

DO NOT SHUT UP!

A creation of ADAPT Corpus Christi: Fifth Edition

DO NOT SHUT UP or DNSU is an E-newsletter created by the Corpus Christi chapter of ADAPT. We encourage you to stay informed, get engaged, and most importantly-DO NOT SHUT UP!

ADAPT-CC Attends End the Bias Rally at the State Capitol



Members of ADAPT pose in front of the State Capitol holding signs with various messages about Ending Institutional Bias.

ADAPT-CC visited the State Capitol for The End the Bias Rally on March 21, 2019. Our group met with the offices of Representative Abel Herrero, Senator Donna Campbell, Representative Eddie Rodriguez, Senator Juan “Chuy” Hinojosa, and Senator Borris L. Miles.



Left: Members of ADAPT share personal testimonies with a representative for Senator Juan “Chuy” Hinojosa. Right: Members of ADAPT pose with Alejandro Pena, Communications Director for Representative Eddie Rodriguez.

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Melvin Kimbrell poses in front of the State Capitol holding a sign that reads, “\$\$\$\$ Follows the Person”.

“...end this one-sided bias and let us survive and grow alongside our neighbors and family in becoming productive in society again.”

– ADAPT Member, Melvin Kimbrell

Our group educated representatives about Home and Community-Based Services which currently has more than 150,000 individuals on the waitlist for services, in contrast, to the minimal 3,000 individuals who have opted to be institutionalized. We brought to light the exorbitant amount of state funding that goes towards the 13 State Supported Living Centers in Texas that are NOT at capacity-- yet receive a 25% increase in funding each biennium. Our personal testimonies stressed how zero benefits and low wages paid to providers negatively affects our ability to live and thrive in our communities.

We urge lawmakers to:

Fund the Waitlist! Consolidate Institutions! RAISE attendant wages!

A Parent’s Plea by Michelle Pagan

My name is Michelle Pagan. I am the parent of a child with disabilities. My daughter, Lily Cantu is 7 years old. She is Autistic, has Intellectual Disability, Severe Expressive/Receptive Language Disorder, Juvenile Idiopathic Arthritis and Hashimoto’s Disease. Lily is a bright, active, loving and fun child who loves the outdoors, school, swimming, painting and music, among other things. I want nothing but the best for her now and for the rest of her life.

Being a person with disabilities means that Lily requires lifelong supports and services. Unfortunately, those services are not always readily available, and some are at risk of going away all together.

When Lily turns 18, I want her to have the option to choose where she wants to live, to be included in the community, to contribute to society and live as independently as possible.



Michelle Pagan takes a “selfie” with her daughter, Lily.

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I think all parents want this for their children regardless of whether they have a disability or not. To accomplish this, Lily will require some assistance and is currently on several Medicaid waiver/interest lists for that assistance. One of the services that would be vital for Lily's adult independence is the Community Living Assistance and Support Services (hereinafter "CLASS"). CLASS provides home and community-based services to individuals with an intellectual disability or related conditions (ICF/IID) as a cost-effective alternative to an intermediate care facility.



Arms above head hold a sign in front of the State Capitol. It reads, "FUNDIN' THE WAIT'NG LIST MAKES CENTS." There is a picture of a piggy bank next to it.

Unfortunately, **there are currently over 150,000 Texans on waitlists for these services**, with some of these lists having a 14 year wait for community services. Lily is number 58,910 on the CLASS interest list, meaning she could be over 21 years old before she would receive assistance. The only other option available to her is to live in the 1 of 13 State Supported Living Centers in Texas. There is no waitlist to enter one of these institutions. I do not want this to be my daughter's only option for a variety of reasons but most importantly, she would be isolated and not be living in and included in the community.

There are currently 13 State Supported Living Centers (hereinafter "SSLC") in Texas that house about 3,000 people and that number is declining. It costs the state over \$300,000.00 per year to house just one person in one of those facilities. It costs the state \$50,000.00 to support someone to live in the community with support services. For the cost of housing just one individual in an SSLC, the state could support 6 people out in the

community. That makes absolutely no sense. Not only is it more costly to house someone in an SSLC, but it's also dangerous. In 2016, the Office of the Independent Ombudsman for SSLCs reviewed 1,693 "unusual incidents," defined by the Department of Aging and Disability Services (DADS) as an "event or situation that seriously threatens the health, safety, or life of individuals." I do not want my daughter living in one of these institutions.

H.B. No. 1585 relating to the consideration and analysis of the effect implementation of a managed care delivery system under Medicaid has on the interest of other waiting lists, needs to be a top priority. There was no funding for interest list reduction in the last legislative session. The Health and Human Services Commission (hereinafter "HHSC") Exceptional Item (EI) 3, states that not only would funding of 1915(C) and 1115 waiver and Promoting Independence waiver capacity slots provide "comprehensive services to individuals and reduce the state's reliance on higher acuity, more costly care settings such as intermediate care facilities, nursing facilities, and SSLCs", but it would also provide comprehensive services to individuals and

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reduce the state's reliance on general revenue-funded services to maintain individuals' success in the community.

That brings me to the final part of the solution which is to provide access to proper supports in the community. **We need to raise the base wage for Community Attendants.** The success of CLASS and other community services would be impossible without our Community Attendants. A Community Attendant is defined by Title 1 of the TAC, Section 355.11(b) as "the unlicensed caregiver providing direct assistance to individuals with Activities of Daily Living and Instrumental Activities of Daily Living."

Attendants are direct service workers that help the aged and individuals with disabilities with activities such as toileting, transferring, bathing, eating, dressing, mobility, basic household services like laundry, light house work, meal preparation, and accompanying to doctor's appointments. This is not an easy job. Yet, these attendants receive a base wage rate of \$8.00 per hour, with no benefits. Meanwhile, other entry-level jobs are paying more and even offering benefits, making alternative employment much more attractive. With better employment options elsewhere, it comes as no surprise that attendants are leaving the sector. The median caregiver turnover rate across the industry was 66.7% in 2017, the highest rate since 2013. The Texas House Subcommittee on Article II of the state budget has put the equivalent of a 10 cents/hour raise toward Community Attendant base wages. This is unbelievably ridiculous. ADAPT and PACT of Texas is calling for a \$15.00 per hour wage. This campaign is called RAI\$E IT!



Christie Bennett stands in front of the Coastal Bend Center for Independent Living. She is holding a sign that reads: "COMMUNITY ATTENDANTS DESERVE MORE THAN POVERTY WAGES. RAI\$E IT!"

As a parent, I insist that individuals with disabilities and their caregivers should be the ones to decide if the system works or not. **It is not working.**

I am asking you to reach out to your legislators and urge them to consolidate our costly SSLCs, fund the community services waitlist, and RAI\$E Community Attendant wages.

--Michelle Pagan

Want to know how to help?

-Contact your legislators! Send emails, faxes, letters, make phone calls—whatever method works best for you. Need to know who represents you? You can find that information, as well as how to contact them here: <https://wrm.capitol.texas.gov/home>

- Lastly, JOIN ADAPT! Whether you're new to civic engagement or if you're a seasoned advocate, you are invited! We are happy to link you to resources and get you started on the path the effective engagement and advocacy! ADAPT meets at the CBCIL office located at 1537 Seventh Street on the Second Monday of each month at 2pm.

Go to the issues

**For more information on the issues in this edition of DNSU
click on the links below or paste into your browser for more information.**

Waivers for Home and Community-Based services:

<https://www.navigatelifetexas.org/en/insurance-financial-help/texas-medicaid-waiver-programs-for-children-with-disabilities>

Institutional Bias:

<https://www.thearcoftexas.org/wp-content/uploads/2019/03/hb-3080.pdf>

<https://www.thearcoftexas.org/advocacy/>

RAI\$E IT/ Raise base wages for community attendant:

<https://www.txdisabilities.org/community-attendants>

https://spectrumlocalnews.com/tx/austin/politics/2019/02/20/advocates-seek-funding-for-disability-support-services?fbclid=IwAR3OFn5k2MrrdJx4cloS9noMwijuDTnVyFh8GZY-UAHwQcfbZT5jwuLO1_I