Our big news is that Texas Parent to Parent has moved our offices. For the past 14 years, we have been renting space in the AGE (Austin Groups for the Elderly) Building. It was an historic building, 100 years old, with very chopped up spaces, very little parking, very old utilities systems, and a few ghosts – it was built as a Confederate Widows Home in 1908.

We shared the space with several other nonprofits and really enjoyed our time with them – we shared our challenges and dreams, frustrations and triumphs. And learned from each other’s mistakes. It was a great place to start a nonprofit.

But we are thrilled to be in a newly renovated building where the space was built-out for us, we have hot water and lots of parking. If you ever come to Austin, please come by and visit us – we’re at 1805 Rutherford Lane, Suite 201, Austin, 78754.

Otherwise, we have been busy with our statewide conference in June in San Marcos, our annual fundraiser in September, and our latest Regional Conference in Port Isabel this month. Our next Regional Conference is in Tyler on Saturday, February 25th, 2017.

And if your child has been enrolled in STARKids recently, just wanted to let you know that we have formal contacts with United Healthcare, Blue Cross Blue Shield, Driscoll Children’s Health Plan, and Texas Children’s Health Plan so please give us a call if you are having problems with services from these Plans. We’ll try to help.

Making the Switch to STAR+PLUS - Here’s Our Experience!

Debbie Wiederhold, TxP2P Volunteer

Our son has extensive medical expenses that have, up until he turned 21, been covered by private insurance, traditional Medicaid through the Comprehensive Care Program (CCP) and the CLASS Medicaid waiver. (He did have MDCP previously, until his name came up on the CLASS waiting list and we switched to that waiver.) Daniel requires private duty nursing care and quite a bit of medical equipment for him to be able to live in the community and in his own (our) home. Services end with the Medicaid Comprehensive Care Program (CCP) when your child turns 21.

I knew changes were coming with the introduction of STAR+PLUS, and had many days of angst about “giving up” CLASS – since it took us 7 years “waiting” to finally get the waiver. I weighed the options over and over, talking with the CLASS Case Manager and the STAR+PLUS intake coordinators. I also thought at the time that he would no longer have an option when STAR+PLUS was rolling out for all of Texas this year, so I thought we would just go ahead and do it when he transitioned from pediatric to adult care.

Things have changed since that initial thought and individuals are able to keep their current waiver without switching; however, each individual’s needs vary and staying with the current waiver may be the best option for some, and not for others. We had several meetings with both Case Managers from CLASS and STAR+PLUS, even preparing a “mock” budget, but in the end STAR+PLUS was the one that would provide the best care for our son.

I think we made the right decision to go ahead and switch, given the CLASS restraints (i.e., our son uses a lot of private duty nursing care – I still don’t know of a nursing agency willing to sign up with CLASS as a provider; however, there are several nursing agencies that do take STAR+PLUS). Check with your insurance provider if your child/young adult requires nursing care for options.

Since services end with the Medicaid Comprehensive Care Program (CCP) when your child turns 21, and we were already looking at having to change some of Daniel’s physicians due to “aging out”, we just added switching from CLASS to STAR+PLUS in the mix.

Continued on page 2
Making the Switch to STAR+PLUS (Continued)

Since then with Daniel’s STAR+PLUS Case Manager (you still have to have annual budget meetings and set up an ISP – Individual Service Plan – for each year, just like the other waivers). The Case Managers are also required to check in with you several times a year, on the phone and in person, to make sure your child’s needs are being met.

Our relationship with the STAR+PLUS insurance provider has been a very good fit for us. They “go to bat” for items and services for Daniel and help to insure the best quality of care for him.

If you are facing similar decisions ahead (like STARKids), don’t be afraid to ask questions! We are always in transition and this is just another one to add to the list of many!

1st Day of School

Today Natalia let go of my hand before she arrived at her classroom door and ran in. She smiled and waved goodbye without a hint of nervousness.

I want to be as brave as my little girl when I grow up!

"I wonder what you’re doing now,
And if everyone is treating you kind.
I hope there is a special person,
A nice friend that you can find.
I wonder if the teacher knows
Just how special you are to me.
And if the brightness of your heart
Is something she can see.
I wonder if you are thinking of me,
And if you need a hug.
I already miss the sound of your voice
And how you give my leg a tug.
I wonder if you could possibly understand
How hard it is for me to let you grow
On this day know that my heart breaks
For this is the first step in letting you go."

Thank you to our 2016 Corporate Sponsors!!
The Scope of the Problem

Children with IDD exhibiting challenging behaviors often do not receive state-of-the-art mental health treatment; instead the focus is often on managing their behavior with compliance as the primary goal. Caregivers and family members who are accustomed to seeing their child through the lens of the disability can misinterpret behaviors that are in fact symptomatic of mental illness, distress, or past trauma.

**Overshadowing** is the term used when an individual’s disabilities prevent professionals and other caregivers from looking beyond the disability and assessing for possible mental or physical illness. In attributing challenging behaviors solely to the disability, opportunities for recovery are missed.

Cultures of care in both residential and community or family settings have historically been similar with a goal of reducing maladaptive behaviors by removing antecedents and replacing undesirable behavior with behaviors deemed “appropriate.” While positive behavior management can be effective in changing challenging behaviors, if underlying trauma and other mental health issues are not addressed the likelihood of positive outcomes is greatly reduced.

While the mental health needs of children with IDD are often overlooked or ignored, individuals with IDD experience trauma from physical abuse, sexual abuse, exploitation, neglect, seclusion and restraint, institutionalization, abandonment, and bullying at rates higher than the general population.

A 2010 Bureau of Justice Statistics report provides evidence that people with intellectual disabilities were the victims of violent crime at a much higher rate than the general population. Highlights included:

- Adjusting for the varied age distributions of persons with and without disabilities, the violent crime rate against persons with disabilities was 40 violent crimes per 1,000 persons age 12 or older, which was double the violent crime rate for persons without disabilities (20/1,000).
- Among the types of disabilities measured in 2008, persons with cognitive disabilities had the highest risk of violent victimization.

Additionally, a 2013 report released by the Spectrum Institute, *Abuse of People with Disabilities: Victims and Their Families Speak Out*, reveals frightening statistics. The report was the result of a national survey conducted in 2012 with 7,289 respondents including people with disabilities, family members, advocates, therapists, service providers, social workers, law enforcement and child welfare workers. People with disabilities or family members of people with disabilities comprised 67.6% of the respondents.

Some of the report findings include:

- More than 70% of people with disabilities who took the survey reported they had been the victims of abuse.
- More than 63% of parents and immediate family members reported that their loved one with a disability had experienced abuse.
- More than 90% of people with disabilities who were victims of abuse said they had experienced such abuse on multiple occasions.
- Nearly half of victims with disabilities did not report abuse to authorities. Most thought it would be futile to do so. For those who did report abuse, nearly 54% said that nothing happened. In fewer than 10% of reported cases was the perpetrator arrested.
- When therapy is provided to victims with disabilities, the therapy is helpful. Unfortunately, about two-thirds of victims were not referred to a therapist.

Trauma is not the only cause of mental health challenges for people with IDD, but it's among the most significant. Ignoring the impact of trauma on individuals with IDD creates environments where challenging behaviors are often ineffectively met with physical, chemical, or mechanical restraint intended to control behaviors. These interventions are not only ineffective, but they may also re-traumatize the individual, causing further psychological harm.

Professionals in the disability field have historically relied on behavior management strategies to address challenging behaviors with limited consideration of the potential for underlying trauma or mental illness including the possible impact of past abuse, neglect, or other traumatic events often experienced by this population. Likewise, professionals working in the mental health field often lack expertise and experience when working with individuals with IDD. This skill shortage was recognized in a 2008 NADD article, *Graduate Training in the Mental Health Needs of People with Intellectual Disability: Preparing the Next Generation*. The article stated:

It appears that the limited treatment availability for dually diagnosed persons in the U.S. is due, in no small measure, to the lack of a systematic, federally supported plan for the care of these individuals. A further and equally critical factor is the apparent absence of academic training in graduate programs (Rush, Bowman, Eidman, Toole, & Mortenson, 2004; VanderSchie-Bezyak, 2003; Werger, 2007). Butz, Bowling, and Bliss (2000) conducted a review of the published literature on the efficacy of psychotherapy with dually diagnosed persons. They concluded that there is a growing body of literature on the topic, but that psychologists need to be better informed about this work. Few professional psychologists receive adequate preparation in the area of mental health in ID, and many feel unprepared to treat individuals with dual diagnoses (VanderSchie-Bezyak, 2003). It seems that the growth in research has yet to make its way into graduate academic training.

At the same time that the mental health needs of many individuals with IDD are not being appropriately addressed, interest in trauma-informed practices in a multitude of agencies and professions is expanding exponentially. The Substance Abuse and Mental Health Services Administration is just one...
An Unseen Population: IDD and Trauma (continued)

Continued from page 3

federal agency that has devoted significant resources to trauma, including creating the National Center for Trauma Informed Care (NCTIC).

It is time that agencies coordinate efforts to address the mental health needs of individuals with IDD. This coordination should look past historic practices and existing organizational structure and develop new expectations that people with IDD will have a right to the same state-of-the-art mental health treatment as any other population.

Challenges/Barriers
Some of the continuing barriers preventing people with IDD from receiving appropriate mental health services include:

• Too few professionals (mental health and IDD) have an understanding of the impact of trauma on children with IDD and lack the skills and expertise to assess, diagnose and treat.
• Behavior management techniques are often used without consideration of the impact of trauma. Even positive behavior management may be unsuccessful if underlying trauma is not addressed.
• Misperceptions relating to the effectiveness of standard therapies and treatments for children with IDD.
• Lack of expertise in the treatment of children with IDD and co-occurring mental illness.
• It is often more difficult to assess and treat trauma in children with IDD. Professionals may not want to devote the time and resources needed.
• The historical paradigm of attributing behaviors to the disabilities and relying on behavior management is hard to break. The basic premise of trauma-informed care is asking “what happened to you” instead of “what’s wrong with you.” For children with IDD, we still too often view behaviors through the lens of “what’s wrong with you” and focus on how we can fix instead of focusing on past trauma and searching for ways to help the children recover.

Top 3 Essential Messages
• Expand awareness of and expertise in the use of trauma-informed care, positive behavior support and person centered planning and how these three need to work together instead of in isolation.
• Identify and promote the use of state of the art mental health treatment for children with IDD including trauma-informed care, in-home modeling and mentoring.
• Address the lack of capacity in the current workforce to assess, diagnose and treat mental health conditions in children with IDD.

The Hogg Foundation partnered with the National Child Traumatic Stress Network (NCTSN) to develop The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma. This is a two-day train-the-trainer opportunity. The foundation has also awarded a grant to SafePlace in Austin, Texas, to provide the training in Texas. For more information or to obtain a schedule of upcoming trainings, please contact Michelle Schwartz at sschwartz@safeaustin.org.


If you or your child has a professional diagnosis of autism, Texas Children’s Hospital Autism Center invites you to learn more about SPARK, a new online research study sponsored by the Simons Foundation Autism Research Initiative. The mission of SPARK is clear: speed up research and advance understanding of autism by creating the nation’s largest autism study. Joining SPARK is simple – register online and provide a DNA sample via a saliva collection kit in the comfort of your own home. Register in person at the Texas Children’s Hospital Autism Center by contacting Andrea Simon | andrea.simon@bcm.edu | 832-824-3624, or visit www.SPARKforAutism.org/TexasChildrens. Together, we can help spark a better future for all individuals and families affected by autism.

In Memoriam

One thing we learned a long time ago is that among children with disabilities and special health care needs, some leave us way too early. It’s a sad reality we all hope will not happen but some of us will grieve our child’s death. All of us here at Texas Parent to Parent are deeply saddened when we hear of a family’s loss and grieve with you.

We want to share our condolences to our TxP2P families who have lost a child recently:

Sandra Lynch, volunteer for TxP2P
Katie Barreda, daughter of Yates and Bill Barreda
Clayton Murphy, son of Jennifer Murphy

With deepest sympathy, The Staff, Volunteers, & Board of Texas Parent to Parent
Kayden is a 2 ½ year old boy who bangs his head against the ground and furniture. His parents are concerned that he might hurt himself and that he is unable to communicate what he wants or needs. They are not sure how to handle this challenging behavior.

One of the key principles of behavior management is that the best way to stop challenging behavior is to teach better behavior. Children often hear “no”, “stop” and “don’t,” but for them to learn what they should do instead, we must teach them. Punishments not only do not teach better behavior, they often result in a child replacing a negative behavior with another negative behavior. For longer-lasting, positive behavior, we must focus on teaching children how to get their needs met by using acceptable communication strategies or replacement behaviors.

Another key principle of behavior management is that behavior has a purpose and to know which behavior management strategy to use, we must first try to understand what purpose the challenging behavior serves. Look for patterns in this behavior. When does the behavior usually occur? Under what circumstances? Is the child trying to get something? Get out of something?

It is important to note that challenging behavior can have multiple purposes. A child might bang his head to get attention or an object, to get out of an activity, to seek sensory input, or maybe because he has an ear infection. Children might use challenging behaviors more when tired, hungry, bored, challenged, or over-stimulated. It is helpful to keep records of what happens before and after the challenging behavior to try to find its purpose.

Using Kayden’s example, you might discover that Kayden tends to bang his head when he wants something but is unable to ask for what he wants. He also bangs his head when he doesn’t want to do an activity anymore, so it seems like frustration and inability to communicate are common factors in his head-banging.

His parents, not knowing what he wants, hand him toys and treats to help him calm down because they understandably don’t want him to hurt himself. He finds his head-banging to be very effective to get items and get out of activities, so he continues to do it.

A very effective behavior management strategy is to try to prevent challenging behavior before it happens. In the Winter 2015 issue (“ECI: Strategies to Help Guide Better Behavior”) we discussed effective prevention strategies including:

- maintaining predictable routines
- using transition warnings
- balancing active and calm activities as well as easy and challenging activities
- watching for cues that a child needs help or is getting frustrated
- using clear language to direct children
- positively reinforcing good behavior

Once challenging behavior is already occurring or has already occurred, additional strategies can be useful. Effective, research-based strategies for teaching better behavior include offering choices, using logical consequences, and teaching replacement behaviors.

**Offering choices**

Giving children choices helps to increase motivation and allows children to use their communication skills (Green, Mays & Jolivette, 2011). You can allow children to choose between different activities or materials within an activity, for instance. Examples would be choosing between two art activities or choosing two different colors within one art activity. Choices can be offered verbally, in picture form, or using actual items. Pictures and actual items are recommended for very young children and children with cognitive delays (Dunlap & Liso, 2004). Children can choose using the communication skills they have by pointing, using words or signs, using a communication device, or using eye gaze.

To make offering choices work for your family, give two options that are acceptable to you, available, and desirable to the child (Green, Mays & Jolivette, 2011). More options can be provided to children older than five who do not have cognitive delays.

Allow the child time to process the choices and respond, keeping in mind that children with delays may need more time to process and indicate their preferences. Offer visuals if the child does not respond to verbal choices. Model making choices if the child still doesn’t respond, then prompt the child again to make a choice.

Children will sometimes test to see if they can ignore the choices and have or do what they originally wanted, in which case you can either remain consistent with your choices or choose another behavioral strategy. A child may also need help communicating a choice, so work with a speech and language pathologist if you need help with a communication system.

Using Kayden’s example, when playtime arrives, Kayden’s parents could hold up two items they know Kayden prefers so he can choose one. Another option is to take pictures of Kayden’s favorite items and laminate them or put them in sandwich bags to decrease wear and tear. The pictures can be hung on the refrigerator or somewhere Kayden can reach.

Please note that for pictures to work, a child must understand the concept of the picture representing the actual item, so pictures of the exact item might work better than graphics pulled from the internet, while actual items might work better than pictures if the child doesn’t understand pictures representing the items.

Parents often know which situations or activities are most frustrating for their children, so if Kayden’s parents know he tends to get frustrated during speech therapy visits, they and the speech therapist can offer him choices of activities that will help him work on communicating, making sure to pick items and activities that interest Kayden.

**Logical consequences**

Logical consequences help guide more appropriate behavior by letting children face the consequences of...
their behavior (Fox & Langhans, 2005). For logical consequences to work, the consequence must be clearly tied to the behavior and must happen immediately or soon after the behavior.

A note of caution with logical consequences is that children must have the cognitive ability to understand consequences for this strategy to work. Certain conditions, such as Fetal Alcohol Syndrome, can affect a child’s ability to link consequences with their actions, so more repetition or different strategies would be required for the child to learn and the child may not generalize what is learned to other, similar situations.

Logical consequences are most effective when they are framed as guidance, not punishment. Fox and Langhans (2005) state, “the tone of voice used can mean the difference between logical consequences and punishment.” One way to frame a logical consequence as guidance is to offer the consequence as a choice, for instance, “to go outside we need to put your shoes on.” If the child chooses not to put her shoes on, the logical consequence is that she can’t go outside until she does.

For very young children or children with cognitive delays, it is effective to use first/then statements such as, “first pick up toys, then draw” or “first shoes, then outside.” First/then statements could also be done using pictures or items, for example, “First shoes [hold up shoe], then outside [hold up outside toy or picture of swing set outside].”

Replacement behavior

One of the most effective behavioral strategies to manage challenging behavior is to teach better behavior, or replacement behavior. The replacement behavior serves the same purpose as the challenging behavior, but it is a more positive, less harmful way for children to get their needs met. Since finding a behavior that serves the same purpose is the mission of this strategy, it is important to watch for patterns in the child’s behavior and determine what purpose the challenging behavior serves before choosing a replacement behavior.

For this strategy to be effective, replacement behavior must be easily taught, something the child is able to do, easily noticed and reinforced when the child uses it, and it must work quickly for the child (Dunlap & Duda, 2004). Common mistakes are coaching the child to use words that are beyond the child’s vocabulary, misinterpreting the purpose of the behavior (for example thinking the child is head-banging to get something he wants when he’s really head-banging due to sensory overload), and not making sure the replacement behavior works as well as the challenging behavior. If the new behavior is too difficult or doesn’t work for the child, she will continue to use the challenging behavior.

A useful tip for teaching replacement behaviors is to try to catch the child before the challenging behavior occurs so you can coach a new behavior, help the child use this new behavior, then positively reinforce the child for using it. Positive reinforcement might include praise and making sure the child gets what she asks for (within reason).

Olivia is a child who hits her sister and parents. After looking for patterns in Olivia’s challenging behavior you find that she tends to smile while hitting, she doesn’t seem upset, and nothing seems to occur before she hits to provoke aggression. Because it seems like Olivia is hitting to get her family members’ attention and to interact with others, you can help her request to “play” before she hits someone by coaching using the word or sign for “play” or handing the other person a toy. If she wants the same toy her sister already has, you can help the children play back and forth with the toy or find a similar toy for Olivia to have and at some point they can trade toys.

Using choices, logical consequences, and teaching replacement behaviors requires time and individual attention. Repetition of each strategy is needed for the child to learn from it and start making better choices, but with continued teaching and positive reinforcement of better choices and behavior, most children will show a great improvement in behavior.

Red flags may indicate a need for referral

Sometimes you may need more help figuring out the cause of challenging behavior or strategies to use to help increase more positive behavior. If the child is under the age of three and has any of the concerning behaviors below, call Early Childhood Intervention (ECI) for help with social-emotional development. To find an ECI program in your area call the HSRC Office of the Ombudsman at 1-877-787-8999 and a representative will assist you. Here are some signs that your child might need additional assistance:

- Has tantrums that last 20 minutes or longer.
- Breaks things on purpose.
- Hurts or bites other people or himself.
- Does not look at you when you call his name.
- Does not play with toys.
- Does not engage in any pretend play for 24 months.
- Does not enjoy being around and watching other toddlers.
- Flaps hands, rocks, or sways over and over.
- Does not point at objects she wants.
- Has no words by 12 months.
- Does not notice people or engage in classroom activities.
- Is unhappy most of the time.
- Is anxious most of the time.

We hope these ideas will help you to work with your child in the pursuit of a cooperative, functional relationship.


The Continuum of Decision-Making Supports and Protections for a Young Adult

Caroline Nelson, Parent

Even young adults on a typical developmental path don’t immediately begin making every decision, and assuming every responsibility, the day after they turn 18. There are a variety of supports for decision-making, both formal and informal, that parents of all young adults can consider, regardless of the young person’s disability or level of independence. Decision making supports can apply to medical, financial, educational and personal decisions.

There are four main factors to consider in order to make a meaningful support plan for your individual young adult with his or her own unique needs. The factors are: autonomy, capacity, responsibility for consequences, and protection.

Think about your individual young person. How much decision-making autonomy does he want and need? How capable is he of predicting and taking responsibility for the consequences of his decisions? To what degree does he have, or lack, capacity for meaningful decision-making OR understanding the consequences of his decisions? Does he need protection?

There are a variety of decision-making supports and tools to choose from, depending on the unique answers to these questions. These supports fall into four categories:

- **Autonomous decision-making**
- **Joint decision-making**
- **Decision-making on behalf of the student**
- **Guardianship**

**Autonomous Decision Making**

For a young adult with the most decision-making capacity and ability to handle the responsibilities and consequences that come with autonomy, parents may choose to put nothing formal in place, relying instead on parental leverage, or “power of the purse.” An example of this would be when the parent sets a boundary around paying college tuition or providing a car if their child chooses (or doesn’t choose) a given course of action.

**Joint Decision-Making**

For a young person who might benefit from help understanding decisions, interacting with professionals, and communicating his wishes, but who ultimately has the capacity to make the final decision, a Supported Decision-Making Agreement or Power of Attorney might be appropriate. Both mechanisms assume capacity on the part of the student (including capacity to revoke the agreement or decide contrary to his parents’ wishes). These tools are permission-oriented. In other words, the young person gives the parent (or supporter) permission to assist with decision-making, but does not give away the final decision. A joint bank account serves the same function in that it allows independent decision-making by the young adult, but with the support or monitoring by the parent or joint account holder.

**Decision-Making on behalf of the student**

As we think more about the young person’s capacity to make sound decisions or to deal with consequences, parents may consider mechanisms that do not allow their adult child access to certain types of decisions, in particular, financial decisions. Examples of these mechanisms could include becoming, or naming, a Representative Payee for social security benefits, or putting assets in trust with a trustee as decision-maker on behalf of the young person as beneficiary.

The final category, Guardianship, contemplates a young person who lacks capacity to make meaningful decisions about his adult needs and responsibilities. Unlike the other types of decision-making support, a guardianship removes the adult rights from the person, and vests them in the guardian. A person under a guardianship (a “ward”) functions as a decision-maker the way a minor (under 18 year-old) does: he does not have the final word on whether he can marry, vote, enter into contracts, or make medical, financial or educational decisions. A young person under a guardianship is also the most protected from the consequences of decisions he may attempt to make independently.

Each of these levels of support and protection can be changed, as a young adult continues to mature. The most important thing is to consider your student’s unique decision-making and support needs as he presents today. There is no one right answer.
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