



A Parent's Perspective

TxP2P Quarterly Newsletter

TxP2P Update

Laura J. Warren, Executive Director, TxP2P

As 2017 winds down – all our conferences are done for the year, our annual Vine to Wine Fundraiser is over, and it's already the holiday season – I always go back to the December day we met at a dining room table about starting a statewide parent-to-parent in Texas. Sixteen years later, here we are. Over 7,000 families strong, 1,400 friends and professionals, and over 500 volunteers to help us cover this big ol' state! Thanks to everyone who has helped us in providing support, information and education to thousands of families of children with disabilities, chronic illness and other special health care needs.

If you are able to make a donation this year, please consider making it to Texas Parent to Parent. Now, in its 2nd decade of operation, TxP2P needs to rely more heavily on private donations to support our programs and operating expenses. Thanks to the generosity of individual donors like you, TxP2P has grown and has built a solid foundation of support for families raising a child who has a disability. Now, as we enter 2018, TxP2P needs to focus on the sustainability of this non-profit organization to ensure that it will be around to meet the needs of additional Texas families.

PLEASE NOTE: if your child has been enrolled in STAR Kids recently, just wanted to let you know that we have formal contacts with United Healthcare, Blue Cross Blue Shield, and Amerigroup so please give us a call if you are having problems with services from those three programs. We also have informal agreements with Driscoll Children and Texas Children's Health Plans. We'll try to help.

And happy holidays from all of us at TxP2P!!

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Fall 2017

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Happy Holidays!

Advocacy Update

Linda Litzinger, TxP2P Staff

Advocacy in Public Education

Texas Education Agency (TEA) is conducting an IEP analysis project to inform and improve Texas special education services for students with disabilities. Part of this project includes parent participation in a confidential stakeholder interview. If you are interested in participating, please email Linda Litzinger at linda.litzinger@txp2p.org.

Advocacy in Health Care – MDCP Denials

Historically, annual reassessment denials in Medically Dependent Children's Program (MDCP) Waiver only affected 2% of the MDCP population, but because of a new annual assessment tool that rolled out with STAR Kids, children are suddenly being denied at a 12% rate. **If you received a denial letter 1) quickly ask for an appeal hearing and 2) include that you want to meanwhile continue services as you wait for your hearing.**

Follow this link to see a video on this subject:

[Disability Rights Texas\(https://www.facebook.com/DisabilityRightsTx/videos/1587060784691921/\)](https://www.facebook.com/DisabilityRightsTx/videos/1587060784691921/)



Therapy Rate Cuts

Lisa Brodie, Parent

The past two years have been extremely challenging for children with disabilities and their families and therapy providers in the state of Texas. We have worked to raise attendant wages for our children and to reduce Medicaid Waiver wait lists for children desperately waiting for services and supports in their homes. We have witnessed the federal government investigate Texas school districts for placing caps on special education services. We have also watched the state cut funding for medically necessary therapy services for our children.

In 2015, the 84th Legislature approved \$350 million in Medicaid cuts to therapy providers, to be spread over two years. These cuts were mandated following a flawed study which found that Texas Medicaid pays therapists more generously than programs in other states. This study did not look at the impact of how cuts would impact access to care and therapy services for our children.

Over the course of these two years, Texas families filed suit to stop the cuts but were unsuccessful in their attempt. The House passed House Bill 25 in a unanimous vote to restore the funding cuts, but their effort was also halted when the Senate was not on the same page. A compromise was reached and 25% of funding was restored. Meanwhile, the most recent rate cut and policy changes went in to effect on September 1, 2017.

What is the impact on therapy services in Texas?

Access to medically necessary therapy services is being threatened because of the drastic 18-28% reduction in reimbursement for therapy services, with speech therapy at the higher end of the cuts. Therapy providers can no longer afford to provide services to Medicaid patients.

Home health agencies are closing their doors. ECI centers, which provide federally mandated early intervention services through IDEA, are closing. Consequently, Texas

children are going without crucial therapy services while they sit on crowded waiting lists. Medicaid Managed Care Organizations (MCO) are also passing on cuts to therapy providers resulting in further loss for providers.



Therapy provided by licensed therapy assistants will soon be reimbursed at a lower rate than licensed Master's degree level therapists. Assistants are largely responsible for providing bilingual speech services and serving those in rural areas. This particular change does not support the cost of clinical supervision of assistants or travel expenses for therapists. Agencies may choose to only utilize fully licensed therapists and not employ therapy assistants. This will result in decreased access to speech therapy for those children who require bilingual services and/or live in rural areas, not to mention loss of employment opportunities for assistant therapists.

In addition to the rate cuts, policy changes have impacted the way that therapists bill and code for skilled services. Speech therapists now bill per encounter (or per visit) versus billing for actual time spent with a child. They can also only bill for one type of intervention or service provided per visit. This negatively impacts children who need more than one skilled intervention during a visit, such as dysphagia treatment for a

swallowing disorder and speech therapy for an articulation or language disorder. In regards to reimbursement per encounter, some providers may choose to reduce the length of treatment sessions to contain costs. The length of a therapy session should be based on the unique needs of a child and should only be reduced based on clinical judgment.

What do we need to do?

As parents, advocates, and providers, we must remain active in fighting against these cuts and advocate for medically necessary therapy services for the 60,000+ Texas children who need them. We can do this by doing the following:

- √ Talk with your therapy providers and agencies. Ask how they are advocating for positive change and how you can help advocate for your child.
- √ Follow advocacy groups on social media and participate in parent and advocacy groups. This will be a great resource for you and will provide a community forum to learn about current events.
- √ Call, write, or visit your State Representative and Senator and talk to them about your child. Tell them personally how your child has been directly impacted by these cuts. It may seem intimidating at first, but they want to hear your concerns and it gets easier every time you do it!

How to find who represents you—<http://www.fyi.legis.state.tx.us/Home.aspx>

Texas House of Representatives - <http://www.house.state.tx.us/members/>

Texas Senate —<http://www.senate.state.tx.us/members.php>

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Therapy Rate Cuts

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- √ Attend Texas Health and Human Services Commission (HHSC) public hearings or provide written comments and testimony by email, fax or mail.
- √ Contact the Texas HHSC Office of the Ombudsman to file a complaint any time you have a concern. Provide specific information if your child is unable to access therapy services, for example, they are on a waiting list, there are no providers in your area, or a

provider is no longer accepting patients, etc.

Texas Health and Human Services Commission

Office of the Ombudsman,
MC H-700
PO Box 13247
Austin, TX 787-3247

Texas HHSC and our legislators need to hear from families, not just therapy providers. This isn't just a matter of cost containment or a budget issue. They need to hear

personal stories and put a face with our concerns. This is not about money, but about our children. If our children receive the services they need early on in life, they will be healthier, more successful and will ultimately cost the state of Texas less money in the long run. The time is now! Therapy services for our children will remain at risk as long as the legislature continues to trim the budget and we must advocate and fight for our children.

Transition Frequently Asked Questions (FAQ)

Rosemary Alexander, TxP2P Staff

Why did my adult child move from SSI (Supplemental Security Income) to SSDI (Social Security Disability Income) when my husband/wife retired and started receiving their Social Security retirement benefits? Then we got a letter saying he lost his Medicaid. We need help!!

We hear this question often in our office from parents across the state. There is a new regulation we hope will make this situation easier to navigate.

First, let's discuss why a child on SSI could possibly move to SSDI when a parent retires and starts receiving Social Security retirement benefits.

This could happen if the parent has a child with a disability who qualifies as a Disabled Adult Child (DAC). When the parent completes the preliminary paperwork to claim their retirement benefits, there is a box to check if you have a "disabled adult child." Checking this box starts a chain of events that could eventually move the child from SSI to SSDI. Many times this enables the DAC to receive a higher benefit from SSDI than they were receiving for SSI. (DAC will receive 1/2 of parent's retirement amount)

So let's define what exactly is a Disabled Adult Child (DAC)?

In order to qualify for SSDI as a DAC, you must be unmarried, 18

years old or older, and have become disabled before turning 22 years old. Adult children qualify for benefits under their parent's Social Security eligibility. This means that the parent under whom they qualify must fall into one of the following categories:

- √ Be deceased
- √ Receive Social Security Retirement Benefits
- √ Receive Social Security Disability Benefits

The SSA reviews claims for adult children under the same general eligibility and medical eligibility criteria as they do with any other adult disability application. The only difference in an adult child's eligibility determination is the fact that the parents' work credits (<https://www.disabilitybenefitscenter.org/glossary/social-security-disability-work-credit>) are accounted for rather than the child's in deciding if the child has sufficient contributions to the SSDI fund to meet this portion of the general eligibility criteria for receiving disability benefits.

It is important to note that according to SSA regulations, a child doesn't have to be a biological child of the qualifying parent. A stepchild, grandchild, and some times, even step grandchildren can qualify,

provided the parent or grandparent under whom they qualify for SSDI benefits was their legal guardian.

Back to our FAQ at the beginning of the article. The problem has been the switch from SSI to SSDI for DACs has not been smooth in the past. When the DAC no longer received SSI, they therefore lost the Medicaid attached to it as well. Many people do not know you can simply reapply for Medicaid as a DAC due to Section 1634-C provision of Social Security. Texas has recently acknowledged the problem and is addressing it with a new procedure aimed at streamlining the process.

RULE CHANGE:

There has been a rule change for individuals who lose their SSI and Medicaid due to the start of SSDI on their parent's record. Medicaid will now provide 2 months of gap coverage and send an application form for DAC benefits to the individual upon notification from SSI that the individual has lost their SSI due to the start of SSDI. Applications will be expedited for individuals who receive gap coverage and return their application before the last day of the gap coverage.

<https://hhs.texas.gov/sites/default/files/documents/laws-regulations/handbooks/mepd/>

Transition FAQ

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To summarize, Medicaid is now supposed to notify SSI recipients of the change by sending them a new Medicaid application and provide an opportunity to reapply for Medicaid after they switch to SSDI. They are providing a two-month gap period to complete and submit the new Medicaid application but we recommend completing and sending it in as soon as possible.

Two exceptions to note:

- 1) Some people may be able to receive SSI and SSDI at the same time (concurrently). This would occur if the SSDI payment were less than the SSI payment. In this case, the individual would maintain Medicaid thru SSI and there would be no need to reapply for Medicaid.
- 2) In some cases, an adult child may also have a work history during

which their contributed to the Social Security Disability fund and would therefore potentially qualify for receiving disability benefits paid



based on their own work history. However, in most instances, the amount of benefits an adult child can receive are higher if they qualify under their parents' eligibility instead. This is because the adult child typically has a much more limited work history, which can affect the amount of their monthly SSDI payments.

If the adult child is working, their income must not exceed the SGA (Substantial Gainful Activity) of \$1,170 for 2017 to remain eligible for SSDI. (Note: Subsidies can be used to reduce earnings below SGA). If someone on SSI moves to SSDI on their own work credits, they cannot use 1634-C to maintain Medicaid but there are options such as Medicaid Buy-In for working individuals. Or the individual could switch to Waiver Medicaid if on HCS or CLASS waiver programs.

You can contact our office (866-896-6001 or 512-458-8600) for more guidance on this.

If you have any questions, please give our transition team a call at 866-896-6001 or 512-458-8600!



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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:

*David Silos, son of Karen and Joel Silos
Victor Gallo, son of Carmen Gallo*

With deepest sympathy, the Staff, Volunteers, & Board of Texas Parent to Parent



Early Childhood Intervention (ECI) is a statewide program within the Texas Health and Human Services Commission for families with children birth up to age 3, with developmental delays, disabilities or certain medical diagnoses

(<https://diagsearch.hhsc.state.tx.us/>) that may impact development. ECI services support families as they learn how to help their children grow and learn. We wanted to provide you with a short "ECI At-A Glance." Let's check and see how much you know!!

DID YOU KNOW...

- √ A newborn's brain is 25% of the weight of an adult's brain.
- √ The birth-to-3 period is the fastest rate of brain development across the entire human life span.
- √ By age 3, a child's brain has reached nearly 90% of its adult size.

Most astounding is the fact that the fastest rate of brain development occurs from birth to age 3. This definitely has direct impact on the work that Early Childhood Intervention (ECI) does in early intervention because early childhood experiences, both positive and negative, have life-long effects which means early childhood is a period of both great opportunity and vulnerability. Check out this video on Early Brain Development (<https://www.youtube.com/watch?v=VNNsN9IJKws&feature=youtu.be>)

DID YOU KNOW...

- √ Anyone who has a concern about a child's development can make a referral to ECI.
- √ 55% of the referrals made to ECI come from the Medical and Health services community and
- √ 24% come from Parents/Family/Friends

In Fiscal Year 2016, ECI served over

54,000 children and their families in Texas. ECI has local contractors throughout the state and every zip code is covered to ensure that all families that are eligible for services are able to receive ECI services.

DID YOU KNOW...

There are three ways a child can qualify of ECI services:

√ **First, if the child has a medical diagnosis**

If a child has a medically diagnosed condition that is likely to cause a developmental delay and has a need for services, he or she will qualify for ECI services. (Examples of common qualifying medical diagnoses include:)

- √ Down syndrome
- √ Cerebral Palsy
- √ Seizure disorder
- √ Failure to thrive

√ **Second, if the child has an auditory impairment or a visual impairment**

A child is also eligible for services if he or she has an auditory or visual impairment as defined by the Texas Education Agency (TEA).

√ **And third, if the child has a developmental delay.**

To determine eligibility for a developmental delay, the ECI contractor administers a standardized, evaluation tool, the Battelle Developmental Inventory (BDI) which evaluates all developmental domain areas including cognitive, social interactions, gross and fine motor skills, adaptive skills and communication. The child must have at least a 25 percent delay in 1 or more of these development.

DID YOU KNOW...

- √ Anyone can make a referral to ECI

- √ ECI services are provided by licensed and credentialed staff
- √ ECI services are provided where the child lives, learns or plays
- √ ECI Services are provided to families of all income levels

Early Intervention provides immediate and long term benefits for children and families. If you are concerned, don't wait. Call and find out more about ECI services. Call 1-877-787-8999 or visit the ECI web page at www.hhs.texas.gov/eci. Here are some additional topics you may find of interest:

ECI Resources (<https://hhs.texas.gov/services/disability/early-childhood-intervention-services/eci-resource-guidecentral-directory>): A robust collection of resources of interest to families of children with developmental delays or disabilities.

ECI Professionals (<https://hhs.texas.gov/services/disability/early-childhood-intervention-services/career-opportunities-eci>): ECI has licensed and credentialed professionals who provide services

ECI Program Search (<https://citysearch.hhsc.state.tx.us/>): Find a local ECI program in your area

ECI Videos (<https://hhs.texas.gov/services/disability/early-childhood-intervention-services/eci-outreach-materials>): Learn more about ECI from a family's perspective

Information for Families (<https://hhs.texas.gov/services/disability/early-childhood-intervention-services/eci-information-families>): Learn about the developmental milestones

**DID YOU
KNOW?**

Appearances may not initially allow anyone to realize the depth of his condition. After all, Austin wears weird as a badge. Quirky may be an initial momentary impression, but this is autism as it affects him and it has shades and flares. It's always different and changes over the years and not always for the better.

Puzzling as it is non-linear, the planning for occasions like travel or attending weddings, funerals or christenings are on the order of wire contortionists performance. It requires hyper current determination of what is significant.

Every family is unique, especially every family who includes a child or young adult with a disability, and we are definitely no exception to that. Still on travel days, I see how we stand apart and are noticed for his ways and our ways of being. Experience fused with imagination fuels planning, | sometimes good planning. And it fuels anxiety, second-guessing, fear, raw as it gets in our modern world where social threats are much more frequently encountered than are lions, tigers and bears. Our nervous systems attuned accordingly.

Now it's the Transportation Safety Authority (TSA) agent's eyes that dart like wild. It occurs to me that despite the lengthy, reassuringly thorough interview process I'd submitted to with the thoughtful voice of the airline's representative and the exhaustive arrangements and plans for everything we could imagine could happen, we are still not prepared in the face of the changing nature of my son's condition.

That preparatory conversation when the airline's representative so attentively noted how they would accommodate my son and confirmed the additional allowance for personal items on board in order to accommodate liquid medications and assistive devices in flight, will have no bearing here, now, with the Transportation Safe-

ty Agent facing us.

And I guess that's to be expected; the entities are separate and don't talk, though I'm wondering now if it would have been so hard for them to make a call or send a note to the security personnel on site or for the TSA to invite airlines to share lists of accommodated travelers. But it is part of the reason that in in the past I'd only sporadically reported my son's condition to airline carriers prior to flights.



I did it this time because I'd heard that the accommodations offered would be much wider ranging and inclusive of persons with sensory disturbances like autism. That now, the accommodations were much more comprehensive and improved from the past when the only offer of accommodation was "priority boarding" which never seemed much help for us, particularly because we have no obvious mobility impairment. Unfailingly, the airline agents that handle boarding arrive at the desk moments before they begin seating and seemingly have no procedure to identify registered pre-boarding customers other than their visual survey of those waiting. At that point, we have no chance to introduce ourselves either.

They make their scan of the waiting area and which parties include strollers and/or young child or persons using crutches/walkers/wheel chairs. My son doesn't use those yet there can be mobility issues that affect him too.

It's tricky but in fact allowing my son a chance to get on the flight before it fills really might quell jitters. But in any case, the pre-boarding phase is so quick and without obvious symbols or cues in

our possession, and my son's hesitancy, anxiety and sometimes freezing in place during transitions, we almost never made it to the entrance before they'd moved on announcing that the full crush is on and all passengers allowed to proceed to and through the narrow passage to board.

So I accepted that they were never prepared by that gracious airline representative and now are unprepared and we are unplanned for. So I tell her, while her wild eyes dart at our differences - my skin and hair, my husband, my son - and the longest look as she focuses effort at processing my son's appearance, demeanor and atypical responses and deep voice, distorted and mostly unintelligible, especially without practice and context.

I fully realize that regardless of the personal item accommodation the airline affords me, this TSA agent has no clue of it and surely wonders, "What's with all the stuff? The liquids?" soon after she asked for ID. In addition to producing photo ID for each of us, my husband and I offer to show her our airline ticketing confirmation along with confirmation of our notice to our carrier regarding my son's accommodation request and confirmation of the accommodations they granted. I have dutifully uploaded those and the boarding passes and ticketing information to my phone along with scans of my son's birth certificate and social security card.

I have my passport and Texas Driver License as does my husband because we'd heard that some driver licenses are not compliant with TSA regulation.

She accepts these for my husband and I then asks my son his age and gets no response she can use. I tell her he just turned 18, as of 5 days prior to this flight day. Now she is dissatisfied with my son's photo ID, as it is not state or federally issued, and goes on to say that the scanned birth certificate and Social Security Card are not useful because despite the widespread use of virtual ticketing and payment forms, the TSA has no use for photos or scans of any documents.

So I look through my wallet finding his municipally issued transit ID that bears his photo and features one of my arms, which insisted on holding onto as that photo, was taken. What could be more authentic? It documents our connection. Still she is dissatisfied and as I show her the state issued Medicaid card that bears no photo but ties him to a federal entitlement for persons with disability. I come to the realization that no document or card we're carrying will be enough for her and I tell her, awkward as it is and something I loathe to do in front of him and usually am able to avoid in these sort of situations, that my son is on the autism spectrum.

She informs me that all versions of ID he has is insufficient, as he is 18 years old and no longer a minor. I point to the photo on his school ID but it is not state issued and does not meet their standard. So I refer back to the social security card and birth certificate I've shown and she informs me that scanned copies don't meet TSA standards. TSA expects my son to travel with original documents despite his status as a high school student.

He has no driver license, as many persons with autism do not. While so many of our friends and family in my son's community earned their driver license, I'd managed to weather another milestone/rite of passage that disability would deny him. I offered cheery congratulations to those who shared that achievement with us. Afterward, I realized in addition to coping with another reminder of what sets my son apart from peers, I should have joined in the party and gotten him a DPS issued ID card at 16 as part of his transition plan. Most sons that turn 18 have had a TSA accepted ID for 2 years already in most states. But in the case of persons reaching

adulthood with disability, the TSA does not recognize the types of incidentally acquired ID that it does for the general nondisabled public.

Identifying documents and cards that are meaningful and functional in the lives of persons who have childhood onset lifelong developmental disability have no use for TSA. Typical peers obtain their ID as a matter of course often on their own accord. For us, this is a transition item that should have been on the to-do list, as you see, this TSA agent chose to focus her attention and the resources of the federal government on this gap in transition planning and today the consequence is that this officer require a pat down to release our son to fly with us.

She reacts to my face falling and



tensing, full anguish and the disappointment that he has become subject to this attention. I choose to mention the social dysregulation that is part of how autism spectrum disorders manifest. Now, this TSA agent lady wants guidance pronto: I am to tell her in one or two words how she should go about accomplishing this body search she's decided on. What she should remember? She needs tips - a rule of thumb. Quick!!

I tell her in a word what we know, which is mostly that we don't know much, "He is unpredictable." She grimaces so I choose two pieces of additional information "Use your words and speak normally." She starts talking to him now in a cooing fashion and I attempt to correct this by stating "that's baby talk" in the most even tone I can muster and that draws her glare. I explain, "That's not normal, you sound like you are talking to a baby and he's a man."

I chose to say it, felt I had to, knowing how baby talk may offend my son, and lead to the sort of outbursts we like to avoid, particularly when in the company of federal agents. Trying to

be brief and efficiently guide her but I can tell now that it is not appreciated though she asked me. She doesn't like the advice and definitely not the correcting or coaching, which she responds to as reprimands.

My son continued to do remarkably well that day despite this hiccup. He went through the pat down and I guess it all turned out fine. This is true especially if I forget the way that the male TSA officer assigned to conduct the additional screening stepped out from behind the curtain relieved and smiling when it was all done. He recounted how well my son did with his requests and federally sanctioned personal boundary crossing during this preposterously unnecessary procedure. I know the officer was hoping to reassure me by marveling at the way my son had calmly submitted to the search and concluded the episode by reciprocating with gentle patting on the officers stubbled cheeks.

"Bless them for they know not what they do!" This officer had no clue how creepy his retelling of his experience sounded to me and the context of our son's situation and our struggles to set appropriate physical boundaries in social settings with strangers and in public. He certainly had no idea how easily and in how many ways it all could have taken a wrong turn and derailed our travel day throwing us from the high wire and exposing my son's condition in spectacular fashion. We feel the chill as they never will and escape their screening area with our chance to vacation and visit the precious steadfast family that we just have to see.

P.S. Interestingly, TSA personnel on the corresponding nonstop return flight originating from New York City's JFK airport were completely satisfied with the scanned birth certificate and SSN but said that the school ID was TSA acceptable...that day. So they kept their hands to themselves and reserved their resources for criminal threats.

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Conference Schedule

Date	Conference Title	Location	Registration Information
Nov. 18, 2017	2017 AccessAbility Fest	San Antonio	http://www.accessabilityfest.com/
Feb. 4-6, 2018	Inclusion Works	San Antonio	www.thearcoftexas.org/events
Feb. 17, 2018	2nd Annual East Texas Parent Conference	Tyler	www.txp2p.org
Feb. 21-23, 2018	Texas Transition Conference	Houston	www.ttc.tamu.edu/
Feb. 27-28, 2018	Central Texas African American Family Support Conference	Austin	ttps://ctaafsc.com