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WAKE UP CALL: PREGNANT AND PARENTING TEENS WITH DISABILITIES

Karen H. Jones Constance O. Woolcock-Henry and Desirae M. Domenico University of Georgia

Pregnancy among all teenagers is a major challenge facing the United States. A literature review indicated little research on the incidences of pregnancy and parenting among teenagers with disabilities, similarities and differences in their educational needs when compared to their non-disabled peers, and how programs address their specific educational needs regarding pregnancy and parenting. Our investigation includes a review of literature related to teen pregnancy, pregnant and parenting youth with disabilities, and programs designed to assist teen parents. It also alerts professionals to the lack of information regarding teens with disabilities who are pregnant or parenting and serves as a foundation for future research on the occurrences and educational needs of pregnant and parenting youth with disabilities.

Rates for teen pregnancy in the U.S. are two times higher than any other industrialized democracy and continue to present many problems for society (Aspen Health and Administrative Development Group, 2000; Boonstra, 2002; Yampolskaya, Brown, & Vargo, 2005). Four of 10 pregnancies, approximately one million, occur in women younger than age 20. Teen pregnancy costs the nation seven billion dollars annually and can have a multi-generational impact (Koshar, 2001). In addition, the National Campaign to Prevent Teen Pregnancy (2002) determined that one-fourth of teen mothers will have a second baby within one year of their first baby.

The prevalence of teen pregnancy is reflected not only in the large number of babies born to teens, but also in the adverse consequences and problems associated with these teenage births (Bissell, 2000; Rolling & Burnett, 1997). These problems are described in the literature as pervasive, epidemic, life changing, and irrevocable (Hofferth, Reid, & Mott, 2001; Hong & Wellen, 1993; Schvaneveldt, Miller, Berry, & Lee, 2001). Children born to teen mothers often have birth weights below 5½ pounds, placing these infants in a high-risk category. This translates into a greater risk of low cognitive and emotional development, an increased probability for mortality and morbidity including mental retardation, cerebral palsy, or hyperactivity, and it doubles the risk of learning disabilities such as dyslexia (Dash, 2003; Hao & Cherlin, 2005; Roper, 1991). Further, children born to teen mothers frequently perform lower academically in school and have a higher rate of behavioral problems than their peers. As teens, they, in turn, have an increased chance of becoming teen parents (Farber, 2003; Howard & Mitchell, 1996).

Irwin (1993) claimed the subject of sexuality and reproductive health is often avoided when teaching youth with disabilities, leaving them with an information void that decreases their chances of protecting themselves from unintended pregnancy and parenting. Few pregnancy

prevention or parenting education programs make the necessary accommodations or even recognize that they are serving youth with disabilities (Shapland, 1999). Yet, available research indicates that youth with disabilities are likely to need special help if they are to acquire socially appropriate sexual behavior, to make safe sexual choices, and to become less vulnerable to sexual abuse (McCabe, 1993).

Rationale

Information concerning the incidence of types of disabilities is available, and vital statistics provide information on pregnancies, live births, and induced terminations of teen mothers. However, information regarding the number of pregnant and parenting teens with disabilities and their educational needs has not been previously recorded (Shapland, 1999).

The purpose of this article is to provide a foundation for future research related to youth with disabilities who are pregnant and/or parenting. Currently, there is little research and information available on the incidences of pregnancy among youth with disabilities. There is also insufficient information on whether the educational needs of youth with disabilities differ from those of their non-disabled peers in regards to sexuality, reproductive health, pregnancy, and parenting. Additionally, many teen pregnancy programs do not specifically address youth with disabilities.

Procedures

An exhaustive review of literature was conducted using ERIC, Academic Search Premier, and PsycInfo databases. In addition, 19 agencies were researched to determine which provided information or addressed both issues of pregnant and parenting teens and youth with disabilities. As reflected in Table 1 (see following page), an information void exists regarding the population of pregnant and parenting teens with disabilities. Information on the topic of teen parenting is available from some agencies and information on youth with disabilities is available from others. However, specific information on the delimited population of pregnant and parenting teens with disabilities is not available on a national basis. None of these agencies had information on the number of pregnant and parenting teens with disabilities or on the best practices to use when teaching them about pregnancy and responsible adult living.

Youth with Disabilities

Adolescence may be broadly defined as the transition period from dependent childhood to selfsufficient adulthood. It is a time of conflict and redefinition, as many teens experience a growing interest in heterosocial relationships and their emerging sexuality (Clark & Kolstoe, 1999; Watson, Quatman, & Edler, 2002). Adolescence is a period of psychological and social change that may cause youth with disabilities to experience stress related to conformity with peers (McDowell, 1991). For youth with disabilities, there is an increasing discrepancy between their physical development, which is obvious, and their social and emotional levels that are not so obvious. Adults tend to respond primarily to the physical maturation and assume or expect an equal amount of maturational development in affective areas (Clark & Kolstoe).

Youth with disabilities are challenged daily because they are recipients of services whose providers are often unaware of their learning needs. They frequently receive the same information in the same way as youth without disabilities (Shapland, 1999). However, their unique learning needs may prevent them from retaining and utilizing information they receive through methods presented by community service agencies. Low academic achievement and high dropout rates place them at a very high risk for pregnancy (Wagner, 1993). Students with mild disabilities may receive information that is not adapted to their unique learning needs, while youth with more

Agency Resources Chart						
Agency	Information					
	Teen Parents	Youth with Disabilities	Pregnant & Parenting Teens with Disabilities	Teen Parent Programs	Teen Parenting Programs with Disabilities	Comments
Alan Guttmacher Institute	\checkmark			~		
American Association of Family & Consumer Sciences						Referred to state affiliates
Association for Career and Technical Education						Referred to state affiliates
Association for Retarded Citizens, US		~				
Child Trends	✓					
Children's Defense Fund		~				
Council for Exceptional Children						Sex Education Focus (1991)
Georgia Campaign for Adolescent Pregnancy Prevention	~					
National Campaign to Prevent Teen Pregnancy	√					
National Center for Educational Statistics		~				
National Center for Education in Maternal & Child Health	√	~	√	~		
National Center for Health Statistics	✓	~		~		Sexuality Education (1992)
National Center for Research in Vocational Education						
National Dropout Prevention Network	√	~				Selected abstracts
National Health Information Center						
National Dissemination Center for Children with Disabilities						Sexuality information for youth with disabilities
National Organization on Adolescent, Pregnant, Parenting, & Prevention	✓					
National Institutes of Health	√					
Sexuality Education Information Council of the U.S.	√		\checkmark	~		
U.S. Department of Education	✓	~				Referred to NCRVE

Table 1Agency Resources Chart

severe and obvious disabilities do not receive much, if any, information relating to their sexual development (Doren, Bullis, & Benz, 1996).

Visible Disabilities

Teens with visible disabilities, which include some types of mental retardation, cerebral palsy, and/or other physical impairments, fall into society's more common perception of disabilities. These youth are more easily identified. However, there is a lack of awareness on the part of parents and professionals to acknowledge these individuals' sexuality and, therefore, a failure to provide them any program addressing sexual development, reproductive health, and pregnancy prevention (Blum, 1997). Individuals with physical disabilities may have very different educational needs than individuals with mental disabilities and may, therefore, need specific programs addressing sexuality and pregnancy prevention.

Invisible Disabilities

Teens with invisible disabilities may be more readily included in society. The largest and most common group represents youth with learning disabilities (LD), a disorder in one or more of the basic psychological processes involved in understanding and using spoken and written language (Henkel, 2001). While youth with learning disabilities may have average or above average IQ scores, they experience difficulty in the basic skills of reading, math, and writing. They may have auditory processing and visual perception problems that affect how they receive and process information. Youth with emotional and behavioral disorders and attention deficit disorders are challenged by impulsivity, inability to attend, and poor organizational skills that impact their ability to learn new information as well as to relate socially (Wenger, Kaye, & LaPlante, 1996). Teachers and service providers may not recognize the learning styles of these students and as a result, present information on sexuality, pregnancy, and parenting in the same format to all students.

Teen Pregnancy

Research has identified a number of factors related to individual behavior, family and community situations, and cultural pressures that underlie teen sexual and contraceptive behavior, pregnancy, and childbearing (Kirby, 1997; Moore, Miller, Morrison, & Glei, 1995; School Board News, 1999; U.S. Department of Health & Human Services, 2003). Race, ethnicity, income, and the family structure children grow up in have an important influence contributing to their risk for teen pregnancy (Blum, Beuhring, Shew, Bearinger, Sieving, & Resnick, 2000; Kirby, 1997; Hao & Cherlin, 2005; Miller, 2002). Other factors related to teen pregnancy include, age at first intercourse, goals, self-esteem, educational expectations, and career aspirations (McCullough & Scherman, 1991; Stewart, 2003). Farber (2003) identified additional factors considered to influence teen sexual risk taking and pregnancy such as community environment, intimate relationships, peer environment, and individual characteristics. Farber claimed that having more of these factors present in an adolescent's life places him/her at a higher risk for becoming teen parent.

Risks For Teen Pregnancy

Risks for teen pregnancy are clearly described in the literature: low achievement test scores; poor academic achievement that often leads to high dropout 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; or poverty (McCullough & Sherman, 1991; Hockaday, Crase, Shelley, & Stockdale, 2000; Stewart, 2003; U. S. Department of Health and Human Services, 2000). Poor academic performance is a risk factor for both males and females (Young, 2001). Teen parents often have low basic education skills, and often are behind grade level for their age (Furstenberg, Brooks-Gunn, & Morgan, 1987). Koshar (2001) found that many adolescent females who became pregnant were already experiencing academic difficulties in school.

Pregnancy at any age generates developmental changes, but in a teen it can create a developmental crisis. When the stress of two developmental stages, adolescence and young adulthood are compressed, successful completion of both tasks is compromised (Rodriguez & Moore, 1995; Tapert, Aarons, Sedlar, & Brown, 2001). Failure to accomplish such developmental tasks not only places the teen at risk for further developmental difficulties, but it places the children of these teens at biological, social, and psychological risk. In addition to the risks discussed in the Introduction, other complications experienced by children of teen mothers include, inadequate school performance and life-long learning disabilities (Dash, 2003; Merrick, 1995; National Campaign to Prevent Teen Pregnancy, 2003; Rothenberg & Weissman, 2002).

Although evidence suggests the effectiveness of several programs to prevent adolescent pregnancy (Blum, 1997; Brantlinger, 1992; Shapland, 1999), the subgroup of adolescents with disabilities is rarely acknowledged in the literature addressing teen pregnancy. Discussions on teen pregnancy tend to view all teens as the same, except for cultural background and gender (Blum et al., 2000). Although adolescents 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 population (Carter, 1999). Yet, this population of teens confronts service providers and policymakers with unique challenges in developing and providing appropriate programs and services to meet their needs (Wolff & Foster, 1993).

Risk Factors for Teen Pregnancy Among Students with Disabilities

Having a disability places a teen at further risk for pregnancy, as the disability itself may lead to many of the factors cited above (Yampolskaya, Brown, & Greenbaum, 2002). In addition, youth with disabilities experience other challenges that further complicate the problem. A 1995 survey of youth with disabilities planning for transition from school to work and the community (Shapland, Vanderbury, & Eisland, 1995) revealed that many have no one to talk to about typical teen concerns such as drugs, alcohol, sexuality, anger, or despair. While their peers without disabilities often said they talk with parents and other peers concerning these subjects, youth with disabilities often experienced isolation. These conversations can serve as practice for establishing appropriate social skills. Acquiring social skills is an important part of normal adolescent development, fostering the teen's growth into an adult who has positive self-esteem, can make healthy sexuality choices, and can move toward independence (Shapland et al., 1995). According to the National Information Center for Children and Youth with Disabilities (1992), youth with disabilities need information about values, morals, friendship, dating, love and intimacy, how to protect themselves against unwanted pregnancies and sexual exploitation, and positive parenting roles and responsibilities.

Wong, Wiest, and Trembath (1998) compared regular education students with students with disabilities, and found the latter were more likely to participate in antisocial behaviors, despite reporting they did not wish to. Teachers in a study by Sprouse, Hall, Webster, and Bolen (1998), consistently rated youth with disabilities as exhibiting higher incidences of social perceptual difficulties. Social perceptual difficulties include defiant behavior, lack of cooperation, and lack of self-control. These types of social behaviors can contribute to disenfranchisement of youth with disabilities from their peers without disabilities. How one feels and sees oneself greatly impacts development and future outcomes. One of the antisocial behaviors youth with disabilities could be persuaded to participate in is premarital sex (Ventura, Matthews, & Curtin, 1998).

Youth with disabilities often receive negative messages that affect their self-esteem. Lack of social opportunities leading to social isolation can build feelings of incompetence, dependence, loneliness, and a feeling of asexuality. Often family and professionals' over-protectiveness emphasizes the teen's deficits, leading to unhappiness, self-consciousness, and the inability or

lack of initiative to make decisions (Sprouse et al., 1998). Teens in the lowest quartile of academic achievement, including those with disabilities, are three times as likely to become parents and leave school prematurely (Children's Defense Fund, 1995; Manlove & Moore, 2001; Wagner, 1991). Youth with disabilities are four times more likely to be sexually abused or exploited than their typical counterparts. The most obvious reason relates to cognitive limitations to determine safety (Shapland, 1999). However, risk increases with lack of knowledge of sexuality and lack of information on exploitation. The situation is further complicated by the impulsivity, low self-esteem, poor decision-making skills, and lack of social opportunity of many youth with disabilities.

It is not a new phenomenon that individuals with disabilities desire to engage in sexual relationships, marry and have children (Brantlinger, 1988). Young maternal age coupled with identified disabilities has highlighted the need for support programs focused on teaching teen parents basic child-rearing practices and safety measures to ameliorate environmental risks (Tymchuk, Hamada, Andron & Anderson, 1990). However, the most appropriate time to reach students is before they are sexually active (Shapland, 1999).

School Dropout

About one-third of female dropouts report pregnancy as the reason for leaving school (National Campaign to Prevent Teen Pregnancy, 2002; Brindis & Philliber, 2003). Regardless of academic standing, about 25% of teen mothers have a second baby within one year of their first baby (Children's Defense Fund, 1986, Kreinin, 1998). Although limited, documentation of pregnant teens in special education indicates pregnancy rates of this group of adolescents are similar to, if not greater than, those of non-special-education students. In a study conducted by Kleinfeld and Young (1989) with a random sample of pregnant teens served by the San Diego Adolescent Pregnancy and Parenting program, 20% were in special education compared to 10% for the overall school district. Females in special education who were younger than 16 and had poor academic skills were five times more likely to give birth than those with average academic skills (Muccigrosso, Scavarda, Simpson-Brown, & Thalacker, 1991). The National Longitudinal Transition Study, conducted from 1987 to 1993, reported that of individuals with disabilities who had been out of school 3 to 5 years, 16% of males were reported to be fathers and 41% of females were reported to be mothers (Stanford Research Institute [SRI], n.d.).

A pregnant teen is more than three times as likely to drop out of high school as her non-pregnant counterpart (Children's Defense Fund, 1995). Typically, teen mothers earn about half the lifetime income of women who delay childbirth until their twenties, and have lower career aspirations, occupational prestige, and less satisfaction with career progress (Center for Population Options, 1991; Hockaday et al., 2000; Nord, Moore, Morrison, Brown, & Myers, 1992). Youth with disabilities are at greater risk of lifelong economic and social harm if they drop out of school (Blackorby, Edgar, & Kortering, 1991; Wagner, 1991; Shapland, 1999). Rothenberg & Weissman (2002) found that 7 out of 10 females who became teen mothers did not graduate from high school. SRI's (n.d.) longitudinal study determined that 54% of females with disabilities who dropped out of high school were likely to be mothers. No specific data was found on the dropout rates of youth with disabilities who were pregnant or parenting. Therefore, a logical deduction would be that a pregnant or parenting teen who also has a disability would be at greatest risk for not completing high school and less likely to become competitive in the workforce.

Pregnancy Prevention and Parenting Programs

Literally hundreds of teen pregnancy prevention programs have been launched over the past 30 years in an effort to combat teen pregnancy and thus reduce the problem (Franklin & Corcoran, 2000). These have included educational programs, programs that improve access to

contraception, and multi-component programs. Educational programs include those that teach only abstinence plus effective contraceptive practice. Programs designed to improve access to contraception include the development of school-based or school-linked clinics and adaptations of family planning services to increase their accessibility and appeal to youth. Multi-component programs may include some combination of job readiness training, academic tutoring, delayed sexual activity, life-skills training, self-esteem, parenting, recreation, mentoring, sexuality education, and health and mental health care (Zero Population Growth, 1997).

Teen pregnancy prevention efforts have emphasized education, skills, abstinence, and access to contraception. However, the definition of what constitutes teen pregnancy prevention is best expanded to include activities that seek to instill teens with confidence and a sense of the future, critical elements to promote a pregnancy-free adolescence (U.S. Department of Health and Human Services, 1999). Throughout most of the literature on pregnancy prevention, there is little discussion related to accommodating youth with disabilities. Successful strategies in pregnancy prevention for youth without disabilities can be a starting point in examining the best accommodations for youth with disabilities.

Learning Styles

The goal of educators and policymakers is to maximize learning for all students. A number of studies suggest that educational programs can yield increases in the socio-sexual knowledge of students with mild intellectual disability (Lindsay, Bellshaw, Culrose, Staines, & Michie, 1992; Penny & Chataway, 1982). The literature also indicates the possibility that the academic performance of youth with disabilities may be affected by their cognitive learning style, which is greatly influenced by their culturally induced cognitive style (Ramirez, 1982).

Numerous learning strategies can be used to teach academic and social skills to youth with disabilities in general and special education classrooms (Ysseldyke, Algozzine, & Thurlow, 2000). Since there is evidence in the literature that youth with disabilities benefit from certain learning strategies and methodologies in general and special education areas, it can be inferred that these strategies and methodologies would also be needed to teach them about responsible adult behavior, including pregnancy, its prevention, and parenting.

Sex Education

In general, teens learn about sex from their parents, sex education programs in school, and friends. Despite the fact that teens are sexually active, have babies, and are at-risk for contracting AIDS, high-quality sex education programs have been offered to only a small percentage of teens (Kirby, 2001; May, Kundert, & Greco, 1993). Irwin (1993) stressed that information shared with teens about sexual health should be no different for teens with disabilities. However, much of the available printed material on reproductive health is generic in nature, rarely mentioning considerations that may be needed for youth with disabilities. In our search, we located more references related to sexuality and sex education than pregnancy and parenting. However, many of these were dated earlier than 1992 (Finger, 1990; Hingsburger, 1990; Kempton, 1988; Sugar 1990). Some were out of print (Kupper, Ambler, & Valdivieso, 1992; Summer, 1986; Way, 1982). Only one discussed contraceptive choices for individuals with disabilities (Hakim-Elahi, 1992).

In a study of youth with mild disabilities and their teachers, Brantlinger (1992) reported only a third of the teachers offered comprehensive sex education or family life programming to their students, and he noted there was a limited amount of information available on sex education in special education classrooms. When given appropriate learning opportunities, youth with

disabilities can learn the basics of appropriate health management and benefit from directed discussion and activities that relate to personal relationships (Carter, 1999). As youth with disabilities are fully included in society, they need guidance and instruction (May et al., 1993) appropriate to their learning needs. McCabe (1993) discussed the rights of people with disabilities to develop relationships with others and to be informed about their sexuality, pregnancy, contraception, and sexual transmitted diseases. According to May et al., if the rights of youth with disabilities are to be upheld, we must examine instruction that includes sex education and parenting skills for these individuals.

According to Shapland (1999) a broad-based curriculum including human anatomy, contraception, sexually transmitted diseases, decision-making, and future goal setting are all important issues for youth with disabilities. Suris (1996) asserted that when developing sex education programs for youth with disabilities, the first step should be to identify teens needing special accommodations and assess individual needs. Information should appeal to various learning styles, including auditory, visual, and experiential materials. Youth with disabilities may have difficulty generalizing information to various settings, so providing *teachable moment* opportunities for *real life* relationships will assist in giving context to information about sexuality and reproductive health (Shapland, 1999).

Intervention Programs

Participants in a survey conducted by the National Dropout Prevention Network rated programs for pregnant teens as one of the strategies most effective for dropout prevention (Shapland, 1999). Although efforts to reduce the rates of teen pregnancy in the United States have spanned two decades, there are few well-evaluated programs, and even fewer evaluation results that have been published (Carrera, Dempsey, Philliber, & Philliber, 1992; Stahler, DuCette, & McBride, 1989). Educators and practitioners have advocated that the most successful teen pregnancy prevention programs are long term (School Board News, 1999). Effective interventions for youth with disabilities must include information about responsible decision-making, adult roles, healthy attitudes about parenting, and positive family attachments (Kirby, 2001).

Some states offer teen parenting programs. Instructors for these programs can determine the number of pregnant and parenting teens with disabilities who receive services through program evaluation. For example, in 2000, Georgia serviced 1,319 single parents in 37 out of 181 school districts statewide (S. Combs, personal communication, March 23, 2005). Similarly, in a 2002-2003 report from the Ohio Department of Education Office of Career-Technical and Adult Education (S. Enright, personal communication, March 26, 2005), nearly 15% of the students enrolled in their Graduation, Reality, and Dual-Role Skills (GRADS) program for teen parents were identified as students with Individualized Education Programs. However, the numbers reported in the programs may not be a measure of the proportion of teen parents in the general population who are identified as having a disability. It is likely that the proportion of actual teen parents with disabilities is higher than the Teen Parenting Program enrollment.

Community Family Planning Services

Family planning services communities across America combine information, counseling, and sometimes the provision of contraception. Over the past several years, much federal and state funding has focused on family planning agencies (Shapland, 1999). The first challenge in such settings is to identify youth with disabilities. This is extremely difficult unless the youth has a visible disability or the clinic is based in the school and the providers have knowledge of the youth's educational needs (Shapland). Community providers have to be aware however, that youth with disabilities are included and must strive to identify them and meet their individual

needs. An awareness that many youth with learning disabilities have difficulty remembering and learning sequences calls for repetition and close follow-up by the staff to assure appropriate retention of the materials taught.

Inclusion of Males

Young men with low academic achievement have the same high risk for promoting pregnancy as young women (Thornberry, Smith, & Howard, 1997.) Being aware that young men being served may also have disabilities is an important pregnancy prevention factor. Studies related to teen fathers are limited; however, there is evidence to suggest that emotional and other costs have not been well documented (Lawhon, 1996; Moore et al., 1995; Sonenstein, Stewart, Lindbert, Pernes, & Williams, 1997). In our search, no specific information was found relating to teen males with disabilities who became fathers or their inclusion in programs about responsible sexual behavior and parenting. The National Longitudinal Transition Study provided post-graduation statistics on the number of fathers with disabilities, but did not indicate if these men became fathers before leaving school. (SRI, n.d.).

Recommendations

Based on the deficient literature available on pregnancy and parenting for youth with disabilities, the following recommendations are made for policymakers and educators:

- 1. Information regarding incidences of pregnancy and parenting among youth with disabilities should be collected and collated.
- 2. Include a component focused on youth with disabilities in the goals and objectives of national organizations and foundations.
- 3. Make pregnancy prevention program facilities, including educational materials, accessible to individuals with disabilities.
- 4. Promote the education of health professionals, and teachers from special and general education on pregnancy and parenting issues for youth with disabilities.
- 5. Provide education and emotional support to families as the primary educators of their child.
- 6. Provide funds from federal and state agencies for appropriate education and health care for youth with disabilities.
- 7. Appropriate federal and state funds to accumulate valid data about the impact of specific programs and interventions for successful strategies.

Summary

As policymakers, administrators, program developers, schools, and parents continue to address teen pregnancy prevention, recognition of the needs of youth with disabilities is essential. It is evident that youth with disabilities, although not distinctly differentiated in the literature and in program planning, are at very high risk for early pregnancy and have specific support and information needs. It is the responsibility of educators and policymakers who work directly with youth with disabilities to ensure that they receive the same opportunities for information related to pregnancy and parenting that all teens receive. The pivotal questions for future research then are: What are the incidence of youth with disabilities who experience teen pregnancy and parenthood; what disability categories do those students represent, what are the educators and service providers best meet these needs?

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