

Long-Term Care Supports and Services For Individuals who have a Disability

A Case for Systems Reform

Cindi Paschall, DFW Area Coalition

Community Now!

Independence from waiting. Freedom from institutions.

www.communitynowfreedom.org



COMMUNITY NOW!

Who: People with Disabilities, Families and Advocates

What: We believe all people with disabilities should live in quality, accountable community settings and that state institution facilities should be down sized and dollars re-directed to fund community services.

Organization Structure: Statewide non-profit 501(c)(3) organization.

Funding: Accept private donations to support the Mission.

Texas Medicaid Waiver Programs, *Community-Based, Long Term Care Supports & Services*

What is a Medicaid Waiver?

- Medicaid Waiver Programs fund services that help people (of all ages) who have a disability, blindness, or who are aging, live in the community instead of an institutional setting.

What we know?

- There are 9 Medicaid Waiver Programs in Texas. Each program has different eligibility requirements, rules, service options, and funding amounts.

Texas Medicaid Waiver Programs, *Community-Based, Long Term Care Supports & Services*

- Estimated cost per person, per month varies per waiver. However costs are ***under \$5,000*** per month.
- There are over ***100,000 people waiting*** for services while their name remains on an “interest list”
- The average wait for services varies between ***4 – 9 years*** depending on the waiver program.

Texas Medicaid Waiver Programs, *Community-Based, Long Term Care Supports & Services*

- Texas ***ranked 49th*** on how well they are providing community-based supports to individuals who have intellectual and developmental disabilities being served by Medicaid.



Texas Medicaid Waiver Programs, *Community-Based, Long Term Care Supports & Services*

- **13,368 people** currently receiving community-based long-term care services or expected to receive services by the end of September 2011 are at risk of losing services in the next biennium (2012/13).



Texas Medicaid Waiver Programs, *Community-Based, Long Term Care Supports & Services*

- Some families have been unable to wait for community-based services and have placed their child in an institutional setting.

266	Small ICFMR	98	Nursing Facilities
54	Medium ICFMR	221	DFPS Facilities
40	Large ICFMR	307	SSLC

State Supported Living Centers

Institutionally Based, Congregate, Long-Term Care Supports & Services for individuals who have an I/DD

What we know?

- There are **13 large institutions** in Texas – more than any other state.
- The Department of Justice, Office of Civil Rights Department **found serious deficiencies** at multiple facilities, a long history of **abuse, neglect, and exploitation** and **failure to serve Facility residents in the most integrated setting appropriate to their individual needs.**

State Supported Living Centers

*Institutionally Based, Congregate, Long-Term Care Supports & Services
for Individuals who have an I/DD*

- The projected number of Facility residents continues to decrease while projected funding increases.

2011 - **4,098** residents | **\$13,149.85** per month/resident

2012 - **3,982** residents | **\$13,886.91** per month/resident

2013 - **3,686** residents | **\$14,662.52** per month/resident

State Supported Living Centers

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- \$ 474,660,142 – projected Facility maintenance costs through 2015

- Residents Level of Need – (LON)

5% Intermittent Care

39% Limited Care

35% Extensive Care

19% Pervasive Care

< 1% Pervasive + Care

So Why is Change Needed?

- \$27 billion dollar revenue shortfall
- Lots of competition for the limited resources
- There are over 100,000 people with disabilities waiting for community based services in Texas
- There is a potential loss of existing services
- Texas Ranks 49th on how well they provide community-based services

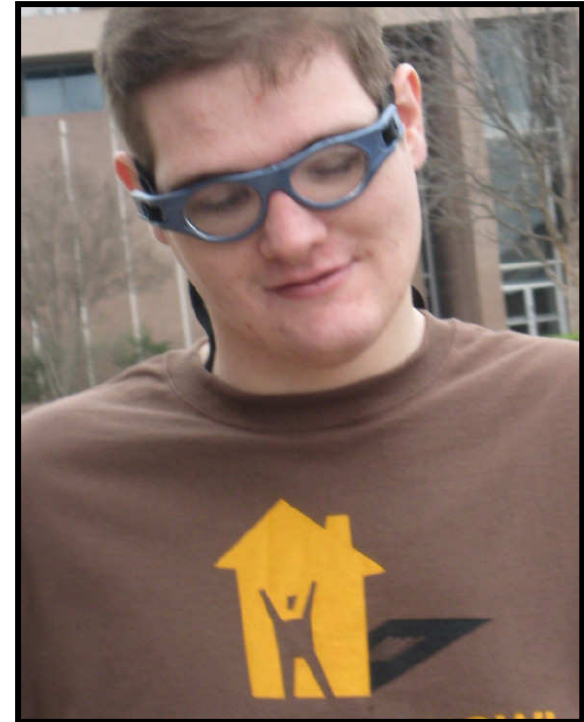
So Why is Change Needed?

- Services provided at a SSLC cost more than services provided in the community
- Facility residents are not served in the most integrated setting appropriate to their individual needs
- Funding for Facility maintenance could be redirected to fund supports & services instead of brick and mortar
- Continued reports of abuse, neglect & exploitation



“There is only one
success...

To be able to spend
your life in your own
way!” – C. Morley



**Everyone wants to have choice and
control over their lives.**



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:

- a) Develop a diversely represented Task Force to guide plan development.
- b) 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.
- c) Ensure supports and services for people living in the community are available, exceptional and accountable.



- a) 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.
- b) 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 SSLC's.
- c) Designate all funding saved through consolidation and closure of SSLC's 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. Expand Consumer Directed Services (CDS) options to all waiver services and ensure information on how to access these services is readily available and accessible.
4. Personal Care Attendants and other Direct Support Professionals must be paid a living wage of plus appropriate benefits.



What We Do?

- Support efforts to assist people who want to leave State Institutions and move into their communities.
- Support educational demonstrations that encourage immediate action by key Statewide leaders.
- Educate the community through multi-media presentations regarding the abuse in Texas' institutions, lack of accountability and the need for long-term care reform.



- Help produce documentary films to expose the abuse, lack of accountability, and institutional failures in Texas.
- Provide on-going information about the need for long-term care reform, including the reduction of "interest" lists, known as a waiting list, and the closure and consolidation of Texas institutions.
- Organize local Community Now! networks.
- Provide small, one-time grants, up to \$250.00 to individuals who leave a Texas institution to live in their community. The “Free Hasseb Fund” Grants provide an opportunity for an individual to purchase a house warming item of their choice.



What You Can Do?

Take Action – Raise Your Voice!

- ✓ Attend a hearing
- ✓ Meet with your legislator
- ✓ Attend a peaceful rally
- ✓ Make a phone call
- ✓ Schedule a COMMUNITY **NOW!** presentation/screening
- ✓ Send an Email or Fax a letter
- ✓ Connect with COMMUNITY **NOW!**
 - Website
 - Yahoo group
 - Facebook
 - Blog



COMMUNITY **NOW!**

To quote Senator Juan Hinojosa, D-McAllen,
"It's important to put a face behind the cuts so that when we make decisions, we understand the full implications of our decisions."

