

Addressing the Transition from Pediatric to Adult Primary Care for Young Men and Women with Special Health Care Needs/Disabilities



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Workgroup Representation

- MCHB, Division of Children with Special Health Care Needs
- HRSA Office of Women's Health
- HRSA Office of Program Planning and Evaluation
- HHS Office on Women's Health
- HHS Office on Disability
- New Editions Consulting, Inc.

Project Objectives

- Gain a better understanding of:
 - Existing challenges, barriers, and opportunities for male and female youth with special health care needs/disabilities as part of the transition from pediatric to adult primary care services.
 - Similarities and differences in the transition experience between male and female youth with special health care needs/disabilities.



Background

- HRSA MCHB defines children and youth with special health care needs as those:
 - “who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”* According to the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), 13.9 percent of children under 18 years of age in the United States, or approximately 10.2 million children, were estimated to have special health care needs.**

- One transition model supported by the American Academy for Pediatrics is the medical home model.

*CSHCN: Conditions and Functional Impact, retrieved November 2008 from www.mchb.hrsa.gov/chusa07/popchar/pages/107ccfi.html

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Methodology

- Phase I- Literature Review
 - Focus on youth with SHCN, aged 14-30
 - 20 articles reviewed
 - Four domains – general health and well-being, behavioral health, mental health, and reproductive health
- Phase II – Discussion Groups (n=4)
 - Participants aged 18-27
 - Male Group (n=9)
 - Female Group (n=7)

Select Literature Review Findings

- There is a lack of transition models that represent sex and gender issues for young men and women with special health care needs/disabilities in transition.
- More research may be needed to establish and evaluate best practices for counseling adolescents with special health care needs/disabilities on risk behaviors and education and health promotion.
- There is a lack of research on primary health care issues beyond reproductive health for young men and women with special health care needs/disabilities in transition, particularly research examining the unique experiences based on sex and gender issues:
- Additional research is needed to explore differences in primary care experiences among young men and women with special health care needs/disabilities.

Discussion Groups

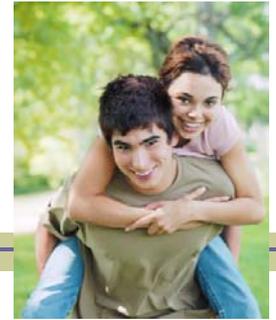
- Characteristics
 - Aged 18-27
 - Male Group (n=9)
 - Female Group (n=7)
 - Self-selected
 - Range of sensory, physical and cognitive disabilities
 - Recruited from relevant organizations
- Informed Consent provided
- Incentive provided for participation

Key Discussion Group Findings

- Common Themes
 - Misconceptions in the health care community
 - Specialist as Primary Care Provider
 - Shift from parent-centered care to patient-centered care
- Female-specific Themes
 - Diet, nutrition, exercise
 - Violence
 - Reproductive health care
- Male-specific Themes
 - Health insurance navigation
 - Support for family
 - Cost of services



Lessons Learned



- Non-gender specific
 - Definition of “transition” from research and practical perspectives
 - Inclusion of youth in decision-making process
 - Concerns about health system fragmentation, care coordination

- Gender-specific
 - Concerns about long term health issues (young women)
 - Concerns about supporting families (young men)

Limitations

- Self-reported information
- Social desirability
- Self-selection bias
- Small discussion group size
- Not representative of all youth with special health care needs/disabilities
- Limited resources

What the Youth Teach Us

- **“They do studies about us, so shouldn’t they include us?”**
 - Include youth in the decision-making process.
- **“The transition itself went fine. It is easy to get an insurance card, but hard to get a doctor.”**
 - Focus on helping youth with special health care needs navigate the adult health care system.



What the Youth Teach Us

- **“If I get married, would I need to start paying for my own medical insurance? How much does it cost? Do I need a job with health care and a 401k?”**
 - Provide information to young men about being in a relationship and supporting a family.
- **“I am trying to find a doctor to be completely open with me. Can I get pregnant? Can I have kids? Will they have my disability too?”**
 - Provide information to young women about preparing for pregnancy and being a parent.



More information

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