LETTER FROM CTD EXECUTIVE DIRECTOR DENNIS BOREL

Dear Disability Rights Supporters and Partners,

2016 was quite a year. It brought some notable advocacy wins, successes for our annual arts programs, and a big step forward for the long-term sustainability of CTD with the purchase of a new building. Formerly a guitar store, our new home at 1716 San Antonio Street inspired the pop music theme of this year’s report.

But we also saw a completely unexpected shift in power at the federal level that is going to make some of our hardest fights even harder. Access to healthcare and the federally protected guarantee of an education for children with disabilities are among many things that we expect to be disrupted under the new administration.

We have not lost hope, however. Since the close of the last legislative session in 2015, CTD has worked hard to secure a seat at the table on multiple critical issues. While we know we won’t win every fight, we are poised to use our knowledge and hard work to promote public policy that benefits and protects Texans with disabilities—and maybe even more importantly, to counteract legislation that will do harm.

Read on for an overview of the work we did over the last 12 months to strategically position ourselves for this year’s Texas Legislature—our Top Ten Hits of 2016!

For a barrier free society,

Dennis Borel

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: Rodney Hanneman*
Vice President: Crystal Lyons* **
Secretary: Judy Telge
Treasurer: Frank Santos

At Large Members
Region 1: vacant
Region 2: John Curnutt*
Region 3: Regina Blye*
Region 4: vacant
Region 5: Marshall Burns*
Region 6: Francis Key*
Region 7: Gene Whitten-Lege
Region 8: Jet Schuler

Staff
Executive Director: Dennis Borel
Director of Advocacy: Chase Bearden*
Chief Operations Officer: Denise Ellison**
Director of Communications: Laura Perna
Film Festival Coordinator: William Greer*
Editor/Researcher: Susie Angel*
Public Policy Specialist Chris Masey**
CDS Payroll Administrators: Karen Glover and Rosie Williams
CDS Claims Analysts: Erin Jones and Kit Cuny

* Person with a disability
** Parent of a child with a disability

On the cover: Brianna Dupuie sustained a traumatic brain injury as an infant, but thrived with appropriate physical, speech, and occupational therapy. After losing access to those services, Brianna’s family was among those leading the charge against cuts to Medicaid therapies for children. More on page 2.
CTD’S TOP TEN HITS OF 2016

1 Takin’ Care of Business during the Interim

This time of year, the Legislative session is on everyone’s mind—including ours. But the work we’ve done over the past 18 months to prepare for session and advance our mission outside of the Capitol has led to some significant wins. Most notably, through key appointments and participation in leading workgroups, we’ve secured a seat at the table on multiple critical issues. That’s why we’re listing our interim advocacy work as our #1 achievement of 2016. A few areas where we represent Texans with disabilities:

Drug Utilization Review Board. The DURB makes important recommendations on Medicaid drug formularies (lists of drugs that Medicaid covers). The DURB is made up of doctors and pharmacists; CTD’s Dennis Borel is the only exception—a representative from a consumer advocacy organization.

Policy Council for Children and Families. Appointed by the HHSC Executive Commissioner, CTD’s Chris Masey serves as vice-chair for this body that works to improve education, health, and human service delivery to children with disabilities and their families.

Texas Board of Architectural Examiners. Former governor Rick Perry appointed CTD’s Chase Bearden to the TBAE in 2009 and Governor Abbott has reappointed him, where he continues to give Texans with disabilities a voice in decisions that affect an accessible built environment and statewide regulations.

We also serve on bodies working on accessible parking, consumer protections, guardianship, recreation, financial independence for people with disabilities, and much more.

Finally, for the first time, we have published a study on raising the community attendant wage, one of our longest-standing legislative efforts. Completed in December, we plan to use “Crushing the Workforce: Poverty Wages Undermine the Availability of Critical In-home Services for Seniors and People with Disabilities in Texas” in our advocacy efforts during session to push this critical issue.

CTD’s Staff Appointments, Boards, Committees, and Workgroups

Dennis Borel:
- Promoting Independence Advisory Council
- Drug Utilization Review Board
- Medicaid Managed Care Consumer Protections Workgroup
- Guardianship Reform & Supported Decision Making Workgroup
- Texas MOST Coalition (Medical Orders for Scope of Treatment)
- Texas Oral Health Coalition
- Texas Forward Steering Committee
- United Healthcare State Advisory Committee
- United Healthcare National Advisory Board
- Superior HealthPlan State Advisory Committee
- Texas Rowing For All Board
- CORE Health Foundation Board

Chase Bearden:
- Texas Board of Architectural Examiners
- Parking Mobility Board of Directors
- Medicaid Managed Care State Advisory Committee

Chris Masey:
- Policy Council for Children and Families (Formerly Children’s Policy Council)
- TX ABLE Advisory Committee
- Austin Mayor’s Committee for People with Disabilities
- Supporting Minds Coalition
- Association of People Supporting Employment First (APSE) Public Policy Committee
- Down Syndrome Association of Central Texas (DS ACT)
- Texas Parent to Parent

Susie Angel:
- Stop Abuse for Everyone (SAFE)
- Austin Interfaith Inclusion Network (AIIN)
Under Pressure from CTD, therapy providers, advocates, & parents, State leadership begins to change its tune on cuts to Medicaid therapies for children

In 2016, several major new stories broke that revealed a bleak picture for children with disabilities in Texas, including devastating healthcare cuts. CTD took action on all fronts:

- While in Washington DC to discuss pharmaceutical policy with the Texas delegation, CTD’s Dennis Borel took the opportunity to raise the issue of the cuts. It struck a cord with the senators and congressmen, and we asked them to intervene.

- We featured the Dupuie’s, a family actively working to counteract these cuts in our June/July newsletter, with an accompanying action alert.

- We added our voices to a packed State Capitol press conference in September.

- Through regular posts on social media, we kept our membership updated on developments—and you responded! In 2016, our posts about cuts to Medicaid therapies received more attention than any other issue or news development.

We are hopeful that the public’s rapt attention will help parents and advocates successfully pressure key decision makers to restore funding for Medicaid therapies in early 2017. Notably, in late November, House Speaker Joe Straus publicly indicated his intention to do so.

This kind of response takes a coordinated effort. Our partners on all issues—not just Medicaid therapies—make our work possible. 2016 partner organizations include:

- AARP
- Accessibility Professionals Association
- ADAPT of Texas
- American Cancer Society
- American Council of the Blind of Texas
- Austin Clubhouse
- Austin Mayor’s Committee on People with Disabilities
- Autism Society of Central Texas
- Center for Disability and Development at Texas A&M
- Center for Public Policy Priorities
- Chatelle & Associates
- Children’s Hospital Association of Texas
- Clarity
- Community NOW!
- Cover Texas Now!
- Disability Rights Texas
- Down Syndrome Association of Central Texas
- Easter Seals of Central Texas
- Girling Health Care
- Guardianship Reform Advocates for the Disabled & Elderly (GRADE)
- Guardianship Reform & Supported Decision Making Workgroup
- Hogg Foundation for Mental Health
- Mothers Advocating Medical Marijuana for Autism (MAMMA)
- National Alliance on Mental Illness (NAMI)
- National Association of Social Workers - Texas Chapter
- National Multiple Sclerosis Society - Lone Star Chapter
- Providers Alliance for Community Services of Texas (PACSTX)
- Personal Attendants Coalition of Texas (PACT)
- State Independent Living Council (SILC)
- Texans Care for Children
- Texas Centers for Independent Living Network (TEXCIL)
- Texas Association of Goodwills
- Texas Association of Home Care and Hospice
- Texas Association of Interior Design
- Texas Center for Disability Studies at the University of Texas
- Texas Chapter of the Paralyzed Veterans of America
- Texas Council for Developmental Disabilities
- Texas Forward
- Texas Hospital Association
- Texas Medical Association
- Texas MOST Coalition (Medical Orders for Scope of Treatment)
- Texas Parent to Parent
- Texas Pediatric Society
- Texas Physical Therapy Association
- Texas Public Policy Foundation
- Texas Star Alliance
- Texas State Teachers Association
- The Arc of Texas
- The Gathering Place
- VSA Texas

... and others!
This is not my beautiful house...

Wait, yes it is! When we learned that TSTA, our landlord of 25 years, was selling their building, we won’t lie, we were concerned about where we would land. But with that worry, came the sense that we might be on the verge of something really exciting. As proud owners of 1716 San Antonio St., we can confidently say that we were right!

Since we moved in this summer, in addition to continuing daily operations, we have:

- Recorded an episode of A Common Thread for KOOP radio with Thor Armbruster on our annual Pen 2 Paper Creative Writing Contest.
- Been the site of Samuel Swafford’s Boy Scout Eagle Project. Sam organized and oversaw the addition of drop-leaf tables along the south porch, mulching of the trees along San Antonio and installation of rose trellises.
- Optimized the building as an office space, with pro bono assistance from our friends at the Texas Association of Interior Designers. Improvements are ongoing!
- Welcomed as many visitors as we could stand, including students from Huston-Tillotson University, partners, sponsors, grantors, and more! We put our spatial capacity to the test Oct. 27 at our official Grand Opening.

Our Consumer Directed Services Division (CDS) helps people who need attendant care to manage their own attendants and remain in their homes. As a growing enterprise since we began in 2007, our client base has increased to over 300, who employ over 450 personal attendants. Plus, we added two new fantastic staffers to the CDS team, Karen Glover and Kit Cuny.

We are proud to serve and support these Texans in their chosen communities and their wonderful attendants. For example, this summer, CDS payroll administrator Karen Glover nominated one of those attendants, Gaynell Smith, for Amerigroup’s annual Caregiver of the Year award. We’ll let the nomination speak for itself:

“Gaynell unexpectedly took over the care of her sister when her mother died in 2013. She had previously cared for the daughter of an acquaintance, without pay, and feels she was being prepared to later care for her sister, who has a severe seizure disorder and needs constant supervision and assistance. Gaynell is unfailing positive, patient, and encouraging to others. Though she gave up a full and active lifestyle to care for her sister, she says she is making lemonade out of the lemons by taking her sister out in the community as much as possible, and focusing on the growth and rewards that come from loving and caring for someone with special needs. (Gaynell also has the best voicemail greeting I have ever heard.)”
Young Americans featured at 13th annual Cinema Touching Disability Film Festival

We returned to the Alamo Draffthouse Village on November 4 & 5 for two nights of film celebrating the achievements of young people with disabilities and deafness. We are delighted to report the Festival was a huge success, bringing in big crowds, screening outstanding feature length and short films, and even exceeding our fundraising goals!

On our program were this year’s features, The Rebound and Deaf Jam; winning entries from our international short film competition; a Q&A with Austin Paralympian David “Super Dave” Wear; live ASL & spoken slam poetry; and more!

Youth is Gonna Come: Statewide organizing at Raise Your Voice! Roundtables

CTD’s advocacy team and Alison Mohr-Boleware of the Hogg Foundation for Mental Health brought our extensive knowledge of the legislative process and current issues to the University of Arlington and My Possibilities in Plano. We employed some new meeting strategies that facilitated the rapid exchange of ideas and connection building among participants and educated us about issues specific to North Texas.

We also tapped local self-advocates in both locations to tell “from the trenches” stories about making positive legislative changes as private citizens. Dorothy Hill, who has worked on ventilator assistance public policy for decades, captivated our Arlington attendees, and we were pleased to present her with our Justin Dart Memorial Award for Outstanding Service.

Already, we’re seeing major results from our organizing efforts, as Roundtable attendee Zelene Lovitt can attest:

“I met the CTD folks at their advocacy roundtable in Plano. When I contacted them for help with a critical issue for my grandson, I discovered I was not alone. They offered me the concrete support and guidance that led to a successful resolution of our issue. Having someone standing at my side gave me the confidence to take appropriate action. Knowing who to contact and how to deal with systems was a gift CTD gave us and believe me, we are very grateful.”

The list of conferences that we presented at this year includes:

- Jan. 14: Comptroller of Public Accounts (CPA) on the Texas ABLE Act
- Feb. 6: Down Syndrome Guild of Dallas on the Texas ABLE Act
- April 4: SILC Annual Conference, San Antonio on the Texas ABLE Act
- May 10: Republican Legislative Campaign Committee, Naples, FL on long-term services and supports (LTSS)
- June 17: Texas Parent to Parent’s Annual Statewide Parent Conference, San Marcos TX on Texas ABLE Act
- Aug. 17: Therapeutic Recreation Summit, Burton TX on advocacy
- Sept. 9: Adult Day Care Association of Texas, Austin on advocacy
- Nov. 29: Our Lives Annual Conference, El Paso on accessible vehicles-for-hire
Don’t Stop Me Now! Making transportation better for Texans with disabilities

We’ve continued our work with Parking Mobility to promote better enforcement and public awareness of accessible parking in Travis County. CTD’s Chase Bearden was elected President of the PM board early this year.

Transportation Network Companies (TNCs), also known as ride sharing apps, like Uber and Lyft, are getting ready for a show down this Legislative session. Some legislators want to create statewide rules that regulate this emerging industry. On the other hand, some Texas cities, like Austin and Houston, already have such rules in place—and would rather keep local control. In all clamor, the topic of accessibility has been largely absent. That’s why we’re pushing state leadership to keep people with disabilities in the conversation and commit to our Principles of Accessibility in Vehicles-for-Hire.

CTD is also lining up to support legislation banning the use of hand-held devices while driving, also known as texting while driving. We’ve listened to our members who have said that pedestrians with disabilities are at high risk from distracted drivers, either due to lack of mobility, low profiles in wheelchairs, or sight or hearing disabilities.

Great stories and performances from Everyday People with Pen 2 Paper and the Lion & Pirate

We’ve closed the books on the 7th year of our annual disability-focused writing contest, and once again, are pleased to share some truly remarkable work from around the world. This year’s contest received 96 entries from 15 different countries, including our Grand Prize winner “Just Breathe” by Carrie Salberg. Work ranged from observations of precocious children with disabilities (Nothing I Cannot Do, A Father’s Pride, Hanging Five) to glimpses into intense personal journeys (Scarring, Sea of Madness, Sea of Love, Framelight) to much more sinister scenarios (God’s Scrubber, Alcatraz), and a lot more!

In addition, we co-hosted 11 The Lion & Pirate Unplugged open mics with VSA Texas at Malvern Books, making a space for poems, songs, stories, visual art, and performances that defy categorization from Austinites (and a few visitors) with and without disabilities. In March, we featured Houston-based poet, activist, and long time Pen 2 Paper supporter Maria Palacios, who shared poems from her collections Dressing Skeletons: A Poetic Tribute to Frida Kahlo, and Poetic Confessions Volume I.

Thank You for Being a Friend, CTD Cats and Dogs

Like the small victories and coffee, the love of our pets keeps us going on the tough days. Our last hit of 2016 is dedicated to them: Rio, Jake, Wilson the Wonderdog, Paco, Mickey, Tatertot, Tugboat, Theo, Ripley, Cinnamon, Patches, Hank, Najm, Ajax, and Melody.
From left: CTD Board member John Curnutt joins Dennis Borel at the Raise Your Voice! Roundtable in Arlington; cover image from our Crushing The Workforce report on attendant wages; Dennis Borel with fellow advocate Dawn Carlton at our Grand Opening; ASL poet Theron Parker interprets Lewis Carroll’s “The Jabberwocky” at our Cinema Touching Disability Film Festival.

Coalition of Texans with Disabilities

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