

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.

Community Now! & ADAPT Press Conference



On January 18, 2012 disability rights advocates including individuals living with a disability label, family members and others gathered outside Rick Perry's Campaign headquarters demanding a meeting with Governor Perry's Staff, Lt. Governor Dewhurst Staff, and Commissioner Chris Traylor of the Department of Aging and Disability Services (DADS).

Concerned with the disparities of institutional care and home and community based services, they wanted a meeting with Texas leaders to discuss ways to reform the long-term care service delivery system.

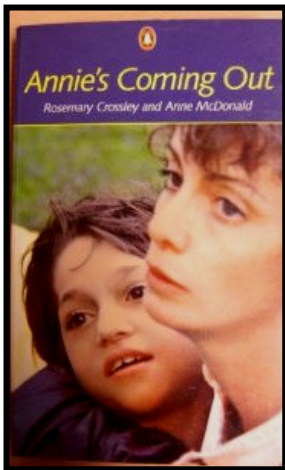
Texas Medicaid expenditures continue to highlight the preference of institutional vs. community-based services.

Preserving the expensive system of institutions, despite the declining resident population and continued lack of compliance and reports of abuse neglect and exploitation, while simultaneously cutting cost-effective community-based services



and increasing the amount of time a person lingers on an "interest list" for services, leads many to believe that Texas is heading towards a crisis of epic proportions. To quote Sara Watkins, a Community Now! board member and disability rights activist, "Texas must begin to align with other states and end the institutional bias. We have to rebalance the system by implementing more home and community based services."

Independence from waiting. Freedom from institutions.



Annie's Coming Out

by Rosemary Crossley & Anne McDonald

A Book Review (blog) by Paul Mastin

It's not often that a book makes me cry. This book made me cry.

Several months ago I read William Horwood's unique and powerful novel *Skallagrigg* which follows a young girl's journey from an institution, where she had been placed by her family due to her cerebral palsy, to independence. Mr. Horwood commented on my review, noting that one of the inspirations for *Skallagrigg* was *Annie's Coming Out*, the story of Anne McDonald's journey from isolation in an institution--and in her own body--to communication, interaction, and self-determination.

So what's so sad about that? First of all, it's heartbreaking to read about the conditions under which Annie and her peers lived. Institutionalized their entire lives, these children, who had cerebral palsy or other severe disabilities, were trapped in a sort of limbo. The parents had placed the care of the children in the hands of the hospital. The hospital had written the children off as little more than vegetables. They suffered under the most horrible forms of abuse and neglect imaginable. Annie was a teenager before Rosemary Crossley came to work at the hospital and began experimenting with different means of communicating and began to build relationships with Annie and the other children.

In spite of the progress Crossley made with the children, using progressively more complex methods by which the children could spell out words and sentences, her superiors refused to acknowledge that the children could think and communicate on their own. Eventually Annie began to assert herself and started a legal fight for her freedom from the hospital. Eventually, to the chagrin of the hospital and government overseers, Annie won her freedom, setting a precedent for legal rights of the disabled.

By improving her communication and bringing her case to the attention of the courts, Annie's case drew unwelcome attention to the hospital and its treatment of children. Hospital officials began to retaliate by separating communicative children from one another and ramping up the neglect. Annie lived in Australia, and the events of the book take place in the 1970s, but I am sure the attitudes and conditions described prevailed in the U.S. then, and, in spite of many improvements in care and therapy, are probably still around today. Reading *Annie's Coming Out* will make you want to stand up for the civil rights of disabled, institutionalized people in your community.

The saddest portion of the book, the section that put me over the edge, was Annie's reaction to her friend Stephen's death. As part of the hospital's retaliatory measures, Stephen was isolated from other patients and not allowed visitors. He was given no means of communicating. In his isolation and lack of hope, he died. Annie writes: "Stephen's death was the end of my belief in God. Previously I had wanted to believe in a caring God, who could love even people like us. No one who loved Stephen could have let him die a prisoner of his own body and of the Health Commission." I believe in a loving God, but I can scarcely blame Annie for her attitude, heartbreaking as it is. My prayer is that others in her shoes will get a taste of the grace and hope God offers.

Texas' Institutions



A closer look...

There are 13 large institutions in Texas - known as State Supported Living Centers - serving a total of 4,019 individuals. The population at each center varies. The Rio Grande SSLC has the fewest number of residents at 71. The Denton SSLC has the highest number of residents at 518.

- **reports of abuse, neglect and exploitation at the SSLCs has increased over the past two years** from 981 in 2010 to 1228 in 2011 as noted in the Annual Status Report – SSLC FY 2010 & FY 2011
- the January 16, 2012 Lubbock SSLC Monitoring Team Report noted **compliance with only 27 of the 171 provision areas, a mere 16 percent of all areas** – other Monitoring Team Reports note similar compliance percentages
- the January 15, 2012 Richmond SSLC Monitoring Team Report noted **progress toward credentialing staff as BCBA's had stagnated**
- the December 9, 2011 Denton SSLC Monitoring Team Report noted **there were substantial lapses in the provision of active treatment and failure to intervene in order to ensure the safety of individuals living in the center**
- the December 6, 2011 Mexia SSLC Monitoring Team Report noted **1590 injuries reported between 2/1/11 and 7/31/11, including 25 serious injuries resulting in fractures or sutures**
- the October 22, 2011 Monitoring Team Report of the San Antonio SSLC noted **28 individuals (10% of the population) had DNR orders for conditions that were not terminal** – monitors questioned whether the "Do Not Resuscitate" (DNR) practices were within the generally accepted professional standard of care
- the October 12, 2011 Brenham Monitoring Team Report noted **direct care staff interviewed were not knowledgeable of the communication programs and communication plans and how the individual communicates was not consistently included in the personal support plan**
- the September 10, 2011 El Paso Monitoring Team Report noted **little work was done to educate individuals, their family members and LARs, and staff about the variety of community living and working options that might be available to individuals**

In January 2012, the US Department of Justice and the state of Virginia reached a settlement agreement that expands home and community based services. ***The Settlement Agreement in Texas is weak and business is as usual; leaving individuals who have a developmental disability at great risk.*** We must continue to educate others about current conditions and the need for long term care systems reform. Reform that must include consolidation/closure of the SSLCs, redistribution of funds to home and community based services, and the development of a system of accountability. MLK, Jr. reminds us that our lives begin to end the day we become silent about the things that matter. There comes a time when you must take a position and stand up for what is right. It may not be popular or easy, but it is necessary; and the time is NOW! It has been said that the world is a dangerous place to live; not because of the people who are evil, but because of the people who don't do anything about it. So we ask, "If not you, who?" "If not now, when?"

View all DOJ Team Monitoring Reports to date at: http://www.communitynowfreedom.org/DOJ - Monitoring_Reports.php.

Community Now!

Legislative Recommendations for Long Term Care Reform

- 1) Direct the Health and Human Services Commission to develop a long range plan to re-balance long term care services for Texans with Disabilities. This plan should include the following components:
 - Develop a diversely represented Task Force to guide plan development.
 - Close and consolidate State Supported Living Centers (SSLC) as the population decreases. The closure process must include the choices of those choosing to remain in these facilities and ensure those who wish to leave have every opportunity to do so.
 - Ensure supports and services for people living in the community are available, exceptional and accountable.
 - People transitioning from SSLCs to community settings should develop a Person Directed Plan to ensure the successful transition in order to meet individual needs.
 - Money Follow the Person protocols utilized for people with disabilities exiting nursing homes and private ICF-MR facilities should be incorporated to support people exiting SSLCs.
 - Designate all funding saved through consolidation and closure of SSLCs to fund people with disabilities on Waiting Lists for community services and supports.
- 2) Consolidate Medicaid Waivers into a system that determines services based on needs generated through Person Centered Planning.
- 3) Personal Care Attendants and other Direct Support Professionals must be paid a living wage plus appropriate benefits.
- 4) Expand Consumer Directed Services (CDS) options to all waiver services and ensure information on how to access these services is readily available and accessible.

For more information, send an Email to Joe Tate at: tate392@gmail.com or the Community Now! email address: communitynowfreedom@gmail.com.

To learn more about Community Now! visit our website at:

www.communitynowfreedom.org

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My story, *the Statement of Albert Carl Metz:*

When I was born, my parents were first told that I would not live through the night. When I DID live through the night, my parents were told that I could not eat and that they would not feed me. However, my mother went to my room and started breast feeding me, and I swallowed; I was then allowed to eat. I lived at home for the first years, and got around, often, by crawling. My father nick-named me “Sparky”. He says that I looked like an A/C Spark Plugs TV ad cartoon character. People tell me that I have a role similar to a spark plug in that I “get things going.”

I was in Enid State School, in Enid Oklahoma from 1970 to 1980. I guess the reason my mother sent me there was because my grandfather, who was living at home, was becoming more confused with age. When I first arrived at the State School at age 13, my impression of the place was “so so.”

But my impression was not so good when my mother told me that the State School policy was not to let me return to my home for the first three months. This seemed like a strange and bad policy to me. The school said immediately that I did not belong there, due to my high IQ; but they kept me. That was before passage of the Americans with Disabilities Act. I would not have been allowed to stay in that environment.

Another State School policy I found out about right away was if I did not want to eat; they forced it down my throat. I was restrained when being fed, lying in bed with my arms and legs tied. I choked on food from being fed in a horizontal position. More than 100 times over the years, I cannot even count, I required the Heimlich maneuver when I was being fed. This did not happen at home, where I ate by myself, using utensils, at my own pace. In fact I do not recall ever choking like this at home.



Another big change I found right away at the State School was that of having no privacy at all. I had a girlfriend Mollie. We were boyfriend and girlfriend from 1970 until she died there in 1977 from complications from double pneumonia and when I was 20, officially an adult. We were never allowed to be alone together. We were the talk of the campus. Mollie told my mother that she wished we could marry and honey moon in Hawaii. I asked her how we’d get there. On my good looks? People who knew how close we were told me Mollie’s last words were “tell Sparky I love him.”

In 1980 I left the State School, too old to remain there. I went to a nursing home called Sunnyside. The nursing home was somewhat better than the State School. The force-feeding was over. After a year or two there, I talked my brother Dale into taking a job there. He met my sister in law while he served there. The staff turned over constantly, however, except for some who were family members. There were promotions to medication aide, according to my sister-in-law, which took place not because of merit or seniority, but because those who reliably did their day to day-aide work and knew the patients’ schedules were too capable to promote, while others who couldn’t or wouldn’t

do the work were trained and kicked upstairs. They witnessed one LPN who had not yet received her nursing license, who bent over and stabbed herself with the scissors in her pocket, and later blamed a patient.

In one case, a resident taunted a patient until he attacked her. Another patient faked seizures to gain help. Another had been tied up by his folks at all times; Sunnyside used handcuffs to tie him down to his bed after he caused damage.

If I wished to travel out after "curfew" I was not allowed. And, unless I was signed out by another person, I could not leave at all. Again, there was a "no sex" policy, no privacy allowed. Residents would sometimes sneak off to the boiler room for this purpose, but were punished if caught, banished to their rooms. I threatened several times to run away from Sunnyside.

One good result of moving to Sunnyside was that several patients who needed more care than myself moved out into their own apartments. They were about my age. The first two moved out together and had an attendant between them. My father found out about this. He found out how to get attendant care going when his company transferred him to Austin, Texas. In January, 1990 I moved from Oklahoma to Austin. I moved into my own apartment. When I first moved in, there was a guy who also had cerebral palsy who lived two down, and he told me about ADAPT. (Americans Disabled for Attendant Programs Today). Currently live in Austin, in a duplex which I've gradually made accessible using both city and my own money; I use the main-line bus system daily (ADAPT had a big hand in insuring that busses, including Greyhound, have lifts or ramps.)

I am on the internet, have a voice device that I type into when others are unable to understand my speech, and have served as a salesman for my father's scooter repair/sales shop, before he retired. My life is worth living, and I've come a long way from the day my parents were told that the hospital could/would not feed me.

Albert Carl (Sparky) Metz

Sparkymetz@sbcglobal.net

The Special Child



The Child ~ yet ~ unborn spoke with the Father... Lord, how will I survive in the world? I will not be like other children · my walk may be slower · my speech hard to understand · I may look different. What is to become of me?

The Lord ~ replied to the child... My precious one, have no fear, I will give you exceptional parents. They will love you because you are special, not in spite of it.

Though your path through life will be difficult, your reward will be greater... You have been blessed with a special ability to love ~ And those whose lives you touch will be blessed ~ Because You Are Special

This poem was given to me by my mom when my son, Morgan was 2; he is now 26 years old. While the verbiage used to describe a person living with a disability label is different today, the sentiment will never change. - *Michelle Dooley, Community NOW! Board President*

Augmentative & Alternative Communication (AAC)

WHAT IS AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)?

Augmentative and alternative communication (AAC) helps individuals who cannot rely on their natural speech to communicate. It is a set of tools and strategies that a person uses to solve everyday communicative challenges. Communication can take many forms such as: speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech generating devices, etc. People with more involved speech or language challenges rely on AAC to supplement existing speech or replace speech that is not functional.

"I'm a great believer that *any tool* that enhances communication has profound effects in terms of how people can learn from each other and how they can achieve the kind of freedoms that they're interested in." — Bill Gates

AAC RESOURCES

- AAC Institute: <http://www.aacoinstitute.org/>
- International Society for Augmentative and Alternative Communication (ISAAC) <http://www.isaac-online.org/english/home>
- United States Society for Augmentative and Alternative Communication (USAAC) <http://www.ussaac.org/>

ADDITIONAL TECHNOLOGY RESOURCES

- Assistive Technology Act of 2004 – Public Law 108-364 – to view a copy of the act, visit: <http://resnaprojects.org/nattap/library/laws/pl108-364.pdf>
- Texas Department of Assistive and Rehabilitative Services (DARS) Specialized Telecommunications Assistance Program (STAP) – STAP is a voucher program that provides financial assistance for the purchase of specialized assistive equipment or services for individuals whose disability interferes with their ability to access the telephone network - <http://www.dars.state.tx.us/dhhs/stap.shtml>
- Texas Technology Access Program (TTAP) – TTAP leads the state's efforts to carry out the federal Assistive Technology Act of 2004 - <http://tatp.edb.utexas.edu/>
- The Family Center on Technology and Disability - <http://www.fctd.info/show/home>

AWARENESS VIDEOS

- Assistive Technology Enabling Dreams - <http://www.youtube.com/watch?v=zZ5CkpgVQJ4&feature=related>
- Only God Could Hear Me - <http://www.youtube.com/watch?v=2r9pvtNTx4k>

*"For a person who does not have a disability, technology makes life easier.
For a person who has a disability, technology makes life possible."*

- Unknown

Community **Now!** Supports the

MY MEDICAID MATTERS OUTREACH AND EDUCATION CAMPAIGN



MY MEDICAID MATTERS MISSION

To inform policymakers and the public about the benefits of Medicaid and what could happen to Texans if Medicaid were reduced or eliminated.

SPEAK UP! If Medicaid matters to you, let your friends, family & elected officials know...

- **“MY MEDICAID MATTERS”** Describe why the Medicaid program is important to you and your family.
- **“CUTTING MEDICAID HURTS PEOPLE”** Describe what would happen to you or your family if you lost your Medicaid benefits.
- **“IT HURTS BUSINESS, TOO”** For every \$1 cut from Medicaid almost \$4 of business activity is reduced.
- **“PROTECT THE MEDICAID PROGRAM”** Ask Congress, Texas legislators, and policymakers to protect the Medicaid program because it matters to you and millions across the country.
- **“SLASHING MEDICAID MEANS LOST JOBS”** Cuts eliminate jobs, which will hurt the economy by pulling billions of dollars in health care spending out of our Texas communities.
- **“MEDICAID HAS BROAD PUBLIC SUPPORT”** According to a recent Kaiser Family Foundation poll, 60% of Americans want to maintain Medicaid, and only 13% support cuts to Medicaid.

MY MEDICAID MATTERS GOALS

- Educate Texans, Texas legislators, policymakers and Congress about the real people whose health, independence, families and jobs are supported by Texas Medicaid: children, mothers, Texans with disabilities, seniors—and the workers and professionals who assist them every day.
- Monitor and STOP damaging cuts, block grants, waivers or caps that will harm Texans, our families and our communities.
- Advocate for access to decent health care and community-based services and supports. Tell our leaders that deficit reduction and sustainable budgets **MUST** use a balanced approach that includes new revenues and does not rely on cuts alone. New revenues in the mix preserves the Medicaid, CHIP and Medicare services and supports that Texans count on!

For more information, contact: Joe Tate – Policy Specialist, Community **Now!**

1-830-305-0613 or tate392@gmail.com

To view the My Medicaid Matters brochures (*in English and Spanish*) visit us at:

www.communitynowfreedom.org

Helpful Resources, News You Can Use

Conferences

2012 TEXAS STATEWIDE INDEPENDENT LIVING CONFERENCE – April 22 – 24, 2012

Texas Statewide Independent Living Council - <http://www.txsilc.org/conference/>

ADDRESSING KEY LIFE TRANSITIONS FOR USERS OF AAC - March 24, 2012

Vanderbilt Kennedy Center: <http://kc.vanderbilt.edu/site/newsandevents/calendar/page.aspx?id=3126>

GOOD INTENTIONS AREN'T ENOUGH: TEACHING SOCIAL THINKING TO INDIVIDUALS ENTERING AND LIVING IN THE ADULT WORLD – February 9, 2012 & February 10, 2012

<http://www.socialthinking.com/workshops/workshops/houston-workshops>

February 9, 2012 – Preparing for the Transition into Adulthood

February 10, 2012 - Skills You Need to Learn in School to Help you Live as an Adult

LET'S ALL PLAY, INCLUSION IN RECREATIONAL PROGRAMS CONFERENCE – March 7 – 8, 2012

National Inclusion Project: http://www.inclusionproject.org/level_2.php?id=50

SCHOOL SUCCESS & BEHAVIORAL INTERVENTIONS IN ASD – March 5, 2012 & March 6, 2012

Spectrum Training Systems, Inc: <http://www.spectrumtrainingsystemsinc.com/plano.html>

March 5, 2012 - 6 Critical Elements for Teaching Individuals with ASD

March 6, 2012 - No More Meltdowns: Handling Challenging Behaviors & Teaching Social Skills

SURVIVE AND THRIVE WITH ADHD 24th ANNUAL CONFERENCE - February 17 -18, 2012

ADDA - Southern Region: <https://www.adda-sr.org/>

TEXAS ADVANCED LEADERSHIP AND ADVOCACY CONFERENCE (TALAC) - February 26 - 28, 2012

Center on Disability and Development, Texas A&M: <http://talac.tamu.edu/>

TEXAS GUARDIANSHIP ASSOCIATION 2012 ANNUAL CONFERENCE - April 18 – 20, 2012

Texas Guardianship Association: <http://texasguardianship.org/>

VOLUNTEER EXTRAVAGANZA AND ADVOCACY NETWORK TRAINING – Various Dates & Locations

Texas Parent to Parent: <http://www.txp2p.org/>

February 4, 2012 – North Richland Hills ▪ March 31, 2012 – Corpus Christi

Applicants Sought

2012 ADVOCATES IN DISABILITY AWARD (ADA) APPLICATION

The HSC Foundation: <http://www.hscfoundation.org/2012ADA.php>

Application deadline – February 28, 2012 (by 5:00pm EST)

AUTISM CAMPUS INCLUSION LEADERSHIP

The Autistic Self-Advocacy Network (ASAN)

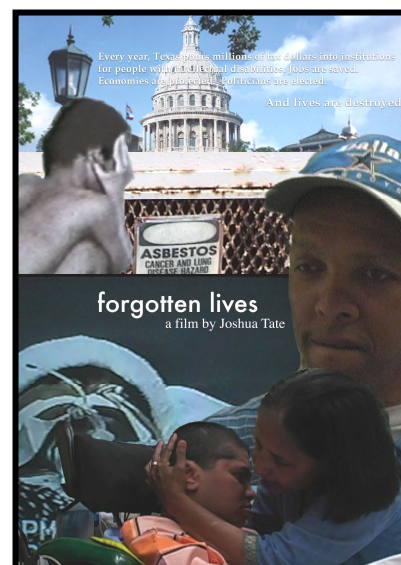
<http://myemail.constantcontact.com/ASAN-Invites-Autistic-Students-to-Participate-in-Leadership-Training.html?soid=1104220830834&aid=S09w4EH1lyA>

Application deadline – March 30, 2012



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

Building Community & Social Capital, Videos by Al Condeluci

Al Condeluci has been an advocate, a catalyst for building community capacities, and leader in understanding social culture since 1970.

Recently, he recorded several videos on the UCP/CLASS YouTube Channel. In Part 1 of this series, Al discusses inclusion and the four steps toward building a healthy and happy community. **View *Building Community with Al Condeluci- Four Critical Steps***. In Part 2 of the series, Al talks about how important it is to build relationships and walks you through the different levels of relationships with graphic cues. **View *Building Social Capital with Al Condeluci- Graphing Relationships***. To view the videos, visit: <http://www.youtube.com/watch?v=GY9gEKExsyE>

"INDEPENDENCE is not measured by the number of tasks we can do without assistance, but by the *quality of life* we can lead **WITH** assistance."

- Americans with Disabilities Act of 1990