blueprint

for
System Redesign
in Illinois

Executive Summary

January 2008

Human Services Research Institute

7420 SW Bridgeport Road Suite #210
Portland Oregon 97224
Voice: 503-924-3783 fax: 503-924-3789
www.hsri.org

Prepared in partnership with
the Illinois Council on Developmental Disabilities

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A Blueprint for System Redesign in Illinois

Executive Summary

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Gary Smith, John M. Agosta and Jaime Daignault
Contributors: Eric S. Zaharia and Ernest McKenney

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Portland, Oregon 97224
503-924-3783

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About the Authors

The Human Services Research Institute (HSRI) was founded in 1976 and is a non-profit, tax-exempt corporation. For over 30 years, HSRI has assisted states and the federal government to enhance services and supports to improve the lives of vulnerable citizens, such as those with developmental disabilities or mental illness, or low income families. HSRI has provided consultation in such areas as strategic planning and organizational change, funding, systems integration, quality management and assurance, program evaluation, evidence-based practices, family support, self-advocacy, self-determination, and workforce development. For more information, go to: www.hsri.org.

HSRI has offices located in Cambridge, Massachusetts and Portland, Oregon. This *Blueprint* was prepared by these three staff of the Oregon office:

Gary Smith joined HSRI in 2001 and serves as a Senior Policy Fellow. He has worked in the human services arena for over 30 years, concentrating on policy analysis and advocating for policy changes to promote person-centered services and supports in the community. He is a nationally recognized expert regarding Medicaid-financed long-term services, focusing on federal and state policies that affect individuals with developmental and other disabilities. Mr. Smith has conducted major projects on behalf of the Centers for Medicare & Medicaid Services (CMS), including *National HCBS Quality Inventory* and the revision to the HCBS waiver application, including the preparation of the accompanying instructions and technical guidance. Mr. Smith also has conducted major technical assistance engagements on behalf of several states, such as California, Colorado, Georgia, Louisiana, North Carolina, Tennessee and others.

John Agosta is an HSRI Vice President. He completed his doctorate in Rehabilitation Research at the University of Oregon, specializing in research methods and community supports for people with disabilities. Employed at HSRI since 1983, he has been involved with nearly all efforts at HSRI surrounding family support issues, facilitated development of strategic plans, conducted analyses of state systems for people with developmental disabilities (e.g., Arkansas, Idaho, Oregon, Hawaii), and has studied specific facets of the field (e.g., trends in supported employment, managed care, self-determination). He is a nationally recognized expert in topic areas such as family support, self directed supports and community systems regarding policies that affect individuals with developmental disabilities.

Jamie Daignault is a Policy Associate at HSRI. With a graduate degree in Special Education and an undergraduate degree in Family and Human Services, she has worked in the field for several years in both direct service and research capacities. Her primary responsibilities at HSRI presently involve project coordination. Currently, for example, she coordinates a project providing technical assistance to states rebalancing their long-term care systems funded by the Centers for Medicaid and Medicare Services, serves as an instructor for the Self-Advocate Leadership Network, and is co-founder of *The Riot!*, a national e-newsletter written by and for self-advocates.

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In Memoriam
Gary Smith

It is with great sadness that we must inform you that Gary Smith passed away on November 4, 2007. Gary joined the Human Services Research Institute in 2001 and served as a Senior Policy Fellow. He was the lead author in compiling this *Blueprint* and other products related to this project.

In fact, this work was among his very last and was special to him. One of his first jobs in public service after leaving the Navy all those years ago was as staff to Governor Jim Thompson. In the mid 1970s he provided budget analysis and oversight for several major state agencies and programs, including developmental disabilities, mental health, public health, Medicaid, and corrections. Because of that experience we understood his strong connection and dedication to this project. And so, from that beginning to this end, the circle is completed.

Overall, Gary was a towering figure in the developmental disabilities field. His prodigious knowledge of Medicaid financing to help fund human services programs and his understanding of the rich history of our field were unmatched. He was a resource to hundreds of people around the country in so many different ways. He was always generous with his time and his expertise and never let an email request for help go unanswered.

More than that, he was committed to what we do and to the well being of people with disabilities. He was constantly trying to exhort us all to do better.

He was a dear friend, one of the funniest and most decent people any have ever met. We will miss him terribly as will all who worked with him.

Please spend a moment to remember Gary Smith.

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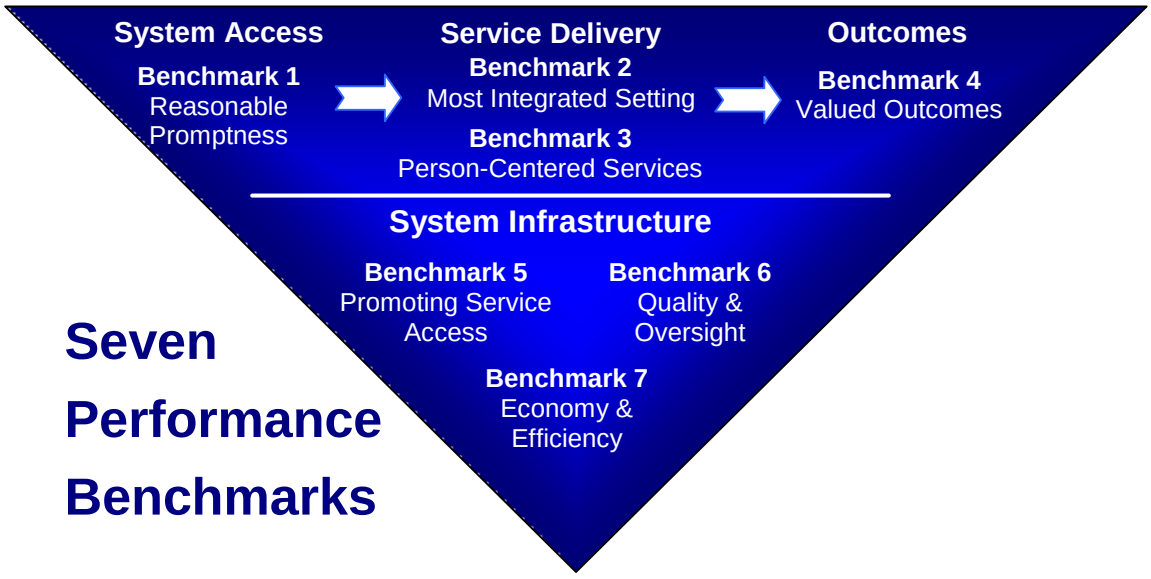
Executive Summary

The Illinois Council on Developmental Disabilities (ICDD) engaged the Human Services Research Institute (HSRI) to develop a *Blueprint for System Redesign.* The *Blueprint* is intended as a concrete system redesign action plan for reducing Illinois' over reliance on serving people with developmental disabilities in large congregate care facilities and increasing access to quality supports in the community. The *Blueprint* outlines an action plan for the next **seven years** to reconfigure the Illinois system to more effectively support people with developmental disabilities and families in their communities.

The *Blueprint* is the third and final report in a series of three reports prepared by HSRI. In its first report (*Illinois System Environmental Scan Project Brief*), HSRI reported the results of its interviews of Illinois stakeholders concerning the state's efforts to support its citizens with developmental disabilities. The second report (*Gap Analysis: Services and Supports for People with Developmental Disabilities in Illinois*) appraises the present performance and capabilities of the Illinois developmental disabilities service system.

Blueprint Framework

There are seven fundamental, top-level performance benchmarks that may be applied to the provision of publicly-funded services and supports for people with developmental disabilities. As illustrated by the following graphic, Benchmarks 1-4 generally concern system performance dimensions related to gaining entrance to the system, service delivery and associated outcomes. Benchmarks 5-7 concern system infrastructure or the operational elements that under gird the system. These performance benchmarks framed the HSRI *Gap Analysis* and are carried over to the *Blueprint:*



1. People with developmental disabilities have access to and receive necessary publicly-funded services and supports with reasonable promptness.
2. Services and supports are provided in the most integrated setting appropriate to the needs of the individual.

3. Services and supports are person-centered.
4. The provision of services results in the achievement of preferred outcomes for people with developmental disabilities.
5. There is an infrastructure that facilitates the ready access of people with developmental disabilities and families to services.
6. Services must continuously meet essential quality standards and there must be confidence that quality oversight systems function effectively and reliably.
7. The system must promote economy and efficiency in the delivery of services and supports.

The *Blueprint* has been crafted with the foregoing benchmarks in mind: namely, what steps can Illinois take that would result in improved system performance against these benchmarks?

Six Action Plan Focus Areas

Given these performance benchmarks, **16 Action Steps** have been identified that are keyed to **Six Major System Redesign Action Areas** related to service delivery, system capacity and system infrastructure. Further, these areas are inter-related and should be regarded as a unified, intertwined series of actions that build and depend on one another. Over the seven-year *Blueprint* period, the state should take steps to:

- Embrace the principle of supporting people in the most integrated setting by reducing the role that large congregate care facilities play in the Illinois service system.
- Strengthen existing community services by taking actions to retain a competent workforce, build capacity to address challenging individual needs, and improve oversight of community services.
- Expand system capacity so that by 2014 all people who have emergency or critical needs will be served with reasonable promptness.
- Redesign service coordination and single point of entry to assure people with develop-mental disabilities are linked to the services that best meet their needs and have an independent source of assistance when they need it.
- Redesign services and funding to promote person-centered service delivery.
- Measure performance and engage in quality improvement to guide better system performance through quality improvement along with better outcomes for people with developmental disabilities.

System redesign is a complex endeavor. The **seven-year** time horizon for the *Blueprint* was purposely selected in recognition that many of the system redesign action steps will take time and resources to put into motion.

Still, it is important to emphasize that the *Blueprint's* action steps are based on practices and policies that have been successfully implemented in other states. It is entirely feasible for Illinois to implement each of these steps. Inaction will have serious negative consequences for people with developmental disabilities. By not taking these steps, policy makers can expect that the state will: (a) continue spending substantial sums to maintain large facilities, such as the SODCs, that people increasingly do not want and that run afoul of oversight authorities, (b) find it increasingly difficult to accommodate new applicants for services so that wait lists will continue to grow, and (c) continue to oversee a community system that is increasingly challenged to address the needs of people already receiving services. In addition, forestalling action will likely make action later more costly and difficult to undertake. The time to act is now.

It is entirely feasible for Illinois to implement each of these steps. Inaction will have serious negative consequences for people with developmental disabilities.

Funding and Financing

Implementing the *Blueprint* will require that Illinois step up its funding of developmental disabilities services. As was pointed out in the *Gap Analysis*, Illinois' present level of funding is sub par in relationship to nationwide norms. Current funding is insufficient to meet present service demand or support the delivery of high quality services.

Where the *Blueprint* has fiscal implications, they are identified as to their direction and general magnitude. The *Blueprint* stresses the use of more economical services and supports to the extent possible. However, it would be misleading to represent that the action steps outlined in the *Blueprint* could be implemented without additional funding.

As a general matter, however, the additional spending that is necessary to implement most of the action steps contained in the *Blueprint* can be offset in part with federal Medicaid dollars. Overall, where Medicaid is utilized, one half of the additional outlays can be offset through federal reimbursement. Expanding system capacity, for example, can be financed in large part by expanding HCBS waivers for people with developmental disabilities. Similarly, many of the costs associated with improving the service delivery system infrastructure also are apt candidates for Medicaid financing.

Action Steps by Area

System redesign is an exciting opportunity for Illinois to commit itself to achieving excellence in service system performance. The *Blueprint* lays out a complex, intertwined action agenda for system redesign in Illinois. It is not, however, a detailed implementation plan. The implementation of each action step will require considerable additional follow-up activities and more detailed planning. Implementation will best proceed if it is conducted as a collaborative enterprise among constituencies that stresses full transparency.

In this context, we strongly recommend that it be launched by enlisting Executive and Legislative branch sponsorship. In advance, a Redesign Steering Committee should be appointed that includes leadership with decision-making authority. Care should be taken, however, to assure that the Committee is composed of participants who are committed to achieving the objectives set out by the *Blueprint,* and that the Committee process not be used to forestall needed action. Instead, the Steering Committee should be clearly charged with helping state officials to push forward by working out implementation details and generating support for planned system changes. To ease the way, this Steering Committee should have its own budget to

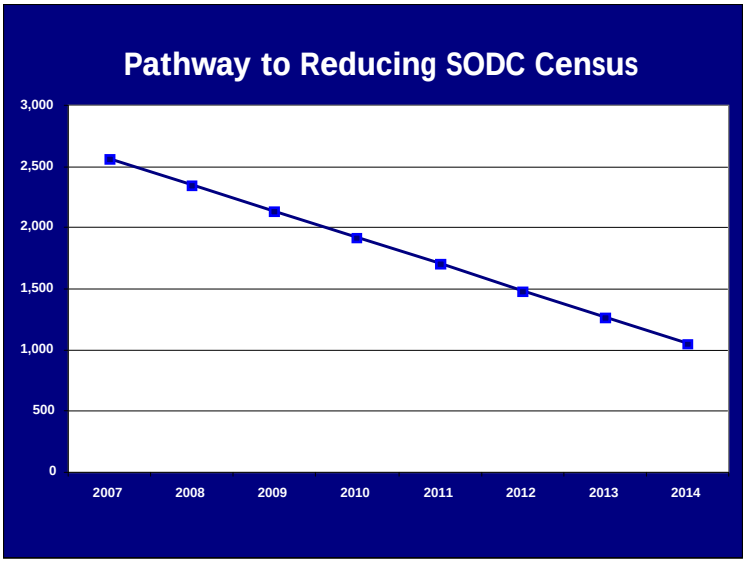
defray meeting and other expenses and support the meaningful participation of people with disabilities and families. The Steering Committee should have ongoing, *independent* staff support during the duration of the *Blueprint* period. The Steering Committee should be required to prepare periodic reports about its activities and these reports should be widely disseminated across constituencies.

Action Area 1: Support people in the most integrated setting possible.

The HSRI *Gap Analysis* revealed that a disproportionate number of Illinois citizens with developmental disabilities are served in large and very large congregate care facilities. In 2006, 63 percent of all persons in Illinois who received residential services were served in facilities that did not meet the most integrated setting benchmark – i.e., living arrangements that support six or fewer persons. About one-half of these individuals were located in very large facilities that served 16 or more persons, including 2,763 residents of the nine very large State Operated Developmental Centers (SODCs). Illinois SODC litigation was two-thirds higher than the national norm. Illinois substantially lags behind nearly all other states in fostering the provision of services in the most integrated setting.

During the *Blueprint* period, Illinois should take four action steps to realign its services so that a greater proportion of individuals are supported in the most integrated setting.

Action Step #1. Illinois should reduce the number of people served at its State Operated Developmental Centers (SODCs) to no more than the projected nationwide norm by 2014. This action would entail reducing the number of people served at the SODCs from 2,563 individuals in 2007 to 1,051 persons in 2014.



Based on recent trends, by 2014, it is expected that nationwide 7.7 individuals per 100,000 in the general population will be served in large state-operated facilities (in 2006, there already were 22 states that served 7.7 or fewer people per 100,000 in the general population in large state facilities). Taking into account projected Illinois population growth during the *Blueprint* period, the reduction of SODC census by 1,500 or approximately 216 persons per year would be required for Illinois to reach the national norm. Factoring in attrition in the SODC population, achieving this objective would require placing about 180 individuals per year (about 15 per month) into the community. During this period, five of the nine SODCs should be closed.

Action Step #2. Illinois should enact "Money Follows the Person" legislation to accommodate the transition of ICF/DD residents who prefer to receive services in the most integrated setting.

Action Step #3. Illinois should adopt policies and offer financial incentives to encourage provider organizations that operate large ICFs/DD to transition to

supporting individuals in the most integrated setting.

Action Step #4. Illinois should bar the development of new residences, funded through the CILA program, that serve more than six individuals. In addition, the state should take necessary steps to modify its payment policies to facilitate the downsizing of 7-8 bed facilities to six beds or less.

Action Area 2: Strengthen community services.

There is widespread agreement among Illinois stakeholders that there are major shortcomings in the delivery of community services. Provider agencies are struggling to acquire and retain a stable, competent workforce. In turn, workforce instability spawns major challenges in assuring the quality of services and supports. The extent of state oversight of community services is regarded as insufficient and is a continuing source of concern across the full spectrum of stakeholders. In addition, there are gaps in the capacity of the community system to address the needs of individuals with especially challenging conditions.

These shortcomings stand as major impediments to Illinois expanding services to support people who have unmet emergency or critical needs as well as foster the delivery of services in the most integrated setting. Because of these problems, the present community system is not a solid platform to support system expansion and reconfiguration. There are three principal action steps that must be taken to overcome these shortcomings.

Action Step #5. Illinois must boost funding for community services and promote improved conditions for workers so that community agencies can pay competitive wages and attract a stable competent direct support workforce.

Action Step #6. Illinois must build the capacity to support people with challenging conditions in the community.

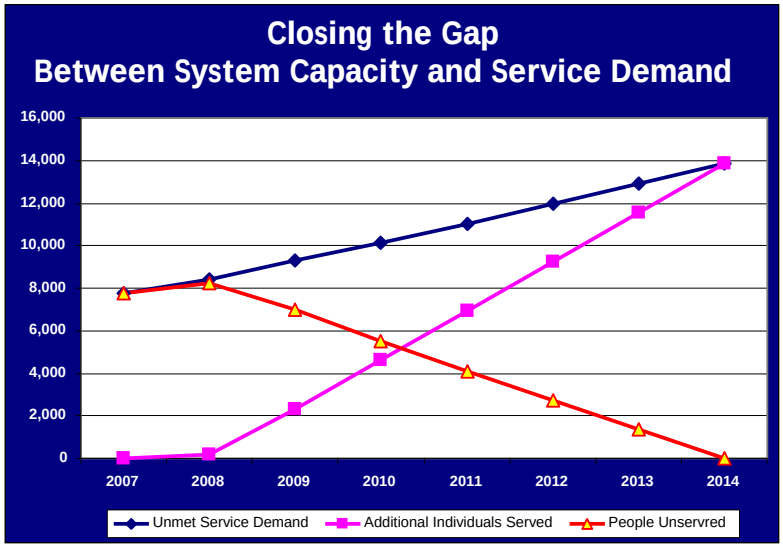
Action Step #7. Illinois should take several steps to strengthen oversight of its community services system.

Action Area 3: Expand community capacity.

Illinois faces a major strategic challenge: keeping pace with the rising demand for developmental disabilities services. As discussed in the *Gap Analysis*, there already is a substantial shortfall in system capacity to meet the expressed demand for developmental disabilities services. As of August 2007, there were 7,784 people who had unmet emergency or critical service needs. This translates into a shortfall in system capacity of about 35 percent. If left unattended, the number will swell to almost 14,000 by 2014. In large part, this shortfall stems from Illinois' sub-par performance in funding developmental disabilities services.

The *Blueprint's* seven-year time horizon extends through 2014. An important goal for Illinois is that the developmental disabilities system has sufficient capacity to respond with reasonable promptness to the legitimate needs of people with developmental disabilities. In response, the state should progressively reduce its waiting list each year until it catches up with service demand. By doing so, the state will additionally reduce pressure to utilize existing large congregate facilities while emphasizing more economical and preferable community service options.

Two action steps for addressing service demand are offered:



Action Step #8: To close the gap between system capacity and service demand, system capacity must grow at a faster pace than service demand until the gap is closed. Attempting to catch up with service demand all at once, however, would be very challenging. As a consequence, it is recommended that Illinois expand system capacity at a steady pace by serving an additional 2,316 people each year between 2009 and 2014. As illustrated, expanding capacity at this pace will enable system capacity to catch up with projected service demand by the year 2014. By employing the HCBS waiver to finance this expansion, Illinois will be able to secure federal Medicaid dollars to underwrite one-half of the cost of this expansion.

This action step carries significant cost. Still, steps to address the wait list are among the most important that can be taken to deemphasize reliance on large, congregate care options over time. Moreover, it is important to keep in mind that one half of the estimated cost of $69 million per year can be offset with Medicaid federal dollars.

Action Step #9: Illinois should concentrate on expanding home-based services as the primary tool for addressing service demand. Consideration should be given to breaking out home-based services into a separate HCBS "supports" waiver.

Action Area 4: Redesign service coordination and single point of entry.

Effective, *external* service coordination is essential to the effective functioning of a developmental disabilities service system. External service coordination ensures that service plans reflect the needs and preferences of individuals. External service coordination also is a vital quality assurance component. Additionally, to ensure that people with developmental disabilities are connected to the most appropriate services, it is important that a state operate a single point of entry system through which all persons seeking service pass.

With respect to both of these key system structural components, Illinois needs to pursue two fundamental system redesign action steps.

Action Step #10. Illinois needs to establish an adequately funded external service coordination system.

Action Step #11. Concurrently, Illinois should put into place a comprehensive single point of entry system.

Action Area 5: Redesign services and funding.

As discussed in the *Gap Analysis*, the current Illinois developmental disabilities system is not structured along person-centered lines. Individuals are slotted into programs and funding is tied to service agencies. Person-centered service delivery principles

demand that funding be portable and flexible so that services and supports can be customized around each person's needs and preferences.

To this point, the *Blueprint* action steps have focused on addressing major shortcomings in the Illinois developmental disabilities service system, especially with respect to serving individuals with reasonable promptness, bolstering community services, and reconfiguring service coordination and quality assurance. These fundamental action steps are necessary so that the service system has the necessary resources and capabilities to respond to the needs of individuals with developmental disabilities.

The action steps that are recommended would reposition the service system to more strongly embrace person-centered service delivery principles. These steps include: (a) modifying funding so that dollars are attached to individuals rather than specific types of services; (b) revamping and modernizing rate-setting methods; (c) scaling up the use of self-direction systemwide; and, (d) placing greater emphasis on outcome oriented services. In general, these action steps are recommended for completion during the 2009 – 2011 timeframe.

Action Step #12. Illinois should restructure community services funding along person-centered lines to promote flexibility in service plan design and portability.

Action Step #13. Illinois should adopt data-based, data driven rate determination methods for community services.

Action Step #14. Illinois should scale up the use of self-direction systemwide.

Action Step #15. Illinois should place increased emphasis on the delivery of outcome-oriented services and supports.

Action Area 6: Measure performance and quality improvement.

Developmental disabilities service systems are inherently complex. By any measure, they are costly systems to operate. As a consequence, it is important to measure performance along a variety of dimensions in order to gauge the effectiveness of the system in serving people with developmental disabilities. As is the case with large scale enterprise, performance measurement serves as the platform for engaging in focused quality improvement.

Action Step #16. Illinois must make a major commitment to measuring system performance and engage in continuous quality improvement.

Conclusion

Over the past 30 years Illinois has invested heavily in large, congregate care facilities for people with developmental disabilities. Even as the state began to establish a community services system, it has maintained a commitment to larger facilities. Now, the state is faced with difficult policy choices over how to respond to the needs of its citizens with developmental disabilities. This circumstance is fueled by a growing service wait list, changing expectations among people with developmental disabilities and their families, concerns over the performance of the present system, chronic under-funding and other factors. Illinois is at a crossroad.

Going forward, what should Illinois do to address the needs of its citizens with developmental disabilities most efficiently and effectively? Clearly, present fiscal and policy trends in Illinois cannot suffice. Illinois must make changes in its present response to the needs of its citizens with developmental disabilities. Yet change, after all, imposes choice.

To guide the way, six primary action areas were fashioned along with sixteen associated action steps. Four key elements to all of the actions recommended include a commitment from DHS/DDD policymakers to:

- √ Downsize the SODC census significantly, including closing five facilities.
- √ Create incentives for ICF/DD providers to transition into the waiver system.
- √ Invest heavily in home-based supports through a HCBS waiver to establish a proper platform to expand community service capacity.
- √ Strengthen the existing mainstay HCBS system, including increased funding, improvements in infrastructure and emphasis on preferred person-centered outcomes.

A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."

Alfred Dam

People with developmental disabilities nationally argue strongly for support systems that look decidedly different than what exists in Illinois. As articulated in the Alliance for Full Participation Action Agenda (Alliance for Full Participation, 2005):

> "We [people with disabilities] do not belong in segregated institutions, sheltered workshops, special schools or nursing homes. Those places must close, to be replaced by houses, apartments and condos in regular neighborhoods, and neighborhood schools that have the tools they need to include us. We can all live, work and learn in the community."

There is no reason to believe that people with developmental disabilities in Illinois will settle for anything less.