# CTD Coalition of Texans with Disabilities



# 2021 Annual & Legislative Report

Disability Advocacy Awareness Arts & Consumer Direction in year two of the COVID-19 pandemic.

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cover photo text

Right: the Texas Capitol with COVID testing tents at the North entrance

All photographs by CTD unless otherwise noted.

The uncertainty, unease, and conflict that marked 2020 continued steadily in 2021. A case in point: the 87th Legislature grew from a 5-month session into lasting almost the entire year. In response, we are combining our Annual and Legislative reports for 2021.

Reflecting on this year's accomplishments, our team is grateful for our leadership, membership, and culture of responsiveness that has allowed us to make great strides toward our mission—even as our times become ever more unsettling and contentious.

Uncertainty about Capitol protocols due to the pandemic and the wild card of the winter storm set the stage, to say nothing of the issues facing our lawmakers and advocacy communities. An unprecedented three special sessions into the fall continued the trend of pitched and prolonged battles in this legislative year. In such an environment, our team had reservations about what positive changes we'd be in a position to support for Texans with disabilities. However, we responded to quickly shifting circumstances and surprising developments and are pleased to report that our wins were significant.

While this marathon legislative session took up enormous resources for CTD (indeed, for many advocacy organizations), it was not the only site of our accomplishments. Our staff also made strides in advocacy work outside of the Capitol, community engagement, arts programming, and promotion of consumer direction.



#### STATE BUDGET

At the beginning of the year, it appeared that COVID-19 and the economic downturn would put a big squeeze on available funding. Then the state produced less restrictive budget figures, and the promise of federal rescue funds gave us reason for optimism. Of course, we don't take any funding for granted, especially in a session with limited access to the Capitol, legislative offices, and committee hearings. The following accomplishments in the state budget (SB 1 / HB 1) are the result of the confluence of circumstances and opportunities in this unusual year and steadfast advocacy from the CTD budget team, Executive Director Dennis Borel and Advocacy Director Jolene Sanders-Foster.

# **Community Attendant Wages**

Community attendant wages were ignored by legislators with no increase over the base hourly wage of \$8.11 for most community care programs. Over the last four legislative sessions, the total base wage raise has been 25¢, compounding a crisis in recruiting and retaining community attendants.

However, in the third special session, legislators appropriated federal funds from the American Rescue Plan Act (ARPA). Initially, there was zero ARPA money for community attendants, but determined advocacy by CTD and allies resulted in \$178M for "retention bonuses" and some of that will benefit direct care workers in assisted living centers and ICFs.

In a separate ARPA bucket of money set aside for home and community based services, approximately \$400M is allocated to attendants for bonuses. CTD advocated for the inclusion of attendants in the CDS option and to replace one-time bonuses with a series of smaller bonuses, to avoid an unintended loss of public benefits for attendants, over

50% of whom receive public benefits as persons of low income.

As of the printing of this report, it remains unclear how all this will be implemented, but we can say

- there will be no increase in the hourly wage rate,
- extra money will get in the pockets of attendants, mostly through a series of bonuses, and
- the total amount for compensation and payroll taxes from both buckets is likely between \$400M and \$500M.

This means the bonus funds are roughly equal to an 89¢ raise for one year.

That needs to be the beginning of a larger effort to create a sustainable community care system, which is where older adults and people with disabilities want to live.

We'll advocate for a meaningful, permanent raise for this critical workforce in 2023.

# Medicaid community waivers interest lists

Interest lists received \$76.9M for approximately 1,500 new slots, less than 1% of the current number of unduplicated persons on the interest lists. For a person adding their name today, the wait could be easily 30 years or more.

## Early Childhood Intervention (ECI)

This critical program for kids with disabilities from birth to three years, received an additional \$33.9M.

# Intensive Behavioral Intervention (IBI, also known as ABA)

The state landed on the right side of Early Childhood Intervention funding and backed our colleagues in the autism community to finally get ABA/IBI services covered by Medicaid. ABA/IBI Services in the autism program moved into federal compliance with an appropriation of \$111.9M.

# Safe Gun Storage

The Safe Gun Storage program in the Department of Public Safety was continued with \$500,000 in funding.

# 2021 By the Numbers

**\$945,885,821** moved in state budget

**4,864** emails and tweets sent by CTD members to 114 legislators and staffers

**1,120** Participants in advocacy education

103 Bills worked on

42 Advocacy partners

33 Media Hits

27 Partner sign-on letters

23 Workgroups/ advisory boards

## **VOTING**

In 2021, disability and self-advocates across the country have been railing against laws and proposals that would restrict voting for Americans with disabilities. As we learned on a Raise Your Voice call this summer from our partners at Secure Democracy, Texas has become ground zero in the fight to protect hard-won voting rights.

In 2021, this fight began with HB 6 (Cain) / SB 7 (Hughes). This so-called election integrity bill would have created significant barriers to voters with disabilities (as well as other low-income voters and voters of color). From requiring proof of disability for mail-in ballots, to giving untrained poll watchers permission to video record anyone they believed was violating the law, to limits on curbside voting, the passage of this bill would have set the civil rights of voters with disabilities back decades.

From our team, Executive Director Dennis Borel and Deputy Executive Director Chase Bearden took every opportunity to work with HB 6/ SB 7's authors and supporters to mitigate its effects on people with disabilities, as well as coordinated with our partners and the voting rights community to push back against voter suppression efforts in general. Still, CTD and many of our partners, notably, Disability Rights Texas and Secure Democracy, opposed HB 6, SB 7, and all versions of omnibus elections bills filed in both the House and the Senate.

Our mitigation efforts paid off with the final voting bill that passed during the second special session. The following provisions do **not** appear in SB 1:

- requirement to prove one's disability. Early versions of SB 7 would have required voters applying to vote by mail due to a disability to attest to the nature of their disability, potentially revealing confidential medical information. Voters applying for mail-in ballots for all elections in a calendar year would have been required to attach documentation of their disability from their doctor or a government agency to the application. This provision was removed in later iterations of the bill after strong push back from the disability community.
- A requirement that an individual assisting a voter with a disability show ID.
- Allowing untrained volunteer poll watchers to record video in polling locations. A provision in SB 7 would subjected voters receiving have assistance to beina recorded. even while at the voting station completing their ballot. Initially, the bill contained no safeguards on the distribution of images captured at a polling place. Later versions of SB 7 added such safeguards, and the final passage of SB 1 removed the provisions authorizing video recording altogether.

In addition to preventing these provisions from passing into law, we had other wins, with help from many of our partners and our members making their voices heard:

- HB 1382 (Bucy) passed in the regular session to create a secure online system to allow voters to track the status of their mail-in ballot applications and mail-in ballots.
- In a surprising twist, Rep. Bucy House floor amendment ensuring protections for disability accommodations be added to SB 1. The Senate allowed that amendment to stand and did not remove it when the bill went to the conference committee. The "Bucy Amendment" protects the ability of voters with disabilities to request and obtain reasonable accommodations and modifications to voting procedures to which they are entitled under state and federal law. We believe this amendment will also help give us the grounds to allow people access to using their signature stamp and requesting an accessible mail-in ballot a reasonable as accommodation.
- A Mail-in Ballot Cure provision is included in SB 1, the omnibus elections bill that passed in the second special session. It creates a procedure for election officials to notify voters of errors on their mail ballots and to provide them with an opportunity to cure the error so that their ballot counts. The cure language even allows voters to use the online tracking system referenced above to cure certain errors remotely.
- Sen. 7affirini included vital а amendment to SB 1 referencing CTD's testimony on the lack of Voting Machine Accessibility Training Videos and the use of accessibility features found on the voting machines. Sen. Zaffırini's amendment requires the Secretary of State to conduct a study regarding the implementation of educational programs, including the production and publication on the Secretary of State's website of instructional videos, to help voters with disabilities understand how to use voting systems used in Texas.

One voting issue we're returning to in 2023: CTD and our partners at the American Council of the Blind of Texas have long argued that voters with visual and certain motor impairments should have access to electronic mail-in ballots. Technology has made it possible for voters who use screen readers or assistive devices to cast a private, independent mail-in ballot. But, by largely ignoring HB 3874 (Bucy), the state refuses to make it legal.

#### **ACCESS TO CARE**

#### **Dental**

For the past several sessions, CTD's Dennis Borel has led legislation to add a preventative dental benefit for adults with disabilities. In 2017, we got a study; in 2019, a pilot to look at comprehensive dental care; and this year, preventative dental reached the finish line.

From February to May, language for a preventative benefit passed through quite a few different bills, finally landing in two Medicaid omnibus bills, HB 2658 (Frank) and SB 1648 (Perry) (right, Dennis with Ken Smith in front of the Senate chamber, where SB 1648 finally passed). The important take away is that, this fall, the state will prepare for the provision for a preventative visit to the dentist each year for adults in STAR+PLUS non-HCBS.

In addition, legislators funded a comprehensive dental pilot program, which they passed in 2019.

HB 2056 (Klick) has made tele-dentistry available on a permanent basis. This will extend the reach of preventative dental services to Texans with disabilities (and many others) who may have delayed dental visits because of difficulty leaving the home, barriers reaching or at dentists' offices, or no available dentist nearby. Virtual access will also give dentists an idea of what accommodations they'll need to make to treat their patients in person.

# **Caregiver Visitation**

SB 25 / SJR 19 (Kolkhorst) and HB 2211 (Metcalf) address visitation in care facilities and hospitals by essential caregivers. This hit home: several CTD members were unable to visit family members with disabilities during the pandemic. Often, family members are an informal part of the care team. These bills responsibly permit positive visits while ensuring precautions.

Dennis Borel and CTD's Susie Angel with major partners on the dental bill, Texas Health Institute's Dr. Ken Smith and Texas Advocates' Brooke Hohfeld after a hearing

#### Medicaid

As in sessions past, CTD supported the Cover Texas Now and Sick of It Texas coalitions to address Texas' dismal record of health insurance for its citizens. In 2021, efforts to increase healthcare coverage among Texans got unprecedented momentum, but, even with bipartisan support, a bill failed to pass.

While we wait for another chance to push for coverage for more Texans, these successful bills will allow better access now:

- HB 290 (Cortez), amended onto HB 2685 (Thierry), will prevent children from losing Medicaid health care coverage by reducing the number of midyear eligibility reviews from four to one. It will also give families 30 days, instead of ten days to gather and provide any requested documentation.
- HB 133 (Rose) will allow pregnant women to keep their Medicaid coverage for six months, instead of two months, postpartum.

Dennis Borel with Dr. Ken Smith in front of the Senate chamber, where SB 1648 finally passed

#### Tele-health

During the pandemic, tele-health solutions helped Texas Medicaid enrollees access services and was popular among the families who used it. HB 4 (Price) outlines rules and changes for HHSC to make those solutions permanent. CTD was instrumental in adding certain therapies to telemedicine.



#### **ACCESS TO MEDICATION**

#### **Medical Cannabis**

For Deputy Executive Director Chase Bearden, the care access issue that has come to the fore in recent sessions is medical cannabis. The development of a robust Texas Compassionate Use Program (TCUP) has been incremental, and 2021's HB 1535 (Klick) builds upon previous years' progress. This bill adds PTSD and non-terminal cancer to the list of qualifying diagnoses for participation in TCUP and doubles the legal amount of THC in medical cannabis products.

Chase and our team will continue working in this area. For now, we are encouraged that Governor Abbott signed HB 1535 into law—while just a few short years ago, he was a hard NO on any medical cannabis legislation.



#### **Pharmaceutical Policy**

As a member of the Coalition for Stable Patients, CTD worked hard to pass HB 1646 (Lambert), which would have helped Texas patients by reforming the insurance practice of "non-medical switching." This occurs when health plans or pharmacy benefit managers (PBMs) compel a stable patient to switch from their currently prescribed and covered treatments to an alternative medication preferred by the insurerfor non-medical reasons and without input from the treating physician. Unfortunately, this legislation ran out of time to cross the finish line.

During the regular session, CTD and partner organizations urged the Texas Legislature to step up and protect consumers from Copay Accumulators, a new insurance practice that raises individuals' out-of-pocket healthcare costs. HB 2668 (Price) / SB 523 (Buckingham) would have ensured that health insurers apply ANY copayments toward а consumer's deductible. copayment, cost-sharing responsibility, or out-of-pocket maximum requirements under that consumer's health plan. However, this bill did not pass.

Chase Bearden with long-time partner and cannabis advocate, Shawn Meredith, following a press conference in support of HB 1535

#### Hepatitis C

CTD Hepatitis leadership on C treatment goes back to 2014, when we presented information on a thennew Hep C cure drug to the Sunset Advisory Commission and pushed hard for inclusion of the medicines in the Medicaid formulary. Since then, CTD continued strong advocacy to improve access, including making these cures available to patients before reaching an advanced disease state. This year, CTD was also the only consumer advocacy organization to testify in support of legislation and an appropriation that resulted in SCR 31 (Kolkhorst). SCR 31, signed by the governor, made permanent the access changes in disease states and appropriated a minimum of \$51.1 million

## **CIVIL RIGHTS**

## Guardianship

A bill filed with the best of intentions would have stripped protections in place, such as due process, routine investigations, considerations of alternatives to guardianship, and even standard reporting. CTD was very involved in this difficult and oppositional advocacy, and the bill did not pass.

#### Health Equity

4139 (Coleman) would HB have reinstated Texas' Office of Health Equity to investigate the significant barriers to health and health access disparities that many populations in Texas that face, including Texans with disabilities. The bill received false attacks as promoting transgender health access. even though it had nothing to do with transgender issues. However, groups that have historically faced health and health access disparities, like Texans with disabilities, older adults, and rural folks, among many others, stand to gain from a body whose purpose is to examine and address those trends. HB 4139 narrowly passed the House, but did not make it out of the Senate.

Fortunately, the Department of State Health Services (DSHS) will be using federal funds from the Coronavirus Aid, Relief, and Economic Security Act (CARES Act) to set up the Office of Health Equity, Policies, and Performance. These are one-time funds, so securing continued appropriations in future sessions will be a priority.

# **Organ Transplants**

HB 119 (Landgraf) will protect organ transplant recipients from discrimination on the basis of their disability.

#### CHILDREN WITH DISABILITIES & THEIR FAMILIES

New to the team this session, but already a heavy-hitter in children's advocacy, Advocacy Director Jolene Sanders-Foster led CTD's work on a range of bills to support toddlers and young children with disabilities, special education students, and their families and educators.

#### **Special Education**

When the pandemic hit and schools were forced to shutter their doors, many students with disabilities lost services or saw those services put on hold as districts pivoted to virtual learning. For some students, access to technology and learning on a virtual platform were significant barriers. Early on in the pandemic, state agencies acknowledged the anticipated need for compensatory services for many students.

We are grateful to report that the Legislature responded to this need by passing the COVID Special Education Recovery Act, SB 89 (Menéndez).

SB 89 will require a school district to prepare a supplement to include in a student's IEP regarding whether special services were affected by the pandemic. The supplement documents whether the provision of special services to the child during the 2019-2020 or 2020-2021 school year was interrupted, reduced, delayed, suspended, or discontinued, as well as whether compensatory services are needed.

HB 159 (M. González) will amend current law relating to improving training and staff development for primary and secondary educators to enable them to serve all students more effectively.

It provides the training educators need to teach all students by updating the requirements of educator preparation programs to integrate instruction on topics relating to special education. This bill also enhances requirements for educator certification.

HB 1252 (Moody) extends the statute of limitations on a special education due process hearing from one year to two years, which aligns with federal language and the vast majority of other states. The new limit will go into effect September of 2022, allowing parents of students with disabilities and their advocates a practical amount of time to prepare for due process actions.



Dennis Borel and Chase Bearden plan office visits at the Capitol with self-advocates Aiden Armstrong and Edgar Pacheco, Jr.

#### School Discipline & Safety

A Behavior Intervention or Improvement (BIP) is a component Plan special education some students' individualized education plans (IEP). The BIP guides educators and staff in identifying, preventing, and responding to behaviors that impact a student's functional and academic achievement. Currently, BIPs are often only reviewed every three years, which advocates have long argued is not often enough to best serve the students they were created for.

HB 785 (Allen) requires that BIPs in schools are reviewed at least annually, as needed, or revised if found not to be effective. A student's BIP must be reviewed prior to disciplinary action that recommends more restrictive placements, such as Disciplinary Alternative Education Programs. Juvenile Justice Alternative Education Programs, or expulsion. The bill also establishes requirements for schools after each incidence of restraint used on a student.

Special education advocates had been working to pass the BIP bill for the last two sessions, making this a hard-fought win.

Other bills regarding the safety of students with disabilities in public school settings did not pass this session and may have a similarly long journey:

- revised penal code 9.62 to limit the justification of use of force on students by educators. This bill would have clarified that use of force cannot deprive a student of a basic human need and that it may not include aversive techniques that are prohibited. It also would have defined that use of force is justified only to maintain safety in an emergency situation, and that it is not a form of discipline.
- HB 2297 (Allen), which would have prohibited the use of undocumented, school-initiated early pickups of students, or informal removals/ shortened school days.
- HB 2975 (Hull), known as No Kids in Cuffs, which would have eliminated the use of certain restraints on students under 10 years of age. This would have prohibited the physical restraint or use of chemical irritants on public school students by peace officers and school security personnel.

#### **Inclusive Child Care**

HB 168 (M. González), which did not pass, would have promoted inclusive child care by:

- revising child care licensing minimum standards for child care providers to clarify responsibilities under the ADA preventing discrimination based on disability,
- revising preservice and annual training requirements for providers to include working with children with disabilities and supporting early childhood mental health, and
- ensuring Early Childhood Intervention providers are able to serve babies and toddlers while in child care.

Jen Toon with Maggie Luna and Devon
Driver of the Texas Criminal Justice Coalition
working on their support of HB 30

# **CRIMINAL JUSTICE**

Thanks to the hands-on, in-the-Capitol leadership of our Peer Policy Fellow, Jennifer "Jen" Toon, as well as the effective mentorship of Advocacy Director Jolene Sanders-Foster, CTD made major strides into the area of criminal justice this session. This is critical work because it is well documented that people with disabilities are over represented in the criminal justice system, as well as more likely to be victimized while in the system and receive less access to supportive services. CTD's work this session revolved around ensuring that kids and adults with mental health concerns and/ or IDD have the support they needed in both county and state facilities.

## **County Jails**

SB 49 (Zaffirini) ensures that officials, including sheriffs and personal bond officers, who are responsible for the incarcerated persons in their custody, or for their supervision if they are out on bail, have access to information regarding a mental health condition or intellectual or developmental disability defendants might have. This would ensure that such persons are treated appropriately given their condition and provided with an adequate amount of supervision.

HB 2831 (White) established a permanent advisory committee tasked with monitoring and gathering data

regarding the detention of persons with intellectual or developmental disabilities and providing recommendations and guidelines on the detention of such persons. This bill also includes more training for jailers.

HB 3447 (White), which did not pass, sought to address concerns to help prevent the medical neglect of county jail inmates by:

- requiring the designation of a family liaison officer for each county jail,
- requiring the Texas Commission on Jail Standards to adopt a standard medical authorization form,
- providing for a more streamlined process for the release of an inmate's medical information, including their mental health treatment and status, to family members, and
- providing for complaint inspections and related reporting.

# **Death Penalty**

HB 140 (Rose) would have addressed the use of the death penalty for people with severe and persistent mental illnesses, such as schizophrenia, schizoaffective disorder, or bipolar disorder, by providing protections on the determination that the individual had a severe mental illness with active psychotic symptoms at the time of the offense. This bill did not pass.

#### Youth Justice

HB 2107 (Wu) will ensure that children who need competency restoration as a result of an intellectual disability will receive appropriate services or treatment, including outpatient services as necessary, in order to participate in juvenile court proceedings.

HB 30 (Talarico) mandates that minors in the adult system receive a full education, including requirements to comply with the Individuals with Disabilities Education Act (IDEA), and directs the Texas Department of Criminal Justice to develop an individualized education plan or program for all eligible youth with a disability.

HB 686 (Moody), the Second Look bill, would have required parole panels to consider certain factors relating to growth and maturity when making release decisions for inmates who were younger than 18 years of age when they committed the offense for which they were tried as adults and would have changed parole eligibility for inmates serving a sentence for first degree felonies committed when younger than 18. Despite wide support and passage in both houses, the Governor vetoed this bill.

#### Thank you to our advocacy partners

AARP Texas | Access Empowerment / Parking Mobility | ADAPT of Texas | Alliance for Patient Access | American Council of the Blind of Texas | Art Spark Texas | CDS in Texas | Coalition for Stable Patients | Coastal Bend Center for Independent Living | Cover Texas Now | Disability Policy Consortium (DPC) | Disability Rights Texas | Easterseals Serving Central Texas | ECI Coalition | Education Justice Workgroup | End of Life stakeholders | Epilepsy Foundation Central & South Texas | Every Texan | Guardianship Reform & Supported Decision Making Workgroup (GRSDM) Intercultural Development Research Association (IDRA) | Minaret Foundation | National Alliance on Mental Illness NAMI Texas | National ARP/IEP Advocates | National Association of Social Workers Texas Chapter (NASW TX) | Paralyzed Veterans of America-Texas Chapter | Private Providers Association of Texas | Providers Alliance for Community Services of Texas (PACSTX) | REACH Resource Centers for Independent Living | REV UP Texas | SAFE Austin | Secure Democracy | Sick of It TX | State Independent Living Council | Statewide Leadership Council (SLC) | State Rare Disease Education Initiative (STRiDE) Rare Disease Educational Forum | Texans Care for Children | Texans for Responsible Marijuana Policy (TRMP) | Texas Advocates | Texas After Violence Project | Texas Appleseed | Texas Association of Health Plans | Texas Autism Society | Texas Center for Disability Studies (UT) | Texas Center for Justice and Equity | Texas Civil Rights Project | Texas Coalition for Healthy Minds | Texas Council of Administrators of Special Education (TCASE) | Texas Criminal Justice Coalition | Texas Health Institute | Texas Healthcare & Bioscience Institute | Texas Impact | Texas Legislative Education Equity Coalition (TLEEC) | Texas LULAC | Texas Medical Association | Texas Parent to Parent | Texas Rare Alliance | The Arc of Texas | VELA Families | Women's Justice Coalition

#### **PARKING**

CTD has worked with the Paralyzed Veterans of America - Texas Chapter over the last few sessions to address the shortage of accessible parking places for people with disabilities due to the overuse of eligible Disabled Veteran (DV) license plate users by people without a mobility disability. SB 792 (Campbell) will ensure better availability of accessible parking spaces across the state for both civilians and veterans with a mobility disability and a valid accessible parking placard or plate. This bill received overwhelming support by the Legislature and was signed into law by Governor Abbott.

# **MENTAL HEALTH & IDD**

SB 2074 (Menéndez) would have allowed stakeholder input and the study of best practices across all settings for individuals with IDD experiencing mental illness by creating an advisory council composed of members across a variety of settings. This advisory council would have examined access to care and made recommendations to the legislature. The purpose of establishing this advisory council was to ensure that comprehensive, integrated MH/ IDD services are available and being provided in institutional, public, and private sectors in a person-centered way. This bill did not pass, but CTD will be back on this issue.

#### ADVOCACY OUTSIDE THE LEGISLATURE

Our advocacy work extends far beyond the Capitol and law-making process, through our work with (and sometimes against) state agencies, legal actions, and raising the profile of an issue with the general public.

#### **Board of Social Workers**

Last fall, the Texas State Board of Social Work Examiners (TSBSWE), the board charged with oversight of the social work profession, proposed removing from the Code of Conduct the prohibition against discrimination based on disability, sexual orientation, gender identity and gender expression.

Facing huge pushback from advocates for the civil rights of the disability and LGBTQ+ communities and social workers themselves, the proposed change was reversed within weeks. But in June this year, the Texas Attorney General issued a nonbinding opinion on the matter that the TSBSWE indeed may issue a Code of Conduct removing the prohibition of such discrimination.

According to the National Association of Social Workers-Texas Chapter (NASW TX), forfeiting the protections would prevent TSBSWE from taking disciplinary action against a social work professional for discriminating against a person with a disability. Instead, a person with a disability would need to utilize the court system to seek redress before the TSBSWE could act, resulting in a year(s) long process during which the social worker would remain in practice. Removing these protections could result in a devastating chilling

effect on people in crisis seeking the help of a social work professional.

CTD organized with NASW TX to successfully prevent this change in the Code of Conduct and ensure protection from discrimination for LGBTQ+ Texans and Texans with disabilities.

# I STAND WITH TEXAS SOCIAL WORKERS



I oppose removing any anti-discrimination protections from the Texas Social Work Code of Conduct.

## **#StandWithTXSocialWorkers**

Social graphic by NASW TX

#### **Critical Care Guidelines**

It is a difficult subject, literally deciding who may receive life-saving care when it is not possible to serve all. Mass Critical Care Guidelines (MCCG) are criteria for medical decision-making during crisis circumstances, like the COVID-19 public health emergency, though MCCG could apply in other crises.

In our negotiations with the Texas Texas Medical Association. the Hospital Association, the Texas Nurses Association. and Disability Rights Texas, CTD's position was to prohibit discrimination based on disability and/ or perceived value of life. We accept that having a disability is not a free pass to accessing scarce treatment. Rather, these excruciating decisions should be based only on individualized clinical assessment of each patient. The final includes these protections, MCCG though we hope they are never activated.



#### Press coverage

Raising the profile of an issue through public awareness and media coverage is another non-legislative tactic that can bring policy results. Through interviews, quotes, opinion pieces, and more, media outlets covered CTD's work and our staff 33 times in 2021.

Among this coverage, we are particularly proud of our sustained call to protect the rights of voters with disabilities as legislators battled through elections reform.

In May, the Texas Tribune ran our op-ed that explained in detail how There Is No Election Integrity without Accessibility. Notably, the provisions that we criticized in that piece are tempered or absent from SB 1, the version of the voting bill that passed in the second special session.

The following month, the New York Times profiled a handful of Texans with disabilities, including our Susie Angel and board president Kenneth Semien, on their own needs at the polls and how proposed legislation would inhibit them. Read G.O.P. Bills Rattle Disabled Voters: "We Don't Have a Voice Anymore."

Chase Bearden interviewed by LeAnn Wallace of Spectrum News

#### Lawsuits

When public pressure and direct advocacy fail to address unjust or harmful policy, legal action is our next recourse.

In 2021, CTD joined one lawsuit led by Disability Rights Texas against the Texas Education Agency (TEA). Our complaint is that TEA has refused to come into compliance for 14 years with federal laws concerning special education students older than 18. To summarize, TEA fails to provide a no-cost alternative to support these students in complaints about their education, creating an extra barrier to a free and appropriate education (FAPE), guaranteed by the Individuals with Disabilities Education Act (IDEA).

The suit against TEA remains pending, as do the five other suits we've been involved in prior to this year.

Filed in 2010, the Pre-Admission Screening and Resident Review or PASRR suit covers people with IDD in nursing homes to improve access to relocation to the community and/or receive treatment for IDD in the facility. Following a drawn out court battle that concluded in 2018, this suit is still awaiting the judge's decision.

In 2020, CTD joined four lawsuits to protect the rights of voters with disabilities. Two, we won (regarding signage for curbside voting and drivethrough voting). The others remain in progress.

- We joined with the American Council for the Blind of Texas in a suit against the state regarding the inaccessibility of paper mail-in ballots to voters with visual disabilities. The suit remains pending in court.
- It remains legal for the state of Texas
  to reject a mail-in ballot based on
  mismatched signatures, without
  giving voters the chance to cure their
  ballot. We joined a Texas Civil Rights
  Project (TCRP) lawsuit to address
  this, which disproportionately affects
  voters with certain mobility or visual
  disabilities. CTD won a preliminary
  injunction in time for the election, but
  the State appealed, and the injunction
  was overturned on appeal.

#### **SXSW Award**

With such turmoil at the start of 2021, we were thrilled and deeply moved that SXSW honored us with a Community Service Award for our work to bring down barriers for people with disabilities in Austin (including at SXSW!) and across the state.

## IN THE COMMUNITY

Engaging our communities is critical to our advocacy work and our mission creating a barrier-free society. We seek to educate and activate Texans with disabilities, their families, and support networks through our own grassroots organizing and all kinds of collaborations with our partners.

#### Raise Your Voice!

CTD's interactive Raise Your Voice! (RYV) events are designed to provide a functional understanding of our state's legislative process while connecting emerging and seasoned advocates. We prepare and support a geographically diverse group of people with disabilities and their supporters to educate legislators about the real good and harm their decisions can mean to Texans with disabilities.

In 2021, we connected and activated hundreds of emerging and seasoned advocates across the state, while providing detailed updates of issues affecting Texans with disabilities in a tumultuous legislative session.

Guests of note included Emily Wolinsky, whose testimonial about her experience in the winter storm as a person with a disability reached national audiences, and Nick Kalla, chief of staff for State Representative Garnet Coleman, speaking about Coleman's efforts to revive the sorely needed Office on Health Equity.

We held 20 Raise Your Voice! calls this year, sparking hours of meaningful conversation and generating thousands of messages to legislators.

#### Presentations, Panels, Trainings

Outside of Raise Your Voice!, our staff gives presentations, sits on panels, and holds trainings on a range of policy and practical topics (like navigating special education systems or the state's Compassionate Use Program). In 2021, our staff delivered content in 38 presentations, panels, or trainings to over 1,100 Texans. Some highlights:

In March, Dennis Borel sat on a panel organized by the North Central Texas Council of Governments, Too Old / Disabled for Healthcare. This well-attended conservation covered some of the ethical and legal considerations of rationing healthcare.

Later in March, long-time CTD partner Cirkiel Law Group invited Jolene Sanders-Foster to speak about proposed special education legislation in the 87th Texas Legislature. On this Facebook Live presentation, she reached over 200 Texas lawyers.

Jennifer Toon took every opportunity this year to speak about her own lived experience with mental illness, criminal justice, and her work with CTD. Jen's contribution to a panel at NAMI Texas' Capitol Day in April received high praise from organizers and attendees alike.

# What People Are Saying about CTD

"Having CTD as a part of the [Stand with Texas Social Workers] press conference was a huge asset to our message, and you all lead by example in ways that inspire our work."

Will Francis, NASW TX Executive Director

"Thank you so much for all you do for the community. Personally, I loved participating in your RYV trainings throughout the legislative session – I learned so much."

2021 RYV participant

"It was the best webinar/training that covered ethics in healthcare w regard to the elderly and or disabled that I have ever attended. I mean wow! Thanks for setting this up; it was invaluable to my professional and personal education."

Too Old / Disabled for Healthcare attendee

"[Jen Toon's] experience illustrates the need for significant reform in the criminal justice system, especially as it applies to supporting individuals living with mental health conditions. Further, Jennifer told her story in a way that elicited positive feedback from numerous audience members. Simply, she is among the most effective advocates at the Capitol and in the community."

Matthew Lovitt, NAMI Texas Peer Policy Fellow

#### **ARTS**

#### Cinema Touching Disability

We count this year's Cinema Touching Disability Film Festival and Lost Reel Short Film Showcase among the bright spots of 2021. Our Fest season began in August, with the launch of our Lost Reel Short Film Showcase, a 30-day online celebration of disability short films from all over the world. To build our Lost Reel program, we select finalists from our short film competition that weren't winners, but were outstanding nonetheless.

Both documentary and narrative shorts made up this year's showcase, including: a Finnish artist's statement about "disrupting purity" (Alternative Way of Being Human), a Deaf skateboarder's discovery of pride in his own identity (Sign at All Times: A Film about Brian Estrada), and a story of a young man with Down Syndrome claiming his independence (Upside). Filmmaker Q&As with 4 Lost Reel directors bookended this year's showcase.



Director of Alternative Way of Being Human, Jenni-Juulia Wallinheimo-Heimonen at a Lost Reel Filmmaker Q&A

The following month, we held our 18th annual Cinema Touching Disability Film Festival, October 15 & 16. This year's event was also completely virtual, streaming to viewers all over Texas and as far away as Singapore!

We opened each night with winners of our international short film competition, the best of 113 entries from 25 different counties. This year's features were:

THE REASON I JUMP, an immersive cinematic exploration of neurodiversity through the experiences of nonspeaking autistic people from around the world, based on the best-selling book by Naoki Higashida.

NOT GOING QUIETLY, a celebrated biopic of Ady Barkan, a rising star in progressive politics and a new father, whose life is upended when he is diagnosed with ALS—and again when a confrontation with a powerful Senator on an airplane goes viral, catapulting him to national fame as a healthcare crusader.

We featured panel discussions following each film with local artists with autism and mainstays in the Austin disability advocacy community.

Ady Barkan joined Cinema Touching Disability by video with closing comments to his film.

Still image from clip by Ady Barkan.

#### Lion & Pirate Open Mic

While our Pen 2 Paper creative writing contest remained on hiatus this year, we were pleased to keep our literary efforts going with the Lion & Pirate inclusive open mic series, co-hosted by Art Spark Texas and Malvern Books. The first weekend of each month, we gathered virtually to hear poems, songs, stories, and more from artists with and without disabilities in Austin, around the state, and across the country. Featured artists kicked off each event, including many of our regular performers and Pen 2 Paper 2020 winners, as well as guests from disabled and gueer music, comedy, and poetry scenes!

CTD and Art Spark Texas teamed up for one more event to close out 2021: the virtual launch of Crip Lyrics: The Unapologetic Poetry of Disability, the debut collection of Denton-based disability activist, speaker, organizer, writer, and poet, Val Vera. In addition to Q&As with Val and illustrator Melissa Marie Eckardt, attendees enjoyed guest performances by celebrated artist-activists Maria Palacios and Leroy Moore.



## **CDS UPDATE**

Our Consumer Directed Services (CDS) Division demonstrated superior commitment with uninterrupted service to over 700 consumers and attendants in 2021. It wasn't only pandemic conditions that strained our CDS services this year: our team has been putting in untold extra hours to prepare our CDS operations for federally mandated (but unfunded) rule changes.

Kudos to Chief Operating Officer Denise Ellison, CDS Director Kit Cuny and team members Laura Harrell, Glenn Erickson, Rosie Williams, and Jeska Savage. Several CDS agencies across the state have closed their doors because of the extreme burdens this mandate puts on them. We are hopeful that 2022 will see the resolution of our preparations and we are committed to continued service to our CDS consumers and their attendants.

## **IN MEMORIUM**

We mourn the passing of two pillars of the CTD family, whose lives were claimed by COVID-19 this year.



An active CTD Board member since 2001, Gene Whitten-Legé (1938-2021) was the longest-serving volunteer board member in our organization's history (left, accepting the 2002 Volunteer of the Year award at our annual Convention). With his wife Pat beside him, Gene's pioneering professional career as a recognized authority on attendant care throughout Texas was remarkable and influential. His vision of an option that empowered people with disabilities and older adults in Medicaid to take control of their attendant care made him a founding father of consumer-directed services (CDS) in Texas.



A long-time and beloved CTD member, Mikail Davenport (1951-2021) received national attention for his Legless Lizard Tour de Tejas in 2007 (left, by The Daily Texan). In this collaboration with CTD, Mikail hand-cycled from El Paso to Beaumont to bring awareness to disability issues facing the Legislature that year, including voting, ADA-compliance, and Medicaid interest lists. To the end, he remained engaged in CTD and disability advocacy work, as well as the Wildflower Unitarian Church as an ordained interfaith minister.

Finally, in May, our staff was grateful to be able to gather in person to celebrate the life of Jeff Kyser, our IT Specialist until his death at the beginning of the pandemic.



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#### **Board of Directors**

CTD's Board reflects the population of Texas in terms of types of disability, geographic representation, ethnicity, and income level.

#### **Executive Committee**

President: Kenneth Semien, Sr.\* Vice President: Crystal Lyons\* \*\*

Secretary: Judy Telge Treasurer: Jet Schuler

#### At Large Members

Region 1: Rick Razo

Region 2: John Curnutt\*

Region 3: Darren Bates\*

Region 4: Darrell Wilson\*

Region 5: Marshall Burns\*

Region 6: Francis Key\*

Region 7: vacant

Region 8: Sean Pevsner\*

#### **Staff**

Executive Director: Dennis Borel
Deputy Executive Director: Chase Bearden\*
Chief Operating Officer: Denise Ellison\*\*
Advocacy Director: Jolene Sanders-Foster\*\*
Communications Director: Laura Perna
Film Festival Director: William Greer\*

Editor/Researcher: Susie Angel\*

Mental Health Peer Policy Fellow: Jennifer Toon\*

CDS Director: Kit Cuny

CDS Payroll Administrator: Rosie Williams, Glenn

Erickson

CDS Claims Analyst: Laura Harrell

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.

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<sup>\*</sup> Person with a disability

<sup>\*\*</sup> Parent of a child with a disability