responsible Choices for Individuals with Developmental Disabilities.
Rosalyn Kramer Monat-Haller
P.O. Box 2103, Summerville, SC 29484


TEACHING CURRICULUMS:
James Stanfield Publ. Santa Barbara, CA

Changes in You Curriculum
Booklets about puberty for girls and boys, Illustrated; simple wording.
Peggy Siegel, Family Life Education Assoc.
P.O. Box 7466, Richmond, VA 23221

Circles I: Intimacy & Relationships; Circles II: Stop Abuse Circles III: Safer Ways.
Walker-Hirsch & Champagne. James Stanfield Publishers, PO Box 41508 Santa Barbara, CA 93140

Life Horizons I & II.
12 parts with 1000 slides to teach/counsel socialization and sexuality to students with DD.
James Stanfield Publishing, PO Box 41058 Santa Barbara, CA 93140.

Learning to Get Along: Social Effectiveness Training
Jackson, Bennett, Faryna, et. al.
Champaign, IL 61821

Life Facts: (Sexuality; Abuse Prevention; Aids; Managing Emotions). Curriculum and large black & white laminated drawings, $199/each
Living Your Life
A sex education and personal development programme for students with severe learning disabilities.
A. Craft/Living and Learning
2195 Turnage St., Salem, OR 97304.

Portfolio: Human Sexuality for the Mentally Retarded
Large illustrations/with suggestions for the educator
Planned Parenthood, 2211 E. Madison Seattle, WA 98112

Positive Approaches
Sexuality guide for teaching developmentally disabled persons. Planned Parenthood of Delaware,
625 Shipley St. Wilmington, DE 19801.

Rights & Responsibilities of Consumers in Residential Care: A Training Guide
Muccigrosso, L., Scavarda, M., & Marion, J.
Socio-Sexual Committee on Sexuality, C/O Jennifer Marion
146 S. Morrison Ave. San Jose, CA 95126
A workshop training guide/$28.00

Teaching Persons with Mental Retardation about Sexuality and Relationships. June Kogut & Susan Vilardo.
A manual which offers guidance for the development and implementation of sexuality education programs.

The Dating Skills Program: Teaching Social Skills to Adults with Mental Retardation.

FILM/VIDEO/VISUALS:
Being with People
Social Skills training program via videomodeling by the New Eticats. James Stanfield Publishing. Funny

Breast Self-Exam Video
Kaiser Permanente
1742 Franklin St., Oakland, CA 94612
Hand Made Love. Diverse City Press
BM 272, 33 des Floralies, Eastman, Quebec JOE1PO
A video designed to teach men how to masturbate safely and appropriately.

He’s No Hero
Young Men's Issues (snappy music)
Intermedia, 1300 Dexter N., Seattle, WA 98109

Jackson Pelvic Models
33 Richards Ave.
Cambridge, MA 02140

Janet's Got Her Period
Curriculum for girls and young women with developmental disabilities. Video and illustrated storybook.
James Stanfield Co.
P.O. Box 41058 Santa Barbara, CA 93140.

Learning to Talk about Sex When You'd Rather Not Video
Special Purpose Films
416 Rio Del Mar, Aptos, CA 95003

Life-size instructional Charts
Planned Parenthood of Minn.
1965 Ford Parkway, St. Paul MN 55116

Making Connections-dramatization of a dating service for people with developmental disabilities. American Film and Video, 6900 Wisconsin Ave. Bethesda, MD 20814
301-652-1477 or 1-800-78-VIDEO

Portfolio: Human Sexuality for the Mentally Retarded.
Large scale illustrations with suggestions for educating.
Planned Parenthood of Seattle-King Co.
2211 E. Madison, Seattle, WA 98112

Sexual Abuse Prevention: Five Safety Rules for Persons who are Mentally Retarded. Video and Guide.
Agency for Instructional Technology
Box A. Bloomington, IN 47402
Sexual Abuse & Self Protection
Seattle Rape Relief Developmental Disabilities Project
film/audiotape/curriculum $495 per kit
1825 S. Jackson, #102, Seattle, WA 98144

Sexuality Education for Persons with Severe Developmental Disabilities. Simple guide with slides and curriculum
Brekke, James Stanfield Publishing

Social-Life Game: for teaching social competency
Dorothy Griffiths, et. Al, York Management Services
York Central Hospital, Richmond Hill, Ontario, Canada

Street Safe and You Have the Right to Say No
Videos to help staff learn how to teach self-protection
Special Purpose Films
416 Rio del Mar, Aptos, CA 95003

Woodrow Project, a Rape & Abuse Crisis Center (1986)
Manual/Video/$99.00. P.O. Box 2984, Fargo ND 58108

The following materials were contributed by The Sexuality and Education Council of the United States “SIECUS”
ORDER FROM: 130 West 42nd Street, #350, New York, N.Y. 1003

BOOKS:
Now What do I do? How to give your Pre-teens your messages. Helping children to grow up to be sexually health adults.
SIECUS

Oh No! What Do I Do Now? Messages about sexuality: How to give yours to your child.
SIECUS

Talk about Sex. A booklet for young people on how to talk about sexuality and HIV/AIDS
The Family Education Program (abuse prevention program for the developmentally disabled)
Information on sexuality and responsible decision making.
The Family Stress Center of Planned Parenthood of Shasta Diablo (1990). 1291 Oakland Blvd. Walnut Creek, CA 94596
TRAINING MATERIALS
Guidelines for Comprehensive Sexuality Education
2nd Edition: Kindergarten - 12th Grade
National Guidelines Task Force
SIECUS
130 W. 42nd Street, suite 350
New York, NY, 10036

Other Resources:
BOOKS
Planned Parenthood/Shasta Diablo
2185 Pacheco St., Concord, CA 94520

Love and Intimacy.
Essays, poems, short stories, book reviews on love, relationships and sexuality. $8.95.
Robert Mauro, Accent Publications
P.O. Box 700, Bloomington, IL 61702

Growing Up: A Social and Sexual Education Picture Book for Young People With Mental Retardation.
Designed to be read to students with moderate to severe mental impairments. Clinical Center for the study of Development and Learning Library. Chapel Hill, NC. (919)966-5171.

Developed by the ARC to assist parents and care-providers to talk about AIDS/HIV with children with learning and developmental disabilities. National Headquarters of the ARC, P.O. Box 1047, Arlington, TX 76004.

Learning to Love
A set of simple books on sexuality, reproduction and health issues for young people with learning disabilities
Education and Publication Unit, Brooks Advisory Center, 153 A, East Street London SE17 2SD England
Mother-To-Be: Guide to Pregnancy & Birth for Women With Disabilities. Interviews with 36 women with disabilities. Demos publications, 386 Park Avenue South, suite 201 New York, NY 10016


Survivor: For People with Developmental Disabilities who have been Sexually Assaulted Los Angeles Commission on Assaults against Women 6043 Hollywood, CA 90028


VIDEOS AND OTHER MEDIA
Like Other People 4477 Roger Williams, P. O. Box 855 Ravina, Highland Park, IL 60035 2 young people with cerebral palsy fall in love & marry. Available for rental through Perennial Films.
Appendix B

Samples

Letter Sample:

April 15, 1997

Dear Program Director/Manager,

We are investigating the extent to which sexuality and social skills training is provided to consumers with developmental disabilities in sheltered and supported work programs and what type of training, if any, is offered. We would appreciate your completing the questionnaire on the enclosed pre-addressed and pre-paid post card and mailing it back to us at our earliest convenience. You will receive a follow-up telephone call in regards to this survey within ten days.

Sincerely,

Joseph O. Turpin, Ph.D, C.R.C.  
Professor,  
Rehabilitation Counseling

Caroline M. Adkison  
Graduate Student,  
Rehabilitation Counseling
Survey Sample:

1. At the present time what percentage of consumers in your program would you perceive could benefit from sexuality and social skills training? ________% 

2. At the present time does your program offer any formalized sexuality training for consumers?
   Please circle: Yes No
   If yes, is sexuality training required as part of your Programming? Yes No
   If yes, is sexuality training offered by staff or by an outside agency?
   Please circle: staff outside agency
Appendix C

Sample Participants

Supported Employment Programs

1. Ability Counts
2. Foundation for the Retarded
3. Industrial Support Systems
4. Partnerships with Industry
5. Social Vocational Services
6. Valley Resource Center
7. Vocational Improvement Program
Work Activity Center/Workshop Programs

1. ARC
2. Ability Counts
3. Advanced Enterprises
4. Foundation for the Retarded
5. Goodwill Industries
6. Industrial Support Systems
7. JOB
8. Morongo Basin Work Activity Center
9. Social Vocational Services
10. Valley Resource Center
11. West View
**Adult Developmental Centers**

1. ARC
2. Able
3. Advanced Options
4. Angel View/Community Access Program
5. B.E.S.T. Enterprises
6. Bumpershoot
7. Cole Vocational Services/First Step
8. Foundation for the Retarded
9. Independent Options
10. Innovative Business Partnerships
11. JOB
12. Mentech
13. OPARC
14. Pass Resource Center
15. Pomona Valley Adult Developmental Center
16. Riverside Resource Center
17. Unlimited Quest
18. Valley Resource Center
19. Voice
20. Westview Vocational Services
REFERENCES


Arc. National Headquarters. (1990). Position statement on sexuality. P. O. Box 1047, Arlington, Texas, 76004 (817) 261-6003; thearc@metronet.com


National Center for Health Statistics (1985)


