

Strong Proud Sisters: Girls and Young Women with Disabilities Access to Health Care: Usage, Expenditures and Barriers

There has been little research on access to health care by girls and young women with disabilities. Most of the studies and writings on access focus on adult women, on persons with disabilities, or on youth with disabilities without regard to gender. The findings from these sources in combination with anecdotal information (Rouso, 1993) suggest several conclusions.

Depending on the extent and nature of their disabilities, girls and young women with disabilities may have more extensive, complex relationships with health care providers and systems than their nondisabled counterparts. They have the same health care needs and issues as nondisabled girls, plus some disability-specific needs that may involve repeated hospitalizations with separations from family, frequent appointments with disability-specific professionals, and a regimen of procedures to follow and/or medications to take at home or at school.

There is some indication that medical care usage is high for people with disabilities, with even higher usage for people with multiple disabling conditions (Trupin and Rice, 1995). Research also suggests that younger disabled people have lower rates of usage than older disabled people, and that for disabled people as a whole, types of usage vary with gender (Jans and Stoddard, 1999; Trupin and Rice, 1995). Disabled women have more physician visits than disabled men, whereas disabled men have more hospital visits than disabled women.



Data on medical usage by disabled youth are not disaggregated by gender; hence there is no way to compare the extent and nature of usage by disabled girls and disabled boys. However, studies from other countries, particularly less industrialized countries, indicate that when resources are scarce, boys and young men with disabilities are more likely to be provided with medical and rehabilitation services than are girls and young women (Rousso, 2000; Groce, 1997). There is need for further research to determine whether a similar pattern exists in the United States, particularly among low income families.

Regarding medical expenditures, for all ages combined, people with disabilities have per capita expenses that are four times as great as for nondisabled people, with the gap increasing with age. Also, for all ages combined, men with disabilities have higher per capita medical expenses than women. The disability and gender gaps are less significant for young people. For girls and young women with disabilities from birth to 17 years of age, *per capita* medical expenses are more than twice that of their nondisabled counterparts (\$1,670 vs. \$734); similarly, for disabled boys and young men, *per capita* expenses are \$1,650 compared to \$620 for those without disabilities (Trupin, Rice and Max, 1995; Max, Rice and Trupin, 1995, both as cited in Jans and Stoddard, 1999). As these figures indicate, youth of both genders have about the same medical expenditures.

The higher *per capita* expenses for people with disabilities may be the result not only of disability-related medical needs, but also of lack of adequate preventive care. For example, Nosek, et al. (1995) report that according to one survey, 67 percent of people with disabilities were not receiving the health services they needed for optimal health. These authors also note that one of the objectives of *Healthy People 2000* was to increase to at least 80 percent the proportion of people receiving all appropriate health screening services and at least one age and gender-appropriate counseling/information service, as recommended by the US Preventive Task Force. According to a 1991 review, only 12 percent of disabled persons had received the entire set of recommended services, and only 8 percent of those with annual incomes less than \$10,000 had received these services. Studies of women with disabilities suggest that women with multiple functional limitations, as well as older disabled women, are less likely to receive cancer screenings than are their nondisabled counterparts (Nosek, 1997; Jans and Stoddard, 1999). Unfortunately, none of the available studies focus on youth, much less on girls.

Given higher *per capita* medical expenses for youth and adults of both genders with disabilities, access to health insurance becomes all the more important. Research suggests that a substantial percentage of disabled youth are uninsured, although the percentages are similar to those for nondisabled youth. For example, the US Census Bureau, using 1994–1995 SIPP data, reports that 15.7 percent of youth with disabilities between the ages of birth and 21 are uninsured, compared to 16.4 percent of nondisabled youth. A slightly lower percentage of youth with severe disabilities are uninsured (14 percent), compared to those with non-severe disabilities (16 percent).

Several sources indicate that youth with disabilities are more likely to be covered by public insurance than are their nondisabled counterparts, with the likelihood increasing further for youth with severe disabilities. For example, according to 1989 NHIS data, disabled children and adolescents under the age of 18 are twice as likely (25.9 percent) to be covered by public programs as are nondisabled youth (13.9 percent) and are less likely to depend solely on private

insurance (54.7 percent compared to 77.7 percent). Children with severe disabilities are even more likely to depend on public programs (32.7 percent) and less likely to rely on private insurance alone (49.5 percent) (LaPlante, Rice and Cyril, 1994). The 1994-95 SIPP data show similar patterns.

Unfortunately, these figures are not disaggregated by gender, so we do not know how girls and young women fare. Nor do these data necessarily reflect the picture today, since in recent years eligibility requirements for public programs have become more stringent. Here is what we do know about gender differences as well as the impact of these changes. Children with disabilities under the age of 18 who meet the program definition of disability and the financial means test are eligible for Supplemental Security Income (SSI), a program of the Social Security Administration. In most states, individuals eligible for SSI also are eligible for Medicaid. Data from 1988 to 1998 indicate that fewer girls than boys receive SSI, and hence Medicaid, and that the gap has been growing over time. The higher rates of disability among boys compared to girls do not totally account for the benefits gender gap (Jans and Stoddard, 1999), so girls with disabilities may have limited access to Medicaid.

In fact, both disabled boys and girls may be inadequately served. A 1996 change in the definition of childhood disability resulted in the disqualification of nearly a quarter of a million children with disabilities who had previously been eligible; even after appeal, some 100,000 children are likely to lose benefits (Schulzinger, 2000). While Congress required states to continue Medicaid coverage for children dropped from SSI, many children were inappropriately dropped from Medicaid as well. It is also significant that the 1996 changes in the law require that youth with disabilities receiving SSI must be reevaluated at age 18 to see if they meet the more stringent adult definition of disability. In the two years since 1996 for which data are available, about one third of youth with disabilities designated eligible for SSI under the childhood definition of disability were deemed ineligible by the adult definition. State Medicaid agencies are supposed to determine whether youth with disabilities who no longer qualify for SSI might meet other state eligibility requirements for Medicaid before dropping them from the Medicaid roles; no data are available on whether this has actually happened (Schulzinger, 2000).

While more research definitely is needed, there is some indication that the greater reliance of children and youth with disabilities on public insurance may be a mixed blessing. In a 20 state survey of 2,200 families with disabled children conducted by The Family Partners Project (2000), families whose primary health coverage was paid by Medicaid reported greater satisfaction with their child's plan and gave higher ratings on most items regarding health plan performance than families with private insurance. On the other hand, anecdotal information suggests that for some, public insurance may limit health care options; for example, physicians may be reluctant to accept Medicaid.



Also, as Fiduccia and Wolfe (1999) describe, recent efforts to convert Medicaid into a managed care system may work against recipients with disabilities, who tend to be high users of health care services whose care may be more costly than for their nondisabled counterparts' care. This requires HMOs to purchase additional accessible equipment. HMOs, preferring low use, low cost members, may seek to keep youth and adults with disabilities out, or fail to provide disabled members with adequate care. However, the successful outcome in April, 2001 of a class action lawsuit against a major HMO for giving people with disabilities inferior care puts managed care systems on notice and may result in higher quality health care for disabled members (Lewin, 2001).

Reports on health care issues of adult women with disabilities describe a multitude of barriers beyond inadequate insurance that are likely to be applicable to girls and young women with disabilities as well (Gill, et al., 1994; Nosek, 1997; Fiduccia and Wolfe, 1999). These include: architectural barriers, such as entrances with stairs, narrow doorways, inaccessible toilets and inaccessible examining tables and medical equipment; health care offices; communication barriers, such as the failure to provide sign language interpreters or to provide information and materials in alternative formats, such as large print or on audiotape; and transportation barriers, such as the inability to obtain accessible transportation at a reasonable cost that gets women to and from medical appointments in a timely manner. While some of these

barriers have been outlawed by the Americans with Disabilities Act, compliance varies considerably.

Among the most damaging barriers are attitudinal, including health care providers' negative attitudes and their refusal to treat a woman with a disability, provision of treatment based on misinformation about how a particular medication or procedure might interact with the woman's disability, withholding of disability-related or other information, doing procedures or treatments without the woman's knowledge and/or failing to involve her in the decision making process. At their worst, negative attitudes translate into physical or sexual abuse (Gill et al., 1994; Fiduccia and Wolfe, 1999).

In addition, when disabled women, particularly those with physical disabilities, recall their childhood experiences with the medical establishment, they often recount medical horror stories of public stripping and objectification of their bodies in front of doctors, without regard to modesty or privacy (Gill et al., 1994). For some, survival required dissociation from the body that was no longer in the young woman's control, most likely at considerable expense in terms of body image and self-esteem.

Such negative experiences, to the extent they occur early, are likely to cause girls and young women with disabilities to see health care providers as enemies rather than allies. A study of 31 women with physical disabilities between the ages of 22 and 69, 19 of whom had early or adolescent onset of disability, found that many of the women, in response to negative experiences with medical systems during childhood, had established patterns of compliance or avoidance that remained with them during adulthood, impeding their ability to manage their own health care (Nosek et al., 1995).

Although parents are involved in the health care issues of all youth, their involvement may intensify when the young person has a disability, and even more so when the young person is both disabled and female. While there has been little formal research in this area, it is likely that to the extent that a young person has disability-related medical needs, parents will be involved in additional doctor visits, medical decisions and follow-up activities at home or at school. Depending on the extent and nature of the disability, parents may be called upon to arrange for or provide transportation for doctor visits and assist the young person in following medical regimens. At best, parents can be active advocates, fighting barriers in an unresponsive medical system and serving as role models for self-advocacy; yet it seems likely that parents' ability to advocate effectively will vary, depending in part on their own status based on race, class, and ethnicity, for example.

In addition, anecdotal information suggests that even parents who are effective advocates may have some difficulty empowering their own children with disabilities to take charge of their own health care (Rouso, 1993). For adolescents with disabilities in particular, the very fact that parents are extensively involved in their health care may undermine their strivings toward independence. Whether to take needed medications or to cooperate in therapy sessions may become battlegrounds for self-assertion. The situation is compounded when parents assume an overprotective stance, underestimating a child's capacity to control her own care.

Parents of disabled adolescent girls may be doubly overprotective, assuming that their daughters, by virtue of being both female and disabled, are doubly vulnerable and cannot take charge. Studies of nondisabled youth suggest that, particularly for girls, one major reason for not getting needed health care is not wanting parents to find out, raising issues of confidentiality (Phillips, 1998). This may be even more of an issue for adolescent girls with disabilities, who may have even fewer opportunities for health care without parental involvement.

Surveys of teens with disabilities on health care issues indicate that they are eager to take charge of their own health care, and that they need more information and support to address the formidable barriers they face. Young participants in a Shriners' Hospitals survey of disabled teens and young adults in Florida, Kentucky, Utah and Hawaii identified two major barriers to autonomy in health care: parental overprotectiveness and their own fears. A 1997 Minnesota survey of youth between the ages of 14 and 25 with chronic illnesses or physical, sensory or cognitive disabilities, conducted by the Pacer Center, found that young people were concerned about how to pay for their health care, what can happen if their disability/illness worsens, and how to develop an emergency plan in case that occurs. They also wanted medical providers to give them more information about their disability/illness and medical issues.

Finally, they wanted someone to talk to about how to make their own medical decisions (less than half have such a person). And they also wanted to have contact with an adult with a disability who can serve as a mentor and guide and to have opportunities to talk about health promotion and risk behaviors and concerns including sexuality, family planning, smoking, drugs and alcohol, anger and sadness, and violence (Igoe, 2000). Surveys of nondisabled teens show some parallels. The Commonwealth Fund survey -- which did not include girls with disabilities -- found that nondisabled girls were interested in talking to doctors or other health care professionals about "sensitive topics" such as eating disorders, sexually transmitted diseases, drugs, alcohol, and physical and sexual abuse; unfortunately, only a small percentage of girls had doctors who initiated such conversations (Commonwealth Fund, 1997, as cited in Phillips, 1998).



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