

Assessing the Health Care Needs of Kansas' Young Adults with Disabilities

By Jean Hall, PhD and Barbara Starrett, MHA

A survey and focus groups with 30 young adults with disabilities indicate that nurses and other health care providers can help to reduce barriers to accessing medical services, including transportation issues and provider attitudes toward individuals with disabilities. In addition, health care providers can encourage young adults with disabilities to more fully participate in health care decisions and community life by providing to them information about topics such as birth control, pregnancy, and sexually transmitted diseases (STDs), or activities they can undertake to maintain general health, manage chronic illness, and prevent secondary conditions. In some cases this information may need to be communicated using alternate formats such as Braille or sign language, and activities may need to be structured to use accessible facilities or equipment.

Children with disabilities have a greater need for and a higher rate of contact with the health care system than children in the general populace (Newacheck & Kim, 2005; Newacheck, et al., 1998; Silver & Stein, 2001). Not only do these children have twice as many physician visits, they have seven times as many contacts with non-physician health professionals, including nurse practitioners and physician assistants, psychologists, social workers, and physical therapists, and about 50% more emergency room visits.

Youth with disabilities comprise a special category of children with disabilities because they are in transition from a health care environment that includes parental and school-based supports to one that requires independence and self-advocacy. In addition, as these youth enter adulthood, they become part of a national population segment, 18 to 24 year olds, who are least likely to have a usual place to go for medical care (U.S. Dept of Health and Human Services, 2006). Thus, health care providers need to be aware of their special needs for access to health care services and information, as well as their need for opportunities to participate in decisions about their own health care.

The Kansas Youth Empowerment Academy (KYEA), a youth-driven, non-profit organization, commissioned a study of the experiences and concerns of a group of young community leaders with disabilities with respect to health care, employment, and education. Summarized here are the issues that particularly concern nurses and other health care providers. For the full report, please see <http://www.kyea.org/documents/Healthreport.pdf>

Methods

We collected data in early 2006 using a researcher-written survey and three focus group sessions addressing health care, employment, and education concerns of young adults

with disabilities. The sample was comprised of 30 Kansas Youth Leadership Forum (KYLf) alumni who voluntarily participated in the study without receiving monetary compensation during a KYLF alumni event. These individuals became KYLF participants through a competitive selection process open to Kansas students with a disability in 11th or 12th grade who demonstrate leadership potential in school and community.

The individuals in the study were between 18 and 24 years of age, some of whom recently experienced transition from youth to young adulthood status in the health care system. The sample was 57% male, and 93% White, with the remaining 7% African-American. Most (73%) of the participants lived in their parents' home, but 27% lived independently in either their own home/apartment, with a roommate, or in a college dormitory. No group home residents participated in the study. The sample included representatives from 19 of Kansas' 105 counties, representing both urban and rural perspectives.

Two-thirds of the sample indicated they had a disabling or chronic physical health condition, including 17% with cerebral palsy, 13% who were deaf or hard of hearing, 7% with a traumatic brain injury, 3% who were blind or visually impaired, 3% with gastrointestinal problems, 3% with orthopedic disabilities, and 20% with other types of disabling or chronic health conditions. More than half the sample reported a cognitive disability, with 37% having a learning disability, 13% with attention deficit disorder, and 7% with autism. Additionally, 7% of the sample had mental health problems, and 3% had a speech communication disorder. These conditions were not mutually exclusive, i.e., could be co-occurring.

Findings

Issues concerning health care, health insurance, employment, and community participation emerged from the survey and focus groups. Although health care providers are not directly involved in employment and community participation, we include findings on these topics because insight into the whole person is beneficial when providing health care services.

Health care. Ninety percent of the young adults surveyed could name their regular source of medical care (e.g., doctor's office, hospital clinic), and 87% of them received medical care at least once during the prior year. However, 10% of the sample lacked a regular source of medical care, and 13% had not seen a doctor in the prior year. Maintaining a usual source of health care is particularly



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important in achieving continuity of care for problems that could contribute to and confound other medical conditions, as well as for obtaining preventive health services (American Family Physician, 2000; Pancholi, 2004). The need for consistent care among the survey sample is indicated by two findings: 40% were seen by specialists in the prior year, and 43% took prescription medications—a fourth of whom required four or more medications.

The majority (70%) of the sample indicated they were not prevented from accessing health care services. Other respondents, however, cited three major obstacles to fully accessing and participating in health care services: expense, transportation, and attitudes of health care providers. The health care expense concerns experienced by the general populace are exacerbated for young adults with disabilities because of their greater need for services and lower incomes. Because many individuals with disabilities rely on others for transportation or use public transportation, efficient use of patient time during an office or clinic visit is also important.

The attitudes cited in the survey and discussed in the focus group indicate that many health care providers still subscribe to the "medical model" of disability. These youth said that physicians see their disabilities first and feel compelled to "fix" them rather than to see them as individuals who have the same needs and desires as everyone else. Similarly, fully half of the participants said they had never received any information about birth control, pregnancy or sexually transmitted diseases (STDs) from their doctors. Given that 77% of the participants plan to marry and 70% expect to have children, this finding is rather troubling. The young adults suggested that medical providers learn more about people with disabilities and see them as individuals rather than as their conditions.

Health insurance. Ten percent of the sample reported having no health insurance and another 10% did not know if they had health insurance. Not surprisingly, perhaps, "paying for health care" was the number one area about which the young adults said they needed more information. In the focus group, participants also expressed concerns about increases in their co-pays and medical billing problems. During focus groups many participants voiced discontent with the delays they experience in accessing health care and durable medical equipment. They also experienced difficulties understanding the availability of services, finding doctors who accept Medicaid, and getting referrals to see specialists.

Employment. The survey indicated 70% of participants were currently working full- or part-time for pay and 20% had volunteer positions. Thirteen percent of respondents expected to be working for pay within the next six months. Unfortunately, 20% of the sample feared losing health insurance or disability benefits if they earned too much income. This level of fear may indicate they were not aware of Kansas' Medicaid Buy-In program, Working Healthy, which allows more income while maintaining Medicaid coverage (www.workinghealthy.org).

Community participation. Nearly one-third of participants indicated that they were not satisfied with their current levels of social activity. Active participation in one's community can be difficult for people with disabilities due to inaccessibility of materials, facilities, and communication. For example, for young adults with mobility impairments, participation in physical activities can be hampered by a lack of physically accessible equipment, activities, or buildings. For young adults with sensory impairments, lack of written materials in Braille or audiotape formats, or lack of sign language interpreters also can prevent full participation. Survey respondents indicated they wanted to know more about "becoming more physically active," "how to find a support group," and "how to participate in recreational activities," among their top ten needs for more information. As public health officials become more aware of the importance of recreation and physical activities for maintaining health and managing chronic illness, such activities must be made available and accessible to everyone, including young adults with disabilities.

Conclusions

These findings complement those in Kansas Department of Health and Environment's Disability and Health Program Disability and Health in Kansas report, which stated, "Limited access to health and wellness services and education are a significant barrier to a healthy life for people with disabilities in Kansas" (KDHE, 2002, p. 16). Nurses and other health care providers who come into contact with youth or young adults with disabilities can help to reduce barriers to medical services, including transportation issues and provider attitudes toward the individual. In addition, health care providers can encourage young adults with disabilities to more fully participate in health care decisions and community life by providing to them information about topics such as birth control, pregnancy, and STDs, and activities they can undertake to maintain general health, manage chronic illness, and prevent secondary conditions. In some cases this information may need to be communicated using alternate formats such as Braille or sign language, and activities may need to be structured to use accessible facilities or equipment.



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Jean P. Hall, PhD is a Research Assistant Professor at the University of Kansas. Her research interests focus on health policy and access issues for people with disabilities. She has worked on state and federal projects related to education, employment, and health care for people with disabilities in the educational, welfare to work, One-Stop, Medicaid, and Medicare systems. One of her recent projects was a study funded by the Kaiser Commission on Medicaid and the Uninsured to assess the potential impact of Medicare Part D implementation on dually-eligible Medicaid Buy-In participants. She is currently the principal investigator evaluating the Kansas Medicaid Buy-In program and the Kansas Demonstration to Maintain Independence and Employment. She has prepared and presented testimony at the state and federal levels with regard to these programs and remaining barriers to the full participation of people with disabilities.

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