

The Family Support Network

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51st in the Nation!!

ICDD Exposes "Gaps" and Proposes "Blueprint for System Redesign" Now is the Time to For Change in Illinois

Where are we? Where do we want to be?

We've known for a long time that services for people with disabilities in Illinois are not what they should be.

We know that **people in desperate need wait too long.**

We know that we often **can't get needed services until a family is broken**, an individual's needs have grown far worse, or a parent has died.

We know our system is most **often incapable of supporting people with disabilities or their caring families while they are still strong.**

We know that when that moment of crisis does come, **choices are limited and often far from family and friends.**

The Illinois Council on Developmental Disabilities has taken an important and courageous step by investing in the **"Gaps Analysis" and the "Blueprint for System Redesign in Illinois"**.

The **"Gaps Analysis" identifies "benchmarks"** or minimum requirements for Illinois to be **at least average** as compared to our other forty-nine states and the District of Colombia.

The analysis **summarizes and verifies the many problems that all of us experience:** people living too far from home, having to wait too long for services, having to live with too many people and in segregated settings, not being able to have real jobs in the community, providers stretched beyond their limits by inadequate reimbursement for services.

The **"Blueprint" proposes a seven-year plan** for re-alignment and new investment in services for our loved ones with disabilities in Illinois.

How Embarrassing Can It Be?

How Heartbreaking Can It Be?

According to the newest "State of the States" study by David Braddock of Colorado University, Illinois now ranks **51st in the nation** in numbers of people with developmental disabilities living in settings of 6 or less. How would you feel, how would you behave if you were forced to share a bedroom with someone you didn't even get to choose?

The PUNS Tells Us People Are Waiting!

Current information (Feb 2009) from the Prioritization of Urgency of Need for Services (PUNS) tells us that over **16,611 people are in need of services!**

Our Providers Are Struggling!

Rates do not reflect even close to the real cost of providing services. They struggle to provide quality services in a severely dehydrated system.

A Living Museum of Antique Services

We create new programs. We never give up old ones. People live segregated, expensive lives behind tall fences. Illinois supports 2,500 people with disabilities in State Operated Developmental Centers, third in the nation behind Iowa and New Jersey.

Howe Developmental Center in Tinley Park has been de-certified by the Feds because of findings of abuse and neglect and **twenty-two suspicious deaths.** Illinois now pays 100% of the cost of services there averaging \$169,000 per resident.

This IS About You!

It's hard hearing bad news. It's tempting to hide under your pillow. But, these documents cannot be ignored. Your future and the futures of our loved ones count on your advocacy NOW!

What You Can Do

Read and become familiar with both the “Gaps Analysis” and the “Blueprint”. Both documents can be reviewed in their entirety at www.state.il.us/agency/ICDD.

Call and/or meet with your legislators and the Governor. Ask them to read, understand, and support both documents.

Tell them your family's future depends on their ACTIVE support.

All the help you need is online at the Family Support Network's website; www.familysupportnetwork.org.

Please help. Only working together can we become the change we want to be.

Summer 2008**Dear Family Support Members:**

I was thrilled when Charlotte asked me to write a brief introduction to this newsletter. The Family Support Network has always been a wonderful partner in working on issues important to people with disabilities and their families. This is just one more way to highlight our partnership.

I am equally excited that the Family Support Network is dedicating their newsletter to The *Blueprint for System Redesign in Illinois*.

The Illinois Council on Developmental Disabilities (ICDD) has been concerned for a long time, as many of you have been, about the current status and the future of the state's service delivery system. With limited resources, a system that relies heavily on large congregate settings, and a growing waiting list, we see a looming crisis for our state. To avoid this crisis, ICDD wanted to offer a plan for the future, which is how the *Blueprint for System Redesign in Illinois* came into existence.

The Illinois Council on Developmental Disabilities partnered with Human Services Research Institute (HSRI) for this important project. The *Blueprint* is intended to serve as a concrete system redesign action plan for reducing Illinois' over reliance on large congregate care facilities and increasing access to quality supports in the community. The *Blueprint* outlines a 7 year action plan.

With the most recent State of the States data, we learned that Illinois now ranks 51st in supporting people with developmental disabilities in settings of 6 people or less. As a fairly wealthy state, this is embarrassing.

We hope that you will join us on our crusade. We must educate policy-makers and others on the positive and productive path necessary for our future. We are at a crossroads. We have a choice in moving forward. We must work together to make it a reality.

As a nation, we believe in independence, freedom and the principle that “all men are created equal.” We live in the Land of Lincoln, where we take particular pride in our commitment to these principles. Yet Illinois lags behind nearly every other state on measures important to providing people with developmental disabilities the basic constitutional freedoms available to Americans. We can do better, and working together - we will do better. Gathering support for implementation of this *Blueprint* is one real step we can take now to ensure a better future.

Best Wishes and Thank You!

Sheila Romano

Sheila Romano, Executive Director, Illinois Council on Developmental Disabilities



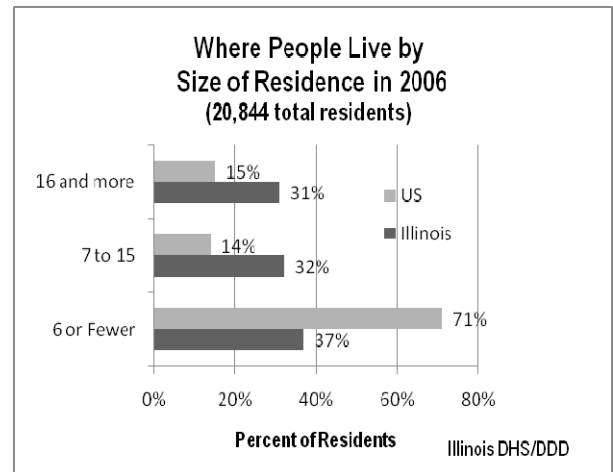
The Blueprint for System Redesign in Illinois

Illinois is at a crossroads. Currently, Illinois serves more than 20,000 people with developmental disabilities through a network of both dispersed community-living services and large congregate care facilities. Moving forward, fiscal and policy patterns must change significantly. Action must be taken to assure that the state utilizes its economic resources efficiently so that present and future citizens with developmental disabilities have the opportunity like any other person; to live, work and play in their communities with the services they need.

A recent review of this system shows that:

1. Illinois lags behind nearly all other states in allocating needed funding for services for people with developmental disabilities and in providing these services in the most integrated settings.

- The system relies too heavily on large facilities that segregate individuals from the community. As shown, 63 percent of those receiving residential services live in facilities of seven or more people as compared to 29 percent nationally.
- The effects on the system are worsened by Illinois' overall lack of investment in developmental disability services. Despite wealth of state, studies show that Illinois' fiscal effort is constantly below the national average.



- The investments Illinois does make are inefficient. Larger facilities are more expensive to operate than smaller community options. Conservatively, the average cost per person living in a State Operated Developmental Centers (SODC) is about \$125,000 per year. Average annual cost per person living in a community residence are less than half that, and even less if the person can receive supports to live at home with family. While individual circumstances vary, overall the state pays a higher cost per individual served supporting fewer people than it might if the funds were reallocated towards community services.

2. If the present community system receives enough resources through proper allocation of funds, it is possible to provide person-centered services and meet the needs of individuals with developmental disabilities.

- Illinois does not provide services with reasonable promptness to its existing citizens with developmental disabilities. Of more than the 16,611 people on the waiting list, approximately 11,428 presently have a "critical" or "emergency" need for services. This number is expected to swell to at least 14,000 by 2014.
- The system does not operate effectively to provide the "person-centered" services with the best chance of resulting in preferred outcomes related to employment and community integration.
- The current community system lacks resources to support people with complex medical needs and behavioral difficulties, help people access the system, coordinate services and assess performance.

Call to Action

In response, ICDD and HSRI call for Illinois policymakers to take significant and prompt action to redesign the current service system.

Sixteen action steps are recommended related to six system redesign areas and will help lead to change, with specific focus on the importance of investment in individuals, families and communities.

Key actions include a commitment to:

- Eliminate the service "wait list" by 2014 by supporting about 2,300 additional individuals annually.
- Invest heavily in "in-home" supports so that individuals can stay at home with their families or live in the community with

needed supports.

- Downsize the number of people currently living in the state's nine SODCs. If action were taken now, by 2014 this would reduce the number of people with disabilities in SODCs by 1,051, allowing five of the nine SODCs to close.
- Enact "Money Follows the Person" legislation to help individuals transition from residence in Intermediate Care Facilities for the Developmentally Disabled (ICF/DDs), SODCs and nursing homes into alternative community residences such as apartments, houses, etc.
- Offer financial incentives for service providers who operate large community facilities (i.e., ICF/DDs) to transition into alternative service venues.
- Strengthen the existing community services system by:
 - Emphasizing and adequately funding services that promote preferred "person-centered" outcomes related to community integration and employment.
 - Improving wages and working conditions for employees, helping community service agencies attract a stable and competent direct support labor force.
 - Expanding community support for people with all types of developmental disabilities, including those with challenging behavior and extensive medical needs.
 - Promoting improved access to services and service coordination to assure that the system is utilized more efficiently and that individuals get the support they need, no more and no less.
 - Implementing individual budget allocation practices to help ensure that funds are spent based on individual needs, rather than on predetermined types of services.

It is entirely feasible for Illinois to implement each of the action steps that are recommended. In contrast, inaction will result in serious negative consequences for people with developmental disabilities.

How Bad is the Need? The "PUNS" Tells Us!

In 2003, advocates celebrated a historic victory when a bill was passed by the Illinois General Assembly creating a cross-disability database or waiting list for services for people with disabilities in Illinois.

In November of 2005, the State began officially gathering information for persons with developmental disabilities using a survey tool called the **Prioritization of Urgency of Need for Services (PUNS)**.

The "PUNS" allows us to have accurate information to use as advocates as we talk to our policymakers. The "PUNS" provides the state with important information as new programs and services are developed. **The "PUNS" will now be the tool the state uses as it decides who will receive services on an individual basis.**

Current and expanded PUNS Data can be found at: <http://www.dhs.state.il.us/page.aspx?item=31193>

- 23,460** people enrolled in PUNS (Prioritization of Urgency of Need for Services)
- 16,611** people still in need of services
- 5,934** people are in emergency need of out-of-home 24-hour residential care
- 1,436** people have a caregiver who will be unable to work if services are not provided
- 13,118** people have transportation needs
- 4,725** people need support to work either in the community or in a disability setting
- 3,545** people with DD are living with caregivers between the ages of 60 and 80
- 609** people with DD are living with caregivers 80 or older