



Thoughts on Transition

by Karen Anzola, Family Voices Staff

As the mom of a 14-year old who has begun that awkward, oftentimes stressful move toward greater independence, I have felt the all-too-familiar tug and pull between holding on and letting go. I have wondered how this might be similar to the experience of the transition with a child that has a disability. Friends who have experienced it and those who are on that path tell me “expect the unexpected” and “you can never start transition planning too early”—words of wisdom for all parents! What I can share is what I have learned as a long-time friend and ally of persons with disabilities and special health care needs, and how my thoughts came together recently when attending and providing support for the KASA Task Force Meeting in Chicago in July.

At the KASA Task Force Meeting, I had the privilege of meeting dynamic, energetic disabled youth and young adults who are well on their way to independence, not timid about expressing their views, even if those views are “unpopular”. They are excited about learning more about disability culture and how they can tap into the disability community, and how they can develop their own leadership skills. They are committed to helping other youth with disabilities learn more about and work with the education and health care systems. They make themselves available to each other to problem solve around issues faced in school and in their home communities, and have pledged to return home to seek out partners who can help them address barriers to their (and others) full participation in their communities.

In talking with the parents of some of these young persons, I learned that they became involved in parent organizations because they were looking for information and “stayed on” in order to make it easier for other families to access needed supports and services. They have learned to maneuver complex systems and readily share their experiences with other parents new to these systems. They are available to other parents to troubleshoot challenging situations. They have sought ways to engage their children in their own care, help them develop their own advocacy skills, and build a circle of trusted friends and adult allies with and without disabilities.

While I see some similarities between the parent movement and the youth self-advocates—both parents and youth are passionate. . . passionate about changing systems so that the path is easier for those that will come after them, and both are committed to making sure their voices are heard—there are distinctive differences. The parent movement has been the “voice for”, and the youth advocates within the disability community are the “voice of”. Within the parent movement, parents have advocated for access to information and resources so that they may secure the most appropriate services for their children. Within the disability community, disabled youth advocate for themselves and their community.

How, then, do parents and their children with disabilities begin to transition so that the youth may be the “voice of”? What I observed at the Task Force meeting is that transition begins in an environment filled with mutual love and respect. Transition begins when parents encourage youth in expressing (in a variety of ways, as they are able) what they want and need and offer a safe place where that can happen. At the Disability Pride Parade in Chicago, I witnessed that transition also begins when parents access and expose their children to the disability community so that they may learn about their community and have people who share their culture take steps to advocate with them.



Network News



Members of the Family Voices family have experienced recent hospitalizations.

Tyler Feist, son of Donene Feist (FV North Dakota) was injured in an on-the-job fire August 15th. He was treated for burns at Regions Hospital in St. Paul, MN and was allowed to return home late last week. Tyler and his mom will return to the hospital this week to learn whether or not he will need skin grafts. The Feist family thanks everyone for the calls and letters and wants you to know that your support and prayers have sustained them. You are in our hearts, Tyler, and we wish you continued healing and renewed strength!

Conni Wells, formerly with Florida FV and the Florida Institute for Family Involvement, had a total right knee replacement recently. Her daughter reports that the surgery went well and that Conni is now receiving intense physical therapy to further her recovery. Sending you wishes for a speedy recovery, Conni!

Dennis Moore, Executive Director of Parents, Let's Unite for Kids (PLUK) in Montana, was severely injured when he fell from the roof of his Billings, MT home in June. In July Moore was moved to the University of Utah Medical Center in Salt Lake City, where he continues to receive intense physical, occupational and speech therapy. We are happy to report that Dennis continues to improve and heal from his injuries and has remained active in PLUK's day-to-day operations. Our thoughts and prayers are with you, Dennis!

Website Resources

■ **Creating a Life Plan for a Family Member with a Disability: The Family Education Workbook**

The Combined Jewish Philanthropies Disabilities Housing Initiative and Jewish Family & Children's Services, using information they have gathered from families throughout the years, have created a Family Education Workbook to help families develop a life care plan for their family members with disabilities. This workbook is a step-by-step guide for families of people with disabilities. [Click here to read more.](#)

■ **New knowledge path edition: Diabetes in children and adolescents.**

The MCH Library released a new knowledge path edition about diabetes in children and adolescents that includes resources about the types of diabetes, its prevalence, treatment and care, and lowering the risk of complications. This electronic resource guide includes a separate section that identifies resources for families. View it online at http://www.mchlibrary.info/KnowledgePaths/kp_diabetes.html

■ **I'm Not Afraid of Needles**

A new book written by the mother of a chronically ill 6-year old is designed to help children cope with a hospital or doctor visit. Check it out at www.kidstalkmag.com

Great discoveries and improvements invariably involve the cooperation of many minds. I may be given credit for having blazed the trail but when I look at the subsequent developments I feel the credit is due to others rather than to myself.

— Alexander Graham Bell

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