

## Transition Digest 04-09 (Nov 11, 2009)

There is one item in today's Transition Digest

In 1989, Surgeon General C Everett Koop brought health care professionals, policy makers, parents, and young adults with special health care needs together at a conference entitled "Growing Up and Getting Medical Care". The purpose of this working meeting was to establish an agenda, define action steps, and begin a process that would assure that individuals with childhood-onset medical conditions and disabilities could access high quality, affordable, coordinated, and continuous medical care and related supports across their life span.

The goals identified by this group were clear – put in place a process for transitioning youth from pediatric to adult-oriented care and assure that quality care is available in the adult system. And while the action steps and strategies appeared to be appropriate, time has shown that they were not feasible or effective. Now, twenty years later, in spite of the best efforts of numerous individuals and organizations, many youth and young adults with chronic medical conditions and disabilities (CMCD) still are not getting needed health care and supports.

Earlier this year, as discussions about US health care reform became more serious, representatives from advocacy organizations, health professional associations, and parent/leadership organizations, came together, under the leadership of Physician-Parent Caregivers (PPC) to find ways of bringing attention to the needs of youth and young adults with CMCD. The first project of the group (the Coalition for Young Adults Living with CMCD) is a white paper entitled "Enhancing Health Care Transition for Youth and Young Adults Living with Chronic Medical Conditions and Disabilities: Suggestions for Reform".

As is documented in this 38 page paper, almost one in five, or 8.8 million, American households include at least one child with a chronic medical condition or disability; and the number of young people who are living with CMCD has increased over the past four decades to over 10 million youth and 5 million young adults. This paper describes the barriers to care for young adults (such as difficulty getting insurance, and the limited number of trained providers); discusses strategies for promoting continuous care (transition services and the medical home model) and includes brief stories about how these issues impact the lives of young adults with CMCD. The paper also lays out a set of recommendations that should be included in health care reform legislation and in its implementation.

I urge you to read: "Enhancing Health Care Transition for Youth and Young Adults Living with CMCD: Suggestions for Reform" by going to the PPC web site: <http://physicianparent.org/>

If you agree with the recommendations for reform included in this document, consider contacting your Congressional representatives, telling them about the White Paper and asking them to make sure that the needs of youth and young adults with CMCD are addressed in health care reform legislation and will be met when this legislation is implemented.

If you work for or belong to an organization that is concerned with the health and wellbeing of youth and young adults with CMCD, please make the organization's leadership aware of this White Paper and let them know that they can "sign on" in support of the recommendations and can also join the Coalition.

Thank you for helping to assure that, when children with CMCD grow up and become young adults, they can get the health care and supports that they need and deserve.

(If you have a problem accessing the PPC site, or downloading the document, please let me know and I will send you an electronic copy.

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