DOCUMENT RESUME

ED 446 401 EC 308 089

AUTHOR Shapland, Ceci
TITLE Sexuality Issues for Youth with Disabilities and Chronic Health Conditions. Healthy & Ready To Work (HRTW) Policy Brief.
INSTITUTION Florida Univ., Gainesville. Inst. for Child Health Policy.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Washington, DC. Maternal and Child Health Bureau.
ISBN ISBN-0-9700909-3-5
PUB DATE 2000-04-00
NOTE 24p.
CONTRACT U93MC00133
AVAILABLE FROM For full text: http://www.mchbhrtw.org/materials.
PUB TYPE Reports - Descriptive (141)
EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS At Risk Persons; Chronic Illness; *Community Programs; Definitions; *Disabilities; Early Parenthood; *Pregnancy; *Prevention; Sex Education; *Sexuality; *Special Health Problems

ABSTRACT

This policy paper addresses sexuality issues of youth with disabilities and chronic health conditions. The first section introduces the problem of teen pregnancy and pregnancy prevention. The second section provides definitions of disabilities including both visible and invisible disabilities. Risk factors for teen pregnancy are identified and discussed next, including risks for all youth, risks for youth with disabilities, poor academic achievement/high dropout rate, low expectations for post high school outcomes, sexual abuse, cognitive difficulties, poor social skills, poor self-esteem and body image, and lack of information. The final section recommends needed actions and focuses on accommodating community programs for youth with disabilities. This section addresses: sex education, community family planning services, comprehensive programs, community partnerships, inclusion of young men, physical accessibility, contraceptive needs, acknowledgment of cultural diversity, and a checklist for programs. Five policy recommendations and a list of programs/resources conclude the paper. (Contains 41 references.) (DB)

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Sexuality Issues for Youth with Disabilities and Chronic Health Conditions

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration
Maternal and Child Health Bureau
Division of Services for Children with Special Health Needs

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Healthy & Ready to Work (HRTW) is an initiative of the Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS).

This document is part of a series of HRTW Policy Briefs that can be downloaded at www.mchbhrtw.org/materials:

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- ***Understanding the 504 Statute: The Role of State Title V Programs and Health Care Providers***
  by Rhoda Schulzinger, Esq. 1999, First Edition
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  by Ceci Shapland. 1999, First Edition
- ***Youth with Disabilities in Transition: Health Insurance Options and Obstacles***
  by Rhoda Schulzinger, Esq. 2000, First Edition

Sexuality Issues for Youth with Disabilities and Chronic Health Conditions

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A "Healthy & Ready to Work" (HRTW) Policy Paper
Patti Hackett, M.Ed. and John Reiss, Ph.D.
HRTW Policy Paper Series Editors

First Edition
April 2000

Acknowledgements

We greatly appreciate the generous support of the Maternal and Child Health Bureau [MCHB], which made development of this document possible. In particular, we thank the following for their assistance:

Merle McPherson, MD, Director, Division of Services for Children with Special Health Needs (DSCSHN), Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS)

Bonnie Strickland, Chief, Integrated Services Branch, DSCSHN, MCHB, HRSA, DHHS

Tom Gloss, Health Policy Analyst, Healthy & Ready to Work [HRTW] Project Officer, DHHS, HRSA, MCHB, DSCSHN

We are grateful for the legal policy consultation and manuscript preparation of Ceci Shapland and the editorial and graphic design services of Minna Newman Nathanson and Gina Bliss Smith.

Additional HRTW information can be located on the web: www.mchbhrtw.org

Recommended Citation: *Shapland, C. 1999. Sexuality Issues for Youth with Disabilities and Chronic Health Conditions.* An occasional policy brief of the Institute for Child Health Policy, Gainesville, FL. (ISBN 0-9700909-3-5)

 This document was supported through a Cooperative Agreement from the DHHS/HRSA/MCHB, Integrated Services Branch (U93MC00133, Project Officer Tom Gloss) and was coordinated by the Center for Policy and Partnerships at the Institute for Child Health Policy [ICHP], but does not imply endorsement of the funding agency.

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Teen Pregnancy Prevention and Youth with Disabilities

Teen Pregnancy: The Problem

Gina always rose every day at 5:30 a.m. and caught the bus to her local high school at 6:45 a.m. Now she has to get up at 4:00 a.m. to bath, feed, and dress her two month-old daughter before school. "Parenting is a very hard responsibility and a big one," says Gina. There is no longer time for hanging out with friends or just "kicking back." The innocence of her youth was cut short at sixteen by pregnancy.

The teen pregnancy rate in the United States is two times higher than any other industrialized democracy. Four out of ten pregnancies — approximately one million — occur in women under twenty. Teen pregnancy costs the nation seven billion dollars annually. Despite the decline of teen pregnancy in the past five years, both experts and public agree it remains a major symptom of a cultural crisis affecting the nation's young people.

Teen pregnancy can have a multigenerational impact. Research shows that children born to teen mothers often have low birth weights (below 5 1/2 lbs.), placing these infants in a high-risk category. This translates into an increased probability for mortality and morbidity, including mental retardation, cerebral palsy, and hyperactivity. It doubles the risk of such learning disabilities as dyslexia. These children do worse in school and have a higher rate of behavioral problems. As teens, they, in turn, have an increased chance of becoming teen parents, dropping out of school, and being unemployed.

The National Campaign to Prevent Teen Pregnancy, founded in 1996, brings a national focus to the problem and raises public awareness of each person's role in supporting adolescents and providing better choices for the future. Its mission is to reduce the teen pregnancy rate by one-third by the year 2005.

Discussions on teen pregnancy view all teens as the same, except for cultural background and gender; programs are planned to meet the needs of this typical adolescent population. However, the subgroup of youth with disabilities — with unique needs that impact both their ability to learn and their choices for the future — is rarely acknowledged in the literature addressing teen pregnancy. This subgroup of teens confronts service providers and policymakers alike with unique challenges in developing and providing appropriate programs and services to meet their needs. But, few teen pregnancy prevention programs make the necessary accommodations or even recognize that they are serving youth with disabilities.

In addressing the general lack of awareness and knowledge surrounding teen pregnancy prevention and youth with disabilities, this paper raises the following questions:

- Who are the youth with disabilities?
- What are their risk factors for teen pregnancy?
- What are their unique needs?
- What accommodations are necessary?
- What are the next steps?
- Where are the best programs and resources?

Section 504 of The Rehabilitative Act of 1973, as amended, 29 U.S.C. Section 6794

Youth with Disabilities: Who Are They?

There are as many definitions of disabilities as there are handicapping conditions. For the purposes of this paper, disabilities are defined as physical or mental impairments that substantially limit one or more major basic life activities, including eating, bathing, dressing, walking, or learning. This is the definition in the Americans with Disabilities Act.

Title 34 of the Code of Federal Regulations (CFR), Part 104

There are an estimated four million children and adolescents with chronic illnesses and disabilities, 6.1 percent of the under-eighteen population. Among children between ages five and seventeen, 5.5 percent have school-related disabilities.

For this paper, this population is divided into those with visible disabilities and those with invisible disabilities. Each group presents unique challenges to teen pregnancy prevention programs.

Invisible Disabilities

Teens with invisible disabilities blend fairly well into mainstream society and so are easily included in mainstream services. The largest and most common group of these youth are those with a learning disability, a disorder in one or more of the basic psychological processes involved in understanding and using spoken or written language. Two and one-half million children in kindergarten through twelfth grade have learning disabilities. Many go through school undetected. (Of adults with severe literacy problems, 60 percent most likely have undetected learning disabilities.) While youth with learning disabilities may have average, or even above average, IQ scores, they experience difficulty in the basic skills of reading, math, and writing. They often have auditory processing and visual perception problems that affect how they receive and process information. Many receive special education services, however individual needs often are not met. Low academic achievement is common, affecting how they feel about themselves and school. Every year, 35 percent — one million — drop out of high school. The National Longitudinal Transition Study, a 1987 and 1990 survey of eight thousand

youth with disabilities in three hundred school districts, reports that 50 percent of young women with learning disabilities are mothers within three to five years of leaving school. Challenges for this group of teens arise because they are recipients of mainstream services whose providers are unaware of their learning needs. They receive the same information in the same way as teens without disabilities. But their unique learning needs may prevent them from learning and utilizing the information they receive in this way from community service agencies. Their low academic achievement and high drop-out rate places them at very high risk for pregnancy.

Also in this category are young people with emotional and behavioral disorders and with attention deficit disorder. These youth are challenged by impulsivity, inability to attend, and poor organizational skills — challenges that impact their ability to learn new information as well as to relate socially.

Visible Disabilities

The group of adolescents with visible disabilities falls into society's more common perception of disability and includes those with mental retardation, cerebral palsy, spina bifida, and other physical impairments. With their obvious disabilities, these youth are more easily identified. However, there is a lack of awareness on the part of parents and professionals to acknowledge such young people's sexuality and, therefore, a failure to provide them any program addressing sexual development, reproductive health, and pregnancy prevention.

Debbie, a young woman with severe physical disabilities says it best, "I guess I never realized how much people look at us as nonsexual. It bugs me the way people ask questions. I really wanted to buy this T-shirt that said, 'Able, but unwilling.'"

Society's notion of people with disabilities as asexual is a common myth that impacts the information and opportunities for teens with more obvious disabilities.

Kelsey, a twenty-year-old woman with muscular dystrophy testifies, "My doctor and parents avoid talking to me about sexuality. . . . We have to remember that our parents have grown up in a society where the word 'sexy' means a healthy, strong, able-bodied man or woman. This could be why parents might think it's impossible for us to ever have a sexual relationship since we have a disability."

Each group of youth with disabilities has their own issues relating to sexuality and pregnancy prevention. Those with learning disabilities receive information that is not adapted to their unique learning needs, while youth with more severe and obvious disabilities do not receive much, if any, information relating to their sexual development.

Risk Factors for Teen Pregnancy

Risks for All Youth

The literature is clear about the risks for teen pregnancy: low achievement test scores; poor academic achievement that often leads to high drop-out rates; low expectation for graduation or post high school outcomes; lack of knowledge and skills to prevent sexual activity or to use contraception; sexual abuse; poverty; and living in a single parent household. Poor academic performance is a risk factor for both males and females.

Risks for Youth with Disabilities

Having a disability places a teen at further risk for pregnancy, as the disability itself leads to most of the factors cited above. In addition, such teens experience many challenges that further complicate the problem.

Poor Academic Achievement/ High Drop-out Rates

The National Longitudinal Transition Study showed that youth with disabilities often exhibit poor basic skills, leading to low academic achievement that, in turn, lead to a high drop-out rate. Of students with learning disabilities, 35 percent — one million teens — dropped out of school. Of those that dropped out, 50 percent become mothers within three to five years after leaving school. The study also found that a higher number of youth with disabilities live in households below the poverty level (68 percent) and more live in single parent homes (37 percent).

A study of young women with mild mental retardation (Wagner 1993) indicates that academic failure and dropping out of school precedes pregnancy. A disproportionate number of special education teens become pregnant. The longer teens stay in school, the longer they avoid pregnancy; however, teens in special education drop out earlier.

Low Expectations for Post High School Outcomes

A sense of promising choices for the future often is not present for teens with disabilities. In the National Longitudinal Transition Study, young women with disabilities were more apt to receive guidance and direction focused on child care and homemaking skills than on employment or further education.

Sexual Abuse

Youth with disabilities are four times more likely to be sexually abused or exploited than their typical counterpart. This population is at such high risk for several reasons. The most obvious relate to physical limitations to defend oneself and cognitive limita-

tions to determine safety. However, risk increases with lack of knowledge of sexuality and lack of information on exploitation. The situation is further complicated when one considers the impulsivity, low self-esteem, poor decision-making skills, and lack of social opportunity of teens with disabilities.

Cognitive Difficulties

Youth with disabilities face challenges in learning new information. Many read at a low grade level, have auditory processing problems, and/or have difficulty attending to information and following through on instruction. Other areas of difficulty include having problems with any task that requires memory, difficulty sustaining effort and accuracy over time, losing things necessary for a task, not retaining what is read, and having difficulty sequencing thoughts. These learning challenges have strong implications for how youth with disabilities receive and process routine information on pregnancy prevention and reproductive health.

Thus, routine explanations and written materials about teen pregnancy prevention have little impact on the knowledge base and practices of these young people. It is clear that information needs to be presented differently for such teens.

Poor Social Skills

Teens with disabilities often have poor social skills for several reasons: inability to pick up on subtle social cues and a need to learn social skills as one learns any new skill — clear, appropriate explanation and practice over and over in real life situations.

Teens with more severe disabilities often lack opportunity for social interactions and experience social isolation. Due to the difficulty of transportation or the inability to be independent, they often do not participate in such usual teen activities as dances, driving around town, or shopping at the mall. They miss out on all the information that teens exchange during these social gatherings and the opportunities for practicing social skills. For those with communication disorders, talking with peers is complicated. It is difficult to join in the "table talk" at lunch time or to chat on the telephone with friends at night.

A 1995 survey of teens with disabilities planning for transition from school to work and the community (Shapland, Vanderburg & Eisland 1995) revealed that many have no one to talk to about many of the typical teen concerns, such as drugs, alcohol, sexuality, anger, or despair. While typical peers say they talk with parents and peers concerning these subjects, youth with disabilities experience social isolation.

Acquiring social skills is an important part of normal adolescent development. These skills assist the teen to grow into an adult who has positive self-esteem, can make healthy sexuality choices, and can move toward independence.

Poor Self-Esteem and Body Image

How one feels and sees oneself greatly impacts development and future outcomes. Societal norms of beauty and desirability are difficult for typical teens to meet. How much more challenged are youth whose disabilities make their bodies look different?

Teens with disabilities receive negative messages that affect their self-esteem. Lack of social opportunity leading to social isolation builds feelings of incompetence, dependence, loneliness, and of feeling freakish, impotent, and asexual. Often, family and professional overprotectiveness emphasizes the teen's deficits, leading to unhappiness, self-consciousness, and the inability or initiative to make decisions.

Lack of Information

Along with lack of social opportunity, the teen with disabilities also may lack information concerning sexuality and reproductive health. Professionals and parents either lack the awareness to consider sexuality as part of the teen's normal growth and development or are fearful of discussing sensitive issues and acknowledging vulnerability. Thus, the topic of sexuality and reproductive health often is avoided, leaving an information void that increases the chances for sexual exploitation and of failure to protect from unintended pregnancy.

A Summary of Risk Factors for Teens with Disabilities

RISKS FOR ALL TEENS	TEENS WITH DISABILITIES
Poverty	Higher (68%)
Single parent household	Higher (37%)
Low academic achievement	Common
School drop out	Drop out sooner
Low expectations for post school outcomes	Focus on child care/ homemaking
Sexual abuse	Four times higher
Lack of sexual knowledge/skills	Complicated by learning difficulties, poor social skills, low self-esteem, poor body image, lack of formal education in sexuality and reproductive health

What Should be Done? Accommodating Programs for Youth with Disabilities

Although teens with disabilities are at extremely high risk for teen pregnancy, there is minimal information in the literature about strategies to address the needs of this special population. Throughout most information on pregnancy prevention, there is no mention of accommodating youth with disabilities.

34 CFR Section 104.35

34 CFR Section 104.35

34 CFR Section 104.36

34 CFR Section 104.37

34 CFR Section 104.7 (a)

There are questions about what specific interventions are successful in addressing teen pregnancy prevention for all youth. Research is scant, poorly organized, and fails to present definitive answers. Despite this lack of good research data, experts are confident about many strategies used over the years, including everything from a comprehensive youth development program to early sex education in the schools. Successful strategies in pregnancy prevention for typical teens can be a starting place in examining what accommodations are needed for youth with disabilities.

Sex Education

Sex education is perhaps the most common and well-developed strategy. Parents should be the first and the main educators of their children. Schools also have been a major provider of sex education. However, many feel that school sex education is started too late and taught by poorly prepared teachers using mediocre materials. Experts agree that the best programs begin early, in elementary school, before children become sexually active. They include a broad-based curriculum of routine information on human anatomy and physiology, contraception, and sexually transmitted diseases, as well as information on communication, decision-making, and goal-setting with a focus on the future. These are all important issues for youth with disabilities. For them any information on pregnancy prevention also must relate to how their disability may affect carrying a baby to term and parenting.

34 CFR Sections 104.41-47

Available at www.ed.gov/offices/ocr/auxaids.html

In developing sex education programs for youth with disabilities, the first step is to identify teens that need special accommodations and assess individual needs. This may be a difficult task if the teen does not disclose information about the disability. An open, caring atmosphere and time to build trust may provide an opportunity to talk about school progress that may indicate learning challenges. When working with youth with disabilities, their developmental learning needs must be considered. Information should appeal to various learning styles, including auditory, visual, and experiential materials. Teens with visual impairments need all information in alternative print forms such as Braille or large print. Careful consideration of reading and comprehension levels is essential. Providing information at a slower pace also may be important.

Before beginning to teach a child, educators should examine their own values and moral beliefs. This is especially important when talking with a child with a disability. The adult should be clear that his or her own personal feelings about disability and belief in what is beautiful will not transmit negative messages.

Reassurance about body changes is important for any child, especially how such changes relate to the disability. Many children with disabilities experience puberty very early or very late. This can be extremely difficult for a teen who already feels different.

Information must be very concrete for youth with mental retardation. Using clear pictures of what is being explained is essential, as is using "teachable moments." Recent newspaper articles or television programs may be helpful in illustrating information. Repetition is an important teaching tool.

Providing opportunities for social interaction is very important. Youth with mental retardation have difficulty generalizing information to various settings. Providing "teachable moment" opportunities for "real life" relationships will assist in giving context to information about sexuality and reproductive health.

There are books specifically for persons with disabilities that discuss their unique sexuality issues and provide information and illustrations that aid in the education process. [See Programs/Resources on page 13 and References/Bibliography on page 14.]

Community Family Planning Services

Family planning services in the community combine information, counseling, and possibly the provision of contraception. Over the past several years, much Federal and State funding has focused on this intervention. Research shows mixed results as many young women do not return or follow through with the prescribed treatment.

The first challenge in such settings is to identify teens with a disability. This is extremely difficult unless the teen self-identifies or the clinic is based in school and the providers are aware of the youth's educational needs. However, community providers must be aware that they most likely are serving youth with disabilities and must strive to identify them and meet their individual needs. All the accommodations discussed under sex education are appropriate in the family planning clinic setting. An awareness that many youth with learning disabilities have trouble remembering and learning sequences calls for repetition and close follow-up by clinic staff.

Accessibility may be an issue for community clinics. It is not enough to alter entrances to buildings, bathrooms, and exam rooms. Accessible exam tables are now available and should be utilized in community-based clinics. [See section on Accessibility on page 10.]

Comprehensive Programs

Comprehensive programs located in community centers, clinics, etc., focus on youth development, not pregnancy prevention. Teens are more apt to use contraception when nonmedical issues are addressed. One strategy of these programs is to examine what motivates a teenager to avoid pregnancy and provide those resources and supports. Most programs include: education, emphasizing postponing sexual activity and pregnancy; a focus on future outcomes, such as further education and choices in employment; and communication, decision-making, and goal-setting skills that help in reaching future goals. Many include a job training component, using peer educators or adult mentors. The main barrier to creating and sustaining such programs is their high cost.

This model is an excellent one for youth with disabilities; it addresses their needs well with its comprehensive focus on life skills and future goals of employment and education. This type of program also provides an opportunity to address the self-esteem and body image issues that are common for youth with disabilities. It promotes confidence in their strengths and skills. Identifying youth with disabilities and their unique needs assists staff in providing the most appropriate accommodations and education.

Community Partnerships

Establishing community partnerships that focus on teen pregnancy prevention and promote and support teens offers them an environment in which to learn to make good choices. These partnerships must include youth, parents — especially youth with disabilities and their parents — schools, churches, businesses, and other community resources such as disability advocacy organizations. Such partnerships can create activities and media coverage emphasizing the individual strengths and gifts of all youth. Including youth with disabilities in community partnerships insures that these youth recognize their ability to contribute to the community and become productive citizens, a strong motivation for focusing their time and energy on building toward a bright future. The entire community benefits from the inclusion of youth with disabilities and is educated in the importance of healthy sexuality development and reproductive health for youth with disabilities. Finally, community partnerships help insure that successful programs are sustained as long as they are needed.

Inclusion of Young Men

It is essential that all young men — preteen and teen — receive the education and support to postpone fatherhood until they are emotionally and financially capable of supporting a child. Young men with low academic achievement have the same high risk for promoting pregnancy as young women. As so many youth with disabilities experience low academic achievement, awareness that the young men being served also may have disabilities is an important pregnancy prevention factor.

Physical Accessibility

Accommodating for cognitive disabilities is important, but it is equally as important to accommodate for persons with physical disabilities. The passage of the American with Disabilities Act has prompted community facilities to be accessible. Most facilities have made accommodations so that entrances to buildings, bathrooms, and offices are accessible. However, accessibility and safety issues for the exam table are equally important. A table that lowers to the height of a wheelchair means that the teen does not have to be lifted onto the table. Safety features should include adjustable handrails. Interchangeable foot attachments offer choice and adaptation for limbs that are spastic and/or have limited range of motion. A custom-designed table can adjust to any physical limitation. [See Programs/Resources on page 13.]

Contraceptive Needs

A teen's disability must be considered in recommending and providing contraception. Barrier methods may be contraindicated in youth who have physical disabilities. Oral contraception may be very difficult for a teen with learning and memory problems. The depo-provera method addresses some of these concerns. As many youth with disabilities take medications, a careful medication history is important before prescribing any contraception.

Acknowledgment of Cultural Diversity

There is much written information for service providers concerning cultural competency in relation to services and supports. Different cultures have different perspectives on disability that may play a role in how a teen and a family react to his or her disability. [See Programs/Resources on page 13.]

Checklist for Programs

The following checklist for program planners summarizes the issues in meeting the needs of youth with disabilities.

_____ Include youth with disabilities and their families in program development.

_____ Include youth with disabilities, their families, and disability advocacy groups on the advisory board.

_____ Identify all youth with disabilities who are in the program.

_____ Emphasize strengths of individuals, accommodate and provide support for limitations.

_____ Individualize programs, such as providing various formats to appeal to different learning styles and including experiential activities.

_____ Support parents as the primary educators whenever possible.

_____ Find community partners, including those from the disability community, to support and sustain the program.

_____ Become informed about the various accommodation possibilities for youth with disabilities.

_____ Provide developmentally – and culturally – appropriate information.

_____ Assess accessibility of clinic and program facilities, including entrances, exam tables, and educational materials.

_____ Promote self-advocacy by providing information that teens can understand and truly utilize.

_____ Provide a sense of future.

Future Steps

The following policy recommendations address sexuality issues for youth with disabilities.

1. Provide sufficient evaluation funding for a period long enough to accumulate valid data about the impact of specific interventions so that successful strategies can be confirmed.

2. Rewrite the goals and objectives of the National Campaign to Prevent Teen Pregnancy to include a focus on youth with disabilities.

3. Promote education of health professionals on sexuality and reproductive health issues for youth with disabilities.

4. Provide education and emotional support to families as the primary sexuality educators of their child.

5. Focus the provision of funds on appropriate education and health care for children and adolescents with disabilities so they can become productive citizens and have equal access to a bright future.

Conclusion

As policymakers, program developers, schools, and parents move forward in addressing teen pregnancy prevention, a conscious awareness of the needs of youth with disabilities is essential. It is apparent that this population, although not singled out in the literature and in program planning, is at very high risk for early pregnancy and has specific information and support needs that must be addressed.

To insure successful future outcomes and a productive life, it is the responsibility of all those who work and care about youth with disabilities to see that they receive the same opportunities for healthy sexuality development and reproductive health available to all teens.

Programs/Resources

There are only a few resources that specifically address sexuality development, reproductive health, and pregnancy prevention in youth with disabilities. The following can provide information in adapting or creating pregnancy prevention programs for youth with disabilities.

The **Americans with Disabilities Act and Reproductive Health Project** is leading the movement toward making services accessible to women with disabilities. Its overall goal is to assist publicly funded health clinics to provide accessible medical, educational, and counseling services to individuals with a wide variety of disabilities, including mobility, hearing, visual, cognitive, and chronic health conditions. The project also provides education for medical and counseling staff about reproductive issues for women with disabilities. Available products include: The Accessible Clinic Manual, The Accessible Clinic Video, Birth Control for Disabled People, Disabled Mothers and Prenatal Services, Social and Ethical Issues of Reproduction and Disability, The Accessible Exam, and Multiplying Choices: Improving Access to Reproductive Health Services for Women with Disabilities.

Americans with Disabilities Act and Reproductive Health Project California Family Health Council
1314 Lincoln Avenue
San Jose, CA 95125
Voice: 408- 283-9226
FAX: 408- 283-9188
Email: fwax man@aol.com

PACER Center is a parent training and information center for families of children and youth with disabilities. PACER information and support on sexuality and reproductive health for families of children with disabilities includes a sexuality curriculum and accompanying video, "I'm a Beautiful Person, Sexuality and Me." These products are for parents just beginning to explore how to address sexuality issues with their child with disabilities. PACER Center also has a library of resources for families addressing sexuality and reproductive health.

PACER Center
4826 Chicago Ave. South
Minneapolis, MN 55417
Voice: 612-827-2966
FAX: 612-827-3065
Email: pacer@pacer.org

The Adolescent Gynecology Teen Clinic focuses on young women with disabilities and chronic illness. It provides information on sexual health, counseling contraception, pregnancy, and disease prevention.

Adolescent Gynecology Teen Clinic
606 24th Avenue South,
Suite 804
Minneapolis, MN 55455
Telephone: 612-376-7650

Local ARC affiliates have resources concerning children and youth with mental retardation. Some have resources addressing sexuality issues. Contact the national office for the location of the nearest ARC affiliate.

ARC of the U.S.
500 E. Border Street #300
Arlington, TX 76010
1-800-433-5255

Planned Parenthood local affiliates have resources and curriculums that address sexuality and reproductive health needs of teens with disabilities.

Planned Parenthood Federation of America: http://ww.ppfa.org/ppfa/index. html

The Family Village Web Site has information for families and professionals on more than three hundred disabilities and chronic illnesses.

The Family Village Web Site: http://www.familyvillage.wisc.edu

The Maternal & Child Health National Center for Cultural Competency provides information on how to design services sensitive to cultural background.

Maternal & Child Health National Center for Cultural Competency — http://www.nmchc.org/html/cf/catalog.cfm

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This Policy Brief is supported through a
Cooperative Agreement (U93MC00133)
from the DHHS/HRSA/MCHB,
Integrated Services Branch
to the Center for Policy and Partnerships
at the Institute for Child Health Policy.

The Institute for Child Health Policy is headquartered at the
University of Florida in Gainesville, Florida
and is a Type I Institute of the State University System of Florida.
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ISBN 0-9700909-3-5

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