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Research Paper

# Future plans and social/recreational activities of youth with special health care needs: The implications of parental help in completing surveys

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## Abstract

**Background:** A major focus of the literature on youth with special health care needs (YSHCN) is the transition to adult health care. As perceptions of disability are a product of interactions between youth and their environment, it is important to understand youth's needs and experiences beyond health care. Few studies have addressed social/recreational activity participation and future plans and none have included parent/caregiver help in survey completion as a potential factor impacting responses.

**Objectives:** We describe activity participation and identification of future plans among YSHCN and examine the impact of receiving parent/caregiver assistance to complete a survey on these responses. Implications for research, policy, and practice affecting programs serving and providing transition assistance for YSHCN are discussed.

**Methods:** Data are from a survey of YSHCN conducted during Alabama's 2010 Title V Maternal and Child Health Needs Assessment. Analyses included descriptive statistics, bivariate analysis, and multivariable logistic regression.

**Results:** Youth who received help completing the survey were less likely to report participating in certain social/recreational activities and key future plans, including hobbies, getting married, having children, and working for pay.

**Conclusions:** For YSHCN, parent/caregiver assistance to complete a survey is a critical consideration in analyses and interpretation of results. Whether, how much, and what type of help received may represent a more objective proxy measure of perceptions of condition severity or impact on abilities than do self-reported ratings of these factors. Our results also raise questions about the distinctions between youth and parent/caregiver perceptions of independence, participation, and potential.

*Keywords:* Youth with special health care needs; Social activity; Recreation; Future plans; Parental assistance; Parent perception

Children with Special Health Care Needs are "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type and amount beyond that required by children generally".[1] According to data from the 2009/10 National Survey of Children with Special Health Care Needs (NSCSHCN), 15.1 percent of children ages 0−17 years and 18.4 percent of youth ages 12−17 years in the United States have special health care needs.[2]

Much of the recent literature related to youth with special health care needs (YSHCN) or youth with disabilities addresses transition to adult health care,[3−7] with less focus on issues related to work, post-secondary education, and independence.[8−10] However, since disability and special health care needs may, to some extent, be products of complex interactions between youth and their environment,[11] it is important to understand the needs and experiences of these youth beyond health care.

Previous studies have focused on congruence between parent or caregiver and child or adolescent perceptions about health-related quality of life (HRQOL)[12−24] and functional health status related to specific procedures or conditions.[25,26] Among those studies addressing parent and child/adolescent perceptions of HRQOL, results are varied. Some conclude that parents underestimate

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HRQOL or there is low consistency between the responses,[14,15,19,20,22–24] while others suggest similarity or moderate agreement between the two views[13,16,18,21] or mixed results depending upon the domain assessed. For example, better agreement is reported on observable areas such as physical functioning and pain, but less correlation is noted on unobservable constructs such as mental health and self-esteem.[17,24,25] Others support a unifying and holistic definition of quality of life (QOL) rather than one that focuses on health or specific health conditions, viewing QOL as a multidimensional concept encompassing the domains of participation and material, physical, social emotional and productive well-being.[27,28]

Several studies have broadened the measurement of QOL to include the importance of social and recreational activity participation and future plans among children and youth with chronic health conditions or disabilities.[8–10,29–32] Few of those studies have included whether a youth received assistance to complete a survey as a demographic feature.[8,9] Further, though other studies have viewed the role of proxy reporters, such as parents, clinicians, or other care providers,[12–15,17,19–27] the issue of the adolescent simply receiving assistance to complete the survey, as opposed to having a proxy reporter, has infrequently been studied. To the best of our knowledge, no studies to date have quantitatively assessed parent/caregiver assistance as a potential factor impacting survey responses related to social/recreational activities or future plans. This provides an opportunity for further exploration given the discrepancies noted in the HRQOL literature and the paucity of research related to broader contributors to QOL such as social/recreational activity participation and future plans, as well as the impact of parent/caregiver assistance in completing surveys.

The purpose of this pilot study is to examine the impact of receiving parent/caregiver assistance to complete a survey on the identification of participation in social/recreational activities and future plans among a group of YSHCN in Alabama. For simplicity we will henceforth refer to the assistance given as parent assistance though occasionally this was provided by another immediate family member who was the primary caregiver for the youth (for example, a grandparent or aunt). We used the proxy reporter literature as the context for this study and to inform our expansion to include parent assistance to complete the survey.[12–15,17,19–27] Further, we used the broader QOL literature to address the dimension of social and productive well-being[27,28] by examining the impact of parent assistance on reported social/recreational activity participation and future plans. Our research question was “Does receiving parental assistance to complete a survey impact the youth’s identification of participation in social/recreational activities and future plans?” We hypothesized that after controlling for selected demographic characteristics and condition severity, parental assistance to complete the survey would impact the youth’s identification of participation in social/recreational activities and future plans for YSHCN. In addition, we hypothesized that the responses for youth who received help to complete the survey would be different from those who completed the survey independently. Further, we describe activity participation, identification of future plans, and the impact of demographics, condition severity, and parent assistance completing surveys. If receiving parent assistance to complete a survey does impact responses and differences are noted between groups of youth who receive help and those who complete independently, then researchers should consider this when analyzing results. Also, there could be implications for policy and practice for programs serving and providing transition assistance and training for YSHCN, youth with disabilities, and youth with chronic conditions. We discuss these issues related to our study findings.

## Methods

### *Data*

Data are from a survey of YSHCN, ages 12–25, conducted in 2009 during Alabama’s Title V Maternal and Child Health Needs Assessment. The youth survey, first fielded in 2004, was adapted from a tool created by the North Carolina Title V Program as a part of their 1999 needs assessment process. The tool was modified for use in Alabama during 2004 and then again for 2009. Surveys were conducted May–September 2009. This survey was available via paper copy or electronic link and was presented both in English and Spanish. Outreach and recruiting related to the survey included using established listserv groups, a Facebook© group, email, links on partner web sites, columns in newsletters, postcards, and paper copies in locations frequented by YSHCN including the statewide community-based offices of Alabama’s CSHCN program.

In addition to a variety of topics, questions included basic demographics (gender, race/ethnicity, age, type of insurance, and county of residence) and condition severity (perceived severity of difficulties caused by special health care needs). YSHCN also indicated whether they participated in 17 social/recreational activities and selected from a list of 10 future plans. Finally, they were asked whether they received help from anyone to complete the survey. Help was identified as someone else: writing down responses for the youth, reading the questions to the youth, translating questions to the youth’s preferred language, or completing the survey totally without the youth’s input.

### *Data analysis*

#### *Recoding select variables*

Location was coded as urban or rural by county of residence based on a report from the Alabama Rural Health Association.[33] Type of insurance was used as a proxy for low income whereby youth who indicated having Medicaid