

# 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 waist and abuse of a failed institutional system.

## Upcoming Community Now! activities...

- **January 24, 2011** ▪ Screening of the award-winning film: "*Forgotten Lives*." Speaking at the event in Austin will be Rep. Elliott Naishtat & Jeff Garrison-Tate. For more information: [cshanewalker@yahoo.com](mailto:cshanewalker@yahoo.com).
- **February 5, 2011** ▪ Screening of the award-winning film: "*Forgotten Lives*" in Longview facilitated by Jeff Garrison-Tate, founder of Community Now! For more information: [communitynowfreedom@gmail.com](mailto:communitynowfreedom@gmail.com).
- **February 5, 2011** ▪ Participation in the Greater Lewisville Special Education PTSA 4<sup>th</sup> Annual Special Needs Activities & Resource Fair. Be sure to stop by our table! For more information: <http://lisdseptsa.txpta.org/>.
- **February 15, 2011** ▪ A Case for Long Term-Care Reform Presentation – Greater Lewisville Special Education PTSA. For more information: [kevanson@grandecom.net](mailto:kevanson@grandecom.net)
- **March 1, 2011** ▪ **Save the date!** "*Texans March for Independence*" – INVEST IN COMMUNITY, NO CUTS! March, Rally, and Legislative Visits. Make plans now to attend. Check back soon for details...

Community Now! has active coalitions in the following area:  
Austin ▪ Dallas/Ft. Worth Area ▪ Corpus Christi ▪ Brazos County

To connect with the coalition in your community contact us:

[communitynowfreedom@gmail.com](mailto:communitynowfreedom@gmail.com). If you don't see a coalition in your areas, please let us know what we can do to help you get one started.

## Inside this Issue

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**NO CUTS TO COMMUNITY-BASED SERVICES – REFORM LONG-TERM CARE!**



## **Inclusion vs. Exclusion - Society is at a Turning Point**

By Jack Pearpoint

"Those who are members of society, and those who are marginalized from society, have a great need for each other's gifts. The sand of ordinary life is lived in community where people spend their days doing very ordinary things. They write, talk on telephones, teach children, play with babies, wash dishes, go for walks, read books, and cry on each other's shoulders. All of this happens in ordinary places on commonplace streets, all the time, everywhere. This very commonness is a real gift, a real benefit not to be ignored. The gift of surviving and growing through change belongs to the outcast. Living on the margin either bums you out and kills you, or it turns you into a dreamer, someone who really knows what sort of change will help and who can just about taste it; someone who is prepared to do anything to bring about change. If these dreamers are liberated, if they are brought back into the arms of society, they become the architects of the new community; a community that has a new capacity to support everyone's needs and interactions."

~ Judith Snow at Frontier College, October 1988, 89th Annual Meeting

Our society has reached a turning point where we must make decisions about values, direction and budgets. We no longer have the luxury of *buying* a piece of all the solutions - and thus never having to answer hard questions. The hard questions are about values - what do we believe in? What kind of future do we want for our children? How do we get there?

My analysis identifies two opposing trends, two waging factions inclusion versus exclusion. This dilemma is broader than "schooling" and education. Most post-industrialized societies have begun to come to terms with the fact of limited resources. The debate is between people who believe in exclusivity and those who believe in inclusion (egalitarian opportunity as the predominant value).

I believe that *inclusive* options (all welcome) will utilize the talents of people who would be discarded and written off in the *exclusive* model. The *outsiders* will bring new perspectives and new talents to *policy conundrums* where we are in a rut and need *fresh ideas*.

The meaning of a policy of exclusion is revealed by a *reliable* senior government official's retort when asked "What should we do about those who aren't in the *main* stream?" He responded partly in jest, partly in frustration: "We train the best, and shoot the rest." The comment was off-hand but identifies the dilemma.

**The unstated underlying assumptions of exclusion are, among others, that:**

- We are not all equal in capacity or value.
- It is not feasible to give equal opportunity.
- We must choose and thus train an elite who will take care of the rest.
- They will benefit through the trickle-down theory.

**Inclusion is the opposite and works from opposite assumptions:**

- We are unique in value; however, each has unique capacity.
- All people can learn.
- All people have contributions to make.

We have a responsibility and an opportunity to give every person the chance to make a contribution.

The criterion for inclusion is breathing, not IQ, income, color, race, sex or language.

**Critics of inclusion say:**

- It's too expensive.
- *They* can't learn.
- *They* don't know what's best for them.
- It can't be done.

**As a critic of exclusion, I say:**

- It's too expensive.
- *They* can learn.
- *They* - people - know a tremendous amount if asked.
- It can be done.

It is unethical, politically unacceptable and repugnant

to write off marginalized people in our society. The cost of welfare maintenance is unbearable, either socially or economically. In short, exclusion does not work.

The critics are right if our thinking and answers are limited to the solutions we already have in place. I want to think about a new system, one that replaces the old, not just reforms it. My vision of the new system is based on the value that *everyone belongs* - all welcome.

We all have the power to listen to voices that are seldom heard. If we choose to make the time, to learn to listen, and to struggle with the pain and frustration that disempowered people feel, we will see new visions, feel new energy, and find hope in our future. There is power in the powerless. We can be catalysts, or encrusted residue. The choice is ours.

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**“Our lives begin to end the day we become silent about the things that matter.”**

~ Martin Luther King, Jr.

## **NO Cuts to Community Based Services Long-Term Care Reform Needed!**

*Cindi Paschall, family member of an adult who lives life with a disability & member of Community Now!*

Texas leadership prides itself on fiscal responsibility. But when you consider spending patters in long-term care services for individuals who have an ID/DD in Texas one might notice an institutional bias as the driving force behind decisions made not fiscal responsibility.

Just the facts...

- Texas ranked 49<sup>th</sup> in the *4<sup>th</sup> Annual Case for Inclusion Report* which ranks all 50 States and the District of Columbia on how well they are providing community-based supports to Americans with intellectual and developmental disabilities being served by Medicaid.
- Texas has 13 institutions – more than any other state.
- There are over 300 children, 21 & under who live in a Texas State Supported Living Center, the name of Texas institutions previously known as State Schools.
- The Legislative Appropriations Request (LAR) for the next biennium shows decreased funding for community-based services. While the numbers of residents in a State Supported Living Center are expected to go down the amount the state spends per person in an institution goes up.
- Long-term care services provided in the community cost significantly less than services provided in a State Supported Living Center.
- Direct support personnel at State Supported Living Centers are paid higher wages than those providing the same services in the community.

Given the estimated \$27 billion dollar revenue shortfall in Texas there will be only so much money to go around. If Texas policymakers continue with current funding patterns the wait for community-based services will increase, funding for some individuals currently receiving services will be cut, and individuals who can't wait to have their needs met may be institutionalized. There is a better way and Community Now! needs your help! There is strength in numbers. *Alone we can do so little – together we can stop cuts to community-based services and reform the long-term care service system in Texas.*

# Community Now!

## Texas 82<sup>nd</sup> Legislative Recommendations for Long Term Care Reform

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- 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 Supportive 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 SSLC's 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 of 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 Joey Tate at: [tate392@gmail.com](mailto:tate392@gmail.com) or the Community Now@ email address: [communitynowfreedom@gmail.com](mailto:communitynowfreedom@gmail.com).

To learn more about Community Now! visit us online at:  
[www.communitynowfreedom.com](http://www.communitynowfreedom.com).





## BEYOND PROGRAMS: **A PARABLE**

Revised and edited from an original work by Michael McCarthy

Take from: <http://northstargallery.com/pages/quotes.htm>

In the beginning, there were placements, and lo we were happy for placements were not mandated for adults who happened to experience severe disabilities, and so, we said, this is good. And placements multiplied and filled our communities.

And then, we said, let us call these persons "clients" and make programs, which focus on serving their needs. And "clients" were defined and labeled, and grouped according to their labels and assigned to programs based on their labels.

And the professionals created services for each label, and state agencies developed unit costs for each service. And programs prospered and multiplied, and we said, this is very good. And many of the professionals began to earn a fine living in the rendering of service to their "clients." And programs multiplied, and we said, this is very, very good.

And as programs continued to multiply, a cry arose: "Let us evaluate our programs to see how good they really are." And program evaluation systems, state regulations, quality assurance committees, compliance plans, and other program measures were created. And they multiplied and filled volumes.

And in those times, a prophet arose who was also a "client", and said to us:

- "I don't want to be a "client," I want to be a person.
- I don't want a label, I want a name.
- I don't want services, I want support and help.
- I don't want a residential placement. I want a home.
- I don't want a day program. I want work that is meaningful and productive.
- I don't want to be "programmed" my whole life; I don't want to be controlled. I want freedom.
- I want to learn to do the things that I like, and to go places I want, when I want.
- I want to have fun and to enjoy life
- I want to have friends.
- I want to love and be loved.
- I want a family.
- I want to contribute.
- I want to live where I want and with whom I want.
- I want the same opportunities as all of you.
- I want to be happy
- I want freedom."

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"It should be a sobering reminder to us that, when the pioneers in our field undertook this task, despite the greatest good will and thoughtful deliberation they led to the development of modern institutional settings. In offering enormous benefits, their work led to the loss of everything important to their beneficiaries." ~Burton Blatt

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And there was a long silence.

And lo, we realized that we must look beyond our programs, our regulations and our labels. But we were deeply troubled, and asked: "What have we done? How can we do what the Prophet asks? Would not each person need their own unique program and system of support based on his own individual measure of its quality."

And the prophet replied: "Even as you say, so should it be done - just as you have done for yourselves."

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*The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy."*

~ Martin Luther King, Jr.

## Grassroots Advocacy Needed!

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Organizing people at the local level will be vital this session. Below are a few ways you can help.

**Educate yourself and others** - Community Now! has developed a power point presentation outlining the need for long-term care reform. If you would like us to present this information in your area contact us: [communitynowfreedom@gmail.com](mailto:communitynowfreedom@gmail.com). This is a great way to bring people together.

**Contact your Representative** - Share your concerns and ask if he/she supports long-term care reform including consolidation of State Supported Living Centers and rebalanced funding. If you don't know who your representative is visit: <http://www.fyi.legis.state.tx.us/>.

**Share your story** - Personal stories make a difference. Remember elected officials like to hear from those who are directly affected by their decisions. The closer a person is to the issue the more credibility their position is given.

- Send an Email, fax or letter (don't forget to include a picture). Pictures are worth a thousand words.
- Meet with your Representative; visit their local or Austin office
- Make a phone call
- Attend a hearing

**Attend a peaceful rally** – Join us on March 1<sup>st</sup> in Austin. Participants will march for independence, be inspired by speakers at the rally, and make Legislative visits. If you need help getting to Austin let us know. Community Now! may be able to offer a stipend to help with travel expenses.

**Sign the INVEST IN COMMUNITY! Campaign petition** – The **Invest in Community Campaign** is run by a coalition of organizations, families, and advocates (Advocates Round Table –ART) concerned about the impact of proposed cuts to community-based services for seniors and individuals who have a disability.

Community Now! is a member of the INVEST IN COMMUNITY Campaign and is working to obtain 100,000 signatures on a petition to present to the 82<sup>nd</sup> Legislature. The message:

**“We, the people of Texas, support home and community-based services and supports for people with disabilities and seniors. We call on the 82<sup>nd</sup> Texas Legislature to oppose any cuts to these critical supports and to fully fund all services that allow people with disabilities and seniors to live with dignity in the community.”**

*The deadline to obtain signatures is February 8, 2011.* For more information, to sign the petition on line or to print a copy of the petition to obtain hand written signatures, please visit:

<http://txp2p.org/InvestCommunity/index.html>.

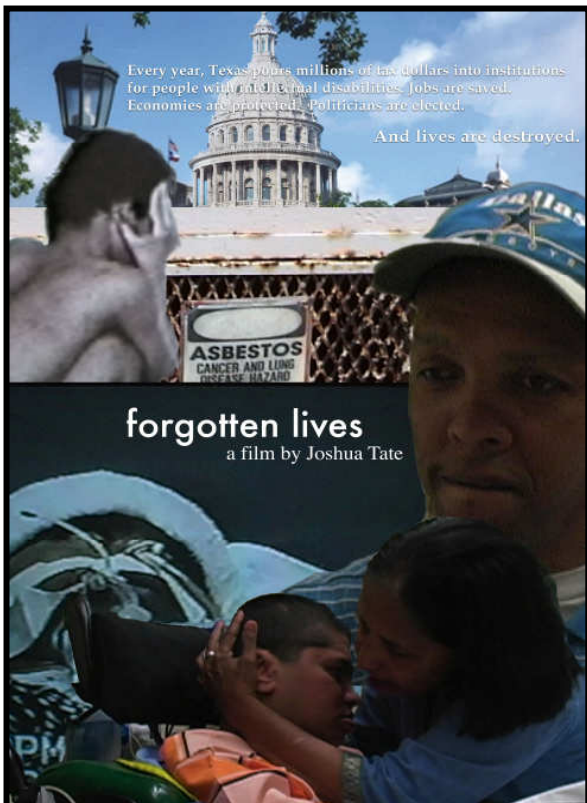
**Stay informed during the session** – Join the Community Now! Yahoo group or blog or visit us on Facebook. We will provide on-going information as it is available.

**Follow Legislation** – to follow Legislation from the time a bill is introduced until it becomes a law visit: Texas Legislature Online at: <http://www.capitol.state.tx.us/>.



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**In the end will remember not the words of our enemies, but the silence of our friends. ~ MLK, Jr.**



## 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.

Contact us to schedule a screening in your area or to purchase your own copy.  
[communitynowfreedom@att.net](mailto:communitynowfreedom@att.net)

All proceeds benefit Community NOW! and are tax deductible.

*"Truly eye-opening and alarming."*  
Chris Garcia, film critic, Austin American Statesman