

# A Parent's Perspective

**TXP2P Quarterly Newsletter** 



# TxP2P Update – What's New? Mental Health Issues

Laura J. Warren, TxP2P Executive Director

hope you are all having a wonderful spring and are enjoying the nice weather. It will be 100 degrees before we know it!

Besides our conferences (see page 7 for more information), we have been busy with lots of calls from parents. The office staff have noticed that we are getting more and more calls from parents of children who have mental health diagnoses, either mental health issues along with developmental disabilities or with straight mental health diagnoses. We have always been told that the services for children with disabilities are few and far between, but that the ones for kids with mental health diagnoses are even harder to come by.

We now know from experience, that with 19 staff members, any one of us can be in crisis at any time with our child. But now that we have staff who are coping with mental health diagnoses, we are learning first hand that these crises are much harder to find resources for.

So we have decided to start educating ourselves in order to be better able to help you with these issues and share the resources we uncover in this journey. This newsletter will be mostly about mental health for your child but also for you – we know as parents we have to care for our mental health as well. I hope you benefit from our shared stories and resources.

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# When Your Child Needs More

By Liz Hong, TxP2P staff

he day my child told me he spent hours a day thinking about killing the kids at school as well as me, I realized that my child needed more help than I could provide. Being new to this issue, I optimistically thought we would just pop him over into a residential treatment center (RTC) for a few months and things would be fine.

Nearly 3 months later, we are still waiting and trying to make this happen. It turns out that because our documentation was insufficient and we had not tried a partial hospital program, placement was just not an option yet!

When your child needs more than you can provide at home, it can be hard to get them into a program, while out-of-pocket costs can be extremely high! For many families, these challenges make it impossible to get their child the mental health treatment they need. Often, these children end up in foster care, as they were unsafe in their own home.

To stop this downward cycle, Senate Bill 44 (2013) has provided parents another way. Parents can contact Child Protective Services (CPS) or refuse to pick up their child from a hospitalization if they have "exhausted all reasonable means available to obtain mental health services." (CPS Handbook <a href="https://www.dfps.state.tx.us/handbooks/CPS/Files/CPS">https://www.dfps.state.tx.us/handbooks/CPS/Files/CPS</a> pg 2200.asp#CPS 2391)

Once a parent takes this step, CPS will investigate the family to determine if the family is doing this solely to get mental health treatment for the child. If they determine that is the case, the family may be able to get joint-conservatorship with the state and funding for an RTC. To learn more about this program, refer to the Investigation and Referral to DSHS Residential Treatment Center Bed Resource Guide. (Texas Department of Family and Protective Services Investigation and Referral to DSHS Residential Treatment Center Bed Resource Guide <a href="https://www.dfps.state.tx.us/handbooks/CPS/Resource\_Guides/RTC\_Resource\_Guide.pdf">https://www.dfps.state.tx.us/handbooks/CPS/Resource\_Guides/RTC\_Resource\_Guide.pdf</a>)

Other options for families who are in a dire situation include reaching out to your local authority. Your Local Mental Health Authority (LMHA) can provide your child with services through the YES waiver, including access to case managers and community living supports to help

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# When Your Child Needs More

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your child build skills. (https://hhs.texas.gov/services/mental-health-substance-use/childrens-mental-health/yes-waiver). Your Local Intellectual and Developmental Disability Authority (LIDDA) can also provide children whose IQ is 70 and above with a related condition with an Intermediate Care Facility for Individuals with an Intellectual Disability or Related Conditions (ICF/IID). (Explanation of IDD Services and Support <a href="https://hhs.texas.gov/sites/default/files/documents/services/disability/other/IDDServicesEng.pdf">https://hhs.texas.gov/sites/default/files/documents/services/disability/other/IDDServicesEng.pdf</a>)

Your LIDDA may also have a waitlist for RTC funding to help you pay for your child's stay. You can find your LIDDA on the HHS website: https://apps.hhs.texas.gov/contact/la.cfm

If you are like me and have a child with severe mental illness who needs more support, you may feel very isolated. It is also not uncommon for parents to blame themselves and feel like if they had just done something differently, things might not have turned out that way.

I tell myself that I will never know whether or not things could have been different, I just keep trying to focus on where we are right now. If you find yourself struggling with blame or guilt, check out this article in the Washington Post, "When kids with mental illness can't live at home." (When kids with mental illness can't live at home. www.washingtonpost.com/news/parenting/wp/2017/01/31/when-kids-with-mental-illness-cant-live-at-home-2/? noredirect=on&utm\_term=.96602e4799ee)

You are not alone, and there are supports and programs out there to help!

# **Risk & Protective Factors for Mental Health Issues**

Liz Hong, TxP2P Staff

ental illness can be a real challenge for the whole family. I **know** this because two of my children and myself battle it every day. The truth is, when one of us has a hard day, it's likely everyone will. And, while having a family member with mental illness is a risk factor for developing it, there are many steps we can take to help lower the chance that it will affect other family members.

Things that increase the chance of having mental illness, such as a parent or sibling with mental illness, poverty and not enough supervision, are called risk factors. Things that make it less likely that mental illness will affect a child are called protective factors. Even the small steps we take towards building the protective factors can make a big difference for our children. Here are 5 protective factors that are commonly talked about.

- Parental resilience This is all about self-care! Taking care of yourself also takes care of your child. It models the behavior we want our children to have, and it helps fill up the patience bucket so that we can respond to challenges in a calm, more effective way.
- Knowledge of child

development - I know we have all had a moment where we have said, "Is this normal?"
Understanding how children typically develop can help us to understand why our children are doing the things they do.
This applies to typically developing children and those with a disability. It is a great way for parents to have appropriate expectations for their child's behavior.

- Child's social/emotional competence When your child can understand what they are feeling, they can learn how to respond to that feeling. Working with your child by describing what they seem to be feeling and by asking during a calm time about how their body feels when angry, upset, etc. can help them learn to identify and appropriately respond to their feelings.
- Social connections We all have limits. Having strong social connections with family and friends can help support us as parents through a listening ear, babysitting or help getting things done. A good way to build your support network is by getting a parent match through Texas Parent to Parent. (Register at txp2p.org and request a parent match.)
- Knowing how to find

resources in times of need – We all need help, resources and formal supports whether for a short or long time. Knowing how to find resources and supports can help you build confidence and support you when times get tough.

• We can help you learn how to find valuable resources, whether grants and assistance for therapies or medications, long term services or local programs. (Call TxP2P at 512-458-8600 or 866-896-6001.) Also, check out Navigate Life Texas for more info on these important supports as well. (Go to navigatelifetexas.org and at the search line type in Mental and Behavioral Health.)

Having a family with multiple people with mental illness has been a challenge. But by learning about how to help my children, and by taking tiny steps like taking care of my own needs, I feel more peaceful. And I can see the positive changes it has created for my children. I challenge you to commit to one small step, like ignoring dishes-in-the-sink guilt, labeling your child's emotions or calling your best friend you have been too busy for, and see if it makes a difference for you and your family.

# A Surprise Just When You Think You Have It Figured Out Mental Health Issues, A Family Story

Compiled from interview by Rosemary Alexander

ancy's son, James, has always been a very social child who has Cerebral Palsy (CP). He uses a wheel chair and has always been in regular classes at school. He talks but can be hard to understand; he has an output device but would rather use his own voice. He never had behavior problems and has always been very engaged with people. He is now 19 and still in public school, spending part of each day at a career development center.

Then during this past spring break, he was suddenly not himself. He became aggressive, hitting himself, rolling off the bed, hitting his head against the wall and telling his mom he hates her! The family had never seen such behaviors. They took him to the hospital, where he was tested for seizures and other problems, but nothing showed up. He is very healthy! He went home with medications

for anxiety and depression.

However, the meds caused him to be kind of crazy, overboard happy, euphoric. Meds were not a solution either. Gradually, he has gone back to being himself, but the family sees him differently and worry that the whole cycle might erupt again.

So what happened? Nancy has looked back at the signs and has concluded that anxiety was always there, but James coped with it. He was holding it in—and the he finally exploded.

The main way he showed anxiety was to constantly ask exactly what will happen next. He always wanted to know the what, when, where and who all day long. Nancy followed her own agenda without necessarily answering all his questions. He was asking for more structure. Now they are providing him with many ways to follow a routine and for him to

know the what, when, where and who.

Nancy says that by the time James was 19, she thought she had CP under control. She wasn't ready for a new set of concerns! "I should have paid attention to the red flags!" She dismissed the signs of a mental health issue. She now takes his questions seriously and talks about plans and supplies a structure. Playing it by ear no longer works!

Growing up is often hard for anyone, but adding in a physical disability and difficulty communicating can make it really hard! Maybe his explosion was a way to seize control of his life. Nancy says he is talking more, using his IPad to communicate more and is "more opinionated." He is deciding what to wear, where to go and when to go much more of the time. And his mom is getting much more creative about reading the signs!

# **Mental Health Advocacy**

**Linda Litzinger, TxP2P Advocacy Specialist** 

e are half-way through the current legislative session! Several bills have been heard in committee to add more school counselors to assist students with issues they are facing. For every mental health education bill, there are probably three bills related to 'hardening' schools by increasing school resource officers and volunteers who have retired from the military. It is too early at the writing of this article to say which way the Legislature will go, as they have been busy passing budgets, school finance and tax relief.

Two great education bills to watch for:

- 1) A bill that defines acceptable and unacceptable behavior modifications.
- 2) A bill to offer more skills to regular education teachers, via modifying educator prep curriculum and enhancing teacher in-service opportunities.

Both of these bills will result in our children having better mental health during school. If you would like to become involved in advocating for these bills, please text me at 512-922-3810 or email me at linda.litzinger@txp2p.org.



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In-Home Attendant Services
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LifeSpan



# Early Childhood Intervention

# **Mental Health Awareness**

ay Is National Mental Health Awareness Month

ECI recognizes that parenting can be rewarding and at times challenging. In recognition of National Mental Health Awareness Month in May, it's important that parents and caregivers recognize the importance of mental wellness. It is commonly accepted that physical health is critical to our well-being. Despite being equally important, mental health is often not addressed with the same rigor as physical health.

National Mental Health Awareness Month is also intended to help raise our knowledge of the signs and symptoms that a mental disorder exists and when it is time to seek support. Trying to tell the difference between natural behaviors and what might be the signs of a mental health condition isn't always easy. Seek support if you have concerns about your mental health. Identifying a potential problem early can help lead to a better outcome.

According to Mental Health America, one may consider seeking support when experiencing:

- Prolonged depression (sadness or irritability)
- Feelings of extreme highs and lows
- Generally feeling fearful, worried or anxious
- Decreasing the time you spend with others
- Changes in eating or sleeping habits
- Strong feelings of anger and resentment
- Delusions or hallucinations

- Growing inability to cope with daily problems and activities
- Suicidal thoughts
- Denial of obvious problems
- Numerous unexplained physical ailments
- Substance abuse (using substances to help you "relax and manage stress")

Substance abuse (using substances to help you "relax and manage stress")

Things that can assist in building balance and overall wellness are good nutrition, exercise, plenty of sleep and a healthy self-image. Each of us goes through stressful times in our lives, and the development of physically and mentally healthy practices can help build up the resiliency we need to maintain our mental health in stressful times.

### Resources

- The National Alliance on Mental Illness (NAMI) https://www.nami.org/About-NAMI
- Mental Health America Toolkit <a href="http://www.mentalhealthamerica.net/mental-health-month-2015-toolkit-download?sid=75381">http://www.mentalhealthamerica.net/mental-health-month-2015-toolkit-download?sid=75381</a>
- Mental Health America <a href="http://www.mentalhealthamerica.net/">http://www.mentalhealthamerica.net/</a>

## **Tips to Rest Your Mind:**



Set aside 5 to 10 minutes throughout the day for quiet time, where you won't be interrupted by calls or emails.



Practice breathing exercises.



Listen to relaxing music.



Take a 5-minute walk to help you manage daily stress.

# School Refusal –What is It and What Do I Do About It?

By Carla Scruggs, Homeschool Consultant, and April Choulat, Integrative Autism Specialist

t happens to every parent sooner or later - your child doesn't want to go to school. Often after summer vacation, kids may be excited to go back to school at first. Then they realize the new teacher requires more homework or the drudgery of getting up early every morning sets in, and they would rather stay home. This is normal.

School refusal, however, is not the normal "I'd rather stay home today" behavior. In fact, school refusal is an emotional disorder; it is not behavioral (though it may manifest itself in unwanted behaviors). When a child refuses to go to school day after day persistently, then one has to consider underlying causes such as anxiety.

This can be triggered by life events such as death of a family member, trauma, bullying at school or a bad teacher. Sometimes the trigger is not known. School refusal can happen at any age.

While the DSM-5 does not list school refusal as a separate diagnosis, it is listed as a symptom in anxiety disorders. It is recognized by organizations such as the Anxiety and Depression Association of America. They define it this way:

> "School refusal describes the disorder of a child who refuses to go to school on a regular basis or has problems staying in school."

Emotional issues are often hidden issues. However, severe anxiety about school may also manifest as headaches or stomach aches. Emotional issues are often not visible and as such are sometimes not recognized as a genuine difficulty the person is having. Some students that demonstrate school refusal may have anxiety or depression and struggle to function to their best ability. They may even feel guilty if they are chastised or admonished for not performing what others expect. If you have ever thought your child

was lazy, you may be misinterpreting their low affect and lack of motivation as willful instead of a symptom of a very real emotional and psychosocial issue.

To put it in perspective, think through a period of depression or anxiety, or maybe you have a more mental health and will make a big serious chronic condition like lupus, or fibromyalgia or chronic pain. What if you were going through a period of poor health and people told you to suck it up and that you were being lazy? This isn't motivating to anyone. The parents may also feel a sense of failure for not being able to get their child to participate in or attend school.

It may take time for a parent to tease out what is going on. I suggest taking some pressure off your child. Try not asking about the results of every test or project at school. Teens in particular do not like the feeling of being scrutinized. If you have good rapport with your child, you may be able to have some heart to heart talks and figure out what triggered the anxiety they are having about school.

If you believe your child is being bullied, this issue needs to be addressed and taken seriously by adults. Ask your child what you can refusal, but sometimes a change of do to help. Talk to your child's teacher and get their perspective. Be very aware of your child's social bound instruction or homeschoolmedia accounts and whether bullying is happening online or through text messages. It is important to remove these sources of bullying if that's something that is happening to your child. Let them know you believe them and are doing everything you can to address the situation.

The underlying trauma has to be addressed as well. Make sure your child is emotionally supported by parents, teachers and even professional counseling or trauma specialists. There are specific therapies for PTSD, such as reflex integration and counseling, which can be helpful. The Pacer Center has resources and stories on its

website designed to help families prevent and deal with bullying. Go to https://www.pacer.org/ bullying/about/ to learn more.

Other aspects to consider are your child's eating and sleeping habits, about any time you may have gone as well as exercise. These basic self -care routines are important for difference for most children who are struggling emotionally. Having a physical outlet that your child enjoys will help him or her burn off stress hormones. If your child does not participate in sports or like structured exercises, perhaps something creative such as dance is another option.

Does your child have a way to express himself emotionally through writing, drawing, art, music or other creative projects? Does your child have goals to distract from things that cause stress or anxiety? How does your family as a unit cope with emotions? Do you frequently honor and accept your feelings, labeling them as they happen? Children need the language to describe how they are feeling. These are all things to think about in cultivating a healthy socialemotional world for your child. Professional counseling may help anxiety that is causing school scenery is the best thing. This may include changing schools, home

According to Dr. Elaine Aron, a leading research psychologist, about "20% of the population is 'Highly Sensitive' and have finely tuned nervous systems that are highly aware and quick to react to everything." Children who fit this category may get more easily overwhelmed or have a rich emotional life that is not well understood in typical classrooms. If you think your child may be Highly Sensitive and you would like additional resources, fill out this online form (http://bit.ly/ sensitivekids) to schedule a chat or stay updated on upcoming trainings and events.

# The Wake-Up Call for Mental Health Issues, A Family Story

Compiled from an interview by Rosemary Alexander

Julie has two children, a daughter with autism and a son who always seemed to get along just fine. Her focus was naturally on the daughter with autism: she worked for years on getting the right diagnosis, the right medications, the right therapies, and by her daughter's early adulthood, felt like she really had a handle on the situation!

Then as her younger son reached adolescence, he began to have some physical symptoms. He would go to school and ask to come home with an upset stomach. He wanted to stay in his room, he ate less and he was withdrawing. She tackled the physical symptoms and took him to a doctor for stomach troubles, tried different meds, even went to a specialist. Some things worked for a while but he wasn't really getting better.

Julie didn't have health insurance to pay for counseling and dreaded going down that path. Finally a friend pointed out that the Local Authority might be able to help. She knew all about the Local Authority for intellectual disabilities and autism, but had not thought of it for mental health issues.

The local authorities used to be called Mental Health/Mental Retardation centers; now they are called LIDDAs or Local Authorities for Intellectual and Development Disabilities. There is one for each county or group of counties and is the local site for Health and Human Services.

The local authority proved to be very helpful. Because of the low family income and the mental health issues facing her son, she was able to get a case manager for him, a doctor to prescribe

medications and a counselor. He ended up with a diagnosis of severe anxiety.

Now that the family has a more accurate understanding of his problems, they have been able to make progress on integrating him back into life. Julie says, "Why didn't I think to turn to a resource that I already knew well—but only for the disability side? Now I also appreciate the fact that there are local services for a teen-ager with mental health issues."

To locate your local mental or behavioral health authority, go to https://hhs.texas.gov/services/mental-health-substance-use/mental-health-substance-use-resources/find-your-local-mental-health-or-behavioral-health-authority.

# Mental Health Resources and Sources of Information

This month we are talking about mental health! In the TxP2P office, we are seeing an uptick in calls from families struggling with the challenges they face when their child has a mental illness. Here are some resources that might help families of children with mental health issues.

### The YES Waiver

Children who are at risk of being placed outside of the home because of mental illness may qualify for the YES waiver. This valuable program provides the child with Star Kids Medicaid, alternative therapies, community living supports, adaptive aids and other methods for helping the child and the family. <a href="https://html.texas.gov/services/mental-health-substance-use/childrens-mental-health/yes-waiver#">https://html.texas.gov/services/mental-health-substance-use/childrens-mental-health/yes-waiver#</a>

#### **Local Mental Health Authorities**

Did you know that your local authority can help both children and adults with mental illness? They will assess the individual and determine their level of need. They can then provide services for families in need of therapy, skills training, medication management and more. <a href="https://hhs.texas.gov/services/mental-health-substance-use-resources/find-your-local-mental-health-or-behavioral-health-authority">https://hhs.texas.gov/services/mental-health-substance-use-resources/find-your-local-mental-health-or-behavioral-health-authority</a>

#### NAM

The National Alliance on Mental Illness of Texas (NAMI Texas) has a variety of <u>education and support programs</u> for individuals living with mental illness and their families and friends. Programs include a family support group that meets once a month and a Family-to-Family Education Program that is a free, 12-week course for family caregivers of individuals with severe mental illnesses. <a href="https://namitexas.org/">https://namitexas.org/</a>

#### **Texas Parent to Parent**

Texas Parent to Parent has staff who are parents of children with mental health issues and are ready to share their experiences and expertise with parents who call. We also have a Mental Health Listserv for parents of children and youth who have a mental health diagnosis. <a href="https://www.txp2p.org/">https://www.txp2p.org/</a> or 512-458-8600, 866-896-6001

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# Mental Health Resources and Sources of Information

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#### Websites

National Institute of Mental Health: includes overview of all major mental illnesses, including symptoms and treatment/therapies. <a href="https://www.nimh.nih.gov/index.shtml">https://www.nimh.nih.gov/index.shtml</a>

Resources to Recovery: A website for families; rtor.org is a gateway website that helps families find resources and support for loved ones with mental health concerns. <a href="https://www.rtor.org/mental-health-">https://www.rtor.org/mental-health-</a> texas/

#### **Information from Navigate Life Texas website**

Supporting a Child through a Mental Health Crisis https://www.navigatelifetexas.org/en/diagnosishealthcare/supporting-a-child-through-a-mental-health-crisis

Call 9-1-1 if you feel your child is in extreme crisis, needs immediate emergency services and you are worried about someone's safety. When you call 9-1-1, explain that your child is having a mental health crisis and ask for a responder who is trained in mental health issues. If the crisis is not quite this extreme, call your local mental health crisis hotline first and ask them what to do. 9-1-1 responders are more likely to take your child to a hospital than to help you manage your child's crisis at home.

- Call your local mental health crisis hotline. Call 2-1-1 and ask for your local mental health crisis line.
- Call 1-800-989-6884 for the Texas Youth and Runaway Hotline or text them at 512-872-5777. They can connect your child with free counseling services through the Services to At-Risk Youth (STAR) program within 24 hours.
- Call 1-800-784-2433 (1-800-SUICIDE) or 1-800-273-8255 (1-800-273-TALK) to reach a suicide prevention hotline. Go to Suicide Prevention Lifeline.
- Call 1-800-950-6264 (1-800-950-NAMI) to reach a trained crisis specialist with the National Alliance on Mental Health.
- Visit **IMAlive.org** to chat online with a trained specialist.

Go to https://www.navigatelifetexas.org/en/diagnosis-healthcare/supporting-a-child-through-a-mental-<u>health-crisis</u> for more information, resources and advice.

Taking Action based on Signals from your Child <a href="https://www.navigatelifetexas.org/en/diagnosis-">https://www.navigatelifetexas.org/en/diagnosis-</a> healthcare/mental-health-for-children-with-intellectual-and-developmental-disabilities

You might look for mental health help for your child if they:

- Aren't acting like themselves maybe their basic skills or abilities have changed.
- Refuse to participate in routine tasks like they used to.
- Have major changes in appetite or sleeping patterns.
- Seem moody extra frustrated, aggressive, angry, worried, or sad.
- Are having trouble sleeping, stomach aches, constipation, or other physical issues with no clear medical reason why.
- Have quick bursts of energy like pacing back and forth, tantrums, or more vocalizations.
- Are trying <u>risky behaviors</u> or doing things to hurt themselves on purpose.
- Have more (or more intense) challenging behaviors than usual.

Go to https://www.navigatelifetexas.org/en/diagnosis-healthcare/supporting-a-child-through-a-mentalhealth-crisis for more information, resources and advice.

#### Don't forget our upcoming conferences:

- TxP2P 15th Annual Statewide Parent Conference, San Antonio, June 21-22, 2019 more information on our home page, www.txp2p.org
- TxP2P South Texas Parent Conference, October 19th, 2019 more information coming soon!



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Texas Parent to Parent 1805 Rutherford Ln., Suite 201 Austin TX 78754

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# Thanks to Global Printing Solutions for printing this Newsletter

# **Conference Schedule**

Date	Conference Title	Location	Registration Information
June 21 - 22, 2019	2019 Statewide Annual Conference	San Antonio	www.txp2p.org
August 1-2, 2019	27th Annual Autism Conference	San Antonio	https://txautism.esc2.net/
August 2-4, 2019	Abilities Expo	Houston	https://www.abilities.com/