

ASSESSING THE HEALTH-RELATED NEEDS OF YOUTH WITH DISABILITIES AND CHRONIC HEALTH CONDITIONS IN NORTH CAROLINA



Executive Summary

**A study exploring the health-related needs
of adolescents with disabilities and chronic health conditions**

**Developed for and in partnership with the
North Carolina Title V Program,
Specialized Services Unit of the Division of Public Health and
the North Carolina Office on Disability and Health**

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I. INTRODUCTION

Growing up as an adolescent with special health care needs is similar to growing up without special health care needs. However, there are important and fundamental differences to consider. The transition of youth with special health care needs from pediatric to adult care, from school to work and into adult life, is more complex. Traditionally, programs have been oriented toward the immediate medical needs of youth rather than their changing health promotion needs from early childhood through young adulthood. For transition to occur effectively, youth, family and professionals must work together to fully address the health-related needs of youth and to support their acquisition of needed skills over time.

Designing the role of a State Title V Maternal and Child Health (MCH) Program in supporting these transition efforts is uncharted territory. Not only are states in the early phases of setting priorities and developing concrete strategies, many are, for the first time, tackling the task of assessing needs and assets and including youth and adults as partners in this effort. While Title V Programs have made great strides in involving families in needs assessment and planning activities, the importance of including the unique perspective of youth themselves has become more apparent.

Qualitative methods, such as well-designed focus groups or interviews, can provide critical insight into the perceptions, experiences, and priorities of specific population groups. They can also capture the authentic voices of those often times left out of the policy making and program development process. With this in mind, a series of focus groups were undertaken in the spring of 2000 to assess the health-related needs of youth with disabilities and chronic health conditions in North Carolina. A series of interviews was also conducted to accommodate the needs of participants with intellectual disabilities. This study was undertaken as a component of the Title V MCH Block Grant five-year needs assessment process and coordinated by the North Carolina Office on Disability and Health.¹ To supplement our findings, an extensive literature review regarding transition for youth with disabilities and chronic health conditions was conducted. This literature review and complete study findings can be found in the full report, “Assessing the Health-Related Needs of Youth with Disabilities and Chronic Health Conditions.”

¹ A collaborative initiative of the State Title V Agency and the UNC-CH Frank Porter Graham Child Development Center.

II. METHODS

Focus Groups

A total of twelve focus groups were undertaken, comprised of 83 participants. These included 6 teen focus groups (n=43); 3 young adult focus groups (n=19); and 3 parent focus groups (n=21). At the beginning of each focus group session, participants completed a written health survey. Focus group participants received a stipend for participation. Participant recruitment for the focus groups was organized by coordinators from established networks and organizations that serve children, youth, and families with chronic health conditions and disabilities throughout North Carolina.

Interviews

Since the focus group format is not the most effective approach for assessing the needs of individuals with intellectual disabilities, four individual interviews were conducted. At the beginning of each interview, participants responded to an orally-conducted health survey. Interviewees received a stipend for participation in the study.

III. FINDINGS AT A GLANCE

A. FOCUS GROUP AND PERSONAL INTERVIEW HIGHLIGHTS

The following are key findings, organized by topic area, derived from the focus groups and interviews. The first three areas address health promotion practices broadly, whereas the subsequent areas address the health care environment. Each topic area corresponds with questions posed to the participants. A listing of the focus group questions and adapted interview questions, with a more detailed summary of responses, can be found in the full report.

1. Keys to Living a Healthy Lifestyle. Participants were asked to identify key elements of a healthy lifestyle.

All focus groups identified:

- Physical activity
- Exercise
- Eating healthy foods
- Emotional well-being
- Social activity

The groups less consistently identified:

- Healthy behaviors (no smoking, drinking, or drugs, and practicing safe sex)
- Regular medical and dental check-ups
- Accepting physical and emotional limits

2. Barriers to Healthy Living. Participants were asked to identify barriers that prevent teens from living a healthy lifestyle.

All groups identified:

- Unhealthy school environments (unsanitary bathrooms and unhealthy cafeteria foods)
- Negative influences of peers/parents/media/athletes

Several groups also mentioned:

- Sedentary lifestyles
- Convenience of unhealthy foods
- Developmental norms of teens (risk-taking and rebellion)

Whereas the issues mentioned above apply broadly to what all teens might experience, the groups also discussed additional concerns specific to youth with disabilities.

- Social isolation
- Inaccessible environments
- Societal perceptions and stereotypes
- Limited opportunities for physical activity

3. Perceived Needs for Maintaining Active Healthy Lifestyle. Participants identified the following areas as necessary for living a healthy lifestyle.

- Inclusive social/recreation opportunities
- Transportation
- Accessible environments
- Disability sensitivity in schools and community
- Self-advocacy training for youth
- Positive disability images
- More information and resources for staying healthy with a disability

4. Satisfaction with Health Care. Participants were questioned about their satisfaction with their health care. Responses were very individualized, ranging from very negative to very positive. There appeared to be correlation between the degree to which the youth/young adult participants had acquired medical self-management and self-advocacy skills and reported satisfaction with providers.

Participants reported high satisfaction with doctors who are:

- Sensitive
- Knowledgeable about disability
- Willing to work with teens in an age-appropriate manner
- Friendly and funny
- Respectful of teens as experts
- Encouraging self-care
- Good listeners and preferably young

Participants reported low satisfaction with:

- Poor provider/teen communication
- Inadequate time spent with teens by providers
- Unpleasant waiting rooms/offices in the health care setting
- Inaccessible medical offices/bathrooms/exam tables
- Lack of information about their condition & preventive health care
- Extensive time away from school for travel to multiple providers
- Inadequate health insurance and high medical care costs (medications, assistive technology)
- Catch-22 between working and maintaining SSI/Medicaid eligibility

5. Concerns Regarding Transition from Pediatric to Adult Health Care. Teens, young adults, and parents expressed different concerns regarding medical transition.

Concerns expressed by **teens** included:

- Beginning new provider relationships
- Finding adult providers with adequate disability knowledge and who can interact in an age-appropriate way

Concerns expressed by **young adults** included:

- Finding a partner in care
- Meeting their insurance needs after age 21
- Unknown effects of aging with a disability

Concerns expressed by **parents** included:

- Getting attentive, available, and knowledgeable adult providers
- Finding adult providers who deal with pediatric-onset disabilities
- Preparing teens for transition

6. Suggestions for Improving Health Care Services. When asked for their suggestions for improving health care for teens with disabilities and chronic health conditions, participants offered the following:

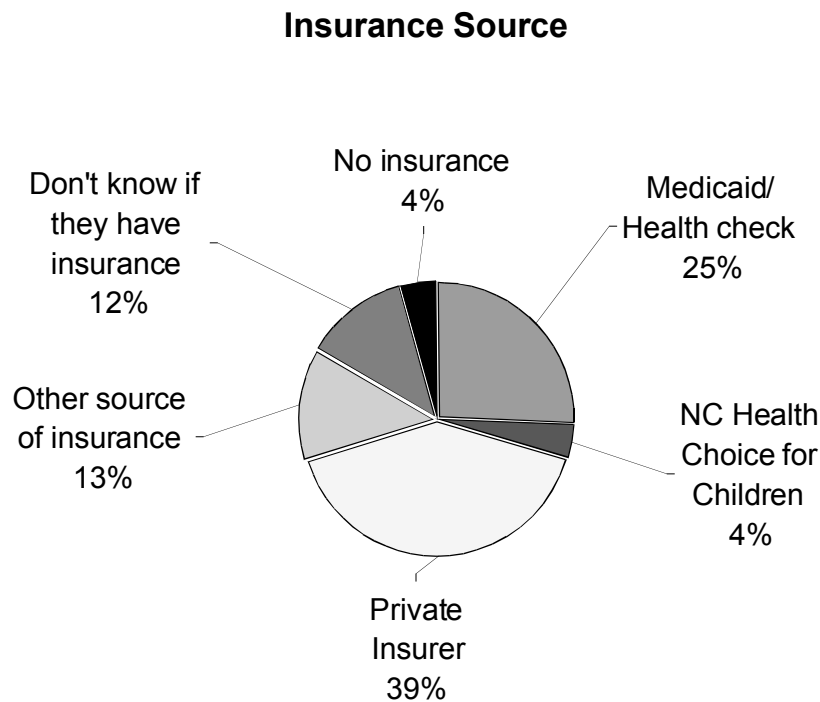
- Improve doctor-patient relationship
- Coordinate care with one primary doctor
- Address insurance needs (cost, access, and benefits)
- Expand health services in schools
- Educate teens on managing their own health care and self advocacy
- Increase information on living well with a disability
- Improve systems for assistive technology (purchasing, maintenance, repair, coverage)
- Make provider offices more teen-friendly
- Provide more/better transportation options to health care visits
- Develop support groups for teens

B. HEALTH SURVEY HIGHLIGHTS

Prior to conducting the focus groups and interviews, all participants completed a health survey. Each of the four versions of the survey is available in the Appendices of the final report. Parents were requested to complete the survey in reference to the characteristics, needs, and experiences of their teen with a disability. Interviewees completed a modified oral version of the health survey. The survey topics included: demographics, health information, current activities, health information needs, and priorities for transition supports.

Health Insurance. The majority of participants reported having some type of health insurance coverage:

- Private insurers (39%)
- Medicaid/Health Check (25%)
- NC Health Choice (4%)
- Another form of insurance (13%)
- Did not know if they had health insurance (12%)
- No insurance (4%)



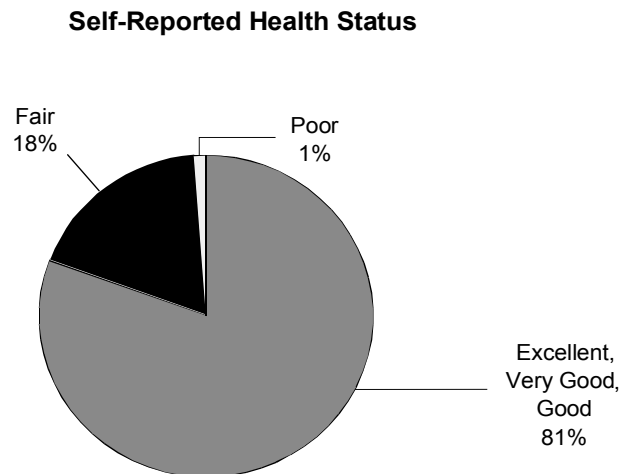
Health Conditions. Study participants self-reported their disability or chronic health condition(s) to include:

- Sick cell disease
- Orthopedic
- Attention deficit disorder
- Spina bifida
- Speech communication disorder
- Respiratory

- Cerebral palsy
- Deaf or hard of hearing
- Blind or visually impaired
- Autism
- Seizures
- Spinal cord injury
- Heart condition
- Mental health problems
- Gastric intestinal problems
- Cognitive disability
- Traumatic brain injury
- Multiple sclerosis
- Neuromuscular problems
- Migraines
- Neck injury
- Back injury

Health Status. Participants were asked to describe their health.

- 81% considered themselves in excellent health, very good or good health
- 18% were in fair health
- 1% were in poor health



Activities and Plans for the Future. While 64% indicated that they are satisfied with their current level of social activity, 31% reported that they are not satisfied and would like to be more socially active.

In regards to participants' plans for the future:

- 80% plan on working
- 70% expect to complete high school
- 66% plan to complete college
- 29% plan to complete graduate or professional studies
- 64% expect to marry
- 52% expect to have children

Health-Related Information Needs. Participants were asked to prioritize their need for various health-related information. Participants from **all** focus groups reported needing more information about these six topic areas, listed in the order of reporting frequency:

- Job/careers
- Successful persons with their condition
- Successful persons with disabilities
- Post high school opportunities
- How to participate in recreational activities
- Paying for medical care

Transition Supports. Participants were asked to indicate their interest in various supports for youth and young adults with disabilities and chronic health conditions in North Carolina. A total of nine options were provided. While participants were able to rate the importance of each option from very important (5) to not important (1), all nine options received an average ranking of important to very important from the majority of respondents.

In priority order, the teens indicated that they would like to see the following options available to support the health of teens with disabilities and chronic health conditions:

1. Have more health education and information available in school
2. Produce a health newsletter for teens with disabilities
3. Have more information on the health-related needs of teens with disabilities at health provider offices
4. Have a statewide health conference for teens with disabilities
5. Have workshops on health issues important to teens with disabilities
6. Produce printed health related resources for teens with disabilities
7. Establish local advocacy groups for teens with disabilities
8. Establish a mentor program in which adults with disabilities support teens with disabilities
9. Develop a web page for teens with disabilities that promotes health

IV. CONCLUSIONS AND RECOMMENDATIONS

Instituting focused, coordinated, well-funded services and supports that provide opportunities for youth with special health care needs to achieve and maintain the best health possible is critical. The following recommendations and strategies are made in response to the needs assessment, review of the literature, and the ongoing work of family representatives and experienced professionals.

NC TITLE V PROGRAM²

- ❑ The Title V Program should support the development of successful models of transition and related services and integrate these into current programs. Models selected must include transition supports beginning at a very young age and proceed through young adulthood that teach and support the individual to assume age and developmentally appropriate responsibility for their health care and other life decisions.
- ❑ The Title V Program should expand to include adolescents with special health care needs as an area of emphasis, with dedicated resources. This should include partnering with the medical community, the early intervention system, schools, and advocacy/community groups to implement programs and activities that improve the transition process.
- ❑ Effective mechanisms to uniformly measure and monitor performance and effectiveness should be developed and integrated into all transition-related services and adolescent-oriented programs.
- ❑ The Title V Program should provide leadership in continually assessing the health-related needs of youth with special health care needs and disseminate this information to all key stakeholders.
- ❑ Title V should continue to support efforts that improve access to comprehensive and affordable health insurance for youth with special health care needs. There needs to be greater emphasis on developing options for insurance coverage beyond age 21.
- ❑ The Title V agency should promote accessibility of all environments - health care, schools, and recreation - and compliance with the Americans with Disabilities Act (ADA) throughout North Carolina.

HEALTH CARE

- ❑ Support for training opportunities and educational materials on disability awareness, sensitivity, and accessibility should be provided for pediatric and adult health care professionals. As a result, professionals will be better able to practice developmentally appropriate and respectful care for adolescents with special health care needs as well as improve their partnerships with youth and families.
- ❑ All facets of the health care delivery system must acknowledge and support age-appropriate and condition-specific independence for adolescents with special health care needs and encourage youth to take as much responsibility for themselves and their health care as their conditions and resources will allow.
- ❑ Health care should be coordinated at one site, preferably within the community of residence for the youth and family.

SCHOOLS

- ❑ Education and school-based health programs should collaborate to assure youth with special health care needs have accessible, developmentally, clinically, and culturally appropriate health and mental health services in the school setting.

² In North Carolina, the Title V Agency is housed in the Division of Public Health, Womens and Childrens Health Section.

- ❑ More information about staying healthy (i.e., physical activity, nutrition) with a disability should be available at the school setting in a variety of user-friendly formats.
- ❑ In order to foster better understanding and inclusion, disability awareness and sensitivity for teachers and peers in the school and community settings should be strengthened through training opportunities and educational materials.
- ❑ School and community efforts to expand physical activity opportunities should be inclusive and designed (and when necessary, adapted) to include all youth.

THE COMMUNITY

- ❑ Community-based health promotion and health education opportunities available for teens should be designed (and when necessary, adapted) to include youth with and without special needs.
- ❑ At the community level, funding for appropriate services, supports, and equipment should be available to allow youth with disabilities to gain transition knowledge and skills specific to health.
- ❑ Opportunities should be regularly provided for teens with disabilities to interact with other individuals with disabilities for peer-to-peer support.
- ❑ Transition-related programs should include support and opportunities for adolescents with special health care needs to have opportunities to interact with positive adult role models who have special health care needs.
- ❑ Parent-to-parent support should be strengthened beyond the early intervention years.
- ❑ Opportunities for youth to develop skills as decision-makers and managers of their own health care, should be supported through collaborative efforts between youth, family members, and professionals.
- ❑ Programs aimed at improving overall quality of life should include education about reducing health-related risks in areas such as nutrition, physical activity, smoking, sexuality, and stress. Often because of system barriers and lowered expectation, adolescents with special health care needs are not exposed to this information; yet this is critical to improving their overall health.
- ❑ Communities should promote accessibility of all environments - health care, schools, and recreation - and compliance with ADA.

These recommendations provide the framework for better meeting the health-related needs of youth with disabilities and chronic health conditions in North Carolina as they transition into all aspects of adult life. Progress will be marked not by the ability to accomplish all the recommendations, but through the development of a thoughtful and systematic plan that involves youth, families, and professionals in every phase of the process.

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