

COMMUNITY NOW!

... promoting inclusive communities for all people marginalized because of a disability



MISSION

Community Now! is a statewide nonprofit organization passionately committed to promoting inclusive communities for all Texans often marginalized because of a disability.

WE BELIEVE...

Our loved ones with disabilities should have the option to live in their communities and not languish on long waiting lists for services or forced to live in a dangerous, dehumanizing segregated institution.

The services for our citizens with disabilities must be nothing short of exceptional and that those responsible for providing these services must be held accountable.

Public policy and tax dollars must be aligned to support Texans with disabilities who want to live in smaller, more cost efficient settings in their communities and no longer support the waste and abuse of a failed institutional system.

From the Presidents Pen

I'm Michelle Dooley and I have been elected as the new president of Community Now! I'm looking forward to a very busy and productive year. As you can read in this newsletter we have a lot of work to do for the remainder of this year and 2012 in order to be ready for the next legislative year which will begin in January 2013. This time needs to be used for educating the public and legislators about our concerns for our loved ones and friends. The abuse and neglect is still happening in the 13 State Living Centers (formerly Texas State Schools) in spite of all the millions of dollars being thrown that way. We have asked the Department of Justice to return to Texas and investigate the abuse that is still happening. In Texas there are still 100,000 people on waiting lists for community services. We need to stand together and say enough is enough.

I want to thank our past President David Wittie for his leadership during this last Legislative session. With his leadership Community Now! hosted the largest march and rally for the disability community at the Capitol in Austin. David made legislative office visits every Wednesday during the session.

Without all the visits and testimonies by David, Joe Tate and friends in Austin the cuts very well could have been worse.

Please join us in 2012 as we prepare for the next legislative session. In the meantime we are launching our first fundraiser in Austin. We hope to see you there. If you are not able to attend donations may be made on our website. (Details are in the newsletter.) At this time we have active coalitions in Austin, Bryan College Station, Corpus Christi and Fort Worth, but would like more throughout the state. If you are interested in starting a group in your area, contact our Policy Specialist Joe Tate at 830-305-0613.

Michelle Dooley



"Coming together is a beginning. Staying together is progress. Working together is success." – Henry Ford

Independence from waiting. Freedom from institutions.



Tickets: \$10 in advance \$15 at the door

Silent Auction!

COMMUNITY NOW!
Presents:

1st Annual 'Break the Cycle Jam'

*Free Our
People!*

Join us at Fiesta
Gardens on
Saturday
November 12
from 5-9pm
-THE COUCH-
-Mat Kreutz-

*A concert in the park with sweet sounds and delicious pints from local Austin bands and breweries.

*Support this state wide nonprofit in their fight to end institutional bias in Texas.

*Texas has the most state run taxpayer funded congregated care facilities in the nation.

*Help us break the cycle of abuse and neglect!

www.communitynowfreedom.org

Come out for an evening of fun and show your support!

Tickets are available with a minimum \$10 donation per person.

Donations can be made online at: www.communitynowfreedom.org.

Please print your receipt and bring it with you to redeem your ticket.

Unable to join us, please consider making a donation.

Your support ensures our work continues.

Sponsorship packages are available. For more information,

http://www.communitynowfreedom.org/uploads/Sponsorship_Packages.pdf

For questions, contact Joe Tate, by phone 1-830-305-0613 or tate392@gmail.com.

INSTITUTIONS vs COMMUNITY

“...uphold the rights and desires of Texans with disabilities to benefit from a system of services and supports that are consumer driven by allowing individual and family choice and control.” – Integral Care’s Board of Trustees

The issue of institutions vs. community-based care is not new. For years now, people have talked about, and at times debated the issue. Discussions often center on cost, quality of care, a person’s basic civil rights and personal preference/choice.

During the last legislative session, legislative leaders were encouraged to create a budget that reduced unnecessary spending. For advocates of community-based services and individuals who live life with a disability, this brought hope. Perhaps this would be the beginning to an end of the institutional bias in Texas. But it was not! Instead, the Texas Legislature adopted a state budget that preserves the expensive system of institutions, despite the declining resident population, while simultaneously cutting cost-effective community-based services for persons who have a disability and a desire to live in the community. Hypocrisy at its best!

The impact and the reality of these decisions are service limit reductions, 100,000 plus people waiting on “interest lists” for services, and the elimination of some community-based programs. As a result, individuals who can no longer wait – or if the reduction in services limits no longer meet their support needs – are being forced to consider placement in an institution. And to think some call this a system of choice! Really?

It is also a conscious decision to support a flawed system of abuse. Historically, care provided in Texas’ institutions has been questioned. Reports by state and federal agencies continue to document the on-going abuse, neglect and exploitation of residents.

Also documented is the deviation from professional standards of care and failure to serve residents in the most integrated setting, a violation of the Olmstead Act.

Texas has more institutions, and people living in institutions, than any other state. Ten states have closed all institutions, and others have developed a plan for closure. Texas has done neither. Since the beginning, Community Now! has, and continues to, advocate for long-term care systems reform.

We believe Texas Legislators should...

- Direct the Health and Human Services Commission – HHSC to develop a long range plan to re-balance long term care services for Texans who have a disability.
- Consolidate Medicaid Waivers into a system that determines services based on needs generated through Person Centered Planning.
- Expand Consumer Directed Services (CDS) options to all waiver services and ensure information on how to access these services is readily available and accessible.
- Create a system of accountability.

We also believe...

- Personal Care Attendants and other Direct Support Professionals must be paid a living wage plus appropriate benefits.

If you believe reform is needed, please consider how you can become involved. We must work together for change.

Actions to consider...

- Start a Community Now! coalition in your community. Need help, contact us. We are glad to help out.
- Follow Community Now! on Facebook or through our Yahoo Group to stay up to date on issues related to long-term care supports and services for individuals who have a disability. Links to both on our website: www.communitynowfreedom.org.
- Call and/or visit your legislator. Take advantage of their time in the District. Share your story! Don't know who represents you, visit: <http://www.fyi.legis.state.tx.us/>
- Make a donation. Community Now! relies on individual donations to continue our work.

Community Living Assistance and Support Services (CLASS) – New Service Limits *Updated*

(If a service is not listed, new services limits were not calculated.)

CLASS Service	Highest Number of Units Provided Now (per year)	New Service Limits (per year)	Not to Exceed if Exception Approved
Adaptive Aids & Dental	\$10,000	\$6,935	\$10,000
Minor Home Modifications	\$10,000 lifetime limit	\$7,515 lifetime limit	\$10,000
Respite	30 days	29 days	30 days per IPC year
Behavioral Support	600 hours	192 hours	
Occupational Therapy	154 hours	83 hours	
Physical Therapy	213 hours	91 hours	
Prevocational Skills	\$43,656	\$13,965	
Specialized Therapies – Combined (aquatic, massage, music, recreational, hippo/horseback riding)	\$41,733 combined	\$10,118 combined	
Speech Therapy	84 hours	56 hours	

Discontinuation of Hydrotherapy - This service has been removed from the list of Specialized Therapies available through CLASS. (DADS Information Letter No. 11-134 – dated October 26, 2011)

Home and Community-based Supports (HCS) – New Service Limits *Updated*

(If a service is not listed, new services limits were not calculated or services were not impacted.)

HCS Services	Highest Number of Units Provided Now (per year)	New Service Limits (per year)	Not to Exceed if Exception Approved
Adaptive Aids/Durable Medical Equipment	\$10,000	\$1,057	\$10,000 per year
Behavioral Support	216 hours	(see below)	
Dietary Services	71 hours	3 hours	
Dental	\$1,000		
Occupational Therapy	104 hours	8 hours	
Physical Therapy	152 hours	30 hours	
Social Work	300 hours	10 hours	
Speech and Language Pathology	119 hours	49 hours	
Supported Employment	150 hours	126 hours	150 hours per year
Supported Home Living Based on Level of Need (LON)			
LON 1	3,099 hours	923 hours	
LON 5	4,373 hours	1,337 hours	
LON 8	4,656 hours	1,868 hours	
LON 6	5,286 hours	2,098 hours	
LON 9	6542 hours	3,546 hours	

HCS Behavioral Support

New service limits for behavioral support were proposed at 10 per year. In response to stakeholder feedback, DADS will not impose a service limit on behavioral support in the HCS Program. This change will be reflected in revised program rules upon adoption. (DADS Information Letter No. 11-135 – dated October 28, 2011)

The In Home and Family Support (IHFS) Program For Persons with ID was eliminated

This program provided direct grant benefits to individuals who have physical disabilities and or their families to help them purchase services that enable them live in the community. Eligible people choose and purchase services that help them to remain in their own homes.

Medically Dependent Children's Program (MDCP) – New Service Limits

(If a service is not listed, new services limits were not calculated or services were not impacted.)

MDCP Service	Highest Number of Units Provided Previously (per year)	New Service Limits (per year)
Adjunct Support Services	3,164 hours	1,875
Respite	3,887 hours	2,096 hours

Community Based Alternatives (CBA) – New Service Limits

(If a service is not listed, new services limits were not calculated or services were not impacted.)

CBA Service	Highest Number of Units Provided Now (per year)	New Service Limits (per year)	Not to Exceed if Exception Approved
Adaptive Aids/Durable Medical Equipment	\$10,000 (cap)	\$2,050.00	
Dental	\$10,000 (cap)	\$4675.00	\$10,000
Medical Supplies	\$10,000 (cap)	\$1,736.00	
Minor Home Modifications (lifetime limit)	\$7,500 (cap)	\$6,550.00	
Occupational Therapy	85 hours	61 hours	
Personal Assistance Services	7,625 hours	2,135 hours	
Physical Therapy	120 hours	86 hours	
Respite	30 days (cap)	24 days	
Speech, Hearing & Language Therapy	151 hours	69 hours	

State Supported Living Centers – State funded abuse, neglect and exploitation

Increased funding and staff positions, security cameras, an Ombudsman and monitoring by the Department of Justice have not stopped the abuse, neglect and exploitation at the State Supported Living Centers (SSLCs). In fact it has increased.

Annual Spending on State Supported Living Centers FY 2004 – 2011 & Budgeted Spending for FY 2012

- 2004 - \$388.66 Million
- 2005 - \$407.72 Million
- 2006 - \$442.36 Million
- 2007 - \$462.05 Million
- 2008 - \$509.49 Million
- 2009 - \$593.57 Million
- 2010 - \$641.06 Million
- 2011 - \$646.66 Million
- 2012 - \$648.57 Million (budgeted)

Below is the Annual Status Report for the State Supported Living Centers – FY 2010. The number of SSLC complaints/investigations for FY 2011 increased by 247. To view the Annual Status Report for the State Supported Living Centers – FY 2011, visit the Community Now! website at: http://www.communitynowfreedom.org/uploads/Annual_Status_Report_-_SSLC_FY_2011.pdf.

STATE SUPPORTERD LIVING CENTERS	Abilene	Austin	Brenham	Corpus Christi	Denton	El Paso	Lubbock	Lufkin	Mexia	Richmond	Rio Grande	San Angelo	San Antonio	TOTAL
Number of Investigations Conducted	93	65	53	82	52	24	86	44	234	32	33	122	61	981
Types of Investigations:														
Exploitation	1	4	3	9	1	0	5	0	11	0	0	4	0	38
Neglect	22	17	3	5	9	4	4	5	24	2	2	9	4	110
Physical Abuse	64	34	41	53	31	20	74	36	159	29	28	87	51	707
Sexual Abuse	3	10	4	13	11	0	3	1	33	1	2	19	6	106
Verbal Abuse	3	0	2	2	0	0	0	2	7	0	1	3	0	20
Number of Investigations Involving:														
Contractor	0	0	0	0	0	0	1	0	0	0	0	0	0	1
Direct Care Worker	60	48	37	64	36	15	56	28	185	24	22	101	53	729
Support Staff	1	1	0	2	1	1	0	0	5	0	0	3	0	14
Medical Staff	3	3	2	2	1	0	2	1	7	1	3	3	3	31
Relative	0	0	0	0	0	0	0	1	0	0	0	0	0	1
Volunteer	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Number of Investigations Involving:														
Suicide	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Death	8	1	0	0	1	2	1	0	2	1	0	0	1	17
Hospitalization	3	0	0	1	2	0	0	1	4	0	0	1	3	15

STOP *wasting lives and tax payer money.*

CLOSE/CONSOLIDATE *& redirect funding into the community.*

A CALL TO ACTION

From the www.disabilityisnatural.com E-Newsletter by Benjamin Snow

I'm a 23-year-old college student with big dreams for my life! I also have cerebral palsy, and I use a power wheelchair and other assistive technology devices. I want to get through college and make a difference in the world, I like to stay up late and sleep in, and—well, I'm just a regular person. But you wouldn't know that by how some people behave.

During a recent visit with one of my grandmothers, we ate several meals in her retirement community, and were joined by my grandma's friends. At lunch in the "deli," an older gentleman and I had enjoyed a great discussion about today's politics. As we hurried off to another activity, the man asked, "By the way, how long have you been incapacitated?" I *really* wanted to stay and have a *lengthy* conversation about his choice of words—I *am not* "incapacitated"—but there was no time, so I simply replied that I was *born* with cerebral palsy.

At another meal with my grandma and her friends, the dining room hostess passed out menus to everyone except me. I was busy talking and didn't notice this until I heard my mom say, "He needs a menu, too." Did the hostess presume I couldn't read, or did she think someone else was in charge of what I eat? A few minutes later, when the server came to take our orders, she asked my mom, "What does he want?" My mom said, "I don't know; you'll have to ask him." The server *did* speak to me then, but amazingly, she seemed to "forget" several other times, so my mom and I both reminded her to speak directly to me.

Why does this happen? I don't want to believe that people are intentionally prejudicial or cruel. It seems, instead, it's a result of ignorance. Because people with disabilities have, historically, been "hidden away" behind the walls of segregated environments and/or have not participated in the mainstream of society for whatever reasons, many people *without* disabilities have had little or no social interactions with them, so when they do, it seems they simply don't know what to do or how to act!

After the events at my grandmother's, my mom and dad and I talked about these situations. My mom reminded me of similar things that have occurred throughout my life—like when I was very young, sitting in my wheelchair, minding my own business, and people asked my mom, "Can he talk?" (Why would they assume I couldn't?) She had more stories like that: perfect strangers who tried to hug me, pray over me, and/or give me money, as if I was a refugee from the Jerry Lewis Telethon! These actions seem to be the result of pity. At the other extreme are people, like the ones at my grandmother's, who ignored me. And there have been lots and lots and lots of stares, too. (My mom says she could write another book just about this stuff!)

Yes, it must be ignorance, the same kind of ignorance that people of color, women, and members of other so-called minority groups have experienced. The Civil Rights, Women's, and other Movements helped to reduce that ignorance, as people from these groups took their rightful places in schools, at lunch counters, on buses, in the workforce, and other settings in their communities.

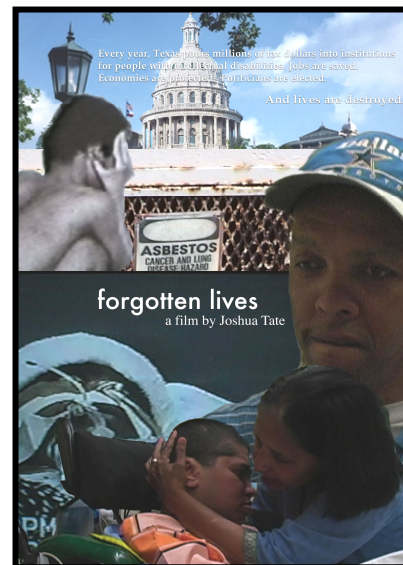
It seems the solution to reducing ignorance about people with disabilities is the same. So this is a **CALL TO ACTION** to children and adults with disabilities: *get out there and take your rightful place in society!* The sooner more of us are out there, the more opportunities we have to educate others—*simply through our physical presence*—and the sooner others will learn that people with disabilities are regular, normal, ordinary people, too!

P.S. For proactive strategies on handling awkward situations, see "Humor to the Rescue: What Do You Say When...?" and "Why Do We Apologize?" on our family's website, www.disabilityisnatural.com.

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Community Now!
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Forgotten Lives, A film by Joshua Tate

Forgotten Lives is a 44 minute award winning film that chronicles the horror and abuse perpetrated against Texas' most vulnerable citizens inside state institutions and offers hope for a future of freedom and dignity in the community.

"He who passively accepts evil is as much involved in it as he who helps perpetrate it. He who accepts evil without protesting against it is really cooperating with it." – MLK, Jr.

**Despite Reforms, Abuse
Continues at Texas
Institutions for Disabled**
Texas Tribune 10-20-11

**Seven staff fired from Corpus
Christi State Supported Living
Center after abuse and
neglect allegations**
Corpus Christi Caller Times
10-14-2011

**Denton facility for mentally
disabled hasn't fixed deficiencies**
Ft. Worth Star-Telegram
7-31-2011

Help **STOP** the abuse and neglect of individuals who have a disability and tax payer dollars.
Take action. Stand up for long-term care systems reform.