

Family Story - Strength in Numbers

Gay Nowlin, TxP2P Volunteer, Humble, TX

I just returned home from an ARD meeting. I always experience mixed emotions when I attend ARDs. On the one hand, I am glad to hear how my child has improved over the course of the semester. On the other hand, you can't help but feel overwhelmed with having to face (yet again) the truth that he will never be "like everyone else". We will make strides, and at times we will stall in his development. At other times we might regress before haltingly moving forward yet again.

As I am talking to others in the disability community, I ask them if they go through these cycles of joy and depression and the answer is almost always "Yes, I do." Of course, I wish no parent had to feel this way, but there is some relief in knowing that I am not the only one feeling this way. Our son, Sam, was

diagnosed with autism at age 3. He will turn 8 late this summer. I sometimes lull myself into thinking there will be an end to this "cycle", but in truth, it never ends. Some days are just better than others. That is where I have decided to dwell. I am not in denial about the bad days, but if I continue to focus on those, I will freeze up and he will suffer in the long run.

At times, my husband has said, "This may be as good as it gets." I can't give in to that. I recently saw a video on HBO called Autism - The Musical. One mother on the video said that if her child takes one step today that they didn't take earlier, it is one step closer than we were. I have to keep looking for ways to

teach my son. When no one else can offer suggestions, I must lie awake at night thinking of creative solutions for him to know the difference between a penny, nickel, dime and a quarter. I must think of a way for him to understand that eating with your mouth open or with food on your face is



unacceptable to those around you. Give up - never! Get down sometimes - sure! That's what we are all here for. To lift the other one up when they need it. It never seems like we are all down at the same time, and there is definitely strength in numbers - especially those who understand.

I am grateful for my parent to parent matches and for the Texas Parent to Parent organization. You're right there when I need it!

Top Ten Things to Prepare for (Health Care) Transition

Kathy Griffis-Bailey, DSHS CSHCN

Transition is just another word for change. Everyone experiences change in their lives. For children and youth with special health care needs (CYSHCN) and their families, the term transition most often has come to mean the change from childhood or teen years to adulthood.

ALL young people experience this transition. Some experience transition easily or in shorter periods of time. Others struggle with their changing bodies, conflicting thought processes, and new responsibilities. No two young people experience transition exactly the same way. Every family feels the impact of this transition.

In many ways, CYSHCN really are no different. They also go through transition, some more easily or quickly than others. Each CYSHCN is unique in ability and achievement. Many CYSHCN need more help with transition than other children and youth. This need calls for information, resources, adaptations, and accommodations not usually needed by all.

There are some common transition topics that need instruction or special direction. Some of these topics

include self-determination, education, employment, housing, insurance, transportation, and recreation. Also important, but sometimes overlooked, is health care. When physical and mental health and wellness are not well-managed, young adults with disabilities cannot learn, work, or play.

At some point in time, almost all children approaching adulthood must change from seeing doctors and other providers treating mostly children to those that treat adults. This change is known as health care transition. Like other life transitions, success depends upon parental leadership. Below is a list of "top ten" things parents can do to prepare for their children's health care transitions to adulthood. If you have a young child, go ahead and read through the list. None may have to be done today but knowing what they are will help you plan for the future!

1. LEARN as much as you can about your child's disability or chronic illness. It's really up to you! Become the expert on the current research

and hunt for information from various reliable sources. Some medical conditions change a lot with puberty and maturation. Ask your child's doctor for information about changes that might occur for your child. Ask other parents and share the knowledge you have gained.

2. SEEK a clinic or practice that matches your needs for a medical home. A medical home is the place where the doctor(s) and other staff know you and your child. The staff is available and open to you and your child. They work with you in partnership. They seek to locate and collaborate with community resources.

They coordinate your child's medical care. They also work with you as a team to prepare and plan for changing your teenaged child to an adult medical home and/or other doctors for adults. Sometimes it takes several years to complete this change. When your teen enters puberty or no later than about age 14, ask what can be done to begin health care transition planning.

3. TEACH your child about his/her

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