

# Kansas

## connections

Rural Health Education and Services

Vol. 14 No. 2 Fall 2006

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**KU**  
**MEDICAL**  
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**RURAL**  
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## Youth Empowerment Academy

### *Focus group reveals insight into health care*

As the world of medicine undergoes incredible changes in methods of treatment, as well as the process by which care is delivered to patients, the need for education and advocacy has become increasingly great. According to the Kansas Youth Empowerment Academy (KYEA), young people with disabilities have more opportunities and more challenges than at any other time in the nation's history, and the need for this education and advocacy for youth with disabilities has increased.

The Kansas Youth Empowerment Academy (KYEA), is a non-profit organization established to house leadership forums and other programs to empower young people with disabilities. KYEA provides youth with disabilities the encouragement and information about resources that will enable them to develop as leaders and become agents of change.

The mission of the KYEA is to promote and support the development of youth with disabilities to become empowered community leaders. This is achieved through the implementation of various programs that target youth with disabilities through education, mentoring, and peer support. KYEA, through Sunflower Foundation grant funding, launched the "Creating Youth Agents of Change" program to help youth identify health-related issues and develop advocacy strategies that "put them in the driver's seat" for promoting health-related change.



**Participants of the Kansas Youth Empowerment Academy discuss the challenges they face with regard to health-related issues.**

The program began with an information-gathering phase among past participants of the Kansas Youth Leadership Forum, a program sponsored by KYEA. Jean Hall, PhD, and Barbara Starrett, MHA, Center for Research on Learning-Division of Adult Studies, University of Kansas, were integral in distributing a written survey and assisting with focus group sessions about health-related issues that concerned youth with disabilities, such as health insurance, employment, education, and transition from school to community life issues.

Thirty youth participated in the survey and ranged in ages 18-24 years. Participants represented 19 of Kansas' 105 counties, and 30 percent (9 participants) represented rural counties. Survey results and focus group findings from

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the participants conveyed personal insights and experiences regarding access to health care, as well as employment and educational issues related to having a disability.

It was reported through the study, that 23 percent of the participants were not satisfied with their current medical care, and 30 percent reported barriers to seeing the doctor, including expense, lack of transportation, lack of insurance, and attitudes of the medical staff regarding disability.

Young adult Kansans who participated in the health survey were asked if they had discussed their changing health care needs as they transitioned to adulthood. Forty-seven percent indicated they had not, while 33 percent said they had, and 20 percent replied they did not know. When asked if they had developed a transition plan for their changing from adolescent to adult health care needs, 40 percent said they had not, only 17 percent indicated they had, and 43 percent did not know.

Participants responded that most doctors see their disabilities first and feel compelled to “fix” them, rather than see them as individuals who have the same needs and desires as everyone else. This concern is illustrated through the fact that half of the participants said they had never received any information about birth control, pregnancy or STDs from their doctors, yet, according to the study, 77 percent of the participants plan to marry, and 70 percent expect to have children.

Starrett indicates that this factor is a large concern. “It is apparent that these youth are not being provided with information about sexuality, STDs, and AIDS issues. It is essential that parents and doctors create an awareness for these youth and get the information out.” Starrett also states, “Adults will find a way to engage in sexual activity, so it is imperative that they receive information regarding issues surrounding this activity.”

As a result of the focus group, it was

suggested the medical providers have a difficult time getting past the medical model of disability and feedback indicates that these young adults feel as though medical providers need to learn more about people with disabilities and to see them as

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**Barbara Starrett, MHA,  
Center for Research on Learning-Division  
of Adult Studies, University of Kansas**

individuals rather than as their conditions.

The KYEA program, “Creating Agents of Change,” has provided insight into the needs of youth with disabilities regarding health care. This opportunity for youth to share their experiences with health care related issues reveals that many youth with disabilities are not able to, or were not provided access to services and information that could improve their health and well-being. With these findings in hand, both Hall and Starrett indicate they hope the survey will be conducted again next year to determine if attitudes or access has changed for these young adults with regard to health care.

Hall feels as though the survey and focus group have provided an awareness and insight into the challenges that many youth with disabilities face. Hall encourages health care providers to “listen to the person, make the health care process a team effort, be aware, and don’t neglect to consider the individual’s perspective...the person with the disability is the expert.”

**“Creating Agents of Change” program has provided insight into the needs of youth with disabilities regarding health care.**

