



Report of the Texas Autism Council

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Texas Autism Council

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Disclaimer

This report was not authored by and does not reflect the views and opinions of the Texas Health and Human Services system, its component agencies, or staff.

Executive Summary

The purpose of this report is to briefly summarize the state of ASD-related services in the state of Texas, with a focus on those services provided by the Texas Health and Human Services Commission (HHSC). The report focuses on successful iterations of service programs, emphasizing what it looks like when those services work best. The report also provides recommendations for how to increase the number of successful outcomes for individuals with ASD and their families across service delivery models, and ways to address limitations that impact the ability of families to access successful or supportive service environments. The report draws on the experiences of professionals and families in order to provide a detailed and specific account of several successful and challenging circumstances encountered by people with autism, their families, and the professionals who serve them around Texas. The overarching goal of the report is to provide multiple examples of positive situations reflecting the best practices within the service provision models of HHSC.

Based on those examples, the Texas Autism Council makes the following recommendations:

1. Increase identification of and services to young children with autism to increase proportion of children with autism receiving services at younger ages
2. Increase transition services and adult programming in anticipation of impact of increasing prevalence rates on adult population of individuals with autism
3. Increase number of service providers across all programs by increasing reimbursement rates and decreasing barriers to collaboration and creativity
4. Increase family and professional awareness of all programs and reduce barriers to enrollment and participation for families and individuals

Introduction

Charge of the Council: The Texas Autism Council has been charged to summarize and make recommendations to the Commissioner of the Texas Health and Human Services Commission about issues related to autism and the provision of services to people with autism and their families. The goal of this report is to provide a brief summary of the services available to individuals with autism and their families across Texas, to identify areas of success within those services, and to provide a vision for ways in which those services can best be structured and funded within the state to maximize the benefit to the most people with autism and their families as possible.

Due to the increasing prevalence of ASD, the recent reorganization of HHSC, and the diverse number and type of services provided by HHSC, it is important that the Texas Autism Council carefully consider the unique and cumulative impact of those changes and services on people with ASD across the state. The goal is to identify where this diversity of services and models is working best while also identifying ways that efficiencies can be found to better maximize the impact of the available resources.

Background

Autism Spectrum Disorder is a neurodevelopmental disability characterized by impairments in social communication and social interaction across multiple contexts and the presence of restricted, repetitive, and stereotyped patterns of behavior, interests and activities^{2, 18}. Autism is the fastest growing disability in the country^{2,6,8} and in Texas^{4,5,6}. The prevalence of autism is currently 1 in 59², and is increasing^{1,2,3}, with 2.79% of children nationally and 1.54% of children in Texas receiving an autism diagnosis in 2016¹⁷. Conservative estimates suggest there are at least 250,000 individuals with autism in Texas^{5,6,16}. From early childhood intervention¹⁶ through to adult services⁴, individuals with autism are requiring more supports and resources than ever before. The most dramatic example is within Texas Vocational Rehabilitation (VR) services, where the number of individuals with autism receiving services has doubled from 3000 to 6000 customers from 2010-2017. In the most recent state total, 18.75% of VR customers are identified as having autism⁴. Students identified as eligible for Special Education (SPED) services with autism in Texas have increased in number and proportion⁵. 13.5% of students receiving SPED services in 2018-2019 received an autism label (71,951 total) –up from 9.3% of students in 2012-2013 (41,206 total with Autism)⁵. The percentage of Early Childhood Intervention clients qualifying for services with an Autism identification has increased to 6.4% in 2018, up from 5.8% in 2016¹⁶. The smaller increase in ECI, and the overall lower proportion of individuals with an Autism diagnosis in ECI services, is likely due to the difficulty of securing a formal autism diagnosis before the age of 3 for the majority of families in Texas.

Prevalence of ASD by Age Groups	Estimated Numbers
Children with ASD in Texas Birth to 3	26,129 * ^{6,16}
Children with ASD in Texas in K-12 Education	71,951 ⁵
Adults with ASD in Texas	125,000** ⁵
Overall Number of Individuals with ASD in TX	223,080-250,000+

**Most recent numbers from 2017-2018*

***No comprehensive estimate is available. Prevalence is likely underestimated and is based on a rough estimate from 20 years of exit data from special education services.*

The increasing number of people with autism has put a strain on state resources, while also providing a unique opportunity to explore ways to better serve a growing population through HHSC services. HHSC provides a number of powerful and important supports and services to individuals with autism and their families. Those supports are listed below. Programs which most directly serve autism are included, but many HHSC services influence the quality of care of individuals with autism.

HHSC Service	Link
Early Childhood Intervention	https://hhs.texas.gov/services/disability/early-childhood-intervention-services
Office of Disability Prevention for Children	https://hhs.texas.gov/about-hhs/process-improvement/office-disability-prevention-children
Medicaid Programs	https://hhs.texas.gov/services/health/medicaid-chip
Children’s Autism Program	https://hhs.texas.gov/services/disability/autism
Community Partner Program	https://www.texascommunitypartnerprogram.com/
2-1-1 Texas Information	https://www.211texas.org/
Texas Autism Resource and Research Center	https://tarrc.org/
State Supported Living Centers	https://hhs.texas.gov/services/disability/intellectual-or-developmental-disabilities/state-supported-living-centers-sslcs
Aging and Disability Resource Center Program	https://hhs.texas.gov/services/aging/long-term-care/aging-disability-resource-center
Community Resource Coordination Group Program	https://crcg.hhs.texas.gov/
Local Intellectual and Developmental Disability Authorities	https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/local-idd-authority-lidda

The next section of the report will provide specific, concrete stories of success and of challenge for families and professionals dealing with autism in the state of Texas. Each story will highlight what's working best, while also recognizing what can work better. It is hoped that positive, solution-focused recommendations will allow HHSC and the Texas legislature to make the best decisions possible in their designation of resources for the design and delivery of services for people with autism in Texas. The emphasis will be on highlighting overarching interagency or across-organization cooperation as a means of providing concrete examples of ways in which HHSC is implementing the ultimate best practices in autism.

Successes, Challenges, and Recommendations

Each of the recommendations below are informed both by existing data and also the professional and personal experience of the council members and their colleagues who assisted in gathering data and stories from both the family and professional viewpoints for this report. The stories of success described in the sidebars below occurred because service providers, families, and professionals came together to address unique needs within existing systems.

Two primary conclusions can be drawn from the most successful implementations of programs summarized above:

First, the most successful implementations of these programs allow families and providers the most flexibility to make decisions in their unique situation. Autism spectrum disorder is characterized by unique expression of symptoms across each individual. Therefore the needs of individuals with autism are complex and often different from each other. There is no cookie-cutter treatment for ASD. Therefore, programs like the Children's Autism Program and others that show the most consistent positive effect are often those that allow the service delivery to be individualized to the child. Service delivery models that allow flexibility allowed the experts to apply that expertise in situations that are culturally, educationally, and socially sensitive.

Second, successful implementations of these programs are interdisciplinary in practice. Because of the pervasive impact of autism symptomology in the lives of people suffering on the spectrum, intervention can rarely be successfully implemented by one professional at a time. Programs that utilize a variety of professionals, including: applied behavior analysts, school psychologists, speech pathologists, occupational therapists, physical therapists, parents, teachers, physicians, counselors, and social workers have the ability to address the needs of people with autism in effective ways that cannot often be achieved in the absence of multiple professional perspectives. Having a more informed and professionally connected group of service providers benefits all the individuals in any setting in which the more collaborative professionals work.

Flexibility and interdisciplinary practice define successful outcomes in autism spectrum disorders. When designing the next generation of supports for children with autism in Texas, it is highly recommended that priority be given to those programs which can demonstrate not only individual, flexible programming but also involve the presence and influence of multiple professionals in service provision.

List of recommendations:

1. Increase identification of and services to young children with autism to increase proportion of children with autism receiving services at younger ages

Helping Earlier: Permian Basin Community Centers Early Childhood Intervention program and behavior supports offered through PBCC collaborated to provide families with children with autism or at-risk for autism applied behavior analysis therapy in low doses with the focus being on parent training and setting up the environment for success. Children without a diagnosis or who were waiting for a diagnosis are receiving services even before the formal identification. PBCC's success represents the importance of increasing acceptance of a variety of service providers within ECI, the power of creative partnership, and how increasing training efforts for ECI contractors and more efficiently accessing current services available within ECI can directly benefit families earlier in life.

A Quick Start: The parents of A.F. were lucky enough to connect with a developmental pediatrician when she was very young. The doctor diagnosed her with ASD at 18 months and the family started with ECI when she was 27 months old. The ECI experience was through Easter Seals, and the therapies "kick started" A.F.'s behavior and speech in the right direction. It was short, less than a year before she aged out and went to PPCD, which is where she really accelerated. Through all of the therapy experiences, parents being able to participate (essentially turning therapy sessions into caregiver workshops) was more beneficial for our family than the sessions themselves. A.F. had a smooth transition into PPCD and, later, into kindergarten. She goes to her neighborhood school and is included with regular peers.

Recommended Actions

Concrete ways HHSC can follow this recommendation based on lessons from the stories:

It is vital that more children be identified earlier and begin receiving services at younger ages. Texas lags behind the rest of the country in early identification and diagnosis of autism¹⁷, and that means children and families are not getting the early help they need. To do so, there are several concrete steps HHSC can take to achieve that goal.

- 1). Improve ECI Child Find and Office of Disability Prevention for Children reach and resources to increase screening and identification as early as possible.
- 2). Prioritize efforts to increase the proportion and rate of children with ASD served by ECI to reflect the actual proportion of young children suspected of being impacted by ASD.
- 3). Build partnerships with professionals who can help facilitate timely assessment and services, such as child psychologists and pediatricians. This will also increase

inter and intra agency collaboration to ensure families receive a better continuity of care and are more efficiently brought into the full array of available supports. For example, the CAP can provide important supports, but only once a child has a diagnosis on the spectrum. If CAP and ECI providers are working together, it's more likely that a child could transition between these programs with no or minimal delay.

4). Provide annual, mandatory, training to ECI providers about ASD, ASD screening, and ASD diagnosis. Additionally, offer that training to all early childhood providers and organizations across all state agencies and services.

5) Require or strongly suggest that all ECI providers participate in the Community Partner Program.

2. Increase transition services and adult programming in anticipation of impact of increasing prevalence rates on adult population of individuals with autism

Building Bridges: Byron Ross, a faculty member at the University of Houston, developed a Peer-Mentoring Program in which undergraduate students from the National Student Speech-Language Hearing Association serve as the mentors to students enrolled at the University of Houston who have a diagnosis of ASD. The program's overall purpose is to provide levels of support to students with ASD in the areas of organization, social support, and personal responsibility. Mentors work with the mentees to establish semester goals that the mentees would like to accomplish as a part of the program. The program is not currently funded through HHSC, but represents the sort of programming that higher functioning individuals with autism attending college need to be successful.

Adapting to Need: As a behavior specialist employed by an HCS provider we have had individuals be admitted to services and their current behavioral status is high. We provide them with more intensive 1-on-1 supervision up front rather than waiting up to 3 months for their severity status to change. They're assigned a higher level of need upon admission with close supervision of a behavior analyst and behavior plans and documentation are reviewed every 3-6 months and basically the level of support from both staff and the behavior analyst decreases over time and eventually fades out. More support up front can really set a person up for success. This also decreases the use of emergency services and hospital stays and increases the quality of life of these individuals.

Recommended Actions

Concrete ways HHSC can follow this recommendation based on lessons from the stories:

As the population of adults with ASD in Texas explodes, it is important that state services anticipate the increased need and strain on an already thin system⁴. This is the area with the most potential growth and impact across years, and has a correspondingly larger set of recommendations. HHSC can take several steps to help get ahead of the transition boom, including:

- 1). Offer increased training for providers across programs to be more familiar with ASD and become more welcoming of clients with ASD. Take advantage of organizations that can train in volume (such as university programs) to develop training in this area in ways similar to the professional training funded by the Texas Higher Education Coordinating Board's Autism Grant Program.
- 2). Offer increased training and awareness of waiver programs and available services for providers serving adults.
- 3). Conduct more school outreach to increase proactive transition planning. This can include pro-active counseling about which waivers families should consider at

the time of sign-up, and encouraging schools to identify transition specialists or counsellors to join the Community Partners Program.

4). Provide flexibility in how severity is determined to allow providers to take advantage of higher levels of support proactively rather than reactively. For example, allow an initial determination at a higher level of need and after a short amount of time, reevaluate. Keep clients from needing to fail to access intensive supports.

5). Train local authorities to approve clients coming off of diversion waivers to receive same level of need and support as client coming out of residential facility. For example, create an automatic level of need for any individual coming out of any inpatient setting.

6). Create a mechanism to move between and among waivers and other state services –families shouldn't have to turn down some to access others. As individuals age, their needs and issues change, and with the years-long waiting lists, it is hard to anticipate what is needed 10-15 years in advance.

7). Create programs for individuals of varied functional levels –students attending college or a postsecondary program also need supports.

8). In the long term, consider consolidating the waivers into a single process and funding pool rather than having separate silos and programs. Increase number of service providers across all programs by increasing reimbursement rates and decreasing barriers to collaboration and creativity

3. Increase number of service providers across all programs by increasing reimbursement rates and decreasing barriers to collaboration and creativity

Exponential impact: Prior to becoming a provider for the Children's Autism Program through HHSC, the ABA clinic at the Burkhart Center for Autism Education and Research in Lubbock served an average of 3 to 4 clients a month and had a full-time staff of one clinician and several graduate students. With funds received as a provider for the Children's Autism Program, the ABA clinic has exponentially increased the reach and impact of their ABA services for families across West Texas. The clinic now averages 15 to 16 clients a month in Focused ABA services alone (with an additional 20-30 a month in social skills classes and TWC supports) and employs three full time clinicians and four graduate students. Staff and students supported by Focused ABA funds have been able to help expand the clinical offerings of the Burkhart Center beyond just the Focused ABA activities to over 15 distinct clinical and family services including camps, social skills classes, community provider training, and TWC client services including ASD and ABA supports. State support through the Children's Autism Program has meant that significantly more families and individuals with autism have received services in West Texas than ever before, and has had an exponential impact on the sorts of services a previously small clinic could offer. Best of all, well over half of those individuals with autism now served are from rural, low income and minority families who otherwise would have no access to these services.

Responsive Regulations: When providers for the Children's Autism Program approached program staff with concerns about how eligibility and time in the program were calculated, program policies and procedures were modified to allow providers to better design programming to meet family needs and take advantage of the limited number of hours each family qualified for across their child's life. The change had an immediate impact on the quality and flexibility of programming while also maximizing impact for families.

Recommended Actions

Concrete ways HHSC can follow this recommendation based on lessons from the stories:

There continues to be a provider shortage among all autism services in the state of Texas^{7,9}. HHSC programs target already underserved populations, and offer access to services in ways other providers often don't or cannot. It is urgent that HHSC cultivate and grow its provider pool across all programs. There are some specific ways we recommend that be done, including:

- 1). Continue to foster provider networks and responsiveness within programs. Find ways to invite and sustain dialogue with providers³. For example, the regular provider call for the CAP, which is a positive and reinforcing opportunity for CAP providers to problem solve, celebrate, and improve their services through collaboration.

- 2). Give program directors the authority to modify programs to be responsive to provider needs and concerns, as described in the sidebar.
- 3). Aggressively seek providers through networking, attendance at professional conferences, and personal contacts with providers.
- 4). Make as transparent as possible the application and provider enrollment process so that as many potential providers as possible know how to apply. Also, streamline the application process to reduce the burden for application on providers who might be smaller, have less administrative support, or operate in settings with less institutional or logistical resources.
- 5). Provide application support from program staff for new applicants in programs like ECI, CAP, CPP, and Head Start.
- 6). Continue open enrollment rather than enrollment windows to make it as easy as possible for potential providers to apply any time they are able and ready to do so.

4. Increase family and professional awareness of all programs and reduce barriers to enrollment and participation for families and individuals

Training Matters: UNT provides a Positive Behavior Supports and Management Workshop to Medicaid waiver providers and their staff. This free workshop is available for Medicaid waiver providers and their staff who work with individuals with IDD and autism. This is a great resource for local providers and the workshop is offered at different locations across the state, so transportation and lodging shouldn't even be a concern. Staff are given tools they can implement same day with their team. The training is based on behavior analysis and other evidence-based strategies. The information is simple and broken down into steps which makes it easy to implement. The focus of the training is on building up positive interactions between staff and individuals they are supporting. UNT have been hosting these workshops for the past several years and the workshops continue to improve.

Changing Cultures: The Burkhart Center at Texas Tech University has become a provider for a number of state programs, including the Children's Autism Program, TWC ASD and ABA supports, TWC CRP services, THECB teacher and parent training, and TEA teacher training. By housing a variety of state services in one building, all clinical staff become familiar with a variety of options for our families, and we are much more responsive and flexible with families that come into our center because we can both offer a wider variety of services, but also refer to a much larger network of other supports based on the relationships we've built across the state as part of the provider networks created by many of the programs.

Changed Cultures Change Outcomes: The Burkhart Center was recently involved in the case of a 10-yr old boy with ASD, Traumatic Brain Injury, problematic sexual behavior, and a history of trauma who was living with an older, adoptive parent. The boy had responded negatively to several treatment attempts and had escalated into suicidal and homicidal ideations both at school and home. His behavior had escalated to the point that he was hospitalized in a pediatric ER with full physical and chemical restraint and a guard at the door. We helped convene a full treatment team of the school, Human Services, CPS, STARCare (our LIDDA), the family, the Burkhart Center, a local psychologists office, and the hospital team. It was determined that he qualified for and was in urgent need of at least temporary inpatient, residential treatment. No facility in the state of Texas would accept him due to the complexity of his case, however, and he was left in the ER setting for over four months. During that time, the team used its connections and experience to help the family apply for and receive both immediate crisis intervention and also one of the diversion waivers to avoid the need to send him out of state to a residential facility. With those increased resources and the support of the school, all involved state agencies, and the Burkhart Center, the boy is now living with his adoptive brother in the community and receiving intensive supports there. The relationships formed through familiarity with the gamut of state resources and program allowed the treatment team to avoid a residential placement that would have likely extended for years and left the boy institutionalized moving forward.

Recommended Actions

Concrete ways HHSC can follow this recommendation based on lessons from the

stories: As described above, it is vital that families and professionals be aware of

both the existence of and how to apply for the powerful and helpful services offered

by HHSC. To that end, we recommend a number of initiatives to improve awareness of and access to information about HHSC programs, including:

1). Continue to support TARRC¹¹ and statewide resource websites and resource lists^{10,11,12,13,14,15}. Dedicate staff time to ensuring HHSC programs are listed on and available to the parent and professional groups maintaining area and state-wide resource lists^{10,11,12,13,14,15}.

2). Create an expectation among HHSC service providers that every parent and family contact leads to a concrete change. For example, any time a family enters an HHSC office, they are given a list of resources, have signed up for a service, or have an appointment to continue the dialogue. Staff time should be allocated to allow follow-up calls or emails with visitors to minimize families falling through the cracks.

3). At the provider level, disseminate information about enrolling in the Community Partner Program, and consider making enrollment in that program mandatory (or at least strongly encouraged) for providers in in HHSC programs.

4). Increase dissemination of and increase awareness about active partnership opportunities among providers and with area Aging and Disability Resource Center Program staff, Community Resource Coordination Group staff, Local Intellectual and Developmental Disability Authorities, and 2-1-1 Texas teams so that providers and families know who they are and can take advantage of what they bring to the table. A particularly helpful example of programmed networking are the regular provider phone calls and meetings facilitated by the Children's Autism Program that allow providers from across the state to meet, problem solve, and work directly with program staff to address the needs of families and professionals.

5). Develop or facilitate specific ASD training to potential providers (say, like the UNT training in the sidebar) to increase professional willingness to engage with this population.

Conclusion

Successful service delivery models are powerful and present across the state. There are many good things going on and models to learn from. Nevertheless, the majority of children & individuals with autism in Texas do not receive adequate services. Especially urgent are the need to more effectively identify and serve young children at risk for autism and the need to prepare for and serve the surging number of young adults with autism graduating from the school system and entering adult services. HHSC services across the domains described above continue to evolve and respond to the increasing need, but there is much work left to be done. Without continued and increased investment from the state legislature, the majority of individuals in the state of Texas will still not receive access to adequate support or protection. It is critical that the legislature of the state of Texas increase both the funding for and the diversity of programs for people with autism across the state, and that efforts are made to increase awareness of and enrollment in programs currently provided. Particular focus should be made on growing from successful and evidence based programs and models already in existence. The current LAR provides additional funds to grow programs described in this report, and the council enthusiastically recommends its full support.

Acronyms

Acronym	Acronym Defined
ABA	Applied Behavior Analysis
ADRC	Aging and Disability Resource Center
ASD	Autism Spectrum Disorder
CAP	Children's Autism Program
CPP	Community Partner Program
CPS	Child Protective Services
CRP	Community Resource Provider
CRCG	Community Resource Coordination Group
ECI	Early Childhood Intervention
HCS	Home and Community-based Services
HHSC	Health and Human Services
LAR	Legislative Appropriations Request
LIDDA	Local Intellectual and Developmental Disabilities Authority
PPCD	Preschool Program For Children with Disabilities
SSLC	State Supported Living Center
TEA	Texas Education Agency
THECB	Texas Higher Education Coordinating Board
TWC	Texas Workforce Commission

Appendix A. References

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Appendix B. Stories of Success & Struggle

These stories are included exactly as submitted by families and professionals so that those reviewing this report can hear those voices directly if they so desire. The stories were solicited by members of the Texas Autism Council from among their personal and professional networks, and shared with the council as this report was being prepared.

Success #1

THHSC Services Involved:

Target population: Early Childhood Intervention (ECI)

I am the mother of a 5 year old boy with Autism that was diagnosed officially at the age of 18 months but started services as early as 14 months of age. We live in Cameron County in the city of Brownsville, Texas, and we are Hispanic. When we started noticing that something was not right with my son, I was laid-off from a job that I've had for 7 years due to his medical conditions and needs. We enrolled for help with THHSC while we figured out what was wrong with my son. I have been unemployed ever since as his condition and needs got bigger. We currently have no income besides child support and SSI as my husband just recently lost his job. It is hard to find a job that will allow you to leave to attend the child's needs like taking to and from school, therapy, and constant doctor visits and specialists.

We did Early Intervention Services when my son was about 14 months old and Wendy Galliki was our person. Excellent guidance on her part and that made a difference on getting the confidence to work on the things needed to be done quickly. We received Medicaid services, which paid for all of our appointments and made sure we got the right care wherever we needed to go...even if it meant going out of town. We also received financial services for food, WIC for food and DMV services. Additional special equipment was provided for my son's sensory needs.

Families and ECI working together has allowed: I have had good experiences but bad as well. It seems that they are not empathetic and quick to judge the income status at home and seem to have a hard time understanding why us parents cannot work or cannot hold a job long enough when caring for special needs children. It is uncomfortable to walk in those offices because you feel that you are constantly looked down to when we try really hard to make it with the little resources or help we get. Getting a call for an interview feels anxious because of

the way they talk to you like you are lying about this situation. Most of the time the help is not enough because it is very expensive to care for a special needs child, but we struggle to make it every month. There have been great agents that seem to understand the struggle (usually the people that have somebody with a disability in their family), I wish as a parent that people would at least talk nice to us being that we truly have it hard at home.

Meaningful outcomes: When you encounter the right team of agents, social workers, therapists, and doctors life gets easier! I have been able to find resources in my community, join support groups, have a great relationship with educators and nonprofits available in my area that help me find activities for mi kids.

Since I've had mostly success with the outcomes despite the bad experiences, here are my 3 things that make my story a success...

1. It was very important for me to find people that gave me the confidence that anything I do for my child is worth it. This helped me feel better about myself and prepare me for the road I was about to take on. Being a parent is hard, and being a special needs parents its 10x harder and nobody prepares you for that. The people that work for these agencies that went the extra mile for us made the difference.
2. Being able to find support groups where I could meet other parents going thru my same situation. Most of these people are more than willing to help out with advice or tips on how to do things because they either know or went thru it with their already older kids on the spectrum. Some of the agencies are very well informed on local support groups and are able to refer people to them.
3. The programs are constantly changing, covering more things as time goes by according to demand. As Autism is on the rise, so are the needs for services and these agencies are trying to keep up with the demand. Things that might not be covered today will probably be covered in the future.

How can it be better? Empathy makes a difference. We want to be treated with respect and not feel guilty for asking for services needed by our children. The income limits should be higher because caring for a special needs child is very expensive... child care, the use of natural supplements, gas to and from therapy, trips to doctors more often, those are things that are not always covered by insurance and not counted towards out daily or monthly spending.

Just my personal experience. How I get a headache every time I have an interview with the agencies because nobody likes to be treated like they are less than

everybody else that has an actual job. I happen to be unemployed because I am having a hard time finding a job that gives me the luxury of leaving every time my son is in distress and needs me, or when he needs to go to therapy, or when he is having a bad day at school. That is the way we are being treated in our area, the agents are often rude. Like I said before, not all of them are like that, but a little empathy class would be nice.

Please look into ABA (Applied Behavior Analysis) therapy... it needs to be covered by Medicaid... this therapy might be expensive TODAY but it will help the quality of life of these kids, and some could even get better to the point where they can be in the regular class environment, which lowers the usage of money spent by insurance in the long run. Do something about the little kids and you can potentially improve their quality of life so much that you don't have to pay for them when they get older. Please...

Success #2

THHSC Services Involved: Early Childhood Intervention (ECI)

Target population: Children under 3 years with developmental delays and/or diagnoses

Families and ECI working together has allowed:

Permian Basin Community Centers Early Childhood Intervention program and behavior supports offered through PBCC collaborated to provide families with children with autism or at-risk for autism applied behavior analysis therapy in low doses with the focus being on parent training and setting up the environment for success.

Meaningful outcomes:

Children without a diagnosis or who were waiting for a diagnosis could go ahead and receive services. Research supports that young children who receive aba services prior to a diagnosis of autism could decrease the need for supports as they get older and even fail to meet the criteria for a diagnosis.

The collaboration between programs, the directors of these programs and the director of PBCC pushing teams to work together by submitting referrals and encouraging collaboration, flexibility by the directors to implement the program according to what families needed

How can it be better? Increasing acceptance of a variety of service providers within early childhood intervention, increasing training efforts for ECI contractors, accessing current services available within ECI – for example, Pathways out of Fort Worth.

This was a result of people meeting each other, finding out what each party is doing and encouraging collaboration. This was a great experience to be a part of and I know it can be replicated in other areas. Pathways out of Fort Worth are doing a similar thing by providing training and supports to local ECI teams, this is another great opportunity for ECI contractors. I think as the state moves to accept and be open to outside providers, the more children will receive services at this very young, important age.

Success #3

THHSC Services Involved: HCS Waiver Services and PASSR

Target population: Mostly adults with IDD

Families and HSC Providers working together has allowed:

When an individual with autism enters HCS services, it is apparent there is a lack of training and awareness among providers regarding characteristics of autism and the best strategies to use when working with these individuals. As a behavior specialist employed by an HCS provider we have had individuals be admitted to services and their current behavioral status is high. The struggle comes when their level of need is not accurate and as a company we have individuals we have had to eat the cost and provide them with 1-on-1 supervision. Because of this, I have used a high number of behavior supports initially to provide support to staff and work to decrease the intensity of behaviors.

Meaningful outcomes:

With my high level of support and an assigned 1-1 we have had positive outcomes. In one situation we had an individual we were able to submit documentation and get the level of need increased and we have also had the situation where an individual's intensity and frequency of behavior decreased to where the level of need they were originally assigned with was accurate.

The support of the company I work for to allow me to focus on one or two individuals at a time like that and our case managers working to get behavior

support units on individual's plans quickly. The acceptance of our company realizing that an individual needs a higher level support even though we will not get reimbursed at that level for at least three months.

How can it be better? A way to fade levels of need for individuals entering HCS services where they're assigned a higher level of need upon admission with close supervision of a behavior analyst and behavior plans and documentation are reviewed every 3-6 months and basically the level of support from both staff and the behavior analyst should decrease over time and eventually fade out. This level of support would have to be justified by the behavior professionals.

This is the way I provide services at my company and it seems to work long term. There are some logistical issues involved, but more support up front can really set a person up for success. This would also decrease the use of emergency services and hospital stays and increase the quality of life of these individuals.

Success #4

THHSC Services Involved: HHS Positive Behavior Supports and Management Workshop

Target population: Medicaid waiver providers and their staff

Medicaid Providers working together has allowed: This free workshop is available for Medicaid waiver providers and their staff who work with individuals with IDD and autism. The state of Texas has allocated funding and created a contract with the team from UNT to provide this training. This is a great resource for local providers and the workshop is offered at different locations across the state, so transportation and lodging shouldn't even be a concern.

Meaningful outcomes: Staff are given tools they can implement same day with their team. The training is based on behavior analysis and other evidence-based strategies. The information is simple and broken down into steps which makes it easy to implement. The focus of the training is on building up positive interactions between staff and individuals they are supporting.

UNT Behavior Analysis team is a great contractor and their product has not only been proven as they are the main trainers of behavior support training at the Denton State Supported Living Center, they have been hosting these workshops for the past several years and the workshops continue to improve.

How can it be better? Better advertising to encourage more provider participation, maybe an incentive – also maybe a way to do a train-the-trainer program. This was a really awesome experience and would be appropriate for all levels of staff from direct care up to management. I plan to attend next year and hopefully take some staff with me.

Success #5

THHSC Services Involved: Early Childhood Intervention (ECI)

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Meaningful outcomes: Children without a diagnosis or who were waiting for a diagnosis could go ahead and receive services. Research supports that young children who receive aba services prior to a diagnosis of autism could decrease the need for supports as they get older and even fail to meet the criteria for a diagnosis.

The collaboration between programs, the directors of these programs and the director of PBCC pushing teams to work together by submitting referrals and encouraging collaboration, flexibility by the directors to implement the program according to what families needed

How can it be better? Increasing acceptance of a variety of service providers within early childhood intervention, increasing training efforts for ECI contractors, accessing current services available within ECI– for example, Pathways out of Fort Worth.

This was a result of people meeting each other, finding out what each party is doing and encouraging collaboration. This was a great experience to be a part of and I know it can be replicated in other areas. Pathways out of Fort Worth are doing a similar thing by providing training and supports to local ECI teams, this is another great opportunity for ECI contractors. I think as the state moves to accept and be

open to outside providers, the more children will receive services at this very young, important age.

Success #6

THHSC Services Involved: Early Intervention Services, Speech Therapy, Occupational Therapy

Target population: I'm a 46 year old mother of two. I live in Brownsville, Texas, Cameron County. I'm of Hispanic Background. My oldest son is 17 years old. My youngest is five (diagnosed with autism). We are a medium income level family.

My son is a 29 week old preemie. Since he was about 18 months old I knew something was not quite right. Because he was a preemie I had a very difficult time getting anyone to help me or even believe me. I would always be told that he was premature and I should give him time.

In great part I believe this is because of a combination of lack of information (from medical caregivers or specialists) and to misconceptions about what autism is. I had a very hard time getting a diagnosis.

I received a lot of support from Wendy during this time. She encouraged me to talk to my doctor and helped me a lot through the whole process. She always was always willing to listen to me and give my advice based on her experience. I cannot say I got the same kind of support from my Occupational Therapist. During this time they switched Jacky for a young, recently graduated therapist who definitely did not have the experience to give me the help I needed.

Families and ECI working together has allowed:

Success:

1. Having someone like Wendy as my therapist. Who is so professional and really dedicated to her job.
2. My kid is thankfully doing very well, but I think it had a lot to do with me not giving up and looking everywhere I could for help.
3. The commitment Wendy has to her kids. She is always looking for ways to help me be more informed, or share resources she finds and that makes a huge difference to me since there are not a lot of places to get help or information from.

Struggle:

1. Not having a competent ot therapist at a time that was crucial for my son to get as much help as possible.
2. Wendy being so overwhelmed with work. I think she has too many kids and her schedule is not planned in the most efficient way. Having to be driving across town to get to appointments does not help.
3. I think the whole process to even get ECI to be involved in my case was hard. It took a long time.

How can it be better? I think ECI definitely needs more resources in order to have more therapists and more experienced ones. There are so many kids and not enough therapists.

They also need more resources to get materials to teach parents how to help their kids. And maybe even more training to keep therapists current on the latest things that are being successful in treating kids.

Success #7

THHSC Services Involved: ECI through Easter Seals Central Texas

Target population: Family in Austin; daughter with ASD is now 6

Families and ECI working together has allowed: The parents of A.F. were lucky enough to connect with a developmental pediatrician when she was very young. The doctor diagnosed her with ASD at 18 months and the family started with ECI when she was 27 months old.

Here's what A's mom says about their ECI experience:

Our ECI experience was fine in some ways and excellent in others (through Easter Seals). I don't have any complaints about her ECI therapist, but her first speech therapist, Sarah, and case manager, Laura, were phenomenal. All therapy was done at her preschool, no in-home sessions.

Sarah was speedy and thorough with communication, I received a report almost instantly after her sessions. Sarah left for maternity leave and the second therapist was not as on top of it. Most of the time, I had to initiate communication with her and the ECI therapist. They responded, but I think Sarah and Laura may have raised the bar and expectations.

Laura, the case manager, provided great guidance for us which was so important when just starting this autism journey.

Both therapies "kick started" Alex's behavior and speech in the right direction. Honestly, I think it was more beneficial for us to learn what to do than it was for her.

Overall, our experience was fine. It was short, less than a year before she aged out and went to PPCD, which is where she really accelerated.

Weekend schedule options would have been great so we could be present during therapy sessions, learn and continue the exercises daily. ([my husband] wasn't a stay-at-home dad then.) Through all of the therapy experiences, I think being able to participate (essentially turning therapy sessions into caregiver workshops) has been more beneficial for our family than the sessions themselves.

Meaningful Outcomes: A.F. had a smooth transition into PPCD and, later, into kindergarten. She goes to her neighborhood school and is included with regular peers.

How can it be better? This family had the good fortune to get a diagnosis early and the parents took action right away. They turned to multiple sources for reliable information and advice and then followed it. They also took full advantage of their own flexible schedules at the beginning, later deciding that it made sense for A's dad to stay home full-time. A's parents continue to network with other parents and also to expose A to a wide range of social and athletic activities. This is an example of a family where things fell into place early and where the parents were willing and able to take a very active role. It's a great picture of family/agency collaboration.

Success #8

Identified Services Not THHSC Involved: At the University of Houston, one resource available to students with disabilities is the Center for Students with Disabilities (CSD).

Target population: The direct consumers are college students (young adults) with ASD at a public university in Texas. Because they are college students their parents are also indirect consumers.

Students and University of Houston Center for Students with Disabilities working together has allowed: While the CSD serves a broad range of needs, it does not offer the specific levels of support that meets the needs of many students with ASD. That prompted Byron Ross, a faculty member in the Communication Sciences and Disorders Department to develop a Peer-Mentoring Program in which undergraduate students from the National Student Speech-Language Hearing Association serve as the mentors. Students enrolled at the University of Houston who have a diagnosis of ASD serve as the mentees.

The program's overall purpose is to provide levels of support to students with ASD in the areas of organization, social support, and personal responsibility. Mentors

work with the mentees to establish semester goals that the mentees would like to accomplish as a part of the program. Mentors are required to meet with mentees a minimum of 3 hours per week to work towards the goals.

Meaningful outcomes: There are different outcomes for different students based on their goals. Some outcomes are academic success, some inclusion, some is increased personal responsibility; increased organizational skills, some professional preparation. I think having a peer as a mentor is largely responsible for the success of this situation. When the information about organization, study tips, etc. come from a same-aged peer, it appears to be more meaningful for the peer. Especially when the mentee has a limited social networking circle.

How can it be better? Although the mentors are happy to volunteer their time and resources, I think it would be more effective if there was a stipend for the mentors. The mentors often work jobs in order to help pay their tuition, so a stipend would be helpful to them as they donate their time to the program. They often take their mentees to social events, fundraising events, etc.; and we always do an end of the semester outing. It would be helpful if I could pay the mentors and mentees admission with some type of funding. Also, my vision is to collaborate with other professionals to do guest presentations, programming, etc, and I would like to also be able to provide a stipend for those professionals.

Mentees personal reports to their mentors indicate that the experience is beneficial for them. They often express their gratitude to their mentors for their help and their time. Parents of the mentees also express their thanks and report that it makes a difference in their child's life. One parent reported that she cannot be on campus with her son, so it is comforting knowing that this support system is on place for him. The first student mentee graduated from the university in December 2017. I was able to attend graduation and he credited the peer mentoring program in being a part of his success.

Struggle #1

THHSC Services Involved: IDD Crisis Services

Target population: Children and adults with IDD, including autism, who are experiencing a crisis

Identified Crisis: Crisis services are presented in a way that indicates their immediate availability and most local authorities have a crisis team. While this service is much needed by families in Texas, the reality is that accessing services can be quite difficult for some families. Areas for growth include having experienced crisis team members or contracting with experienced personnel; Crisis teams being available during a crisis and not having the family or provider have to wait for services, which then is no longer a crisis; Crisis teams receiving proper training or at least structuring the program to provide hands-on support to families or providers experiencing a crisis.

Meaningful outcomes:

Potentially, when families, providers and the crisis team with the local authority work together, families may be able to keep their loved one at home a little bit longer. Families would be given access to resources to prevent future crisis from occurring. Providers would have an alternative to calling the cops or placing an individual in the hospital and this cycle could greatly decrease.

As funding was made available for this service, the logistics of the service were left up to each local authority. Availability of qualified professionals also affects the quality for local authorities in some areas.

How can it be better?

The reporting of how many individuals have requested help versus how many individuals have received help and information on what that help looks like would be a vital statistic to represent this program.

Hospitals, schools, providers and other entities should be made aware of crisis services and encouraged to call them first, especially for someone with autism and/or IDD, instead of local law enforcement or turning these individuals away.

This is a much needed service in our state and the need will continue to rise, especially as it relates to individuals with autism. The service has already done so much and further refinement would make it that much more successful.

Struggle #2

THHSC Services Involved: HCS Waiver Services and PASSR

Target population: Mostly adults with IDD

Identified Struggle: I am the mother of a 17 year old son on the autism spectrum living in Cameron County. We are white Americans, English speaking, with an income over \$50,000 per year. Struggle looks like having to search for services. I often meet families who have no idea about different services that may be available. Unfortunately for many of these families who work, the services that their child desperately needs are unavailable due to them having an income. It makes no sense to only offer services to people with disabilities who come from low income families. Even for working families with medical insurance, often the insurance companies deny services and the end result is that therapies and services that could help make the difference between dependence and independence are not available or affordable to those who need them most.

The story of our son is a success, but unfortunately not due to help from THHSC. We did have early intervention help for our son when we lived in Washington State, but in Texas, there was nothing available to him because everything was based off of our income. I only consider his story a success because he has definitely exceeded our expectations and the expectations given to us by his doctors throughout the years.

In our 11 years living in the state, my son only qualified for services for one year through the MDCP program. During that year, we took advantage of the therapies he qualified for- speech, physical and occupational and also were able to get him back into new leg braces. After a year, even though our son's diagnosis was the same, the state decided he no longer met their criteria for MDCP and he was removed from the program. During the year when he was in the MDCP program, his number came up for a program with less services that we declined due to the MDCP offering him more supports. Had it been better explained to us that he would have a good chance of losing his services, we would have opted for the lesser program. Instead, because we didn't take the lesser program in order to stay in the MDCP program, he lost his chance to ever be offered that program again.

Even though our son was originally considered to be on the moderate to severe end of the autism spectrum, he has made great improvements. It is unfortunate that he couldn't qualify for programs through THHSC because I know he would have had the opportunity to advance more. We have done the best that we could do as a family given the resources that we had, but it has definitely been a struggle. In one year, our son will be an adult and will eventually receive services when his number comes up after years of waiting. In my opinion it would make much for sense for services to have been offered to him during his younger years so he would have

had more of an opportunity to be more self-sufficient as an adult, but that was not the case here in Texas.

Meaningful outcomes:

My son is in his senior year of high school and still spends a big part of his day in a self-contained classroom with a one on one aid needed for the entire day. He will start working with Texas Workforce Commission to hopefully help him find a job that he may be qualified to do in the future. His options are very limited though and we as a family know that we will need to provide care for him for his entire life.

Despite the lack of services offered to my son, I will always consider him a success based on his own merits. We were told he may never walk, but yet he runs track events at Special Olympics. We were told he may never speak, yet he is able to make his wants and needs known.

Our son is constantly learning and capable of doing new things. I only wish there were more services and supports that were available to him during his younger years to have given him the opportunity to have more choices as an adult.

How can it be better?

Services need to be more available to those in need. Money invested in these individuals when they are younger would in the long run save the state money because many of them could progress to become self-sufficient adults. Having waiting lists of 10 plus years only serves to keep these individuals dependent for aid for the rest of their lives instead of giving them the help they need early on.

Struggle #3

THHSC Services Involved: UNKNOWN

Target population: College Students with ASD

Identified Struggle: Jacob S. was delayed in meeting all of his developmental milestones. When the parents asked the pediatrician why he was not walking or talking by age 2, they were told it was because his older brother did everything for him, and he didn't have to do for himself. Parents continued to be concerned that Jacob could not talk and what he tried to say, could not be understood, at all. He was in daycare from the time he was 6 weeks old and no one ever spoke to the parents that Jacob should be screened for ECI services, not even the pediatrician.

Nor was he identified early on for other services available, mostly due to parent income disqualifying him for many services.

Jacob finally was identified for speech services in the 2nd grade and qualified through the 8th grade. His other delays were never addressed. He never learned how to ride a bicycle, because he could not balance without the training wheels. He continued to have difficulty in social situations, maintaining friendships, and after parents continuous requests, was finally diagnosed with Autism at the age of 15. By this time, he struggled with peer relationships, he was socially withdrawn, and was diagnosed additionally with a generalized anxiety disorder.

Jacob finished high school with honors, receiving little to no services but qualified with Texas Workforce Commission (TWC) for college assistance, he received several scholarships and he began attending university in the fall of that year. He chose a nursing major and has struggled along the way but has always pulled through. This year, Jacob is a senior in the BSN (Bachelor of Science in Nursing) program. He continues to struggle with making friends, stress, and anxiety. He does not have the support of the university, as they see anxiety in a nursing program as a weakness. So, he suffers silently, without support. He has 1 ½ semesters left before graduation and worries he can't make it through this semester due to the expectations of the program. Jacob also asked about having an emotional support animal and was told it would be frowned upon and placed in his file.

His parents fear he will not be able to complete college and graduate. TWC has assisted in funding the majority of Jacob's degree but there are no resources to offer additional support by way of therapy or other services.

How can it be better? The percentage of adults with Autism who are able to successfully complete university is minimal. More emphasis needs to be placed on supporting those adults, offering services to help them graduate. Vocational rehabilitation should also search out other supports for those youth; if the support would not only be available but encouraged, maybe more adults with Autism would successfully graduate and join in the workforce.