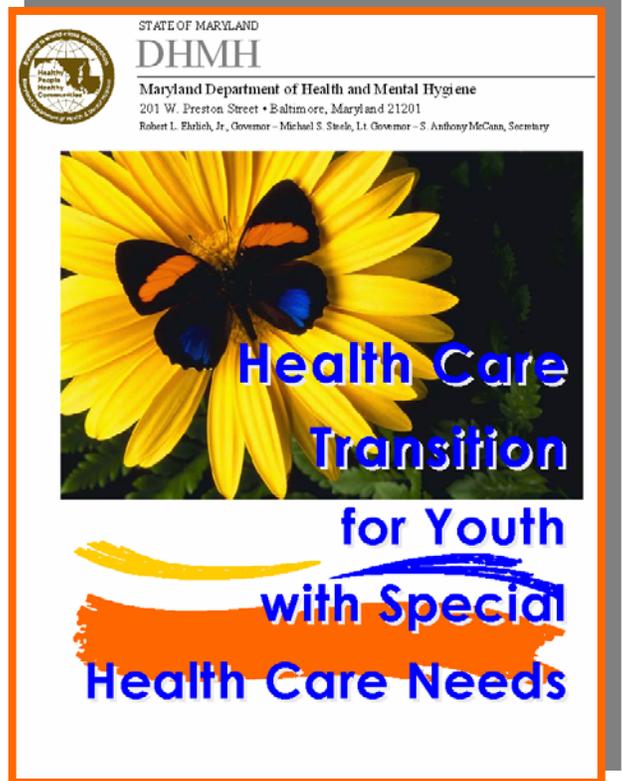


It is estimated that 8.6 million U.S. children between the ages of 10 and 17 have moderate to severe medical, physical or emotional conditions or cognitive disabilities. Each year, more than a half-million of these children will turn age 18, a milestone that introduces new roles, responsibilities and challenges to them and their families. Among the many changes faced by children and youth with special health care needs (CYSHCN) will be health care “transition,” commonly defined as “helping teens and young adults with chronic health conditions plan the move from child-centered to adult-centered health care systems.”<sup>1</sup>

The KellidgE Group conducted 13 focus groups for Maryland parents and youths, with 79 parents and 31 adolescents or young adults from 67 families taking part. The medical conditions of the CYSHCN whose families participated in these focus groups included Attention Deficit-Hyperactivity Disorder (ADHD), Asperger’s syndrome, brain injury, cardiac problems, cerebral palsy, Crohn’s disease, Down’s syndrome, endocrine deficiencies, Marfan syndrome, manic-depressive illness, mental retardation, narcolepsy, Pierre Robin syndrome, quadriplegia, thyroid deficiencies (including hypo- and hyperthyroidism, and the absence of a thyroid), and unspecified developmental or cognitive delays.

KellidgE Group staff worked closely with the OGCSHCN project team to develop and refine the list of questions that would be used in the parent and youth sessions. The instruments covered the following topics:



<sup>1</sup> University of Illinois at Chicago, Division for Specialized Care for Children, “Transition Information Sheet for Families,” July 2002. This definition is also used by Maryland’s Office for Genetics and Children with Special Health Care Needs.

- ✚ **Finding a Doctor Who Treats Adults:** Families were asked about the length of time the child has been seeing the primary physician; the need to transition to a doctor who treats adults; actions taken to find a new doctor; and concerns about the transition to a new doctor.
- ✚ **Managing the Child’s Medical Care:** The focus groups sought information on how the family currently manages the child’s health care, including who makes appointments, maintains records, helps with medications, etc.; steps being taken to increase the youth’s role in health care management, where appropriate; and the role of the current doctor in preparing the adolescent to take more responsibility for health care issues.
- ✚ **Impact of Medical Condition on Other Issues/Transitions:** Extent to which the youth had been given information on the impact of his or her condition on issues such as marriage, children and sex; the role played by the current doctor in discussing these issues; the desired role of the future doctor in discussing these issues; and the role played by current and future doctors on other transition issues, like job training, employment, or finding a place to live.
- ✚ **Insurance:** Families were asked to discuss how the adolescent’s health care is currently paid for, and how it will be paid for in adulthood.

The Kellidge Group prepared tri-fold brochures, flyers, and tabloid-sized posters for distribution to parents through the project’s recruitment partners. For certain regions or target populations where only a few recruitment partners were available, The Kellidge Group used print and broadcast media to reach parents.

The Kellidge Group relied extensively on individual and institutional partners to help identify and recruit focus group participants. Recruitment partners are critical to reaching narrow sub-populations and when the issue being researched is highly confidential. For this project, recruitment partners included medical institutions, physicians and other medical personnel, parent advocacy and support groups, local and regional health departments, and service organizations. Mailings were sent to approximately 280 individuals and organizations.

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