

Every session has its wins and its losses, and 2019 was no different. While we suffered some crushing moments, it only takes a small step back to recognize that we helped to move the needle a little—or a lot—on all of our issues.

The Coalition of Texans with Disabilities at the 2019 Legislature

CONTENTS

- 2: Introduction: Texas' Progress in 2019
- 4: State Budget & Attendant Wages
- 6: I/DD Pilot & Dental Services
- 7: Transportation
- 8: Medical Cannabis
- 9: Public Education
- 10: School Mental Health
- 10: Other Bills
- 11: Voting
- 12: Looking ahead to 2021

Coalition of Texans with Disabilities 1716 San Antonio St., Austin, TX 78701 PH: (512) 478-3366 F: (512) 478-3370 www.TXDisabilities.org info@txdisabilities.org







@TXDisabilities

CTD is a 501(c)3 nonprofit organization with Federal Tax ID #74-2071160.
CTD is a social and economic impact organization benefitting Texans with all disabilities of all ages. CTD is a membership organization controlled by people with disabilities.

All photographs by CTD unless otherwise noted.

The production of this report is made possible with support from





PROGRESS IN 2019

Like all the legislative sessions CTD and our partners have ever worked, 2019 was no slam dunk, walk in the park, or any other uplifting analogy.

We are calling this a "progress report" session: we absolutely did not get all we sought, but did make some progress in most areas, such as:

- a dental services pilot for adults with disabilities
- a small raise in the attendant wage and a reworded budget rider
- movement in the special education environment, and
- an expanded list of diagnoses that will qualify a person for access to medical cannabis under a doctor's supervision.

We influenced the movement of \$409 million in the State Budget.

We scored game changers on post-secondary education for people with disabilities and guardianship compliance.

We had major involvement in killing a priority bill that would have added hurdles for voters with disabilities.

On a breakthrough public health rider, CTD advocated for a program of promoting safe gun storage against powerful opposition. In these violent times, that has increased relevance.



Our 2019 advocacy team, from left, Laura Perna, Chase Bearden, Chris Masey, Tiffany Williams*, and Dennis Borel.

In the following pages, we give a Progress Report on our issues from 2019, including some broader context of how far we've really come, how much backsliding we've prevented, and how far we have yet to go in our work toward a barrier-free Texas.

Seldom is a legislative victory a solo effort. CTD salutes and thanks our many partners before and during the session, especially The Arc of Texas and ADAPT of Texas.

By the numbers...

+120 bills and budget items

\$409M influenced in State budget

293 advocates led on...

120 Capitol office visits

68 advocacy partners

5+3 live advocacy trainings + training videos

AARP Texas

Access Empowerment/ Parking Mobility

ADAPT of Texas

Alliance for Patient Access

American Council of the Blind of Texas

Association of Texas Professional Educators (ATPE)

Autism Society of Texas

Brazos Valley Center for Independent

Living

Center for Public Policy Priorities

Coastal Bend Center for Independent Living

Collin County Democrats with Disabilities

Cover Texas Now

Disability Rights Texas

Disability SA

Down Syndrome Association of Central Texas (DS ACT)

Texas (D3 ACT)

Easterseals Serving Central Texas

Epilepsy Foundation Central & South Texas

Family Eldercare

Family to Family (F2F)

Guardianship Reform and Supported Decision Making Workgroup (GRSDM)

Helping Restore Ability

Houston Center for Independent Living

Imagine Arts

Meals on Wheels Central Texas

National Alliance on Mental Illness (NAMI) Texas National Association of Social Workers Texas Chapter

National Infusion Center Association

Panhandle Center for Independent Living

Paralyzed Veterans of America- Texas Chapter

Personal Attendant Coalition of Texas (PACT)

Pride PHC Services

Private Providers Assn of TX

Protect Texas Fragile Kids

Providers Alliance for Community Services of Texas (PACSTX)

REACH Resource Centers on Independent Living

REV UP Texas

Rise Center for Independent Living

San Antonio Clubhouse

San Antonio Independent Living Services (SAILS)

State Independent Living Council

SymbioWellness

Texans Care for Children

Texans for Responsible Marijuana Reform

Texas Advocates

Texas Appleseed

Texas Assn of Home Care and Hospice

Texas Association for Behavior Analysis (TX ABA)

Texas Association for Interior Design (TAID)

Texas Association of Goodwills

Texas Association of Health Plans

Texas Associations of Community Health Plans

Texas Center for Disability Studies (UT)

Texas Civil Rights Project

Texas Council of Administrators of Special Education (TCASE)

Texas Democrats with Disabilities

Texas Dental Association

Texas Dental Hygienists Association

Texas Down Syndrome Advocacy Coalition (TXDS ADV)

Texas Forward

Texas Gun Sense

Texas Health Institute

Texas Hospital Association

Texas Impact

Texas MAMMAs

Texas Medical Association

Texas Nurses Association

Texas Oral Health Coalition

Texas Parent to Parent

Texas Physical Therapy Association

Texas Silver-Haired Legislature

The Arc of Texas

The Arc of the Greater Mid-Cities

VSA Texas

plus numerous businesses, lobby firms, legislators, aides, and state agency professionals.

STATE BUDGET

Author and education administrator James W. Frick put it best: "Don't tell me where your priorities are. Show me where you spend your money, and I'll tell you what they are." In keeping with a long history of underfunding services for Texans with disabilities, our State Budget doesn't make it a point to support our community. Yet, in a Legislature that often operates in crisis management, gains were made on HB/ SB 1. We helped secure:

- \$87 million for a raise in the base wage of community attendants
- a budget rider on attendant recruitment and retention
- \$66 million to address the community waiver interest lists
- \$46 million for Comprehensive Rehab Services (800 persons per year)
- \$1 million to fund the Safe Gun Storage rider
- \$5 million to fund guardianship compliance monitoring (SB 31), and
- \$204 million increase for special education

Attendant Wages

Attendant wages has been one of CTD's top priority issues for years. Recruitment and retention of this crucial workforce is at high risk due to an extremely low base wage, no benefits, increasing demand, and alternative employers paying much higher wages.

Every year, we highlight the urgency of this worsening situation to decision makers, yet the Legislature has moved at a glacially slow pace to respond. The rises in costs of living and wages in other jobs far outpace the stagnating base wage for attendants each session. Many legislators understand the argument and know it is real. But no matter how hard and effectively advocates work, too many decisions are based on the crisis of the day and, far too often, people with disabilities are left at the end of the line.



ADAPT of Texas and PACT took over the Texas Capitol rotunda in February, demanding an increase in attendant wages from the current floor wage of \$8 per hour. Laying on the floor, unable to get in their wheelchairs, they showed the importance of community attendants.

In 2019, the Texas Health and Human Services Commission (HHSC) requested funds for a 50¢ per hour raise for the lowest paid attendants. We urged the Legislature to go beyond this minimal increase to create adequate pay and ensure reliable attendant care. We recommended an increase in the base wage of \$8.00 to \$13.00 per hour over the 2020-2021 biennium.



A Pizza Hut ad offers \$20 per hour plus benefits for delivery drivers. A modest raise to support attendants is not asking for the moon. The Texas Advocates (above) were one of many groups to make this point at their March rally day, which CTD supported.

In 2019, legislators appropriated \$87 million to raise the wages of the lowest paid community attendants serving Texans enrolled in Medicaid. It's a big number, but it only shakes out to an **11¢ per hour** raise.

Local media elevated attention on attendant wages this session, and our Susie Angel took every opportunity to weigh in:

- Texas Tribune, March 26: Everyone wants a piece of the Texas budget. It's hard to succeed when most of the money is accounted for
- Texas Tribune, Under the Dome, April 1: Meet the advocates lobbying Texas lawmakers for more money and support this session
- Austin-American Statesman, April 8: Legislature balks on significant pay bump for home health aides



Susie Angel (right) and Dennis Borel meet with Nelda Hunter, chief of staff for state Rep. John Zerwas. Photo by the Texas Tribune.

Encouragingly, we influenced a **budget rider on attendant recruitment and retention**, requiring HHSC to address more direct strategies: a focus on the lowest-paying community programs, convening a cross-agency forum, and directing managed care organizations to prioritize a solution.

We got language removed that would merely identify the problem and replaced it with a direction to develop a plan. While the rider contained no money, it may ultimately prove more beneficial in the long-term as we advocate for a truly sustainable workforce with adequate compensation.



We took a new approach to attendant wage advocacy this spring, teaming up with Family Eldercare and the St. David's Foundation to present a public screening of the documentary film, CARE, followed by a panel discussion on April 12. From left, CTD's Dennis Borel, St. David's Foundation Executive Vice President of Community Investments William Buster, care attendant Margaret Schwartz, Family Eldercare Director of Housing and Community Services Joyce Hefner, Senior Adults Specialty Healthcare Clinical Nurse Specialist Cherie Simpson, and Family Eldercare CEO Kent Herring.

Elsewhere in the State Budget...

... we worked to protect funding for postacute care for traumatic brain and spinal cord injuries in the **Comprehensive Rehab Services** program.

... we fought for funding to **reduce the Medicaid waiver wait list**, which went from \$0 in 2017 to \$66 million in 2019. While this will help some, the wait list is now projected to increase to over 16 years.

... we supported funding for the **Statewide Safe Gun Storage Campaign**, which passed as a rider to Article 5. We agree with Governor Abbott's view that proper gun storage is a public health issue. CTD's Dennis Borel approached this as a personal matter, testifying in hearings and working behind the scenes.

I/DD PILOT AND DENTAL SERVICES

Services for individuals with intellectual and developmental disabilities (I/DD) made significant progress with HB 4533 (Klick), which establishes a pilot for long term supports and services in Medicaid managed care and key defining clauses.

Of note, individuals participating in the pilot will be eligible for services based on **functional need**, rather than age of onset of their disability. CTD played a critical role in including this game changing language in HB 4533. We have long promoted a philosophy of service delivery based on need rather than diagnosis, and this pilot is an important step in putting that approach into practice at the state level.

The bill further promotes **consumer directed services** as well.

That's not all HB 4533 accomplished; it also became a vehicle for **Medicaid managed** care reforms. Consumers will benefit from new ways of appealing decisions, including independent reviews.

Texas Advocates has been delighted to work with the Coalition of Texans with Disabilities on getting a dental benefit for all in Medicaid. We have seen first-hand the need for regular access to dental care with many of the adults with intellectual disabilities whom we serve. This need was echoed in the many stories from self-advocates shared with us on how poor dental health impacted their jobs, relationships, and comfort. These voices will continue the fight for a regular dental benefit in Medicaid for people with disabilities. This past session was just the beginning.

Brooke Hohfeld, Texas Advocates Grant Coordinator and self-advocate



On March 12, CTD's Dennis Borel and Susie Angel served as witnesses at a House committee hearing.

Another major win within HB 4533 is the first ever inclusion of language in statute on **preventive dental services for adults with disabilities** who are not in waiver programs.

CTD became involved in advocating for dental services in 2015. With the passage of a study bill in 2017, we felt that we were in position to pass a services bill in 2019. Before the legislature had even convened, we had gathered considerable support for a bill that would build on our earlier progress. We were optimistic about SB 556 (Kolkhorst) and House companion HB 1467 (Deshotel), which would establish a dental benefit for adults with disabilities in Medicaid, not only improving their oral and overall health outcomes, but also making better use of public funds.

The Legislative Budget Board (LBB)'s fiscal note halted our momentum. The House Human Services committee recognized that the LBB's note was full of unanswered questions and inaccuracies, but it was enough to slow-roll the bill.

We did not give up and set about looking for a living bill to amend, this time with a pilot for

TRANSPORTATION

adult dental benefits. HB 4533 became that vehicle, and Sen. Kolkhorst skillfully passed an amendment on the Senate floor.

It bears mentioning that a number of factors came together to make possible the passage of HB 4533 as amended. These include Rep. Stephanie Klick's existing knowledge and receptiveness to advocates regarding everything that was added to her bill; the many years of work by individuals and organizations to support these services and reforms through legislative means; and the strong, trusting relationships between legislative leaders like Klick and Kolkhorst.



CTD led groups of dental hygienist students on office visits to educate legislators about the lack of dental coverage for this population in early February. We did another round with the Texas Advocates in March.

CTD deeply appreciates the key support of the DentaQuest Partnership for Oral Health Advancement in our advocacy work to expand access to dental care in Texas.



HB 3163 (Springer) requires better markings for accessible parking spaces, includes potential penalties for accessible parking violations, and includes an important education piece.

High speed rail has attracted some controversy, but not from CTD. A fully accessible high speed rail system would be a game changer for Texans with disabilities traveling between major cities. We have worked to secure a seat at the table to encourage this paradigm shift in public transportation. In 2019, all 13 bills opposing the development of a high speed rail line were derailed, and the project is now in the accessible design phase.

Thank you for providing your engagement in this legislation [HB 1576]... Once CTD knew about [the problematic clause] and explained it to the author, the change went smoothly.

> Judy Telge, Coastal Bend Center for Independent Living & CTD Board of Directors

What does annoy us is scooters. We supported SB 549 (West), which would have regulated shared motor-assisted scooters, making it illegal to leave them as barriers. The bill had some support, but not enough to get it to the Governor's desk. This isn't the last time we'll be working on the scooter issue.

We helped score an additional win by adding accessible vehicle language to HB 1576 (Phelan), which will allow Medicaid to cover the cost of a rideshare to doctor's appointments and other healthcare visits.

MEDICAL CANNABIS

Nowhere is the relative speed of progress more apparent than in the case of medical cannabis.

HB 3703 (Klick) will expand Texas' Compassionate Use Program (TCUP), extending the qualifying conditions that will allow a person safe, legal access to medical cannabis, from only intractable epilepsy to: other kinds of epilepsy and seizure disorders, autism, MS, spasticity, terminal cancer, and incurable neurodegenerative diseases (like ALS and Parkinson's).

The success of this bill is a testament to its legislative leaders, as well as the work of a broad, passionate coalition, who has dislodged entrenched positions about cannabis in order to improve healthcare outcomes for their families and their fellow Texans. The **Tx MAMMAs** and numerous **veterans** stood at the forefront of this effort, and they were joined by a multitude of disability, public health, parent, and other organizations and individual advocates.

Finally, public opinion in favor of medical cannabis has been growing in Texas, and a CTD media campaign helped to demonstrate this support (right).

There remain many populations who would benefit enormously from safe, legal access to medical cannabis that were left behind by HB 3703: individuals with PTSD, depression and other mental health diagnoses, complex pain management needs, autoimmune disorders, cancer with any prognosis, and others. We know that Texans will continue to suffer because of lack of access, and CTD's work on the issue of medical cannabis is not over.

That said, in three sessions, Texas leadership has gone from a hard NO on medical cannabis to policy decisions guided by science, common



Chase Bearden awaits the fate of HB 3703 on the House Floor with Thalia Michelle and Amy Fawell of the Tx MAMMAs and self-advocate Shawn Meredith.

sense, and compassion. HB 3703 is a remarkable step forward—and we now know where we stand to take the next step for a stronger Compassionate Use Program, based on research and with the health and well-being of all Texans in mind.



PUBLIC EDUCATION

No discussion of recent Texas Special Education policy would be complete without mention of the 8.5% cap. In the fall of 2016, the Houston Chronicle released their report Denied: How Texas Keeps Tens of Thousands out of Special Education, detailing the Texas Education Agency (TEA)'s de facto 8.5% cap on special education enrollment in public schools. Although long-standing Federal laws quarantee each person's right to an appropriate education, the report estimated that 250.000 children had been excluded from necessary services and supports, due to an arbitrary performance indicator that effectively created the cap.

After threat of a lawsuit from CTD and Disability Rights Texas, TEA did commit to removing the cap early in 2017. The Legislature that year went a step further, passing SB 160 (Senator José Rodríguez) and effectively banning TEA from ever implementing a similar cap again. CTD and Disability Rights Texas took lead advocacy positions in pushing this bill, and we led and supported efforts to pass a number of other special education reforms.

After such intense activity in 2017, we were hopeful that special education—and school finance—would finally be positioned for meaningful reform in 2019. Indeed, public education did get a lot of attention, but despite the efforts of many passionate advocates, education professionals, parents, and legislators, results for special education were mixed.

In 2019, CTD worked on or supported numerous bills that would have provided school districts with guidance and resources to address the current systemic failures in both the identification of special education students and delivery of special education services. Two passed: HB 165 (Bernal) will allow students who are enrolled in special education to earn an endorsement on their transcript if they successfully complete the curriculum for the endorsement, with or without modification. SB 139 (Rodríguez) amends current law providing for notice of educational rights for student evaluations to parents.

The massive energy that went into reforming school finance in 2017 led to no result. So special education advocates were hopeful when Governor Abbott declared **School Finance Reform** an emergency item for 2019. While we did not see the transformational change we were hoping for, there were still some notable wins in HB 3 (Huberty), the school finance bill:

- all students will benefit from an increased basic allotment, including special ed students.
- a new weight allotment was established for **students with dyslexia**, which will amount to approximately \$600 per student to be used for additional supports.
- the **overall increase in special education funds** is roughly \$204 million.
- an advisory committee established by the bill will study the cost of special education services in Texas and make recommendations. This study will give special education advocates a much more solid place to start from in 2021.

Stereotypes surrounding students with disabilities have limited access to post-secondary opportunities. As lead advocate, CTD's Chris Masey scored a game changer with SB 1017 (Powell), to create a state advisory council on postsecondary education for people with disabilities. With high drama, SB 1017 passed just minutes before a midnight deadline.

SCHOOL MENTAL HEALTH

It is crucial that schools are fostering a safe climate for all students and are equipped to recognize mental health issues and trauma. Research has shown that students with intellectual and developmental disabilities (I/DD) are at a higher risk for trauma, abuse, and bullying. Too often, schools take punitive measures to address issues like classroom behavior, rather than a nurturing and preventative approach.

In 2019, CTD promoted safe school discipline practices and increasing mental health supports in schools. We worked closely with the offices of Chairman Price and Chairman Taylor, who spearheaded the safe school policies, to ensure that they were taking the needs of students with disabilities into consideration. We worked with their staffs to ensure the language in HB 18 (Price, et al) and SB 11 (Taylor, et al) increased access to mental health supports in schools and in the community, as well as ensured training would be provided to school personnel to promote safe school practices.

SB 11 is a comprehensive approach to school safety, including provisions targeted to teachers, students, school resource officers, and parents.

SB 11 will:

- help protect students with suspected or known disabilities
- increase children's access to psychiatric level of care
- ensure that students and personnel with disabilities have equal access to safety in schools' multi-hazard emergency operations plan, and
- require the Texas Education Agency (TEA) to create a statewide plan for student mental health.

HB 18 increases mental health supports in schools and creates safe learning environments for all students by improving staff development training and trauma informed instructional practices.

HB 19 (Price, et al) will place a liaison from a local mental health authority (LMHA) at every educational service center (ESC) in Texas to connect schools with local mental health resources when students are being referred to services.

CTD Development Disabilities Fellow Tiffany Williams* spoke up for vulnerable student populations with a proponent of over-the-top school surveillance. Texas Observer, March 25: *The Wolf is in the Henhouse*

OTHER BILLS

With advocacy leadership from CTD and AARP Texas, compliance with **guardianship** rules took a major step forward with SB 31 (Zaffirini). Vetoed in 2017, the bill became known as the Abuse,

Fraud, and Exploitation Deterrence Bill and established a monitoring team at the Office of Court Administration. Better yet, the bill carried a \$5 million appropriation. Have you ever seen internet or TV ads practically screaming about bad drugs and lawsuits? Amazingly, Houston TV stations ran more of these than ads for pizza! CTD believes in First

VOTING

Every session in recent memory has seen bills promoted as voter fraud measures that, in practice, would **challenge the rights of voters with disabilities**. SB 9 (Hughes) was this year's example. It proposed new requirements for providing assistance to voters with disabilities, including potential criminal penalties for honest mistakes.

CTD joined a coalition of disability, voting, and civil rights organizations in expressing major concerns about the constitutional legality of SB 9, as well as the chilling effect it could have had on the number of people willing to assist Texas voters with disabilities.

From the letter we sent to the Senate:



We the undersigned members and supporters of **REV UP Texas** collectively and strongly urge you to oppose SB 9. SB 9, by creating new requirements

for individuals providing assistance to voters with disabilities with potential criminal penalties, would have a chilling effect on the number of people willing to assist Texas voters with disabilities and increase barriers for voters with disabilities.

Thanks to the push back from this coalition, SB 9 lost the momentum and support it would have needed to pass the House. SB 9 was a priority bill for state leaders, and stopping the bill is a major achievement.

Looking back, we notice that we've frequently been successful in our fights against bad bills like SB 9. Passing good ones, however, has proven to be more difficult. HB 3354 (Bucy), which we worked on with the American Council of the Blind of Texas, is the latest example. This bill would have allowed voters who are blind or visually impaired to download an accessible ballot for absentee voting. Because the ballot would be downloadable and accessible, the voter wouldn't need third party assistance, thus protecting the privacy of their ballot. Though the bill was based in ideals of fairness and accessibility, it didn't get far. ACBT and CTD are committed to regrouping and making another attempt in 2021.

I don't let my disability get in the way of anything, even voting. We want to be heard like everyone else.

Kathryn Doty, self-advocate with United Advocates

SB 9 would bring increased scrutiny if you're a voter with a disability and that's wrong.

Dennis Borel, in testimony opposing SB 9

Amendment rights and does not object to informational ads. But surveys showed a large percentage of viewers were so scared they stopped taking their medications. CTD served as lead consumer advocate on SB 1189 (Buckingham), which will require clear statements that patients taking prescribed medications should not stop before checking with a doctor.

Non-medical switching is a set of tactics health insurers use to switch stable consumers off their already-prescribed medications for non-medical reasons. It can take months or even years

OTHER BILLS

for a person with a chronic condition and their doctor to find an effective medication; insurance companies should not stand in the way of their stable health. The Coalition for Stable Patients, for which CTD sits on the steering committee, organized amazing support around SB 580 (Campbell) / HB 2099 (Lambert), which would have prohibited non-medical switching practices. Despite almost unanimous passage in the House, SB 580/ HB 2099 was killed by last minute opposition in the Senate.

We joined lead organization Texans Care for Children in urging the Legislature to add HHSC's \$71 million Exceptional Item to the state budget to strengthen and sustain Early Childhood Intervention. This investment would have ensured that young Texans got the early intervention supports they need to get on a strong developmental track and be ready for school. Texans Care has reported that, "the Legislature only funded \$31 million of that request, but it was the biggest increase in years."

HB 29 (Minjarez) allows easier access to physical therapy for people with permanent disabilities. CTD has been working with lead advocates, the Texas Physical Therapy Association, on this measure for years. Finally, with the passage of HB 29, individuals with

private pay insurance can go directly to a physical therapist, without a doctor's referral.

HB 770 (S. Davis) creates an electronic database for settlement agreements involving incapacitated persons, allowing superior preservation and access to the documents.

SB 26 (Kolkhorst) enables SJR 24 (Kolkhorst), which directs sporting goods taxes to **Texas Parks**. This restored funding stream can now be used to improve accessibility, which many parks lack.

SB 747 (Kolkhorst) establishes the **newborn screening program** for earlier diagnosis and intervention of detectable disabilities. Families can save money when they have more time to prepare for a baby with a disability.

Hats off to our colleagues at the Arc of Texas for SB 753 (Huffman), which prohibits subminimum wages in sheltered workshops contracting with the State.



The Arc of Texas team, from left, Kyle Piccola, Alex Cogan, Ali Gentry, and Ginger Mayeaux

Looking ahead, some priorities are already clear for 2021: making concerted another effort blocking non-medical switching, expanding access to medical cannabis. working with American Council of the Blind of Texas on their accessible absentee ballot, and strengthening accessible parking enforcement. We don't need to tell you that we'll also continue the fight for a meaningful increase in community attendant wages, defend the rights of voters with disabilities, and pursue stronger consumer protections in managed care.



To close this year's report, we give our deepest thanks and well wishes to Chris Masev and Tiffany Williams* (above), who are moving on from CTD. From his days as a Fellow to Advocacy Director, brought indefatigable Chris energy and will to policy regarding the education and transition to independence for Texans with I/ DD. In her two short years as Developmental Disabilities Policy Fellow, Tiffany made an enormous impact on student mental health policy, through her trainings with self-advocates and advocacv work.

