

**ASSESSING THE NEEDS**  
**(Health Status, Health Insurance,**  
**Employment, and Education)**  
**OF YOUTH WITH DISABILITIES**  
**IN KANSAS**



*Creating Youth Agents of Change*  
Funded by Sunflower Foundation  
Award No. 05-103-088

**FINAL REPORT**

June 15, 2006



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## **PREFACE**

The Kansas Youth Empowerment Academy (KYEA) officially opened its doors in October 2005. With grant funding from Kansas Rehabilitation Services and matching funds from the Kansas Legislature, this youth-driven, non-profit organization provides the framework to host programs that empower young Kansans with disabilities.

The mission of the KYEA is to promote and support the development of youth with disabilities to become empowered as community leaders. This mission is achieved through the implementation of various programs that target youth with disabilities through education, mentoring, and peer support. It also is achieved through presentations and workshops, provided by the youth, which focus on disability awareness and youth issues. KYEA subsumed into its portfolio of programs the Kansas Youth Leadership Forum (KYLF), which began in 2001 with a mission similar to KYEA's.

KYEA, with funding from the Sunflower Foundation, 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. The program began with an information-gathering phase, using a written survey and focus group sessions about health-related issues that concerned youth with disabilities. Program leaders expanded the focus of these efforts to include health insurance, employment, education, and transition from school to community life issues, because of the interconnection of these issues with the health and well-being of Kansas' youth with disabilities. A sample of past participants in the KYLF program completed the survey and participated in the focus groups.

Jean P. Hall, Ph.D. and Barbara E. Starrett, M.H.A., at the University of Kansas Division of Adult Studies conducted the survey and focus groups. In addition, Dr. Hall analyzed the survey results and evaluated the qualitative information from the focus groups. Her findings informed the advocacy strategy-building phases of the program. This report highlights findings from the survey and focus groups.

## **A**CKNOWLEDGEMENTS

This report was prepared by Jean P. Hall, Ph.D., and Barbara E. Starrett, M.H.A., Center for Research on Learning-Division of Adult Studies, University of Kansas for Kansas Youth Leadership Forum (KYLF).

Thanks to those young adults attending the KYLF Five-Year Reunion in Salina, Kansas on January 7, 2006, who completed the survey and participated in the focus group sessions. Without their willingness to share and give of themselves, this study would not be possible.

Special thanks to Pam Dickens, M.P.H., Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill, for discussion during the developmental stages of this study, and for sharing copies of a project report on which she had worked, *Assessing the Health-Related Needs of Youth with Disabilities and Chronic Health Conditions in North Carolina*.

Special recognition goes to Brenda Eddy, Julia Fonseca and Carrie Greenwood, with Kansas Youth Empowerment Academy, for their assistance with survey preparations and collection. The Kansas Working Healthy program provided financial support and the program Director, Mary Ellen O'Brien Wright, provided valuable input about the survey and focus group questions.

Additional thanks to Michelle Crick and Kari Woods for their assistance in focus group transcription and development of this report.

Gratitude goes to the Sunflower Foundation for recognizing that by empowering Kansas youth with disabilities about health-related issues those youth can become agents of change.



## **EXECUTIVE SUMMARY**

The Kansas Youth Leadership Forum (KYLf), a program of the Kansas Youth Empowerment Academy (KYEA), provides the opportunity for youth with disabilities from across the state to learn about disability issues and become agents of change in their communities. KYLF also provides policy makers and researchers the opportunity to meet with these young people to learn about their life experiences, concerns, and aspirations. “Creating Youth Agents of Change,” a KYEA program, created one such opportunity.

The following report is based on a survey and focus group discussions with alumni of the KYLF. These young men and women conveyed to us their personal insights and experiences regarding access to health care as well as employment and educational issues related to having a disability.

We learned that Kansas' health care, educational, and employment systems often do not meet the needs of youth with disabilities. Further, at the community level, many youth with disabilities were not able to access services that could improve their health and well-being.

Fortunately, these same youth provided suggestions about how to address some of the problems they encounter. What follows is a summary of findings and recommendations.

# **ASSESSING THE NEEDS**

## **(Health Status, Health Insurance, Education, and Employment)**

### **OF YOUTH WITH DISABILITIES IN KANSAS**

#### **FINAL REPORT**

## **I. Introduction**

The Kansas Youth Leadership Forum (KYLf) “Creating Youth Agents of Change” program’s information-gathering phase commissioned this study to identify health-related issues that concerned youth with disabilities, including issues related to health insurance, employment, education, and transition from school to community life issues. The purpose of this study is to provide a basis for developing advocacy strategies that put youth with disabilities in the driver’s seat for promoting health-related change.

## **II. Methods**

### **Health Surveys and Focus Groups**

This study was designed to identify and increase understanding of the health-related concerns of Kansas’ youth with disabilities using quantitative and qualitative data collected through a written survey instrument and focus groups. The survey instrument was written by the research team at the University of Kansas, Division of Adult Studies, based on a similar study in North Carolina (see Appendix A). Three focus group sessions, each addressing a specific topic, i.e., health care, employment, and education, were facilitated by research staff using a prepared set of prompts and questions similar to those used in the North Carolina study (see Appendix B).

### **Sample Population**

The sample population for the survey and focus groups were KYLF “alumni,” who attended a five-year reunion in Salina, Kansas on January 6-8, 2006. These individuals became KYLF participants through a competitive selection process open to Kansas residents with a disability (as defined by the Americans with Disabilities Act) in 11th or 12th grade who demonstrate leadership potential in school and community. A panel coordinated by the local Transition Council selects approximately 45 KYLF participants each year. The KYLF alumni making up the sample population of the study were between 18 and 24 years old.

All KYLF alumni who attended the reunion ( $n = 30$ ) voluntarily participated in the survey and focus groups without monetary compensation. The survey was administered to all participants first, followed by the three focus group sessions.

### **Comparative Evaluation**

Researchers evaluated the survey and focus group results using comparative data. Findings from a similar survey and focus groups made available in the *2001 Final Report: Assessing the Health-Related Needs of Youth with Disabilities and Chronic Health Conditions in North Carolina* (see Appendices A and B) provide comparative

data for our study's findings. We were not able to locate comparable survey information at the national level for this sample population. When possible we provided national data for the general population in the relevant age range, and on occasion data for the general population in the relevant age range for Kansas and/or North Carolina, as comparisons for the sample population.

The North Carolina (NC) study differed from the Kansas (KS) study in the following ways: (1) coordinators from established networks and organizations that served children, youth, and families with chronic health conditions and disabilities recruited participants throughout North Carolina in 2000, and (2) the North Carolina participants ( $n = 19$ ) received a stipend for participation. The Kansas and North Carolina age ranges were similar (between 18 to 24 years of age), as was the fact that participants completed a written health survey prior to participating in focus group sessions.

Neither the Kansas nor North Carolina studies focused attention on dental health care issues. As with other health care, dental health care tends to be impacted by insurance coverage. As youth transition from coverage under their parents' insurance to young adult status with no, limited, or public-only coverage, dental care usually becomes inaccessible. It would be beneficial to incorporate dental health questions into any follow up work with this sample population because of the direct impact of dental health on physical health.

By collecting subsequent and on-going rounds of data at yearly or eighteen-month intervals, the information in this report would readily lend itself to a report card-type format, similar to the *Kansas Children's Report Card* produced by the Kansas Action for Children. To achieve a report-card measurement system, benchmark and indicator data must be available from at least two points in time for comparison against itself as well as comparison against national trends.

### III. Demographic Characteristics

Table 1

#### Survey Samples Characteristics

Category	National general population	NC survey sample	KS survey sample
Prevalence of 18-24 year olds limited in any activities because of physical, mental, or emotional problems <sup>a</sup>	9%	9%	7%
Participant sample size		19	30
Percentage males		37%	57%
Age range		18-24 yrs	18-24 yrs
Race/ethnicity:			
African American		32%	7%
American Indian		0%	0%
Asian or Pacific Islander		0%	0%
Hispanic		0%	0%
White		68%	93%
Participants' county representation:		7:100	19:105
Living arrangements <sup>b</sup>			
College dormitory		37%	10%
Parent's home/apartment		16%	73%
Shared home/apartment		11%	10%
Own home/apartment		11%	7%
Group home		0%	0%

<sup>a</sup>National Center for Chronic Disease Prevention & Health Promotion (CDC), Behavioral Risk Factor Surveillance System (BRFSS), 2005 Prevalence Data: Nationwide (States & DC), Disability; Prevalence Data: North Carolina, Disability; and Prevalence Data: Kansas, Disability.

<sup>b</sup>Data does not total 100%.

## **IV. Findings at a Glance**

### **Findings at a Glance – The Survey**

Survey findings are presented in five major categories: health care, health insurance, employment, education, and community participation.

#### **A. Health Care**

- 10 percent of participants had no regular source of medical care.
- 13 percent had not seen a doctor in the past year.
- 23 percent were not satisfied with their current medical care.
- 30 percent reported barriers to seeing the doctor, including expense, lack of transportation, lack of insurance, and attitudes of the medical staff regarding disability.
- 50 percent had received no information on birth control, pregnancy or sexually transmitted diseases (STDs) from their doctors.
- “Paying for Medical Care” was the most frequently identified area about which they needed more information.

#### **B. Health Insurance**

- 10 percent of participants reported having no health insurance.
- 10 percent did not know if they had health insurance.

#### **C. Employment**

- 20 percent worked full time.
- 50 percent worked part time.
- 20 percent were afraid to work more for fear of losing insurance or disability benefits.

#### **D. Education**

- 40 percent had not received vocational or career training to help them prepare for a job.

#### **E. Community Participation**

- 30 percent were not satisfied with their current level of social activity.
- Being involved in the community in various ways, such as becoming more physically active, finding a support group, and participating in recreation activities were among the top 10 areas about which they wanted more information.

## Findings at a Glance - The Focus Groups

Key focus group findings are organized by subject areas. The first three areas address health promotion practices, whereas the subsequent areas address broader environmental issues of employment and education. Each area corresponds with questions posed to the participants.

### A. Challenges with Health Care

- Participants detailed many of the barriers they experienced in accessing needed health care, including transportation, red tape and delays in getting services and equipment, difficulty finding doctors who accepted Medicaid, difficulty understanding which services were covered, and difficulty getting referrals to specialists.
- Participants discussed the effects of the attitudes of medical providers and how they felt that doctors did not understand the disability perspective, how they could be rude or insensitive to people with disabilities, and how they needed to talk directly with patients rather than through others.
- The transition from children's Medicaid to adult Medicaid is difficult to understand and little information was provided to individuals about the services that were lost (for example, yearly eye exams switched to every four years; dental care was lost; coverage for out-of-state medical care changed).

### B. Suggestions for Improvement to the Health Care System

- The youth suggested a simplified health care system, with scaled co-pays and universal coverage regardless of disability status.
- Medical professionals should be courteous to people with disabilities and treat them as equals with others.
- More education and support should be provided to families of people with chronic health conditions.

### C. Challenges with Employment

- Participants felt that employers were wary of hiring people with disabilities and that once they were hired they were often treated badly in the work place.
- Many participants noted that advancement was difficult and many felt they were passed over for promotions.
- People with hidden or invisible disabilities were uncertain about how and if to tell their employers about their disabilities.
- Lack of transportation could be a barrier to employment.

#### D. Suggestions for Employers

- Define job responsibilities very clearly in the job description and once a person is on the job so that expectations are clear.
- Realize that young adults with disabilities are just as able and motivated to work and do a good job and that they want to advance as much as others do.
- Provide feedback to employees about what is needed and when they have done well.
- Make an effort to become aware of issues around disabilities and promote fairness in the workplace.

#### E. The Educational System: Observations and Suggestions

- At the grade school level, help students with disabilities gain self-confidence.
- At the higher grade levels, more paraprofessionals and alternate formats like books on tape are needed.
- Teachers need more information about teaching youth with disabilities and need to strive not to be afraid of people with disabilities.

## IV. Issues

### Health Issues

#### Health Status

When individuals were asked to self-report their health status, the most consistent response trend across groups seemed to be in the “good” category. The Kansas survey responses, along with the Kansas general population and North Carolina general population are quite similar across the categories. The national general population is within range of these three; the North Carolina survey response does not align with the other data columns. Based on their self-reported health conditions, the North Carolina participants seemed to have more chronic illnesses than the Kansas participants, with higher rates of respiratory and sickle cell diseases. This discrepancy may explain the differences in how the two populations describe their health.

Table 2  
*Self-reported Health Status of Young Adults*

Category	National general population <sup>a</sup>	NC general population <sup>a</sup>	KS general population <sup>a</sup>	NC survey sample	KS survey sample
Excellent	21%	21%	27%	11%	20%
Very good	34%	36%	38%	26%	40%
Good	30%	31%	30%	26%	30%
Fair	11%	11%	4%	26%	7%
Poor	4%	1%	1%	5%	3%

<sup>a</sup>National Center for Chronic Disease Prevention & Health Promotion (CDC), Behavioral Risk Factor Surveillance System (BRFSS), *2005 Prevalence Data: Nationwide (States & DC), Health Status; Prevalence Data: North Carolina, Health Status; and Prevalence Date: Kansas, Health Status.*

## Health Conditions

The following table provides a list of the health conditions experienced by the young adults from Kansas and North Carolina. These conditions are not mutually exclusive, i.e., may be co-occurring.

Table 3  
*Self-reported Disability or Chronic Health Condition of Young Adults*

Category	NC survey sample	KS survey sample
Attention deficit disorder	0%	13%
Autism	0%	7%
Bleeding disorders (hemophilia)	0%	0%
Blind or visually impaired	11%	3%
Cancer	0%	0%
Cerebral palsy	11%	17%
Deaf or hard of hearing	5%	10%
Gastric intestinal problems	0%	3%
Heart condition	0%	0%
Mental health problems	5%	7%
Orthopedic	21%	3%
Respiratory (asthma, cystic fibrosis)	11%	0%
Seizures	0%	0%
Sickle cell disease	32%	0%
Speech communication disorder	0%	3%
Spina bifida	5%	0%
Spinal cord injury	5%	0%
Traumatic brain injury	---	7%
Learning disability	---	37%
Other	26%	20%

Note: Results will not sum to 100% due to multiple responses from participants.

<sup>a</sup>U.S. Department of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research, (1997, October). Table 1. Percent distribution of population by usual source of health care and selected population characteristics, United States, 1996. In Medical Expenditure Panel Survey: Access to Health Care—Sources and Barriers, 1996 Research Findings #3. AHCPH Pub. No. 98-0001. Rockville, MD: Author.

### Source of Medical Care

Results from the 1996 Medical Expenditure Panel Survey (MEPS) indicate Americans were, in general, accustomed to having a usual source of medical care, which many of them could name. They used this source of care for a wide range of services and tended to use more health services when they had this usual or primary source of medical care. Even those individuals who were uninsured seemed to have a usual source of health care, which is consistent with the notion of maintaining a usual source of health care as a beneficial practice (Agency for Health Care Policy and Research, 1996). In 2001 approximately 51.9 million people in the United States, or 18.4 percent of the total population, reported having no usual source of health care (Pancholi, 2004).

The March 2006 *Sample Adult and Sample Child Core Component of the National Health Interview Survey* (U.S. Dept of Health and Human Services, 2006), which was derived from household interviews of a sample of the civilian, non-institutionalized population, indicated young adults (18 – 24 years) were the least likely to have a usual place to go for medical care. For individuals with disabilities, maintaining a usual source of health care is particularly important in achieving continuity of care for complex situations that could contribute to and confound other medical conditions.

Table 4  
*Regular Source of Medical Care for Young Adults*

Category	National general population <sup>a</sup>	NC survey sample	KS survey sample
Doctor's office	57%	79%	67%
Hospital clinic	8%	21%	7%
School nurse/School health center	--	16%	7%
Health center or clinic	--	11%	10%
Don't know	--	0%	10%
No source of routine health care	34%	11%	10%

<sup>a</sup>Percent distribution of United States population by usual source of health care and selected population characteristics from the Medical Expenditure Panel Survey (MEPS) Household Components, 1996 (Rounds 1 and 2), Center for Cost and financing Studies, Agency for Health Care Policy and Research.

## Medical Care Utilization

Increased use of routine medical care among children with special health care needs is well documented (Newacheck & McManus, 1988; Newacheck, Strickland & Shonkoff, 1998; Silver & Stein, 2001). As this population of children becomes young adults and transitions into adult services, their health care needs continue to exist. The responses from the Kansas survey participants indicated a slightly higher utilization of medical care than the United States general population in the 18 to 24 year old age range. This finding supports the notion that individuals with special health care needs utilize medical care more frequently.

Table 5  
*Medical Care Utilization in Past 12 Months for Young Adults*

Category	National general population <sup>a</sup>	KS survey sample
None	24%	13%
1-11 times (less than once a month)	65% <sup>b</sup>	70%
12-24 times (once or twice a month)	11% <sup>c</sup>	10%
More than 24 times (more than twice a month)	--	3%

<sup>a</sup>U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics (2005). Table 75. Health care visits to doctor's offices, emergency departments, and home visits within the past 12 months, according to selected characteristics: United States, 2003. In *Health, United States, 2005: With Chartbook on Trends in the Health of Americans*, Hyattsville, MD: Author.

<sup>b</sup>Data distribution represents 1-9 visits.

<sup>c</sup>Data distribution represents 10 or more visits.

## Specialty Medical Care

Young adults in the Kansas survey were asked what type of specialty medical care they had used during the past year. Sixty percent indicated they had not used specialty medical care; 10 percent had visited a psychologist or psychiatrist; and seven percent respectively had seen an ear specialist, eye doctor and/or orthopedic specialist, additionally, 10 respondents singularly identified individual specialists whose services they had used during the past year. Access to specialty care can be critical to maintaining function for youth with disabilities.

## Deterrent to Medical Care

When the Kansas young adults were asked in the survey what prevented them from going to the doctor or clinic, the majority (70%) indicated that nothing prevented them from going to the doctor. However, 13 percent did indicate expense prohibited them from going, and seven percent respectively responded the reason they were prevented from going to the doctor were transportation barriers, medical staff attitudes, and/or they did not like going. Individually, respondents indicated there were other barriers that

prevented them from going to the doctor; these included no insurance and communication issues with the doctor.

### Health Care Satisfaction

Numerous factors combine to influence health care satisfaction, which can contribute to utilization rates. Individuals who are not satisfied with their health care system may be more reluctant to seek out medical services even when their need is high, which over time can contribute to a less healthy society. Results from a 2002 report by the Agency for Healthcare Research and Quality (AHRQ, 2005) indicated 60 percent of the general population of 18 to 24 year olds was not satisfied with their health care. In contrast, the majority (70%) of young adults with disabilities who responded to the Kansas survey were satisfied with their current health care.

Table 6  
*Satisfaction with Current Health Care of Young Adults*

Category	National general population <sup>a, b</sup>	KS survey sample
Yes	40%	70%
No	60%	23%
Does not total 100%		--

<sup>a</sup>Agency for Healthcare Research and Quality (2005, December). Table 5.1a. Adults age 18 and over who reported going to a doctor's office or clinic in the last 12 months, percent giving a best rating for health care received, United States, 2002. In *Data Tables Appendix: National Healthcare Quality Report, 2005*. AHRQ Publication No. 06-0018. Rockville, MD: Author.

<sup>b</sup>Data distribution includes 18 – 44 year olds.

## Youth to Adult Health Care Transition

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 adolescent to adult health care needs, 40 percent said they had not, only 17 percent indicated they had, and 43 percent did not know.

The Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004) outlines the way in which individualized education programs (IEP) and transition planning are to be developed for individuals with disabilities. This planning, although primarily focused on educational issues, is intended to be inclusive of related issues. The following language from IDEA 2004 defines and specifies expectations of IEP and transition planning.

The term ‘individualized education program’ or ‘IEP’ means a written statement for each child with a disability that is developed, reviewed, and revised in accordance with this section and that includes—

(VIII) beginning not later than the first IEP to be in effect when the child is 16, and updated annually thereafter—

- (aa) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment and where appropriate, independent living skills;
- (bb) the transition service (including courses of study) needed to assist the child in reaching those goals; and
- (cc) beginning not later than 1 year before the child reaches the age of majority under State law, a statement that the child has been informed of the child’s rights under this title, if any, that will transfer to the child on reaching the age of majority under section 615(m).

(Sec. 614(d)1(A)i)

## INSURANCE ISSUES

### Health Insurance

A 2006 publication by the Commonwealth Fund indicates that young adults (19 – 29 years) in the general population are one of the largest and fastest growing groups to be uninsured. This age segment tends to lose coverage under their parent's policies or from state programs around this age (Collins, Schoen, Kriss, Doty, & Mahoto, 2006). Continuous health insurance coverage tends to become more common as age increases.

The majority of young adults in the general population and in the Kansas and North Carolina survey samples reported they had some type of health insurance coverage. The Kansas and North Carolina survey samples were quite similar, with Kansas' public insurance programs providing 40 percent of coverage and North Carolina's public insurance programs providing 32 percent of coverage.

Table 7  
*Insurance Coverage of Young Adults*

Category	National general population <sup>a</sup>	NC general population <sup>b</sup>	NC survey sample	KS general population <sup>c</sup>	KS survey sample
Private insurers	52%	53%	53%	68%	27%
Medicaid / Health Check	12%	12%	32%	9%	37%
State child health insurance program (KS HealthWave; NC Health Choice)	--	--	0%	--	3%
Another form of insurance	4%	35%	21%	8%	0%
Did not know if they had health insurance	--	--	5%	--	23%
No insurance	32%	17%	5%	15%	10%

<sup>a</sup>U.S. Census Bureau, Health Insurance Data (2004). Table HI-2 for 2004, Health insurance coverage status and type of coverage—all people by age and sex: 2004.

<sup>b</sup>National Center for Chronic Disease Prevention & Health Promotion, Behavioral Risk Factor Surveillance System (2000). Prevalence Data: North Carolina, Health Care Access/Coverage.

<sup>c</sup>The Kaiser Commission on Medicaid and the Uninsured (2005, November). Table 19. Health Insurance Coverage of Nonelderly Adults by State, 2003-2004 (19-64 years old). In *Health Insurance Coverage in America: 2004 Data Update*.

### **Prescription Drug Use**

In the general national population, 66 percent of 18 to 24 year olds use no prescription drugs (U.S. Census Bureau, 2006). More than half (57%) the Kansas young adults surveyed indicated they did not take any prescription drugs; 33 percent indicated they took one to three prescription drugs. The remaining ten percent indicated they took four to ten prescriptions, with no one responding that they took more than ten.

### **Insurance Loss Due to Working**

Young adult Kansans were asked if they were afraid of losing insurance by working too much. The majority (70%) indicated they were not afraid; 20 percent indicated they were, and 10 percent did not know. For individuals who qualify for Medicaid or Medicare on the basis of their disabilities, loss of coverage with increased earnings has historically been a true barrier to employment.

## ***EMPLOYMENT ISSUES***

### **Work**

Kansas survey participants, when asked if they were employed, were able to indicate more than one answer to the six options. Seven percent indicated they were not working, and 13 percent said they expect to be working in six months. Seventeen percent were working in part-time volunteer positions and 50 percent working in part-time paid positions. Three percent were working full-time in volunteer positions and 20 percent were working full-time in paid positions.

### **Vocational Training**

Vocational training is an important educational process that helps prepare students for higher education or trade school. When Kansas survey respondents were asked if they had received any sort of vocational training, 40 percent indicated they had not and seven percent did not know. Seventy-seven percent of the Kansas survey respondents indicated future plans of working, while 73 percent anticipated completing college and 30 percent planned on completing graduate or professional studies. With these goals and potential, access to vocational training within the education system becomes extremely important for this population.

## EDUCATION ISSUES

### Information Needs

Young adults were asked to prioritize their need for various types of information. These were the top topic areas for which participants reported an interest and need for more information. One of the top Kansas survey respondent areas of information need was physical activity. This could reflect an appreciation for the fact that adult Kansans with disabilities aged 18 years and older are twice as likely to report being overweight when compared to adult Kansans without disabilities (KDHE, 2002).

Table 8  
*Prioritized Need for Information of Young Adults*

Category	NC survey sample	KS survey sample
Paying for medical care	4 <sup>th</sup>	1 <sup>st</sup>
Successful persons with their condition	1 <sup>st</sup>	2 <sup>nd</sup>
Finding adult specialty doctor	11 <sup>th</sup>	3 <sup>rd</sup>
Becoming more physically active	9 <sup>th</sup>	4 <sup>th</sup>
Eating healthy/nutritiously	15 <sup>th</sup>	5 <sup>th</sup>
How to find support group	7 <sup>th</sup>	6 <sup>th</sup>
Changing bad habits	10 <sup>th</sup>	7 <sup>th</sup>
How to participate in recreational activities	5 <sup>th</sup>	8 <sup>th</sup>
Successful persons with disabilities	2 <sup>nd</sup>	9 <sup>th</sup>
Post high school opportunities	13 <sup>th</sup>	10 <sup>th</sup>
Finding adult care doctor	17 <sup>th</sup>	11 <sup>th</sup>
Job/careers	3 <sup>rd</sup>	12 <sup>th</sup>
Speak up for self with medical care providers	14 <sup>th</sup>	13 <sup>th</sup>
Take care of medical needs independently	19 <sup>th</sup>	14 <sup>th</sup>
Protect self from violence	6 <sup>th</sup>	15 <sup>th</sup>

### Satisfaction with Social Activity

Although 50 percent of Kansas and 74 percent of North Carolina survey respondents indicated that they were satisfied with their current level of social activity, 30 percent of Kansas and 26 percent of North Carolina reported that they were not satisfied and would like to be more socially active.

Table 9  
*Social Activity Satisfaction with Young Adults*

Category	NC survey sample	KS survey sample
Yes	74%	50%
No (too little)	26%	30%
No (too much)	0%	3%
Don't know/Not sure	0%	17%

### Level of Social Activity

Social activity level varied between the categories of “very” and “somewhat” socially active among Kansas and North Carolina survey participants. Most Kansas respondents (47%) indicated they were “somewhat” socially active with 33 percent saying they were “very” socially active. The opposite was true of North Carolina survey participants, with their greatest responses (47%) in the “very” socially active and 32 percent “somewhat” socially active. In this particular age range (18 – 24 years), social activity is usually extremely appealing.

Table 10  
*Social Activity Level of Young Adults*

Category	NC survey sample	KS survey sample
Very socially active	47%	33%
Somewhat socially active	32%	47%
Not very socially active	16%	17%
None	0%	3%

## Dissemination of Sexuality Information

Kansas young adults were asked where they currently receive their information about sexuality issues (e.g., birth control, sexually transmitted diseases (STDs), flirting, dating, and relationships) and how they would like to find out about sexuality issues in the future.

Table 11

*Sexuality Information Sources of Kansas Young Adults with Disabilities.*

Category	Birth control, pregnancy, STDs	Flirting, dating, relationships	Preferred information source
School	37%	27%	33%
Parents	37%	33%	13%
Doctor	50%	17%	20%
Friends	20%	57%	23%
Other	23%	10%	27%
Don't get this information	--	17%	--
Don't want this information	17%	--	0%

## Sexuality Information Interest

Young adults in the general population in the U.S., Kansas, and North Carolina ages 18 - 24 years varied in their awareness of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) and other STDs issues. When asked, "If you [knew] a teenager who was sexually active, would you encourage him or her to use a condom?" their general responses were affirmative, that is 95 percent, 96 percent and 91 percent (CDC, 2000), respectively. We interpret these data as an indication of the populations' sexuality awareness and awareness of consequences.

Kansas young adults who participated in this study were asked if they were interested in receiving additional information about sexuality issues. Two thirds were not interested in receiving additional information; nearly two-thirds of these respondents were young men.

Table 12

*Interest in Additional Sexuality Information.*

Category	KS survey sample males	KS survey sample females	KS survey sample total
Yes	10%	7%	17%
No	43%	23%	66%
Don't know	3%	14%	17%

## Future Plans

Participants in the Kansas and North Carolina surveys provided strong indication that they intended to be contributing members of the community, with their plans to work topping the list of response items in both groups (77 percent in Kansas and 74 percent in North Carolina). Expectations to marry and complete college were the second or third most frequent responses of the two groups.

Table 13  
*Future Plans among Young Adults with Disabilities*

Category	NC survey sample	KS survey sample
Plan on working	74%	77%
Expect to marry	63%	77%
Plan to complete college	68%	73%
Plan to traveling	47%	73%
Expect to have children	47%	70%
Expect to live independently	58%	67%
Plan to complete graduate or professional studies	58%	30%
Expect to complete high school	15%	--

## Transition Supports for Young Adults with Disabilities

Kansas and North Carolina survey respondents were asked to indicate interest in various support services for young adults with disabilities. The survey participants rated the importance of nine options from extremely important (5) to not important (1). All nine of the options identified in Table 14 received an average ranking by the majority of respondents of important, very important, or extremely important. Kansas survey participants indicated their highest priority was establishing advocacy groups for young adults with disabilities and chronic health conditions, while that option was of lowest priority to North Carolina survey respondents. The second highest priority option selected by Kansas survey respondents reflected a similar advocacy/peer outreach focus of wanting to hold a statewide health conference for young adults with disabilities. The North Carolina survey participants selected this as their third from lowest priority. Virtually all of the North Carolina rankings were scored low-to-high, compared to Kansas high-to-low rankings.

One explanation for this contrast might be that as a state, Kansas has a firmly established organization (i.e., KYLF) whose focus it is to promote and support the development of youth with disabilities as they become empowered community leaders. Through their KYLF alumni status, it can be assumed the young adults who participated in the Kansas survey already shared openness toward advocacy strategies as a method of promoting change. The randomly selected North Carolina survey respondents may not have had the opportunity to participate in an organization similar to KYLF, which is

possibly a reflection of how Kansas young adults with disabilities and chronic health conditions might have responded prior to the establishment of KYLF.

Table 14  
*System Supports Preferences for Young Adults with Disabilities*

Category	NC survey sample	KS survey sample
Establish local advocacy groups for young adults with disabilities	9 <sup>th</sup>	1 <sup>st</sup>
Have a statewide health conference for young adults with disabilities	7 <sup>th</sup>	2 <sup>nd</sup>
Establish a mentor program in which adults with disabilities support young adults with disabilities	8 <sup>th</sup>	3 <sup>rd</sup>
Have more information on the health-related needs of young adults with disabilities at health provider offices	2 <sup>nd</sup>	4 <sup>th</sup>
Have workshops on health issues important to young adults with disabilities	1 <sup>st</sup>	5 <sup>th</sup>
Develop a web page for young adults with disabilities that promotes health	5 <sup>th</sup>	6 <sup>th</sup>
Have more health education and information available in school	3 <sup>rd</sup>	7 <sup>th</sup>
Produce a health newsletter for young adults with disabilities	6 <sup>th</sup>	8 <sup>th</sup>
Produce printed health-related materials and resources for young adults with disabilities	4 <sup>th</sup>	9 <sup>th</sup>

## V. Conclusions and Recommendations

### Health Care Issues

The findings indicate that many Kansas young adults lacked a regular source of care or had not seen a doctor in the past year. Having a usual source of care is directly correlated with obtaining a variety of preventive health services (American Family Physician, 2000). Within this group, 40 percent were seen by specialists, and one-third took prescription medications, so regular access to care is very important.

Expense was identified as one barrier to getting needed medical services, but transportation and attitudes of medical providers were also factors. The attitudes cited in the survey and discussed in the focus group indicate that many providers still subscribe to the “medical model” of disability. These youth said that doctors 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 STDs from their doctors. Given that 77 percent of the participants plan to marry and 70 percent expect to have children, this finding is rather troubling. The young adults suggested that medical providers need to learn more about people with disabilities and to see them as individuals rather than as their conditions.

Findings from the Kansas young adult respondents regarding health care issues in 2006 seemed to parallel those identified by the Kansas Disability and Health Steering Committee and Kansas Department of Health and Environment’s Disability and Health Program in their *Disability and Health in Kansas* report produced four years earlier when they said “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).

### Health Insurance Issues

Ten percent of the youth reported having no health insurance and another 10 percent did not know if they had health insurance. Not surprisingly, perhaps, “paying for health care” was the number one area about which the youth said they needed more information. In the focus group, participants also expressed concerns about increases in their co-pays and medical billing problems. They suggested that health insurance coverage be the same for all people, with scaled co-pays.

During the focus groups many young adults 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.

The young adults strongly recommended simplification of the medical system with more uniformity of coverage. Better health insurance coverage, possibly tied with employment, would support an improved situation for these contributing citizens.

### **Employment Issues**

The survey indicated 20 percent of participants were currently working full-time for pay, 50 percent were working part-time for pay, and 20 percent had volunteer positions. Another 13 percent expected to be working for pay within the next six months. Unfortunately, 20 percent feared losing health insurance or disability benefits if they work too much. This level of fear perhaps indicates that they are not aware of the Kansas Medicaid Buy-In program, Working Healthy, which allows people to work more and maintain Medicaid coverage.

### **Educational Issues**

In the survey, 77 percent of participants said they plan to work, but only 53 percent had received vocational or career training to help them prepare for a job. Although the state transition process does not mandate vocational education for all students with disabilities, it does require that services to support transition goals be addressed in the Individualized Education Plan (IEP) for each student. Similarly, only 37 percent of participants reported having received information about birth control, pregnancy, and STDs from school.

In the focus groups, the youth stressed that grade school experiences are important in forming the self-confidence needed to be successful in later years. In high school, they cited a lack of enough paraprofessional support as a problem. They felt that some teachers need more information about disabilities. They also noted that it helps when their parents are involved with school issues.

### **Community Participation**

In responding to the survey, 30 percent of participants indicated that they were not satisfied with their current levels of social activity. Further, when asked to rank topics about which they would like to have more information, “becoming more physically active,” “how to find a support group,” and “how to participate in recreational activities” all ranked in the top ten responses.

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. One poignant response from a group of parents of children with disabilities and adults with disabilities collected in 1998 by Kansas Disability and Health Program addresses this issue: “My community

needs curb cuts and street crossings so that I can travel safely to work and other activities” (KDHE, 2002, p. 7). 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.

As public health officials and researchers become more aware of the importance of recreation and physical activities for maintaining health and preventing chronic illness, these activities must also be made available and accessible to young adults with disabilities. Local support groups provide an opportunity for young adults to network and share insights about how to increase the accessibility of their communities and advocate for needed changes.

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**APPENDIX A.**  
**Health Surveys**  
Kansas Youth Leadership Forum Health Survey  
North Carolina Health Survey

# KANSAS YOUTH LEADERSHIP FORUM HEALTH SURVEY

Assessing the Needs of Kansas Youth with Disabilities



## TELL US ABOUT YOU

**1. GENDER (MARK ONE.)**

Female       Male

**2. Birth Date** (Fill in information.)

Month \_\_\_\_\_ Year \_\_\_\_\_

**3. RACE/ETHNICITY (MARK ONE/FILL IN INFORMATION.)**

African American       American Indian       Asian or Pacific Islander  
 Hispanic       White       Other \_\_\_\_\_

**4. Living Arrangements** (Mark one.)

College dormitory       Parents' home/apartment with at least one parent       Shared home/apartment with friends, relatives, or spouse  
 Own home/apartment (alone)       Supervised group home/apartment with others       Other \_\_\_\_\_

**5. Residence** (Fill in information.)

County \_\_\_\_\_ Zip Code \_\_\_\_\_

## TELL US ABOUT YOUR HEALTH

**6. Do you have any of the following conditions or disabilities?**

(Mark all that apply or list others as needed.)

Attention Deficit Disorder       Autism       Bleeding Disorders (Hemophilia)  
 Blind or Visual Impairment       Cancer       Cerebral Palsy  
 Deaf or Hard of Hearing       Gastric/Intestinal       Heart Condition  
 Mental Health Problems       Orthopedic       Respiratory (asthma, cystic fibrosis)  
 Seizures (epilepsy)       Sickle Cell Disease       Speech/Communication Disorder  
 Spina Bifida       Spinal Cord Injury       Other(s) \_\_\_\_\_

**7. Are you currently covered by health insurance?** (Mark one.)

Yes       No       I don't know

**7A. What is your source for insurance coverage?** (Mark all that apply.)

Medicaid       HealthWave       Private insurer, such as Blue Cross/  
 I don't know       Other \_\_\_\_\_      Blue Shield, Coventry

**8. Are you currently working or expect to be working in the next 6 months?**

(Mark all that apply/Fill in information.)

- No     Yes, part-time paid position     Yes, full-time paid position  
 Yes, part-time volunteer position     Yes, full-time volunteer position  
 Expect to work within 6 months. Please explain \_\_\_\_\_

**9. Are you afraid to work or work more because you might lose insurance or cash disability benefits?** (Mark one.)

- Yes     No     I don't know

**10. How would you describe your health?** (Mark one.)

- Excellent     Very Good     Good     Fair     Poor

**11. Where do you go for regular or routine health care and health check ups?** (Mark all that apply.)

- My doctor's office     Hospital clinic     School Nurse/School Health Center  
 Health center or clinic     I don't know     I don't have a source for routine health care  
 Other(s) \_\_\_\_\_

**11a. Is this the same place you have received regular or routine health care during the past 5 years?** (Mark one/Fill in information.)

- Yes     No. Please explain \_\_\_\_\_

**12. Have you visited a specialist's office in the past year, like an ear doctor, cancer doctor, diabetes doctor, physical therapist, heart doctor, speech therapist?**

(Fill in kind of specialists you have visited in the past year.)

- No, didn't visit a specialist     Specialist \_\_\_\_\_  
 Specialist \_\_\_\_\_     Specialist \_\_\_\_\_  
 Specialist \_\_\_\_\_     Specialist \_\_\_\_\_

**13. How many times all together did you visit a doctor or clinic in the last 12 months?**

(Mark one.)

- None     12-24 times (once or twice a month)  
 1-11 times (less than once a month)     More than 24 times (more than twice a month)

**14. What prevents you from going to the doctor or clinic?** (Mark all that apply/Fill in information.)

- Nothing     I don't like going     Medical staff attitude  
 Too expensive     Transportation getting there     Communication with doctor  
 Other(s) \_\_\_\_\_

**15. Are you currently taking medications?** (Mark all that apply.)

- None                       1-3 prescriptions                       7-10 prescriptions  
 Vitamins                       4-6 prescriptions                       More than 10 prescriptions

**16. Who sets up your doctor or clinic visits; who makes the appointments for you?** (Mark all that apply/Fill in information.)

- My doctor's office                       My specialist's office                       School Nurse/School Health Center  
 My parents                       Hospital clinic                       Other(s) \_\_\_\_\_  
 I do                       I don't know

**17. Do you have a written record of your health treatment, like surgeries you have had, hospitals stays, allergies you have, medicines you take?** (Mark one.)

- Yes     No     I don't know

**17a. If you have a written health record, who keeps the information in it updated and current?** (Mark all that apply/Fill in information.)

- My doctor's office                       My specialist                       School Nurse/School Health Center  
 My parents                       Hospital clinic                       Other(s) \_\_\_\_\_  
 I do                       I don't know

**18. Are you satisfied with your current health care?** (Mark one/Fill in information.)

- Yes     No. Please explain \_\_\_\_\_

**19. Has your doctor or other health care providers talked with you about how your health care needs might change as you become an adult?** (Mark one.)

- Yes                       No                       I don't know

**20. Has a plan for addressing your changing health needs been made with your doctors or other health care providers?** (Mark one.)

- Yes                       No                       I don't know

**21. Has your doctor or other health care providers talked with you about seeing a doctor who treats adults as you get older?** (Mark one.)

- Yes                       No                       I don't know

## TELL US ABOUT YOUR ACTIVITIES AND PLANS

22. Are you in school? (Mark one/Fill in grade/year.)

- No                                      Highest grade completed \_\_\_\_\_  
 Yes, High School  
 Yes, College  
 Yes, Graduate School

23. Have you received any vocational or career training to help you prepare for a job as you become an adult? (Mark one.)

- Yes       No       I don't know

24. How would you describe your current level of social activity? (Mark one.)

- Very socially active (spend a lot of time with others in many activities)  
 Somewhat socially active (spend some time with others doing a variety of activities)  
 Not very socially active (spend very little time with others)  
 None (spend essentially no time with others outside home)

25. Are you satisfied with your current level of social activity? (Mark one.)

- Yes                                       No (too much)  
 No (too little)       I don't know/not sure

26. Do your future plans include any of the following? (Mark all that apply.)

- Completing college                       Living independently                       Working  
 Completing graduate or professional school       Getting married                       Traveling  
 Having children                       Other \_\_\_\_\_

27. Where do you currently get information about issues such as birth control, pregnancy, and sexually transmitted diseases? (Mark all that apply/Fill in information.)

- I don't want this information       School       Parents  
 Doctor                                       Friends       Other(s) \_\_\_\_\_

28. Where do you currently get information about issues such as sexuality, flirting, dating, and relationships? (Mark all that apply/Fill in information.)

- Don't get this information       School       Parents  
 Doctor                                       Friends       Other(s) \_\_\_\_\_

29. How would you like to find out about sexuality issues? (Mark all that apply/Fill in information.)

- I don't want this information       School       Parents  
 Doctor                                       Friends       Other(s) \_\_\_\_\_

**30. Do you need more information about sexuality?** (Mark one.)

- Yes       No       I don't know

**TELL US ABOUT YOUR INFORMATION NEEDS**

**31. Let us know if you have received information about the following issues, and if you need more information.**

(Mark one for each item.)

	Have information	Need more information	Have enough information	No interest
What recreational activities I can participate in and how to find them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to become more physically active/fit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to stop smoking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to eat healthy/nutritiously	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to change bad habits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to protect myself from violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to meet new friends, both with and without disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to feel better about myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to find help if I am depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who to call if I am suicidal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What to do when people treat me differently	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Post high school education opportunities (college, training school)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to find a job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to find a support group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Successful persons with chronic conditions and disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Successful persons living with my condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Effective social skills in the work setting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to find an adult care doctor as I get older	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to find adult specialty doctors as I get older	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to pay for my medical care (equipment, medicine, doctor visits...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My condition or disability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to speak up for myself when meeting with medical care providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How to take care of my medical needs independently (schedule medical appointments, take medicine...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**TELL US WHAT YOU WOULD LIKE TO HAVE HAPPEN**

**32. Tell us what you would like to see happen to support the health of youth with disabilities and chronic health conditions in Kansas. Look over each statement.**

(Mark your opinion for each item.)

	Not Important	Sort of Important	Important	Very Important	Extremely Important
Develop a web page for young adults with disabilities that promotes health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Produce a health newsletter for young adults with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have workshops on health issues important to young adults with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have a state-wide health conference for young adults with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establish a mentor program in which adults with disabilities support teens with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have more health education and information available in school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Produce printed health-related materials and resources for young adults with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establish local advocacy groups for young adults with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have more information on the health-related needs of young adults with disabilities in health provider offices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**33. What other things, not listed, would you like to see happen that support the health of young adults with disabilities and chronic health conditions?** (Fill in information.)

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**Thank you!**

Please leave completed survey with Jean Hall or Barb Starrett  
January 7, 2006

This survey has been supported by funding from the Sunflower Foundation.

## NORTH CAROLINA HEALTH SURVEY

### Tell us about you

**1. Gender**

Female

Male

**2. Birthdate:** \_\_\_\_\_Month \_\_\_\_\_Year

**3. Race/ethnicity (✓ Check one)**

African American

Hispanic

American Indian

White

Asian or Pacific Islander

Other

**4. Living Arrangements (✓ Check one)**

College dormitory

Parents' home/apartment with at least one parent

Shared home/apartment with friends, relatives, or spouse

Own home/apartment (alone)

Supervised group home/apartment with others

Other \_\_\_\_\_

**5. Residence**

a. County \_\_\_\_\_

b. Zip Code \_\_\_\_\_

### Tell us about your health...

**6. Do you have any of the following conditions or disabilities?**

(✓ Check all that apply or list others as needed)

Attention Deficit Disorder

Orthopedic

Autism

Respiratory (asthma, cystic fibrosis)

Bleeding Disorders (Hemophilia)

Seizures (epilepsy)

Blind or Visual Impairment

Sickle Cell Disease

Cancer

Speech/Communication Disorder

Cerebral Palsy

Spina Bifida

Deaf or Hard of Hearing

Spinal Cord Injury

Gastric/Intestinal

Other \_\_\_\_\_

Heart Condition

Mental Health Problems

**7. Are you currently covered by health insurance? (✓ Check one)**

- Yes
- No
- Don't know

**8. Source for insurance coverage: (✓ Check all that apply)**

- Medicaid / Health Check
- N.C. Health Choice for Children
- Private insurer, such as Blue Cross/Blue Shield or WellPath
- Other \_\_\_\_\_
- Don't know

**9. How would you describe your health? (✓ Check one)**

- Excellent
- Very Good
- Good
- Fair
- Poor

**10a. Where do you go for regular or routine health care (health check ups)?**

**(✓ Check all that apply)**

- My doctor's office
- Health center or clinic
- School Nurse/School Health Center
- Hospital clinic
- Other \_\_\_\_\_
- I don't have a source for routine health care
- Don't know

**10b. Is this the same place you went for regular or routine health care as a teen? (✓ Check one)**

- Yes
- No. Please explain \_\_\_\_\_

**11. How many times did you visit a doctor or clinic in the last 12 months?**

(✓ Check one)

- None
- 1-11 times (less than once a month)
- 12-24 times (once or twice a month)
- More than 24 times (more than twice a month)

**Tell us about your activities and plans...**

**12. Are you in school?**

- No, not in school                      Highest grade completed: \_\_\_\_\_
- Yes
  - Middle School                      Highest grade completed: \_\_\_\_\_
  - High School                      Highest grade completed: \_\_\_\_\_
  - College
  - Graduate School

**13. How would you describe your current level of social activity? (✓ Check one)**

- Very socially active (spend a lot of time with others in many activities)
- Somewhat socially active (spend some time with others doing a variety of activities)
- Not very socially active (spend very little time with others)
- None (spend essentially no time with others outside home)

**14. Are you satisfied with your current level of social activity? (✓ Check one)**

- Yes
- No (too little)
- No (too much)
- Don't know/not sure

**15. Do your social activities include any of the following?**

(✓ Check all that apply)

- |   |  |
|---|--|
| <input type="checkbox"/> Community activities (4-H, Scouts)   | <input type="checkbox"/> Movies, plays, concerts |
| <input type="checkbox"/> Church activities                    | <input type="checkbox"/> School clubs            |
| <input type="checkbox"/> Camps                                | <input type="checkbox"/> Shopping                |
| <input type="checkbox"/> Computer (games, internet)           | <input type="checkbox"/> Visit with friends      |
| <input type="checkbox"/> Hobbies                              | <input type="checkbox"/> Volunteer               |
| <input type="checkbox"/> Listen to music                      | <input type="checkbox"/> Work at a job           |
| <input type="checkbox"/> Outdoor activities (biking, fishing) | <input type="checkbox"/> Watch sports            |
| <input type="checkbox"/> Play musical instrument              | <input type="checkbox"/> Watch T.V.              |
| <input type="checkbox"/> Play sports                          | <input type="checkbox"/> Other _____             |

**16. Do your future plans include any of the following? (✓ Check all that apply)**

- |   |   |
|---|---|
| <input type="checkbox"/> Living independently   | <input type="checkbox"/> Completing graduate or professional school |
| <input type="checkbox"/> Marrying               | <input type="checkbox"/> Working                                    |
| <input type="checkbox"/> Having children        | <input type="checkbox"/> Traveling                                  |
| <input type="checkbox"/> Completing high school | <input type="checkbox"/> Other_____                                 |
| <input type="checkbox"/> Completing college     |   |

**17. Let us know if you have received information about the following issues; and if you need more information. (✓Check the appropriate boxes.)**

	Have received information on this topic	Need <b>more</b> information about this topic	Have enough information about this topic	Not interested in this topic
What recreational activities I can participate in and how to find them				
How to become more physically active/fit				
How to stop smoking				
How to eat healthy				
How to change bad habits				
How to protect myself from violence				
How to meet new friends, both with and without disabilities				
How to feel better about myself				
Where to find help if I am depressed				
What to do when people treat me differently				
Post high school education opportunities (college, training school)				
How to find a support group				
Volunteer/community service opportunities				
Jobs/careers				
Successful persons with chronic conditions and disabilities				
Successful persons living with my condition				
How to find an adult care doctor				
How to find adult specialty doctors				
How to pay for my medical care (equipment, medicine, doctor visits...)				
My condition or disability				
How to take care of my medical needs independently (schedule medical appointments, take medicine...)				
Sexuality				
How to speak up for myself when meeting with medical care providers				
Family planning services (birth control, sexually transmitted disease information)				
Becoming a parent				

**18. Tell us what you would like to see happen to support the health of youth with disabilities and chronic health conditions in North Carolina. Look over the following statements and circle the number that is closest to your opinion.**

	<b>Not Important</b>		<b>Important</b>		<b>Very Important</b>
Develop a web page for teens with disabilities that promotes health	1	2	3	4	5
Produce a health newsletter for teens with disabilities	1	2	3	4	5
Have a state-wide health conference for teens with disabilities	1	2	3	4	5
Have workshops on health issues important to teens with disabilities	1	2	3	4	5
Establish a mentor program in which adults with disabilities support teens with disabilities	1	2	3	4	5
Produce printed health-related materials and resources for teens with disabilities	1	2	3	4	5
Establish local advocacy groups for teens with disabilities	1	2	3	4	5
Have more information on the health-related needs of teens with disabilities in health provider offices	1	2	3	4	5
Have more health education information available in schools	1	2	3	4	5

What other things, not listed, would you like to see happen that support the health of teens with disabilities and chronic health conditions?

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## **APPENDIX B.**

### **Focus Group Questions**

Kansas Youth Leadership Forum Facilitator Questions

North Carolina Young Adult Focus Group Questions

**Kansas Youth Leadership Forum  
Five Year Reunion  
January 7<sup>th</sup>, 2006  
Facilitator Questions**

**Please begin your discussion with the following question: We would like to know what are some of the challenges you face when dealing with (*reference specific topic: health care; employment; or education*)?**

**The questions below are to guide your discussion.**

1. We Need To..... (What is the problem?)
2. We Worry About....
3. It is Great When....
4. It Hurts When....
5. We Want The Opportunity....
6. It Would Be Great If You....
7. What is the number one thing you want \_\_\_\_\_ to know about you?
8. We Want.....
9. We Need You To.....
10. The Perfect \_\_\_\_\_ is When/Where.....
11. We Desire Work Opportunities Where....
12. What Would You Like To Be Different.....

## **NORTH CAROLINA YOUNG ADULT FOCUS GROUP QUESTIONS Teens/Young Adults with Disabilities & Chronic Health Conditions**

1. If you were going to explain to a friend what they should be doing to live a 'healthy lifestyle,' what kinds of things would you talk about?
2. In regards to the things you just mentioned, what do you think stops teens from living a 'healthy lifestyle?'
3. What stops teens with disabilities and chronic health conditions from living 'healthy life styles?'
4. What do you feel you needed to stay active and healthy as a teen but weren't able to do or get and why?
5. In general, are you satisfied with the health care that you received when you were a teen?
  - a. What was good about it?
  - b. What needed to be made better?
6. If you could create the perfect health care system for teens with disabilities and/or chronic health conditions, what would you do to make it easier for teens with disabilities and chronic health conditions to be as healthy as possible?
7. What concerns or problems, if any, did you have about changing from pediatric to adult health care, as you aged beyond your teen years?

As a group, given all of what we have said, what are the top five needs regarding health for teens with disabilities and chronic health conditions?

## **APPENDIX C.**

### **Focus Group Responses**

Kansas Youth Leadership Forum Responses (Black Arial Font)  
North Carolina Young Adult Responses (*Blue Times Font Italicized*)

### Challenges with health care and suggestions for improving the system

Challenges	Suggested system improvements
<ul style="list-style-type: none"> <li>• Transportation to health care is often a problem</li> <li>• Red tape and delays in getting equipment</li> <li>• Long delays getting what you need</li> <li>• Doctors' offices seem to have problems on billing insurances</li> <li>• Little help when there are problems with medical billings</li> <li>• Concern for the increases in co-pay for health care</li> <li>• Income limit on health coverage</li> <li>• Difficult to understand the availability of services</li> <li>• Difficulty finding a doctor who will take a medical card</li> <li>• Difficult to get referrals to specialists</li> <li>• Doctors don't understand the disability perspective</li> <li>• Doctors and other health care professionals can be insensitive/rude to the disabled</li> <li>• <i>Unpleasant waiting rooms and offices</i></li> <li>• <i>Difficult physical accessibility of offices and equipment (e.g., no hand rails in bathrooms, inaccessible exam tables)</i></li> <li>• Doctors may not be willing to listen</li> <li>• Difficult if you have multiple doctors you see</li> <li>• Health care professionals need to talk directly to patients</li> </ul>	<ul style="list-style-type: none"> <li>• Courteous treatment</li> <li>• Simplification of the system</li> <li>• State should move to plastic card system</li> <li>• State limits coverage; it should be the same for all people</li> <li>• State should trust the doctor to prescribe what is needed</li> <li>• Fewer middle men in health care system</li> <li>• A truly workable National Health Insurance</li> <li>• <i>Decrease costs and improve systems of purchasing, maintaining, replacing, and repairing assistive equipment</i></li> <li>• People with disabilities wouldn't be made to feel bad because of a disability</li> <li>• Safety net for people needing services or equipment</li> <li>• System supports people with disabilities being fully employed <i>(e.g., sever tie between insurance and employment)</i></li> <li>• Co-pays scaled to not create a hardship</li> <li>• Independent living wouldn't have so many barriers</li> <li>• Persons with disabilities would be viewed and treated as individuals by all health care providers</li> <li>• Health care needs would not divide individuals with disabilities from everyone else</li> <li>• No labels (no "special needs")</li> <li>• System would help not hinder individuals</li> <li>• <i>Educate providers about disability, creating partnerships, and promoting health of persons with disabilities</i></li> <li>• <i>Educate and empower youth on: being self-advocates; locating good providers, and managing health care independently</i></li> <li>• <i>Need direct, improved ongoing access to good information on living well with a disability</i></li> <li>• <i>Comprehensive, affordable insurance coverage (e.g., provide more information on coverage after age 21)</i></li> <li>• <i>Improve transportation</i></li> </ul>

**Barriers and keys to living a healthy lifestyle**

<b>Barriers</b>	<b>Keys</b>
<ul style="list-style-type: none"> <li>• <i>Negative peer pressure</i></li> <li>• <i>Negative media influence</i></li> <li>• <i>Promotion of unrealistic body images</i></li> <li>• <i>Inaccessible exercise facilities</i></li> <li>• <i>Sedentary, indoor lifestyles</i></li> <li>• <i>Convenience of unhealthy food</i></li> <li>• <i>Fear of trying new things</i></li> <li>• <i>Developmental norms</i> <ul style="list-style-type: none"> <li>- <i>Rebellious</i></li> <li>- <i>Immature</i></li> <li>- <i>Invulnerable</i></li> <li>- <i>Present focused</i></li> </ul> </li> <li>• <i>Limited transportation</i></li> <li>• <i>Fatigue</i></li> <li>• <i>Lack of personal control</i> <ul style="list-style-type: none"> <li>- <i>Food preparation</i></li> <li>- <i>Relying on others for assistance/transportation</i></li> </ul> </li> <li>• <i>Issues related to self-acceptance of disability</i> <ul style="list-style-type: none"> <li>- <i>Feeling sorry for oneself</i></li> </ul> </li> <li>• <i>Social isolation and exclusion</i></li> <li>• <i>Societal perceptions and stereotypes</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Physical activity / exercise</i> <ul style="list-style-type: none"> <li>- <i>Recreation</i></li> </ul> </li> <li>• <i>Good nutrition and eating healthy foods</i></li> <li>• <i>Managing stress</i></li> <li>• <i>Social support</i></li> <li>• <i>Emotional well-being</i></li> <li>• <i>Preventive health care</i></li> <li>• <i>Being proactive to ward off problems</i></li> <li>• <i>Accepting physical and emotional limits</i></li> <li>• <i>Developing a personal definition of health</i></li> </ul> <p><b><i>Perceived needs for maintaining active healthy lifestyle</i></b></p> <ul style="list-style-type: none"> <li>• <i>Better transportation options</i></li> <li>• <i>Active social life</i></li> <li>• <i>Disability sensitivity in the community</i></li> <li>• <i>More information about staying healthy with a disability</i></li> <li>• <i>Assertiveness and self-advocacy skills training</i></li> <li>• <i>Ongoing, comprehensive, affordable health insurance</i></li> <li>• <i>Financial resources to stay healthy</i></li> <li>• <i>Greater self-acceptance</i></li> <li>• <i>Greater community integration</i></li> <li>• <i>Better information about disability</i></li> <li>• <i>Positive disability images</i></li> <li>• <i>More accessible physical environments</i></li> </ul>

**Concerns about transitioning to adult health care**

<ul style="list-style-type: none"> <li>• <i>Many expressed satisfaction with the transition to adult care providers although experience greater difficulties in scheduling appointments and coordinating care</i></li> <li>• <i>Critical need to find the “right doctor” that will work as a partner in care</i></li> <li>• <i>Concerned about meeting health needs after 21 when age out of insurance</i> <ul style="list-style-type: none"> <li>- <i>Not sure how medical care and equipment needs will be met</i></li> </ul> </li> <li>• <i>Unknown effects of disability on their health as they age (limited available knowledge base in adult or pediatric arenas)</i></li> <li>• <i>It takes hard work, over many years, with parent and provider support for young adults to develop necessary skills to manage their health care</i></li> </ul>
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**Challenges faced when dealing with employers and employment issues.**

<b>Challenges</b>	<b>Suggested improvements</b>
<ul style="list-style-type: none"> <li>• If they can see the disability...more wary and if they do hire...they baby you.</li> <li>• Transportation (expect independence in finding transportation but provides with ideas)</li> <li>• People with hidden disability; if you are hired then how do you let people know?</li> <li>• Behavior of employer – yells; demeans - How do we manage that behavior...</li> <li>• How do we get people to make assumptions about our capacity? Advancement is difficult...</li> <li>• Negotiating worth...</li> <li>• Managing an environment by taking advantage of opportunities</li> <li>• When you get ignored</li> <li>• Micromanagement</li> <li>• Telling you one thing and expecting another</li> <li>• Pace of how you do your job is not acceptable</li> <li>• Lack of response to application and effort</li> <li>• Attitude of boss</li> <li>• Not hired <i>because</i> of having a disability</li> <li>• Once in a job...can't get promoted</li> </ul>	<ul style="list-style-type: none"> <li>• To have a chance to have your application reviewed</li> <li>• Your resume – look at the resume</li> <li>• No limits on “what career do I want to process” (Reframing to what you can and want versus what are your limitations)</li> <li>• Tests that allow you to demonstrate skill and quality</li> <li>• During application process it's good to have someone assist you</li> <li>• During application process it's good to know what's associated with the job</li> <li>• Want employers to pay attention to young adults with disabilities</li> <li>• Realize young adults with disabilities can do that job...just as able</li> <li>• Realize that young adults with disabilities are just as motivated/that we have initiative</li> <li>• Realize that young adults with disabilities can do that job right</li> <li>• Realize that young adults with disabilities can follow instructions and be team players</li> <li>• Realize feedback is needed...for a job well done</li> <li>• Make some effort to become aware of issues around disabilities</li> <li>• Job environment should promote fairness</li> <li>• Job should offer opportunity to get a step higher</li> <li>• Job environment should project that everyone is appreciated</li> <li>• Job should insure an environment working with people who won't make fun of you</li> <li>• Job responsibilities should be defined so you know what is expected of you</li> <li>• Job should provide an opportunity to explore and discover skill sets                         <ul style="list-style-type: none"> <li>- Travel opportunities</li> </ul> </li> <li>• Perfect job is something you enjoy</li> </ul>

### Employment search suggestions

<b>For Youth Leadership Forum</b>	<b>For Employers</b>
<ul style="list-style-type: none"> <li>• Learn about the application/hiring process</li> <li>• Acquire application as soon as possible</li> <li>• Keep checking with prospective employer after you have submitted an application</li> <li>• Team work with “employer”</li> <li>• Become knowledgeable about the job for which you are applying</li> <li>• Be realistic about the job you apply for</li> <li>• Set achievable goals – set benchmarks</li> <li>• Be yourself</li> <li>• Write down the questions that you have</li> </ul>	<ul style="list-style-type: none"> <li>• Right</li> <li>• Be open to diversity</li> <li>• Think more about accommodations</li> <li>• “do your homework”</li> <li>• Don’t assume you’re smarter just because you’re older</li> </ul>

### Employment skill development

<b>Young adults</b>	<b>Employers</b>
<ul style="list-style-type: none"> <li>• Develop skills                             <ul style="list-style-type: none"> <li>- Keep working at it</li> <li>- Obtain experience</li> </ul> </li> <li>• Manage interview situation                             <ul style="list-style-type: none"> <li>- How the interview is set up (e.g., conducive to disability situation)</li> <li>- How you answer questions</li> <li>- Possibly request materials in advance</li> <li>- How you dress/present yourself</li> </ul> </li> <li>• Brainstorming                             <ul style="list-style-type: none"> <li>- Training sessions</li> <li>- Disability awareness sessions</li> <li>- Career fairs</li> <li>- Classes (e.g., behavior management, sexual harassment)</li> <li>- Asking for appropriate help (e.g., Have an employer ask “what” you need? How you want to be helped.)</li> <li>- Familiarity with available technology to provide employer with information that will assist you in succeeding (overcome reluctance of the unknown, not knowing what to say)</li> <li>- Website</li> <li>- Media work</li> <li>- Flyers</li> <li>- Surveys</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Future Youth Leadership Forum sessions                             <ul style="list-style-type: none"> <li>- PowerPoint – talks about job search</li> <li>- Employment application process</li> <li>- Work site etiquette</li> <li>- Information about what employers expect</li> </ul> </li> <li>• Future session with “employers” to hear what they look for during interviews and in employees</li> </ul>

**Challenges and suggestions for dealing with educators and education issues**

<b>Challenges</b>	<b>Suggestions</b>
<p><i>Teachers</i></p> <ul style="list-style-type: none"> <li>• Say we don't really need help</li> <li>• Have to provide notice for help in the classroom</li> </ul> <p><i>High School</i></p> <ul style="list-style-type: none"> <li>• Regular classes – hard, teachers nice – went to special education – better</li> <li>• Teachers in Ed Center couldn't help me with geometry – My mom was my help</li> <li>• Teachers like kids who do sports</li> <li>• No books on tape</li> <li>• Didn't have paraprofessionals for many of the classes/not enough paraprofessionals</li> <li>• English teacher – pushed me to be good</li> </ul> <p><i>Grade school teachers</i></p> <ul style="list-style-type: none"> <li>• My teachers told me I would flunk, so I worked extra hard</li> <li>• One teacher helped me be confident</li> <li>• One teacher had confidence in me, so I learned</li> </ul> <p><i>Worries</i></p> <ul style="list-style-type: none"> <li>• Worry I'll miss info – need interpreter</li> <li>• I was in special ed, but when I went to regular ed it was better</li> </ul> <p><i>I would change</i></p> <ul style="list-style-type: none"> <li>• Teachers put me down – they need more education about disability</li> <li>• Less fighting at school – teachers pick on people – need teachers who want to teach, not worry about differences in kids</li> <li>• Some teachers need disability education</li> </ul> <p><i>College</i></p> <ul style="list-style-type: none"> <li>• Have to find help</li> <li>• ASC Center help me</li> <li>• Resource center great at my college</li> <li>• If you make good strong relationships, things change</li> </ul>	<p><i>Teachers</i></p> <ul style="list-style-type: none"> <li>• Don't be afraid of people with disabilities</li> <li>• Help and treat everyone equally</li> <li>• Adjust time for lunch, as needed</li> <li>• Help with little things is appreciated</li> <li>• Don't be too smart to teach; take time to teach (e.g., don't read out of the book, give examples)</li> <li>• Be yourself</li> <li>• Don't pick on people</li> <li>• Be more fun; you learn more if you are having fun</li> </ul> <p><i>Parents</i></p> <ul style="list-style-type: none"> <li>• Be supportive</li> <li>• Back me up with school system</li> <li>• Push me to succeed</li> <li>• Helps when parents are involved</li> </ul>

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