



Providing support and information for families of children with disabilities, chronic illness and other special health care needs

TxP<u>2P Update</u>

don't exactly know where the summer went but kids are back at school and it is definitely gone. If you think you missed a newsletter, you did not! We were supposed to have a newsletter out in June but preparing for our 4th Annual Parent Conference on June 27-28th kept us so busy that we were barely able to ask folks for articles. I thought we could definitely have it out in July but we had the Wrightslaw Boot Camp on August 1-2nd to prepare for and it got about half written. So, here we are the end of August (first of September by the time you get this!) and we're still cleaning up, reporting, and invoicing from the conferences. For those of you who attended one or both of the conferences, you know what we have been doing. For the rest of you, I apologize mation and photos, see page 7.

Laura J. Warren, TxP2P

for the lack of contact from us.

And what a wonderful conference it We had more families from more

> areas of the state, with more agencies sending and paying for parents and professionals to come to the conference.



MARK YOUR

CALENDARS - the 2009 Parent Conference will be at the Omni once again on June 26-27th. We will not offer Wrightslaw next year! For more inforVolume 7, Issue 2

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Help TxP2P by using our Randall's Good Neighbor Remarkable Card Number 10043!

Consumer Directed Services... Now Available in the Home and Community-Based (HCS) and Texas Home Living Waivers!

Colleen Horton, Public Policy Director, Texas Center for Disability Studies, University of Texas at Austin

onsumer Directed Services (CDS) is a service delivery option that offers individuals and families more control over their lives and the services and supports they receive. CDS has been available in other programs and waivers for a number of years, but was added to HCS and TxHmL as of February 1st! Those who are currently receiving services through these waivers or are anticipating receiving these services in the future should learn more about this opportunity that allows you to control who provides your services.

What is the Consumer Directed Services option?

A service delivery option defines the way you receive your services. In the traditional agency model, the agency decides who they will send to your home to provide services to you or your child. The CDS option allows the individual receiving the services and/or their family/legally authorized representative to be the emplayer of their direct-care supported home living providers (attendants) and respite service providers. This means that you (not a direct service agency or private provider) are able to recruit, hire, train, supervise, and terminate at will the employees providing these much needed and often very personal services. You no longer have to settle for whoever the agency decides to send to your home. Many individuals currently using the CDS model hire extended family members (aunts, uncles, cousins, etc), fellow church members, neighbors, teachers' aides, etc. - people they know and trust.

Individuals using the CDS model are supported by a Consumer Directed Services Agency (CDSA) that provides administrative support including payroll, payroll tax filing, and more. This agency also assists the individual or family in understanding their duties and responsibilities as the employer.

In addition to having more control over who provides these services, the CDS option allows you to pay significantly higher wages to supported home living attendants and respite providers than what the provider agency typically pays them. As we all know, higher wages can certainly result in higher quality of services.

How do I find out more about

HCS case managers are required to provide information to their clients on the CDS option. While this can be helpful, it is sometimes difficult to receive comprehensive information from the case manager because the direct service provider agency (also the employer of the case manager) will likely lose money if you chose CDS. Cutting out a portion of the administrative costs paid to the provider agency is what allows the CDS client/employer to pay higher attendant wages. If you have difficulty in getting accurate and comprehensive information, you can contact your local Mental Health/ Mental Retardation Center (MHMR), a local disability organization, or the Department on Aging and Disability Services in Austin. Another way to find out more is by talking to individuals or other families who have used this option to maximize their decision making and TxP2P can assist you with this. And, as always, if I can answer any questions, please contact me at:

colleen.horton@mail.utexas.edu

Family Story - Strength in Numbers

Gay Nowlin, TxP2P Volunteer, Humble, TX

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 de-

nial 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

ransition 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.

 TEACH your child about his/her Continued on Page 3

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