faces of change

2008 progress report

VALUE PEOPLE

Illinois Council on Developmental Disabilities

INVEST IN SUCCESS

building a better Illinois for people with developmental disabilities

amplifying voices and promoting capabilities

The Illinois Council on Developmental Disabilities is dedicated to promoting the best interest of people with developmental disabilities through education, outreach and investing in initiatives that improve the quality of life for all Illinoisans with developmental disabilities, from birth through adulthood.

The Council is proud to enhance the quality of life for all individuals with developmental disabilities.

Our mission statement:

"We help lead change in Illinois so all people with developmental disabilities exercise their right to equal opportunity and freedom."

Council members come from diverse backgrounds and include people with developmental disabilities and their families, representatives from various government agencies, service providers and advocates. Council members oversee a variety of initiatives that help ensure people with developmental disabilities have the right to choose and receive the community supports they need.

The Council works hard to amplify the voices of individuals with developmental disabilities and their families because, ultimately, the quality of the state's system determines the quality of their lives. The Council recognizes and promotes the capabilities of people living with developmental disabilities. Collectively, their many voices will force real system change.

The Council invests in people and the organizations that serve people with developmental disabilities throughout the state of Illinois. The Council supports the rights of all individuals as equal citizens of Illinois and assists those who need the Council's support for quality services and opportunities.

The Council is administered by the Federal Administration on Developmental Disabilities, and was created under a federal mandate in 1974 as an amendment to the Developmental Disabilities Assistance and Bill of Rights Act.

Lisa Cesal, 32

from the director

the faces of change are all around us

Dear Friend,

As a new year begins, the Council is looking to a brighter future of equal opportunity, freedom and choice for Illinoisans with developmental disabilities.

Over the last year, scores of individuals with developmental disabilities realized the opportunity to live more independently. Their quality of life is improved as they experience additional supports and services. This is the change we are seeking.

The Council believes individuals with developmental disabilities have the right to live free and independent lives. Thanks to your tireless efforts, the faces of change can be seen in many forms.

As we embark upon a new year with fresh challenges, an even better future for people with developmental disabilities in Illinois is on the horizon. All individuals can and should lead full lives in the community. They can go to school in their community, excel in careers of their choice and benefit from the freedom to succeed. They deserve better than the status quo, and with your steadfast support and efforts we can continue to find new ways to improve the quality of life for all Illinoisans.

Moving forward, the Council is working to craft new partnerships across the state to create a coalition of groups with one focus in mind: the best interest of people with developmental disabilities. We ask that you support the programs, organizations and groups who share this view.

In the following pages, we offer you a glimpse of the change that has resulted from the efforts by the Council. Together, let's multiply the faces of change.

Sincerely,

Sheila Romano

Executive Director
Illinois Council on Developmental Disabilities

chairperson's corner

state's system approaching a 'Tipping Point'

Dear Friend,

In his book, *The Tipping Point*, Malcolm Gladwell defines a "tipping point" as the moment when things happen so rapidly that it seems like everything can change all at once.

Recent events have led me to believe that Illinois might be approaching a tipping point — away from over-reliance on institutions toward individually tailored, quality services that allow people with developmental disabilities to make their own life choices.

Consider these recent occurrences:

- A tentative settlement was reached in the Ligas v. Maram lawsuit filed on behalf of individuals with developmental disabilities who are forced to live in private institutions. The settlement agreement, if approved by a federal court, will give individuals the choice to receive long-term care services in integrated community settings.
- Last September, State officials announced their intention to close Howe Developmental Center in Tinley Park due to the mistreatment of residents and the loss of federal matching funds to operate the facility.
- The U.S. Department of Justice continues its investigation into possible civil rights violations at Howe and another institution in Anna, the Choate Developmental Center. Past DOJ investigations in other states have resulted in systemic changes that favor transitioning people out of institutions.

Is Illinois approaching a tipping point?

If so, we need to be prepared with a transition plan that is practical and economically sound, and that embodies fundamental principles of "life, liberty and the pursuit of happiness" for all. Fortunately the Council has developed such a plan. It's called the *Blueprint for System Redesign in Illinois* and you will find more information on it in this report.

I encourage you to become familiar with the *Blueprint*. Read it. Study it. Advocate for it.

Sincerely,

Lester T. Pritchard

Chairperson
Illinois Council on Developmental Disabilities

"Illinois has relied much too heavily on expensive, large-scale institutions to care for its developmentally disabled residents…most developmentally disabled residents flourish in smaller, community-based settings. Many people are able to integrate into the community and work outside the home."

– *Chicago Tribune Editorial* 9.13.2008

The Corral family: Miguel, Veronica and Irma

faces of change

2008: a monumental year

For many Illinoisans with developmental disabilities, change was far more than a campaign theme in 2008. Change was the reality of their lives.

From Chicago and the surrounding suburbs to the Quad Cities and Mt. Vernon, individuals with developmental disabilities had the opportunity to live in their own communities near their families and loved ones. The Council over the last year expanded its reach, building awareness about the abilities of Illinoisans with developmental disabilities and investing in initiatives on youth advocacy, employment and a range of other quality of life issues.

Along the way, the Council held a series of town hall meetings across Illinois, in cities such as Champaign, Peoria and Rockford, to promote its plan for change called the *Blueprint for System Redesign in Illinois*. These meetings drew the interest of hundreds of self-advocates and their families as well as state lawmakers, other stakeholders and local media.

What are the faces of change? They are the people, advocacy and support groups and other stakeholders who worked together over the last year to improve the lives of people with developmental disabilities. The Council is proud to have brought these various interests together behind a common mission: building system change. The faces of change may be seen in additional options, greater opportunity and the most integrated living opportunities possible for people with developmental disabilities.

In 2008, the Council facilitated that change by advocating, planning, investing, organizing, educating and working with stakeholders to promote the best interest of people with developmental disabilities. Ultimately, the Council helped implement that change by giving people with developmental disabilities the skills and supports to accomplish their goals.

Change is not just about improving and expanding programs and options. It's about helping people reach their dreams. In these pages, behold some of the faces of change.

Jason Nosbaum, 24

a blueprint for change

focusing on a realistic plan to accomplish real change — freedom of choice for all people with developmental disabilities

The system is broken. In 2008, the list of people with developmental disabilities waiting for the supports and services they need surpassed 15,000 — an unfortunate, but extraordinary, benchmark.

Illinois substantially lags behind nearly all other states in providing more integrated settings. Illinois institutionalizes more people with developmental disabilities than any other state. Illinois spends a smaller share of its money on community-based supports than any other state in the nation. This is not acceptable.

The *Blueprint for System Redesign in Illinois*, Illinois' framework for change, represents a comprehensive yet realistic strategy to end the status quo and implement a system that truly works for people with developmental disabilities and also for taxpayers.

The *Blueprint* calls for an increase in services that will eliminate the state's waiting list, meaning more than 15,000 Illinoisans with developmental disabilities will finally have the supports and services they need.

This past year, the Council successfully executed the "Get to Know the Blue" town hall meeting campaign, educating legislators, advocates and the media about the benefits of the *Blueprint*. The Council also conducted educational briefing meetings with numerous members of the Illinois General Assembly to help build awareness about the issues facing people with developmental disabilities.

The *Blueprint* outlines a comprehensive, seven-year action plan through which the state can modernize and streamline services for some 200,000 people with developmental disabilities. Illinois can better serve these individuals at a lower average per capita cost to the state, and the *Blueprint* describes how to do that.

The *Blueprint* is a 21st century solution to a crisis in need of this state's attention. For more information, visit **www.GetToKnowTheBlue.org**.

"The *Blueprint* gives me hope."

– Lorraine McCormick, mom of Brenden McCormick

changing Illinois' future

helping to 'dream big'

Through the Council's support of two community initiatives, Illinois' youth with developmental disabilities are talking about their dreams and taking control of their futures. They are learning to make a difference in their lives and communities. Youth advocacy projects are empowering young people not only to have dreams, but also to chase and accomplish those dreams.

Project MY VOICE

Change is apparent in Project MY VOICE, a three-year project funded by the Council. A collaboration between Indian Prairie School District #204 and Northern Illinois University, Project MY VOICE is preparing youth with developmental disabilities to become self-advocates.

Through MY VOICE, 75 youth (ages 16–21) will learn how to use multimedia. Presentations of videos, pictures and music are prepared to reflect their life goals. The students use these presentations to lead the discussion at their IEP meeting. As their hopes and dreams change, so do their presentations.

"They dream big," says Toni Van Laarhoven, Project Director. "They test stuff out and begin to realize what they want out of life and how they can make these goals happen.

Pathways to Independence

From making a new friend to planning a party at school, the students of Pathways to Independence, a unique self-advocacy project based in Chicago's western suburbs, are learning how to achieve their goals through self-advocacy.

This two-year investment of the Council, in partnership with the West Suburban Chamber of Commerce & Industry, has created change by helping young adults (ages 16–24) with developmental disabilities, achieve maximum self-advocacy and goal-building skills. Since the project's inception in June 2007, family members and school staff have noticed positive change in the project's 60 participants. Over the summer, all the participants attended a two-week advocacy academy to learn how to advocate for what they want.

"Students are speaking up more, showing more confidence and demonstrating better skill sets," says Program Administrator Karen Steffan. "They no longer hope to be heard — they expect it."

"Our students love the fact that people are actually listening to what they want. They really look up to the college students."
– Toni Van Laarhoven

Nelly Aguilar and son Jason Andre, 8

Mary Phillips, 49
John Lammanis, 43

advocacy through empowerment

working to change lives

Finding work is tough in this economy, particularly for people with developmental disabilities. But just like everyone else, individuals with developmental disabilities simply want to live independently and have their own jobs. Thanks to grants from the Council, two groups are working to secure employment for individuals with developmental disabilities.

Individual Advocacy Group

Individual Advocacy Group has successfully found work for several "dual" individuals — people with both developmental disabilities and mental illness — by pairing a focus on mental health with traditional supports for people with developmental disabilities. IAG has helped find jobs for 13 individuals in Chicago, the western suburbs and Sandwich. At least three of the people, who live in small group settings, have found jobs in food service.

"We wanted to work with people who have a developmental disability and who also have a significant mental health component," says Dr. Charlene Bennett, who co-founded IAG in 1995. "We're looking at new techniques and ways of getting them employment by looking at the developmental disabilities side and employing mental health supports at the same time."

Rural Illinois Customized Employment Sustainability Project

Agencies helping people with developmental disabilities in rural Illinois communities have unique issues with placing individuals in competitive and meaningful employment. Thanks to a Council investment, a collaboration called the Rural Illinois Customized Employment Sustainability Project is underway to help individuals obtain jobs in rural communities. The project builds on existing efforts in four communities and is aimed at growing the focus in four more.

"Through our customized employment approach, we assess the interests and abilities of each individual. We review that information with the individual, family and employment staff, and then we develop a plan to answer a particular business need within the community," says Marsie Frawley, a Senior Policy Analyst with Health & Disability Advocates.

Health & Disability Advocates is working together with national consulting firms Mark Gold and Associates and Griffin-Hammis Associates LLC to foster customized employment options. The project will ultimately provide training and technical assistance to eight vocational providers and their rural communities to build capacity to provide customized employment. Ultimately, 32 individuals will become employed or self-employed.

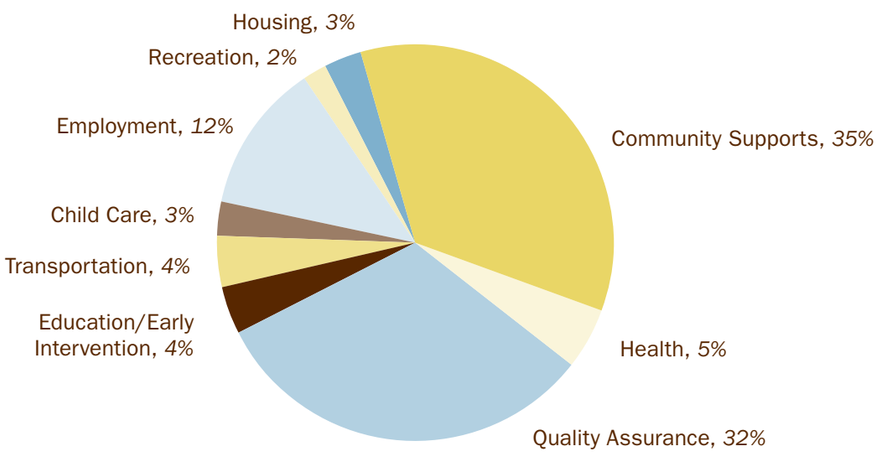
"Working at the restaurant has given me the opportunity to make new friends and be able to think about the possibilities in my future, like getting married, buying my own home and being more productive in my life."

- Sue Nykaza, 27, Bolingbrook
  Individual Advocacy Group member

making an investment for change

supporting community needs

Every Five-Year State Plan outlines the Council's goals and must be submitted to the Council's federal funding entity for approval. Each investment chosen by the Council must directly correlate to the goals outlined in the plan. Through these investments, the Council directs its resources and focus towards a wide variety of initiatives. These initiatives help improve the quality of life and meet the needs of people with developmental disabilities across the state and promote system change.



In 2008, the Council made investments in the following areas of emphasis: Child Care, Community Supports, Education/Early Intervention, Employment, Health, Housing, Quality Assurance, Recreation and Transportation.

2008 Budget: $2,982,298.95
(October 1, 2007 – September 30, 2008)

the building blocks for change

investments that make a difference

Child Care
Parents of children with developmental disabilities depend on properly trained childcare providers to educate and assist with the development of their child. The Council aids parents of children with developmental disabilities in finding the appropriate resources, while providing a peace of mind for all family members.

Education/Early Intervention
In Illinois, full inclusion in school classrooms is still a work in progress. Individuals with developmental disabilities are capable of succeeding in school when given the opportunity. The Council envisions a future where, together, school districts and universities provide an education with infinite opportunities for all individuals.

Health
The Council works with key organizations and leaders in the health care industry to ensure that the best possible health care is available for people with developmental disabilities now and in the future.

Quality Assurance
Individuals with developmental disabilities want the option to choose their future and improve their quality of life. The Council believes that in order to break through barriers, self-advocacy and leadership can help mobilize people with developmental disabilities to achieve success.

Transportation
Reliable and convenient transportation continues to be a major obstacle for people with developmental disabilities. The Council envisions more accessible transportation options statewide through the help of various funding projects.

Community Supports
The Council continues to push for a future of inclusion for people with developmental disabilities in communities throughout Illinois. Community supports are more efficient for Illinois taxpayers and offer people with developmental disabilities the opportunity to live where they choose.

Employment
Individuals with developmental disabilities deserve the opportunity to excel in the workplace. The Council envisions an Illinois where organizations help connect motivated individuals to businesses that recognize the benefits of hiring people with developmental disabilities.

Housing
Thousands of individuals with developmental disabilities dream about living in their own apartment or owning their own home. The Council believes that every person with a developmental disability has the right to decide where to live and with whom, and envisions a future where these decisions can be made freely.

Recreation
The Council supports programs for individuals with developmental disabilities that promote a healthy mind and body. People with developmental disabilities should not be relegated to the sidelines, but rather asked to partake in enjoyable, recreational activities in their communities.

Partners

The Arc of Illinois
CKPR
DePaul University Office of Sponsored Programs
Health and Disability Advocates
The Hope School
Human Services Research Institute
Human Support Services
Illinois State University
Individual Advocacy Group, Inc.
Little City Foundation
Macon Resources, Inc.
National Association of State Directors of Developmental Disabilities Services (NASDDDS)
Niles Township District 219
Northern Illinois University
Public Policy Impacts of Washington D.C.
Serafin & Associates, Inc.
Support Development Associates
South Suburban Training and Rehabilitation Services
Tony Records & Associates
Two Rivers Regional Council of Public Officials
University of Colorado
University of Illinois at Chicago – Department of Disability and Human Development
University of Minnesota
West Suburban Chamber of Commerce & Industry Fund

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Illinois Department of Healthcare and Family Services
Illinois Department Human Services – Community Health & Prevention
Illinois Department Human Services – Division of Developmental Disabilities
Illinois Department Human Services – Division of Rehabilitation Services
Illinois Department on Aging
Illinois Governor's Office of Management & Budget
Illinois State Board of Education
University of Illinois at Chicago – Department of Disability and Human Development

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