

Families of CYSHCN Change Workforce Attitudes

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Families and young adult consumers with special health care needs are now very much a part of the American workforce. They are employed in white collar, blue collar and sales force positions. They have joined the entrepreneurs working from home and are finding and creating new jobs for themselves. With these new jobs comes some attitudinal and policy changes. Often these parents and youth have introduced the need for job sharing, additional sick or flextime in order to care for their medical needs yet continue to work.

Title V has invited parents and young adults into their workforce in a variety of ways. Some states have been able to utilize the civil service system to hire a parent or young adult to ensure the family presence at their policy table. In this instance the employee is a member of the Title V program, or other program(s) representing families, receives state benefits and works within the civil service system. One such example is Meg Steimle, from Wisconsin and a 2009 AMCHP Family Mentor. In her words, "as a parent working for a Title V funded resource center for children and youth with special health care needs (CYSHCN) I feel blessed to be doing what I love! When my son was born in 1994, my life changed and I now had this great experience of caring for a child with significant health care needs. I wanted to share what I had learned, particularly about navigating the system of insurance, education and community programs.

In 2003 an opening became available with the Southeast Regional Center for CYSHCN. I applied and got the job! One of the preferred qualifications was "parent of a child with special needs." It was a perfect fit! I have been working at the Southeast Regional Center for CYSHCN for almost six years and loving it! I help parents become advocates for their children. These parents often take off and get involved in their communities and advocate for what is best for all kids in their community and some of these parents participate in leadership at the state level."

Another option that has been successful is contracting with a local family-run organization such as Family Voices to hire a family. Through this option, families and youth are hired directly by the agency and work either within the program at the state government level or work at the site of the contracted agency to produce the end products outlined in the contract. The drawback to this has been that the employee usually does not have the same benefits as a state employee and the contracted agency may be less flexible in meeting the employee's needs.

A third way of engaging families at the state and national level is through an advisory council or committee membership. Families are usually provided a stipend, lodging, travel and meal expenses for their participation. A 2009 AMCHP Family Scholar, Carol Grady, participates on the Minnesota MCH State Advisory Task Force. Carol states that, "having a child with special needs is such a monumental event in one's life that in many cases, it can make you question what you are doing with your life and send you back to the drawing table in terms of a career. Like so many others, I was drawn into health care largely because of my son, Justin. Currently I work as a registered nurse and I don't honestly know if I'd be doing what I am today if it weren't for Justin.

Minnesota has an MCH State Advisory Task Force, with members coming from such areas as local public health departments, medicine, non-profits and the university. It also has several members that are Consumer Representatives, which is the capacity I serve in. Through our work, we have highlighted areas of concern that warrant further examination, such as infant mortality, health disparities and child/adolescent mental health. Through my participation at AMCHP as a Family Scholar, I believe I can make a better contribution to our quarterly meetings and have a fuller understanding of the policy-making process."

The workforce today includes consumers and families at the decision tables. Families and youth should be included from the design, planning, implementation and evaluation of programs and policies. Families are an integral part of the Title V workforce and workforce planning should focus on the valuable experience that these individuals bring to the position.