



My First ARD Experience

My Steps to Supporting Others

Mary Jane Ledesma, TxP2P Staff

“Your daughter is at a six-month-old speaking level. I have not seen any significant speech growth,” said the speech therapist.

The occupational therapist added, “This child cannot button/unbutton, but she can zip and unzip. Her fine motor skills are very near to her appropriate age level.”

The psychologist stated, “Your daughter is mildly retarded. At this point, I’d say she will not be able to ---, ---, ---.” I blocked out all the rest of this conversation.

“She is doing well in Early Childhood (EC, now PPCD) and at about a one-year-old functioning level,” said the EC teacher. “I need to get back to my classroom, so can I just sign the paperwork now.”

The special education coordinate said. “We agree that she needs to remain in EC for another year. I have a meeting at the main building and I need a cigarette. So let’s sign the paperwork and stay on schedule.

I thought, “Don’t you see the independent, wonderful child I see; the bilingual active little three-year-old who jumps off the diving board, attends gymnastics and can work electronics?”

ARD (admission, review, dismissal) meeting shocked me – my daughter was only 3-years-old at the time. As a professional educator, I knew what to say and do at an ARD, but it was very different as a parent.

Continued on Page 2

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Inside this Issue:
♥ From Our Families - Decisions on Starting School Late for Summer Babies — pages 2
♥ Around the State - ECI - Literacy for the Young Child — page 4
♥ TxP2P - Statewide Conference Update — page 5
♥ Around the State - Hurricanes, Mosquitos & Other Emergencies to Consider — page 6
♥ Around the State - When a Hurricane Strikes — page 6
♥ From Our Families - Great Special Education Websites — page 7
♥ Conference Calendar — page 8

Managing a Chronic Illness at School

Based on an interview with Katrine Nordstrom, TxP2P staff

By Rosemary Alexander, TxP2P staff

Katrine’s daughter, Sol-Marie, aged 16, has Type 1 Diabetes, diagnosed during middle school. So Katrine and her daughter have learned how to manage a chronic illness during the school day.

The first thing Katrine and Sol-Marie do the week before school starts each year is to meet with the school nurse. They bring in the medications to be taken during school hours and go over the accommodations recommended by their doctor. Katrine has learned that the nurse can only provide accommodations and routines laid out by their doctor; her opinion as mom does not get the same results!

One of the accommodations they have agreed on is the timing of Sol-Marie’s visits to the school nurse to test blood sugar levels. Another possibility is to test while in class without supervision. Katrine also consults with her daughter about what works best for her; she learned that Sol-Marie likes to go to the nurse’s office to help her remember to do the testing.

Katrine also has a one-page letter to teachers about the warning signs of low blood sugar. For example, if Sol-Marie is cranky or can’t do the work that she can normally do, the teacher should note this as a sign that her student needs assistance. The nurse may also work with teachers about how to handle this illness, but Katrine wants to be extra sure that the teachers know what to watch for on their own.

Another tool that provides ready assistance in the classroom is a clear plastic box, labeled with the student’s name, which contains snacks to be eaten in case of low blood sugar. All meds stay with the nurse, but the snacks can be available in every one of the student’s classes. Sol-Marie’s 504 status (see below) allows her to eat during class and to test her levels (except in lab class). In one case, the teacher refused to allow the snack, but a friendly letter from Mom

Continued on Page 3

They read reports and made decisions about her education within thirty minutes. They followed a schedule. I felt helpless as they signed the paperwork, emotionless and walked out of the room.

I would never let that happen again. I would be prepared with questions, responses and anecdotes about her successes. I felt that the ARD was impersonal as I experienced it from the parent point of view. The ARD was unintentionally cold, because I was on the other side, as a parent. I was not a full partner in my child’s education.

I learned to handle my own problems with special education services and used all the possible avenues open to me as a parent. Then I saw parents with limited English proficiency unable to access the services. I saw a need and I became a support person for others.

I attended conferences in Florida, Minnesota and California, sometimes as a parent and sometimes as an educator and shared the information with other parents. I asked questions and learned everything about disability rights, school programs, organizations, etc.

I started a support group for Spanish-speaking families who had children with disabilities. We met monthly at the Ronald McDonald House and watched videos of adults with similar disabilities, went on community outings to support each other and discussed various situations about our children – present and future. We learned to:

- * Prepare ourselves as equal partners in the ARD meetings.
- * Have a vision of our child life as an adult
- * Find out what is happening at other schools – networking with other parents
- * Share strategies that work for your child and build rapport with school staff
- * Be proactive in your child’s school; inform yourself about programs

What I want for my child is what I want for every child that steps into my classroom – the best education possible. My child will be included in this world to the best of her ability. My child will be a successful, tax-paying citizen and I will be her tax-paying advocate. You can be, too.

Decisions on Starting School Late for a Summer Baby

Liz Hong, TxP2P Staff

Of my four children, three were born in mid to late summer. Some families chose to wait a year before putting these children into school. The practice of waiting a year is called “red-shirting.” I did not hear about this until my youngest summer baby was already in the public pre-kindergarten program. I did not think it would be an easy task to hold my son back, and so I rolled with it and put him into kindergarten with his peers.

My son has an anxiety disorder. He is a bright and capable boy, but the social/emotional parts of school have always been a big challenge for him.

When we first started him in preschool, he was grumpy and irritable most of the day and unable to eat more than a bite or two at a time. He lost 4 pounds or 8% of his weight the first few months of school. We persevered but it was the most challenging year he has had. By

the end of the school year, he was doing very well during the school day and everything seemed to be on track.

When the next school year came and he was headed to kindergarten, we had his anxiety diagnosis. We had met the teacher and toured the school, and did all the “supposed-to’s” to make the school year start right, but it just didn’t.

That very first day, I promised I would come have lunch with him. Almost as soon as I sat down in the noisy cafeteria, the P.E. coach came over and said the posters on the gym wall had triggered one of my son’s phobias. This was the beginning of another hard year, so in the end, after school refusal behaviors, a botched Section 504 plan (see below) and a series of unfortunate events of our own, we opted to pull him out and homeschool him for a year.

We didn’t get very serious about the homeschooling at that point. My husband and I were just starting new jobs and he was going to Grandma’s house while we worked. We pulled out some workbooks and he practiced his ABCs and 123s with her. At the end of the year, we had found a charter school that seemed to be well situated and open to his mental health needs. We enrolled him and began school that next fall.

When we put him back into school, they requested that he start in kindergarten, although he had already completed the curriculum. I wasn’t confident about his skills and he was still less mature than other children his age so I went along with it. It turned out that this really set him up for success.

When he entered Kinder, he knew most of what he needed to know and was academically ahead of many of the kids in his class.

Continued on Page 4

with the information about her 504 accommodations solved the problem!

Another accommodation is that Sol-Marie needs a buddy to walk through the halls and must never walk alone, in case she experiences confusion and the chance of passing out. Once a teacher thought she and her buddy, who was a good friend, were just trying to get out of class, when in fact Sol-Marie really needed to go to the nurse. They solved the problem by leaving without the teacher's permission. The teacher later learned about the accommodation, so they didn't get in trouble, but this is why Katrine

sends a letter to every teacher.

Katrine suggests, based on her experience, that parents should start talking to their child with medical concerns as early as possible and encourage the child to be as independent as possible. She says encourage your child to be a self-advocate, but always have a back-up plan—that's the school nurse for Sol-Marie. She also advises signing a release so that the school nurse can talk directly with the family's doctor. And finally, she stresses that it's important to keep a clear line of communication open among the doctor, the nurse, the student and the parent, addressing problems as soon as they arise

and building the cooperation of teamwork.

(Section 504 of the [Rehabilitation Act of 1973 \(https://en.wikipedia.org/wiki/Rehabilitation_Act_of_1973\)](https://en.wikipedia.org/wiki/Rehabilitation_Act_of_1973) is part of a federal law that guarantees certain rights to people with disabilities. It was one of the first U.S. federal civil rights laws offering protection for people with disabilities. A 504 Plan at school covers accommodations, services and support the student will be receiving in order to have access to education at school.)

See the Letter below for an idea of what to send to the school about your child.



Ava Sophia [redacted]

6th Grade

Type 1 Diabetic – Insulin Dependant

Mom – Teresa [redacted]

Dad – Todd [redacted]

[redacted]@gmail.com

I have Type 1 diabetes, which means my pancreas does not produce insulin so I wear an insulin pump every day which provides insulin to my body. I also have to test my blood sugar on a regular basis to make sure it is not too high or too low. It can be really dangerous if my blood sugars go low...I can pass out and even die...but high blood sugars are just as dangerous and can keep me from thinking clearly. As long as my blood sugars are monitored and symptoms not ignored, we can avoid most serious and emergency situations.

I am just like everyone else, and I can eat anything just like everyone else...I just have to have insulin to counterbalance the food I eat. When my sugars are high or low it impacts my ability to focus and think clearly which can affect my behavior and my ability to do school work so I may be late or have to leave class early to check my blood sugar. I also need to test my blood sugar before taking any tests in the classroom.

Please allow me to test my blood sugar any time I need to...even during class. I dislike to miss class as much as you dislike for me to miss class, but my diabetes doesn't care where or what I am doing. I also carry a cell phone with me at all times to text my blood sugar numbers to the nurse to keep her informed as well as to help me make diabetes care decisions.

Please call my mom or the school nurse anytime if you have questions.

Here is what to look for: LOW BLOOD SUGAR – hypoglycemia

- Acts drunk or overly silly
- Pale face
- Glassy eyes
- Clueless – unaware - confused
- Might say she is hungry or is "low" repeatedly
- Overly emotional

IF AVA RECOGNIZES THAT SHE FEELS LOW AND NEEDS THE NURSE, HAVE A BUDDY ESCORT HER TO THE NURSES OFFICE...SHE SHOULD NEVER BE ALONE

IF YOU ARE WORRIED BECAUSE AVA IS REALLY OUT OF IT AND LOOKS LIKE SHE WILL PASS OUT...CALL THE SCHOOL NURSE TO COME TO HER ASAP

This meant that when he was anxious and distracted, or refusing to participate, he already had a good portion of the information that he needed to keep up. It also meant that while most of the other children were putting their mental energy into learning, his could focus on social skills and self-regulation.

Had someone ever told me that my son needed to stay back a year, I would have been totally

crushed! The idea that my son was not able to keep up with his peers would have been devastating. Thankfully, by sheer circumstance, my littlest ended up where he needed to be. That year that he had to mature and grow while also learning some academics while he was homeschooled made all the difference. Now in second grade, he is no longer struggling to keep up with his peers.

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Early Childhood Intervention

Literacy for the Young Child

ECI services support families as they learn how to help their children grow and learn. One way that we can all help young children to develop is by introducing books. Books are a great avenue that can help increase literacy for children of all ages including 0 to 3 years of age. Encouraging children to interact with books appropriately can give them valuable skills as they transition into the school system.

How can adults be effective in teaching language and literacy when working with children who have developmental delays? It's easy! Adults can set up a small area just about anywhere and incorporate books, pillows, stuffed animals and a few decorations. A writing center can also be set up nearby.

Several skills can be taught to a child just from having an area designated for reading and writing. These skills can be brought over to the school system when the child enters a structured classroom with other children. The skill gained are as follows:



The child will understand the importance of books. Initially, a child may not know how to interact with books and may put them in their mouths every time they are around one or put writing materials/ paper in their mouth, but an adult can properly show the child how to use the book or writing materials.

For instance, if a 6 month old puts the book in his or her mouth, the adult can redirect and say, "This is a book" and open it up and point to 2 or 3 pictures and say the names at least 2 or 3 times each. Each time the child is exposed to this, he or she will start to correlate the book with learning. Eventually the child will open the book, point to a picture and then try and say it or at least vocalize.

After pointing to pictures in books, the adult can work with the child on drawing one picture that they looked at. Now, the child is learning skills so the picture may not be drawn to scale but they are making an effort. This is called increasing language and literacy for the young child.

The young child will understand boundaries. Classroom settings have many boundaries that are adhered to for safety and to have conducive learning environments. When the child is continuously going to one area often to gain access to books or to write, they begin to learn that if he or she wants a book or wants to write, they can just go to the designated area. This designation of space helps the child to communicate effectively even if he or she cannot speak.

The parent or any adult working with the child can simply ask, what would you like and the child can go over to the area of choice if they are capable. Of course, this will take modeling. The adult will have to continuously act out, I want a book and then go over to the book area or I want to write and then go over to the writing area. This will continue until the child starts to comprehend what is happening. If a child is not going over on their own, the adult can always take the child over to each area and work on activities.

When looking at various age groups, below you will find examples of books that are appropriate for the young child.

Infants 0-6 months

- Books with simple, large pictures or designs with bright colors.
- Stiff cardboard, "chunky" books, or fold out books that can be propped up in the crib.
- Cloth and soft vinyl books with simple pictures of people or familiar objects that can go in the bath or get washed.

Infants 6-12 months

- Board books with photos of other babies.
- Brightly colored "chunky" board books to touch and taste!
- Books with photos of familiar objects like balls and bottles.
- Books with sturdy pages that can be propped up or spread out in the crib or on a blanket.
- Plastic/vinyl books for bath time.
- Washable cloth books to cuddle and mouth.
- Small plastic photo albums of family and friends

Young Toddlers 12-24 months

- Sturdy board books that they can carry.
- Books with photos of children doing familiar things like sleeping or playing.
- Goodnight books for bed time.
- Books about saying hello and good-bye.

- Books with only a few words on each page.
- Books with simple rhymes or predictable text.
- Animal books of all sizes and shapes.

Toddlers 2-3 years

- Books that tell simple stories.
- Simple rhyming books that they can memorize.
- Bed time books.
- Books about counting, the alphabet, shapes or sizes.
- Animal books, vehicle books, books about playtime.
- Books with their favorite TV characters inside.
- Books about saying hello and good-bye.

Resources:

Reach out and Read: <https://www.youtube.com/watch?v=ilazGpNlsGw>

<https://neurosciencenews.com/mri-early-reading-brain-activity-1996/>

<https://www.naeyc.org/our-work/families/13-things-babies-learn-when-we-read-them>

The Importance of Oral Language: https://www.youtube.com/watch?v=Y_K8CKjKj0

We should be reading out loud to every kid: <https://www.youtube.com/watch?v=ZBuT2wdYtpM>

TxP2P Statewide Conference Update

Laura J. Warren, TxP2P Executive Director

Our 15th Annual Statewide Parent Conference was last month in San Antonio. This was our first time to move the location of the conference in 9 years, so we were a little nervous about the new location. We loved the facility at Embassy Suites in San Marcos, but we felt like they weren't accommodating our needs anymore.

The conference was great – we had outstanding speakers, sponsors and exhibitors! We had 685 people, including registered participants, volunteers, staff and exhibitors, and we seemed to fill most of the space. We also enjoyed hearing from our keynote speaker, Susan Anner, about her adventures in raising her son, Zach Anner, who uses a wheelchair and has a career in comedy, acting and adventures. (Google Zach Anner and see his routines on YouTube!) The new conference app we tried, Whova, seemed to be a hit,

although many people missed the handouts at the sessions.

The families especially had a great time at the Family Gathering with the carnival games, face-painting and two bands, The Eddie Ray Band and the Peer to Peer Summit Band. We had a beautiful parade put on by the young adults in the Peer to Peer Summit, a beauty queen and an accordion player welcoming people and hanging out in child care with the kids.

The Wyndham San Antonio Riverwalk welcomed us, but it was clear from our first meeting with our conference team that we

couldn't stay there after this year. There is no room to grow, no nearby restaurants or

amenities, and parts of the hotel were difficult for people using wheelchairs. Then we had trouble with the hotel registration for our participants and an air conditioning shut down on Saturday morning that made us glad to have another new location for 2020.

We will be moving to **Austin** and to **July** next year – the conference will be at the Hyatt Regency Austin on Lake Bird Lake downtown on July 10th & 11th, 2020. Put it on your calendar! And our **South Texas Parent Conference** will be in San Juan at the PSJA Early College High School on Saturday, October 19th, 2019.



Hurricanes, Mosquitos & Other Emergencies to Consider

Liz Hong, TxP2P Staff

With the first hurricane of the year making landfall, we are squarely reminded that hurricane season is upon us! Disaster preparedness is a major challenge for everyone. Families whose child has a disability often find themselves even more unsure about how to be “Texas Ready” for the next natural disaster.

Fortunately, the Red Cross and FEMA have put together a handy guide to help guide your planning process. “Preparing for Disaster for People with Disabilities and other Special Needs” helps you focus on your child’s specific needs in the personal assessment section. This can help you to think critically about your child’s needs and how they may be impacted by a disaster.

This guide also gives tips for creating a personal network to help with planning and preparing for a disaster. Personal networks are a wonderful way for parents to get help and support and to ensure that multiple people know how to meet the needs of the person with a disability.



After a disaster, this can be even more important if downed phone lines or debris filled roads prevent parents from quickly reaching their children. What’s more, personal networks can help families brainstorm and collect the appropriate supplies. To learn more about the personal assessment and personal networks, head over to [https://www.redcross.org/get-](https://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities.html)

[help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities.html](https://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities.html)

With hurricane season and summer heat come mosquitoes. Those dastardly biters can bring with them Zika, West Nile and other arboviruses. To prevent mosquitoes, make sure to clean yard debris and/or litter from your yard and dump standing water. Also make sure to slap on some bug spray to keep the remaining stragglers from biting you. This is especially important for pregnant women, as Zika can interfere with an unborn baby’s brain development.

So get yourself “Texas Ready” for summer, hurricanes, and mosquitos! For more information log on to www.texasprepares.org, www.redcross.org, or www.fema.gov.

When a Hurricane Strikes...

Rosemary Alexander & Katrine Nordstrom, TxP2P

A TxP2P staff member, Katrine Nordstrom, lived through Hurricane Katrina in New Orleans in 2005 and has shared her experience of what the challenges were and ways to be prepared for any natural disaster. Here are several of the issues she, or people she knew, faced after the hurricane.

What will you do if you have no electricity for an extended time – think weeks instead of days? That includes no refrigeration, where you may be keeping temperature-sensitive medications. Katrine has heard of people who actually buried insulin in the ground, where it might be cooler than at the earth’s surface! That’s a really hard one to prepare for—bags of ice only last so long. A back-up generator or a friend with one might help?



What will you do if your child’s medical history, current prescriptions, current appointments, doctor’s names and phone numbers, diagnosis, medical insurance numbers, etc. are water-logged or back at home while you are fleeing a disaster? How about if you have to take your child to a specialist in another town or state and have no information to provide?

Katrine suggests that you put all vital information in the cloud, saving data to an off-site storage system maintained by a third party, such as Google Drive. Instead of storing information to your computer’s hard drive or other local storage device, you save it to a remote database. That way, you can access it from any phone or computer anywhere—as long as you remember the password! You could also email important information to yourself, so you will be able to see it later in saved emails.

What if you are forced to leave home on short notice? The best advice is to have a box ready to go of important information, extra meds and whatever you can think of that would make a difference for a few days while you are displaced. A list to prompt you about what to collect would also be helpful.

What if you and your child get separated? One approach is to be sure you have a meet-up location or other way to reconnect. Also, it would be helpful to be sure your child has information on a bracelet, card or document that goes with them all the time. Katrine says she really likes the Road I.D., used for athletes—you can put on it name, date of birth, diagnosis and 2 parent phone numbers.

Continued on Page 7

And remember, after a flood, there will be standing water everywhere—remember to protect yourself and family from mosquitoes and the Zika virus!

It’s really hard to imagine yourself and family in any of these dire circumstances, but we know that natural disasters can happen anywhere, nearly anytime. It will be a reassurance to know that you have considered what might happen and have planned for what you might have to face someday.

Resources:

- <https://www.roadid.com>
- <https://www.fema.gov/children-and-disasters>
- <https://drive.google.com/drive/my-drive>
- <https://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities.html>

Great Special Education Websites

Compiled by Rosemary Alexander

NavigateLifeTexas, a great resource for any and all issues facing families of children with special needs in Texas:

- <https://www.navigatelifetexas.org/en/education-schools/special-education-101>
- <https://www.navigatelifetexas.org/en/education-schools/ard-process>
- <https://www.navigatelifetexas.org/en/education-schools/faq>

Got questions about Special Education? SPEDTex the Special Education Information Center for Texas, can help: <https://www.spedtex.org/>

Here’s a project of the Texas Education Agency committed to providing accurate and consistent information to parents and families of students with disabilities, created by parents, for parents: <http://texasprojectfirst.org/>

Partners Resource Network is a non-profit that operates the federally funded Texas Parent Training and Information Centers for Texas (PATH, PEN and TEAM): <http://prntexas.org/>

Wright’s Law was created by a couple (lawyer and counselor) who wanted to help people learn about advocacy and special ed law: <https://www.wrightslaw.com/>

Upcoming conferences & this newsletter:

- TxP2P South Texas Parent Conference, October 19th, 2019 - more information coming soon!
- Are you getting this newsletter by U.S. mail but you are ready to get it by email instead? Then please contact Norma at norma.castro@txp2p.org and ask her to make the change. Save a tree!

Thank you to our Statewide Conference Sponsors!!

CDS in Texas

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Texas Children’s Health Plan

In-Home Attendant Services

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Conference Schedule

Date	Conference Title	Location	Registration Information
September 7, 2019	S.W.A.P Conference: Transition from Diagnosis to Diploma . . . and Beyond	Cook Children’s Medical Center, Fort Worth, TX	https://www.eventbrite.com/e/swap-conference-transition-from-diagnosis-to-diplomaand-beyond-tickets-62733453448
October 24-25, 2019	20th Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care	MD Anderson Medical Center Complex, Houston, TX	https://www.baylorcmc.org/search/detail.cfm?cme=1124
November 8, 2019	East Texas Transition Conference—Door to the Future	Trinity Valley Community College, Palestine, TX	https://www.palestineresourcecenter.org/registration