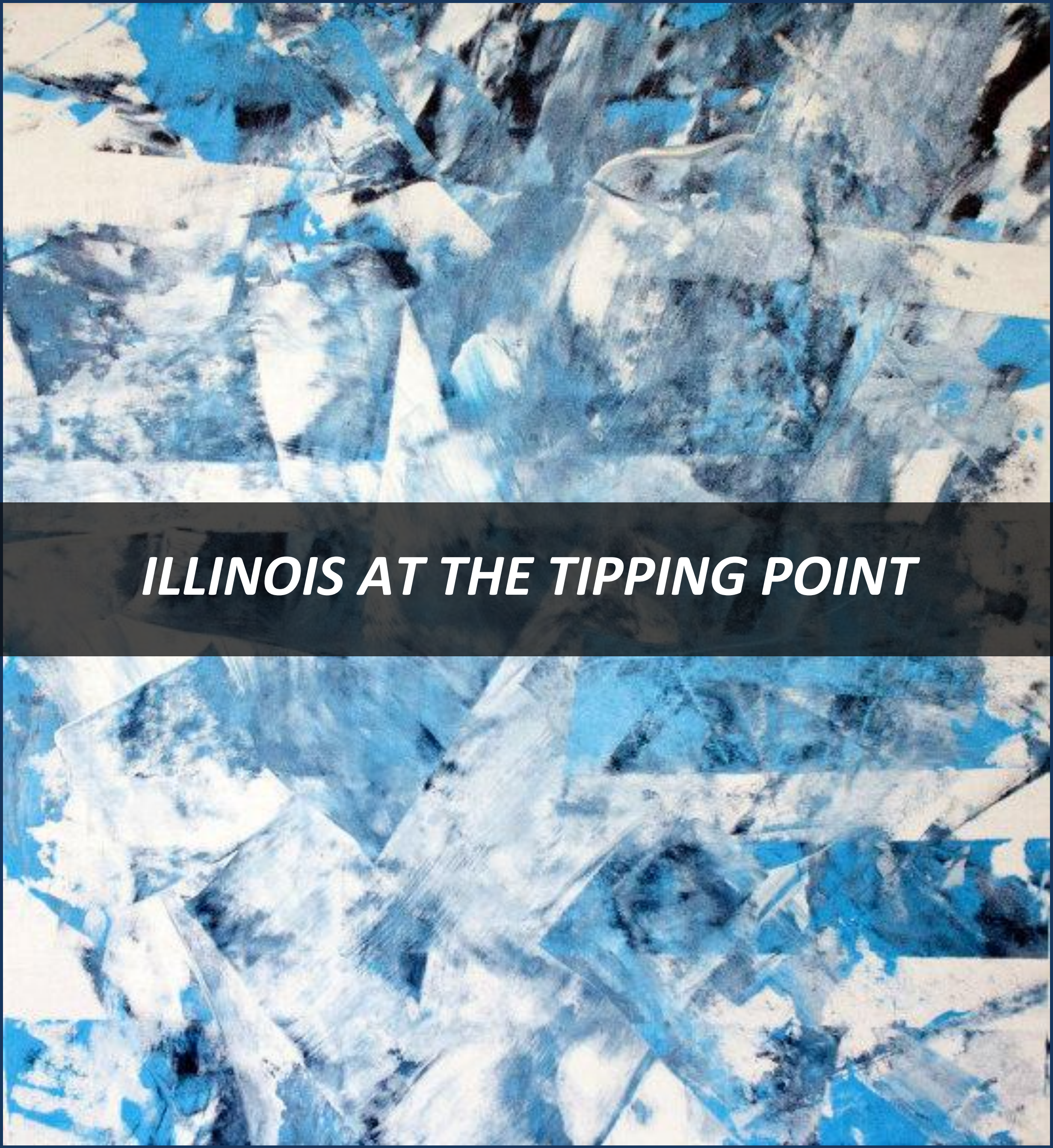
ILLINOIS AT THE TIPPING POINT



Blueprint for System Redesign Update

May 2012

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Illinois at the Tipping Point

Blueprint for System Redesign Update

May 2012

Prepared for:

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About the Authors

The Human Services Research Institute (HSRI), a non-profit, tax-exempt corporation, was founded in 1976 to improve the availability and quality of supports for children and adults with special needs and other vulnerable populations. Working in the fields of developmental disabilities, mental health, physical disabilities, and child welfare, HSRI staff strongly support efforts to improve community-centered responses to human needs, leading to service approaches that are family and person driven and most apt to result in increased independence and self sufficiency. HSRI has assembled a four person team to complete this work.

This report was prepared by the following staff:

John Agosta, Ph.D. is a Vice President at the Human Services Research Institute and has worked with people with disabilities for over 30 years. He completed his doctorate in Rehabilitation Research at the University of Oregon specializing in research methods and community supports for people with disabilities. He has extensive experience with community supports, having worked in direct services and administrative positions within agencies offering community services. At HSRI since 1983, he has worked under contract with state and federal agencies on a variety of projects focusing on community integration for people with developmental disabilities. He has conducted analyses of state systems and studied specific facets of the field (e.g., supported employment, family support, self-advocacy, Medicaid funding trends, and self-directed supports). Presently, he is involved with projects exploring innovative means for supporting individuals with disabilities and their families, evaluating what states may do to reform service systems, and establishing resource allocation protocols to provide individualized budgets for service recipients while making systems more efficient and equitable.

Drew Smith, B.A. is a Policy Analyst at HSRI. Mr. Smith works on several projects related to developing person-centered funding strategies, assessing the impacts of service changes and reductions, and supporting self-advocacy. While at HSRI, Mr. Smith has worked on resource allocation projects in Colorado, Florida, Oregon, Rhode Island, and New Mexico, as well as strategic planning projects in Texas, Florida, New Jersey, Illinois and North Carolina. Further, he works with the University of Minnesota on the *Residential Information Systems Project* (RISP) and the *Family Information Systems Project* (FISP) collecting, analyzing and reporting on state and national service trends for individuals with intellectual and developmental disabilities. He is a graduate of Portland State University in Business Administration.

Jaime Daignault, M.S., is a Policy Associate at HSRI. Her primary responsibilities involve project management and technical assistance to community organizations. She has contributed to several studies of disability service systems including state-level gap analyses and systems reform projects to improve self-determination. Working at the community level, she has provided training and technical assistance to local and statewide self-advocacy groups regarding strategic planning, peer support, and capacity building. She also oversees production of The Riot newsletter, a quarterly electronic self-advocacy and disability rights newsletter.

Yoshi Kardell, M.S.W., is a Policy Analyst at HSRI. She coordinates projects related to self-advocacy. She has several years of experience working for people with disabilities including providing direct support and state level advocacy. Ms. Kardell has worked with self advocates and families to ensure their view and input is part of the resource allocation planning. She has a graduate degree in Social Work from Portland State University and an undergraduate degree in Social Work from the University of Nebraska – Omaha.

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Figures, Charts and Tables

Glossary of Key Terms

In this report, services and housing arrangements for people with intellectual and other developmental disabilities within the state of Illinois are examined. Below, is a list of key terms used commonly throughout this report, as well as their meaning or definition.

Federal Definition of Intellectual and Other Developmental Disabilities

(A) The term "developmental disability" means a severe, chronic disability of an individual that:

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

114 STAT. 1684 PUBLIC LAW 106-402-OCT. 30, 2000

(ii) is manifested before the individual attains age 22;
(iii) is likely to continue indefinitely;
(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.
(II) Receptive and expressive language.
(III) Learning.
(IV) Mobility.
(V) Self-direction.
(VI) Capacity for independent living.
(VII) Economic self-sufficiency; and
(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN - An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

Illinois' Definition of Intellectual and Other Developmental Disabilities

To receive services through the Illinois Department of Human Services, an individual must meet the below criteria for having mental retardation or a related condition[1]:

Mental Retardation refers to significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before the age of 18 years. Significantly sub average is defined as an intelligence quotient (IQ) of 70 or below on standardized measures of intelligence. This upper limit could be extended upward depending on the reliability of the intelligence test used.

A person with a **Related Condition** means an individual who has a severe, chronic disability that meets all of the following conditions:

a. It is attributable to--
    - Cerebral palsy or epilepsy; or
    - Any other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with mental retardation and requires treatment or services similar to those required for these persons.

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[1] To be eligible for services through the Division of Developmental Disabilities (DDD) in Illinois, a diagnosis of mental retardation is required. This term "mental retardation" is out of line with current, people first, language. Therefore, the authors of this report refer to individuals receiving services, or qualifying with this definition as "individuals with intellectual and other developmental disabilities (I/DD)".

b. It is manifested before the person reaches age 22.

c. It is likely to continue indefinitely.

d. It results in substantial functional limitations in three or more of the areas following of major life activity:
  - Self-care
  - Understanding and use of language
  - Learning
  - Mobility
  - Self-direction
  - Capacity for independent living

Home and Community Based Services (HCBS) WAIVERS SECTION 1915(c)

States may offer a variety of services to consumers under an HCBS waiver program and the number of services that can be provided is not limited. These programs may provide a combination of both traditional medical services (i.e., dental services, skilled nursing services) as well as non-medical services (i.e. respite, case management, environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications. However, in general spouses and parents of minor children cannot be paid providers of waiver services.

Application & Approval Process

The State Medicaid agency must submit to the Center for Medicare and Medicaid Services (CMS) for review and approval an application for an HCBS waiver, and the State Medicaid Agency has the ultimate responsibility for an HCBS waiver program, although it may delegate the day-to-day operation of the program to another entity. Initial HCBS waivers are approved for a three-year period, and waivers are renewed for five-year intervals.

Program Requirements

Within the parameters of broad Federal guidelines, States have the flexibility to develop HCBS waiver programs designed to meet the specific needs of targeted populations. Federal requirements for states choosing to implement an HCBS waiver program include:

- Demonstrating that providing waiver services to a target population is no more costly overall than the cost of services these individuals would receive in an institution.
- Ensuring that measures will be taken to protect the health and welfare of consumers.
- Providing adequate and reasonable provider standards to meet the needs of the target population. Ensuring that services are provided in accordance with a plan of care.

States have the discretion to choose the number of consumers to serve in a HCBS waiver program. Once approved by CMS, a state is held to the number of persons estimated in its application, but has the flexibility to serve greater or fewer numbers of consumers by submitting an amendment to CMS for approval.

Intermediate Care Facility For Persons With Mental Retardation[2] (ICF/MR) (1905(d) of the SSA)

An institution (or distinct part thereof) for the mentally retarded or persons with related conditions if --

1. the primary purpose of such institution (or distinct part thereof) is to provide health or rehabilitative services to mentally retarded individuals and the institution meets such standards as may be prescribed by the Secretary;

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[2] This term, Intermediate Care Facilities for the Mentally Retarded is a federal Medicaid term. Illinois, while operating facilities under this definition, refers to these facilities as Intermediate Care Facilities for the Developmentally Disabled (ICFs/DD). This report uses the terminology ICF/DD in place of ICF/MR.

2. the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and
3. in the case of a public institution, the State or political subdivision responsible for the operation of such institution has agreed that the non-Federal expenditures in any calendar quarter prior to January 1,1975, with respect to services furnished to patients in such institution (or distinct part thereof) in the State will not, because of payments made under this title, be reduced below the average amount expended for such services in such institution in the four quarters immediately preceding the quarter in which the State in which such institution is located elected to make such services available under its plan approved under this title.
4. Institution for persons with mental retardation means an institution (or distinct part of an institution) that: 1. Is primarily for the diagnosis, treatment, or rehabilitation of the mentally retarded or persons with related conditions; and 2. Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at his greatest ability. (42 CFR 435.1009)

Community integration, used with respect to individuals with developmental disabilities, means exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals. *Public Law 106-402-OCT. 30, 2000 114 STAT. 1686 (17)*

Inclusion means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to: (a) have friendships and relationships with individuals and families of their own choice; (b) live in homes close to community resources, with regular contact with individuals without disabilities in their communities; (c) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and (d) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities. *Public Law 106-402-OCT. 30, 2000 114 STAT. 1685 (15)*

Supported employment services means services that enable individuals with developmental disabilities to perform competitive work in integrated work settings, in the case of individuals with developmental disabilities: (a) for whom competitive employment has not traditionally occurred or for whom competitive employment has been interrupted or intermittent as a result of significant disabilities; and (b) who, because of the nature and severity of their disabilities, need intensive supported employment services or extended services in order to perform such work. *The Developmental Disabilities Assistance and Bill of Rights Act of 2000 Public Law 106-402-OCT. 30, 2000 114 STAT. 1688 (30)*

Self-determination refers to activities that result in individuals with developmental disabilities, with appropriate assistance, having: (a) the ability and opportunity to communicate and make personal decisions; (b) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive; (c) the authority to control resources to obtain needed services, supports, and other assistance; (d) opportunities to participate in, and contribute to, their communities; and (e) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policy makers, and to play a role in the development of public policies that affect individuals with developmental disabilities. *The Developmental Disabilities Assistance and Bill of Rights Act of 2000 Public Law 106-402-OCT. 30, 2000 114 STAT. 1687 (27)*

Governor Pat Quinn
Fiscal Year 2013 Budget Address

February 22, 2012

In this budget, I am proposing serious spending reductions and efficiencies across state agencies and constitutional offices. …

We must fundamentally restructure our Medicaid program. And we must rebalance and move our most vulnerable citizens from institutions to community care. But cuts and reforms are not enough. …

I believe in a decent quality of life for everyone in Illinois. That's why we must fix our Medicaid system.

That's also why I'm committed to improving the quality of life for people with developmental disabilities and mental health challenges. Our budget includes funding to ensure smooth transitions and coordinated care as individuals go from costly institutions to supportive community settings.

Illinois lags behind the rest of the nation in the utilization of person-centered, community-based care which has been demonstrated to allow people with developmental disabilities to lead more active and independent lives.

Over the next fiscal year, we will close two developmental disability centers: Jacksonville, as well as the Murray Developmental Center in Centralia. We will close two mental health hospitals: Tinley Park, as well as Singer in Rockford.

The approach we are taking to rebalance our system will allow for the safe and smart transition to community care settings for some of our most vulnerable citizens.

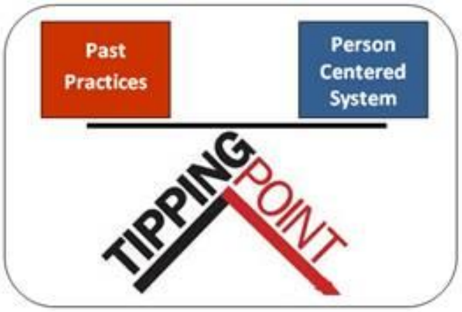
We will comply with all court consent decrees.

We will provide individualized care.

And we will achieve savings for the people of Illinois.

http://www2.illinois.gov/budget/Documents/Budget%20Book/FY%202013/FINAL%20FY13%20BUDGET%20SPEECH.pdf

Executive Summary



Illinois is at a tipping point. Policy makers are committed to moving the service system for people with intellectual and other developmental disabilities (I/DD) forward to achieve financial sustainability and deliver high quality person-centered supports, while also serving additional citizens waiting for services. Yet success will not come easy. The decisions made and actions taken over these coming months and few years will be decisive. Policy makers may act to reshape the system of services, shifting it from one mired in an underachieving past to another that brings promise for a better life for its citizens with I/DD. Or the present momentum for change might be stalled, leaving the state system to muddle on as before. This report offers analysis and guidance for moving the system forward, offering review of present performance and 15 *Action Steps* to establish a progressive person-centered system.

Background

In 2007, the Illinois Council on Developmental Disabilities (ICDD) awarded a grant to the Human Services Research Institute to review of the state's system for delivering services to people with intellectual and other developmental disabilities (I/DD). Two primary reports resulted:

- A *Gap Analysis: Services and Supports for People with Developmental Disabilities in Illinois* (2008) provides an assessment of the 2007 performance of the Illinois service system against seven benchmarks. The assessment draws on previous studies of the system, consultation with national experts, comparisons of performance against other states, and results of interviews of numerous stakeholders in Illinois. [3]
- A *Blueprint for System Redesign in Illinois* (2008) provides an action plan for reducing Illinois' reliance on serving people with I/DD in large congregate care facilities and increasing access to quality supports in the community. Fifteen *Action Steps*, to be completed over seven years, were offered related to service delivery, system capacity and system infrastructure.[4]

In 2011, the Council asked HSRI to refresh the findings originally described in the *Gap Analysis*, review the progress made in Illinois since 2008 to implement the *Action Steps* recommended by the *Blueprint*, and offer additional recommendations as warranted. This report presents a strategic assessment of the Illinois service system for people with I/DD, from 2008 to the present, against seven benchmarks. This report also outlines a recommended strategic path

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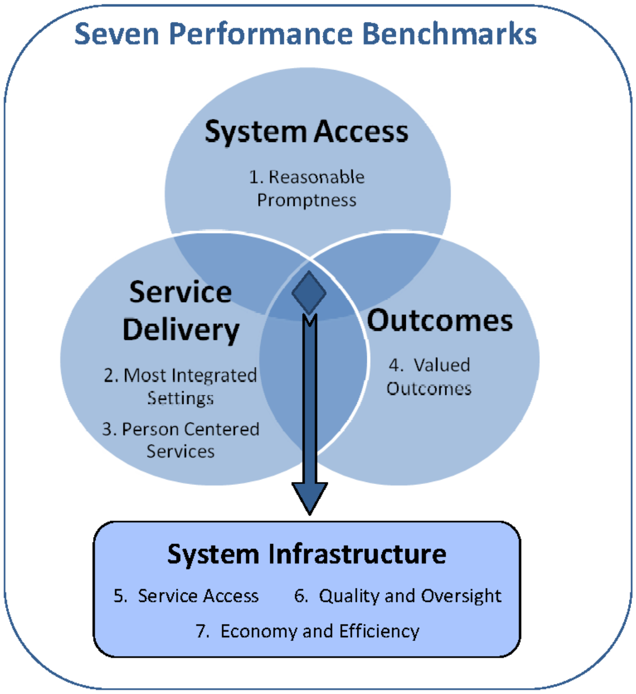
[3] Smith, G., J. M. Agosta, and J. Daignault. (2008). *Gap Analysis: Services and Supports for People with Developmental Disabilities in Illinois.* Tualatin: Human Services Research Institute

[4] Smith, G., J. M. Agosta, and J. Daignault. (2008). *Blueprint for System Redesign in Illinois.* Tualatin: Human Services Research Institute

forward that includes 15 *Action Steps* that Illinois must take to improve performance and better position the state's service system. These actions are consistent with, but not exactly duplicative of, the steps recommended in the 2008 *Blueprint*. We expect that these steps will be undertaken to complement system reforms already underway. What follows are summaries of our review of the state's performance and the 15 *Action Steps*.



Summary of the State's Performance

We assessed the state's performance against seven benchmarks. Benchmarks 1-4 generally concern system performance related to gaining entrance to the system, service delivery and associated outcomes. Benchmarks 5-7 concern system infrastructure of the operational elements that undergird the system. These performance benchmarks framed the first HSRI *Gap Analysis* and 2008 *Blueprint for System Redesign* report, and are carried over to this 2012 *Blueprint Update* report. What follows is a presentation of each benchmark accompanied with findings from 2007 and Illinois' current status.

Benchmark #1: People with intellectual or intellectual and other developmental disabilities have access to and receive necessary publicly-funded services and supports with reasonable promptness.

- **Finding in 2008:** Illinois does not furnish services with reasonable promptness to its citizens with developmental disabilities.
- **Current Status:** Illinois is still not providing services to individuals with I/DD with reasonable promptness and maintains a large waitlist for I/DD services. In fact, the waitlist has nearly doubled since the previous *Gap Analysis* report.

  In 2010 the State provided Medicaid funded I/DD services to 199 people per 100 thousand people in the general population. The national average was 220, leaving Illinois 10.5 percent short of the national marker. Given a state population then of 12.8 million, these findings suggest that Illinois would need to serve 2,688 people to achieve the national service utilization rate. Reaching this goal, however, would not eliminate the service wait list.

… people who have critical near-term needs should be able to count on receiving services within 6-9 months.

In more specific terms, since the original report was written in 2008, the number of individuals registered through PUNS, waiting for – but not receiving – services has more than doubled.[5] As of February, 2012 21,577 individuals were waiting for – but not receiving – services across the three categorizations (Emergency need, Critical need, Planning). Sixty-nine percent of those registered on PUNS have Emergency or Critical need (Emergency: 3,356; Critical: 11,621).

Benchmark #2: Services and supports are provided in the most integrated setting appropriate to the needs of the individual.

- **Finding in 2008:** Illinois relies on large congregate care facilities to serve people with developmental disabilities to an extraordinary extent. Opportunities for individuals to receive services in the most integrated setting are truncated.
- **Current Status:** Illinois is still not providing services to individuals with I/DD in the most integrated settings. The State still relies heavily on the SODCs, private ICFs/DD and 24/7 community group homes for the majority of their service population.

To date, little has changed in comparison to the 2008 report. The State did however close the Howe Developmental Center in 2010 and has announced plans for closure of the Jacksonville Developmental Center in October 2011[6] and the Murray Developmental Center in February 2012[7]. While Howe was the ninth facility to close, eight large State Operated Developmental Centers (SODCs) are still open.

Even with the State's efforts to close the SODCs, the residential services offered in Illinois are still out of step with the rest of the nation. Illinois serves a significantly higher percentage of individuals in residential settings of both 7-15 and 16 or more individuals. In fact, Illinois serves over twice as many individuals in each setting as the 2010 national average. Further, the state serves 50.8 percent fewer individuals in settings of 1-6 (the most integrated setting size). The decrease in the percentage of individuals living in settings of 16 or more translated into a small increase in the number served in settings of 6 or fewer, but a large growth in the number served in 7-15 settings.

Residential Setting Sizes (2010)

Setting Size	Illinois (People Served)	% Illinois (2010)	% Illinois (2008)	% U.S. Average (2010)	% U.S. Average (2008)
>6	8,252	38%	37%	76%	71%
7-15	7,703	36%	32%	12%	14%
16 or more	5,545	26%	31%	12%	15%
	21,500				

(Larson, et al. 2012)

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[5] Illinois makes available data compiled from its use of the PUNS on its state developmental disabilities services website. Go to: http://www.dhs.state.il.us/page.aspx?item=56036

[6] http://www.sj-r.com/top-stories/x441967789/Quinn-again-proposes-closing-Jacksonville-Developmental-Center

[7] http://www2.illinois.gov/budget/Documents/Budget%20Book/FY%202013/FINAL%20Rebalancing%20Fact%20Sheet%20-%20FY2013%20Budget.pdf

Benchmark #3: Services and supports are person-centered.

- **Finding in 2008:** Illinois has not configured its developmental disabilities system to embrace person-centered service delivery. Services and funding are tied to "programs" and service provider agencies.
- **Current Status:** Illinois has committed to embedding person-centered practices throughout its system and is taking steps in this direction, but there is still much to do.

As reflected in the *DDD Strategic Plan FY 2011-2017*, the Division outlines a strong commitment to developing and implementing a person-centered service system. In addition: (a) the State engaged in a major Medicaid conversion effort and shifted from state funded grant-in-aid contracts with service providers to primarily HCBS waiver funding, (b) a provision in the Ligas Consent Decree dictates a clear focus on person-centered planning processes for Class Members transitioning to community-based residences,[8] (c) the State has indicated a commitment to utilizing a person-centered planning process to relocate individuals from SODCs to community residential alternatives, (d) the State is embarking on developing and conducting a series of trainings for state staff, service coordinators, and service providers on person-centered planning, and (e) Governor Quinn in his February 2012 State of the Budget address espoused a definitive expectation that the service system will make dramatic changes to embrace person-centered principles and community-based supports.

> **Thank you for everything that you've done … for all the services that there are…**
>
> **But what you built, we don't want."**
>
> *Rebecca Cokley*

While these are steps in the right direction, there is still much to do. Note that:

- There is a lack of funding for Person-Centered Planning (PCP) made available through the HCBS waiver.
- Case management is restricted to 25 hours per year per person, which limits the time available to effectively conduct the person-centered planning process.
- Individuals who receive HCBS waiver funding have the right to choose their service provider, however, in practice, changing providers can be difficult.
- Even with appropriate resources and accompanying person-centered planning practices, the current service array offers a limited and insufficiently funded menu of services and supports that inhibits delivery of customized services to achieve the very goals of a person-centered system.

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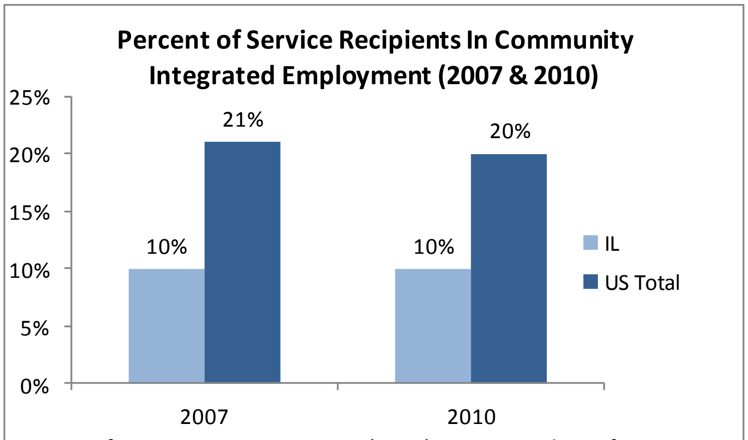
[8] The Ligas Consent Decree states that: *"The process for developing a Transition Service Plan shall focus on Class Member's personal vision, preferences, strengths and needs in home, community and work environments and shall reflect the value of supporting the Class Member with relationships, productive work, participation in community life, and personal decision-making*." (section VII. TRANSITION SERVICE PLANS, 13)

Benchmark #4: The provision of services results in the achievement of valued outcomes for people with intellectual and other developmental disabilities.

- **Finding in 2008:** Illinois does not have systems in place to track individual outcomes or comprehensively measure system performance. Consequently, the State lacks mechanisms to systematically measure performance related to valued outcomes for individuals and for the system as a whole.
- **Current Status:** Illinois has made little progress to promote and measure valued outcomes for both individuals and the system as a whole. Concerns expressed in 2008 continue to be relevant.

  As noted above, there is considerable evidence that person-centered service delivery promotes better outcomes for individuals. Notably, in its *DDD Strategic Plan FY 2011-2017*, Illinois articulates a vision and strategic priority to promote person-centered services across the developmental disability service system. This is a critical step forward. Meanwhile, stakeholders express concerns related to three major areas related to quality of life: (a) living in one's own home or apartment, (b) opportunities for social connections, and (c) securing and maintaining integrated employment. In this latter regard, the accompanying graphic illustrates no change from 2007 to 2010 in the percent of people with I/DD in Illinois who are in community integrated employment, and that state performance is half the national average.



Institute for Community Integration (2010) www.state data.info

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Benchmark #5: There is an infrastructure that facilitates the ready access of people with developmental disabilities and families to services.

Effective "Single Point of Entry" systems provide individuals and families a clear pathway to access services and supports of all types. This includes uniform and consistent application of state eligibility criteria and service authorization policies, including case management.

- **Finding in 2008:** Illinois' developmental disabilities service system infrastructure was fragmented and under-resourced. This posed barriers to people accessing services.
- **Current Status:** Since 2008, circumstances have not changed dramatically on two counts. Systems to support access to services continue to be fragmented and under resourced while information technology (IT) systems remain insufficient.

  Overall, as was the case in 2008, the performance of Single Point of Entry (SPOE)/service coordination functions is divided by service type and funding stream, and is further fragmented within the HCBS waiver program. Further, while the PAS/ISC network serves as the portal to certain types of services, it is not a single portal arrangement. Finally, the limitation on the amount of ISSA services that may be furnished to waiver participants (i.e., 25 hours annually) also remains problematic.

Regarding its Management Information Systems (MIS) or Information Technology (IT) system, Illinois continues to maintain a problematic infrastructure. In 2008, those interviewed indicated that information pertaining to service utilization, associated costs and quality monitoring were insufficient. The same complaints are heard today.

Benchmark #6: Services must continuously meet essential quality standards and there must be confidence that quality oversight systems function effectively and reliably.

- **Finding in 2008:** Stakeholders expressed wide-spread lack of confidence in the quality of services and the effectiveness of state quality management processes. Informants noted serious issues in several areas.
- **Current Status:** The state acknowledges difficulties surrounding service quality and oversight and has set strategic priorities for making improvements. Present circumstances, however, demonstrate that problems persist.

In response, the Division formed the Bureau of Quality management ensure that services are delivered appropriately and that the needs of service recipients are met. Further, the *DDD Strategic Plan FY 2011-2017* demonstrates a commitment to improve matters by defining person-centered quality measures, monitoring performance, and using data and lessons learned to inform future policies and procedures. The State also intends to revise outdated rules and regulations, and ensure ongoing quality improvement. While these key intentions are a good start, present circumstances continue to raise concerns.

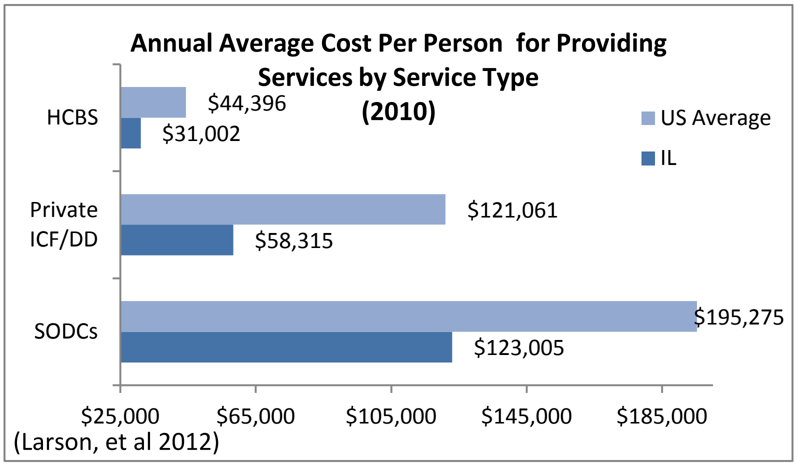
Moreover, a push to promote person-centered approaches and practices suggest that quality assurance mechanisms must be developed to align with new thinking. Such systems must deliver services and supports that facilitate outcomes at the individual and aggregate levels while also implementing quality enhancement strategies.

Benchmark #7: The system must have ample resources and promote economy and efficiency in the delivery of services and supports.

- **Finding in 2008:** Illinois' financial level of effort in supporting services for people with developmental disabilities is subpar. The present system overemphasizes the use of costly service models.
- **Current Status:** Illinois' investment in services for people with I/DD continues to be subpar. In 2010, Illinois expended $48,672 per person on average for HCBS and ICF/DD services. The national average was $60,276, or 12 percent more. In fact, given that 23,869 people received such services in 2010, Illinois would have needed to spend $277 million more just to reach the national average.

In addition, a disproportionate percentage of spending is allocated to SODCs and private ICFs/DD compared to HCBS waiver recipients, resulting in an emphasis on the most costly service models. In 2010, of all those served, 34% receive services in SODCs or community ICFs/DD, compared to 13% nationally. Regarding spending, these Illinois service recipients consume 55% of what is spent overall. Nationally, 33% of expenditures are dedicated to state institutions or community ICFs/DD. The accompanying graphic shows the differences in costs across three models, illustrating that ICFs/DD and SODCs are the most costly.

Overall, the analysis finds that the State spends less per person compared to other states, and the dollars available are used disproportionately to finance high cost services options.


Annual Average Cost Per Person for Providing Services by Service Type (2010)

(Larson, et al 2012)

Fifteen Action Steps

A summary review of the State's performance across the seven benchmarks reveals much to be concerned about. In many ways, one might surmise that little has changed since 2008 and that the system of services faces a number of challenges. Yet, many things have changed.

In its *DDD Strategic Plan FY 2011-2017*, the Division declares a vision for its work whereby:

> *All children and adults with developmental disabilities living in Illinois receive high quality services guided by a person-centered plan that maximizes individual choice and flexibility in the most integrated setting possible. All areas of the State have available a full array of services that meet the needs of children and adults with developmental disabilities living in their local communities regardless of intensity or severity of need. There is no waiting list for services.* (p. 5)

Adding to the momentum of the Division's *Strategic Plan* are expectations among growing numbers of people with I/DD (i.e., self-advocates) that the service system will be changed to embrace person-centered principles to emphasize community integration and self-direction. Joining in to add still further resolve for change are recent actions led by the governor to close two additional SODCs (i.e., Jacksonville and Murray) and the pointed direction for change he declared in his February 2012 *State of the Budget* address to the legislature. In his address, Governor Quinn declared a commitment to changing the service system to enhance and promote the community service system along person-centered service principles.

These combined expectations signal an emerging new alliance for change. Given modest resources and troubled fiscal times, however, actions taken in support of the desired changes must also establish a system that is sustainable, one that is funded and structured to meet the needs of all those in need over time. It must be amply funded, but it also make efficient use of available public resources to yield high quality outcomes. Establishing a sustainable future for Illinois' developmental disability service system must begin with an commitment to provide quality, person-centered supports to all citizens who need them.

In this context, the proposed 15 *Action Steps* are based in principles that blend together services preferred by people with developmental disabilities with disciplined fiscal and management practices. Doing so provides the best opportunity for yielding a person-centered, sustainable future for developmental disability services in Illinois. These steps, displayed below, are organized into five action areas to:

A. Establish clear and cohesive leadership for the developmental disabilities service system.

B. Develop system infrastructure in support of the community services system.

C. Improve the community response to individual support needs to promote person-centered outcomes important to individuals and families, including emphasis on self-direction among people with developmental disabilities and partnerships among service recipients, their family members and others.

D. Serve people in the most integrated setting by reducing further the role that SODCs and ICFs/DD play within the Illinois service system.

E. Expand system capacity so that by 2022 all people who have emergency or critical unmet needs will be served with reasonable promptness.

Summary of 15 Action Steps Proposed in 2012

1. Commit to unified policy direction for developmental disability services throughout DHS to embrace person-centered practice.
2. Invest in self advocacy.
3. Establish a comprehensive Single Point of Entry system, including an adequately funded external independent service coordination system.
4. Strengthen oversight of the community services system and improve the information management system.
5. Establish equitable resource allocation practices to set individualized budgets and advance person-centered services.
6. Pursue implementation of managed care systems in ways to promote person-centered approaches.
7. Invest in in-home supports.
8. Promote mutual support and association among self-advocates and families.
9. Strengthen community-based supports for people with extraordinary behavioral challenges.
10. Scale up the use of self-direction system-wide.
11. Accelerate opportunities for integrated employment.
12. Adopt policies that help individuals and providers transition from ICFs/DD services to HCBS-funded alternatives.
13. Adopt policies to revitalize the commitment to Community Integrated Living Arrangements.
14. Reduce the number of people served at SODCs to no more than the projected national average by 2017.
15. Expand system capacity at a steady pace by serving an additional 1,918 people each year between 2012 and 2022.

Action Area A: Establish Clear and Cohesive Leadership

***Action Step 1:** Commit to unified policy direction for developmental disability services throughout DHS to embrace person-centered practice*

To establish a person-centered service system, Illinois must conduct a systematic review of policies, procedures and program design, and make substantive changes to each. State leaders must also collaborate effectively to communicate a clear vision of a person-centered service system and take consistent policy action to advance this vision. To provide a cohesive message:

- ✓ State leaders should reaffirm a position in favor of person-centered services. The DHS Secretary, in collaboration with the Governor's office, should consistently reaffirm a position in favor of person-centered services and direct leadership at DDD to take action consistent with this commitment without intrusion from other policy making offices.
- ✓ Policy makers should work collaboratively. Under the leadership of DDD, policy makers within DHS and the Governor's office should work collaboratively to align systems change actions to embrace person-centered principles.

***Action Step #2:** Invest in Self-Advocacy*

Self-advocates can be key partners in systems change by demanding preferred services and creating support for the state to change policy and practice towards a person-centered service system. To do so, they must have necessary skills and a powerful voice to influence change on multiple levels. One of the most effective ways for self-advocates to develop such skills is by participating in effective self-advocacy groups. To this end, DDD should:

- ✓ Support the statewide, independent self-advocacy organization that serves as the collective voice of people with I/DD in shaping public policy and practice.
- ✓ Fund peer support services. To offset costs, peer mentoring services should be included in the service array provided by the HCBS waiver.
- ✓ Increase the presence of self-advocates on advisory boards. Self-advocates should be involved in making decisions that have a direct impact on the quality of their daily lives.
- ✓ Promote the role of self-advocate leadership with a "Self-Advocate Liaison" position within DDD to provide self-advocates with visibility and access to decision makers. Medicaid can be used to fund this position and its associated activities.

Action Area B: Develop Systems Infrastructure

***Action Step # 3:** Establish a comprehensive Single Point of Entry system including an adequately funded external independent service coordination system*

Most states operate their developmental disabilities service systems by employing the SPOE model that ensures uniform and consistent application of state eligibility criteria and service authorization policies, including case management. Quality SPOE networks provide individuals and families a clear pathway to access services and supports of all types.

In this regard, effective, *external* service coordination is essential to the effective functioning of a person-centered service system. It is vital for ensuring that service plans are designed to meet the needs of individuals. Moreover, it is essential to efforts to assure service quality through ongoing monitoring of service plan implementation and the health and well being of service recipients.

Illinois has incorporated some components of the SPOE model into the functions of the PAS/ISC agencies; however, this effort is not comprehensive with significant limitations tied to case management. In response, the State should:

- ✓ Expand the responsibilities of the PAS/ISC agencies so that they function as true comprehensive SPOEs for entry of individuals into publicly-funded services;
- ✓ Step up its funding of ISC agencies so that they have improved capability to support individuals who do not participate in the HCBS waiver, including assisting people who have unmet emergency and critical needs to access services outside the HCBS waiver until they can be enrolled in the waiver;
- ✓ Assign ISSA service coordinators the responsibility of facilitating the development of all HCBS waiver service plans;
- ✓ Increase the annual allowance for HCBS waiver ISSA services from 25 to 50 hours;
- ✓ Require ISSA service coordinators to perform direct contact monitoring of HCBS waiver participants served in community residences four times each year;
- ✓ Include performance benchmarks in contracts with PAS/ISC agencies to furnish ISSA services;
- ✓ Contract with an independent entity to perform quality audits of the performance of PAS/ISC agencies in furnishing service coordination.
- ✓ Consider use of the Balancing Incentive Program to establish a SPOE administered through the Centers for Medicare and Medicaid Services (CMS). This program would provide additional funding to support individuals relocating from ICFs/DD and nursing facilities to community alternatives.

BALANCING
INCENTIVE PROGRAM

Action Step 4: *Take steps to strengthen oversight of the community services system and improve the information management system*

A major shortcoming in Illinois is that neither stakeholders nor policy makers know how well the developmental disabilities service system is performing on behalf of individuals and families. Going forward, it is vital that the State establish standardized quality oversight practices and effective means for gathering and analyzing data on system performance.

To establish standardized quality oversight practices, the Division should invest further in the recently formed Bureau of Quality Management, providing this office the means to:

- ✓ Set goals, track and publicly report performance on valued outcomes important to individuals receiving services.
- ✓ Use data gathered to remediate problems and guide enforcement of corrections.
- ✓ Shorten the regular cycle of provider agency review from three to two years.
- ✓ Adopt a standardized risk assessment protocol that will be employed system wide.
- ✓ Maintain membership within the National Core Indicators project to gather data on system performance.
- ✓ Use data to furnish policy makers with comprehensive information about system performance to support quality improvement initiatives.

To improve means for gathering and analyzing data on system performance, the Division should:

- ✓ Work with the Regional Medicaid Office to identify key pieces of information missing in the Medicaid Management Information System (MMIS).
- ✓ In collaboration with the Regional Medicaid office, develop a proposal to improve the current MMIS.
- ✓ Establish the necessary IT systems to capture information concerning the results of monitoring, provider quality reviews and critical incident reporting.

Action Step #5: *Establish equitable resource allocation practices to set individualized budgets and advance person-centered services*

In its *DDD Strategic Plan FY 2011-2017*, the Division illustrates its strong commitment to person-centered services and associated financing to complement such services. Key to achieving these priorities is action to establish individualized budgets for service recipients that are consistent with their assessed support needs. To determine individualized budgets, Illinois policy makers must take at least these four steps:

- ✓ Implement independent, accurate and reliable means for assessing individual support needs.
- ✓ Reach agreement on the service array available and associated service definitions.
- ✓ Conduct an independent cost study to establish an appropriate service reimbursement rate schedule.
- ✓ Reconcile assessments of support needs with an appropriate rate schedule to yield individualized budgets.

Action Step # 6: *Pursue implementation of managed care systems in ways to promote person-centered approaches*

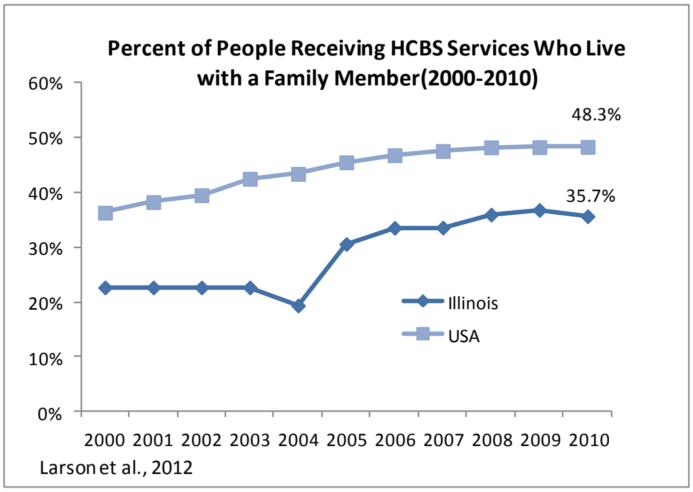
Nationally, in response to a need to reduce costs, states are feeling pressure to adopt Medicaid managed care systems. These systems may target acute care, long term care or both. In addition, they may cut across multiple populations, including seniors and people with a variety of disabilities, including developmental disabilities. Consistent with this trend, Illinois is in the process of implementing, a managed care pilot to include several counties in the Chicago area. The State plans to implement its "Integrated Care Program" in three phases, scheduled for full implementation by 2015. The program will eventually cover medical services as well as long term services and supports across multiple populations, including individuals with developmental disabilities.

The challenge in Illinois, as in other states, is to advance person-centered practices while also applying fiscal discipline within a managed care framework. Toward this end, as Illinois policy makers continue the managed care roll out and expand the practice, they should embrace the National Council on Disability's guiding principles and recommendations for implementing managed care.[9]

Action Area C: Improve the Community Response

Action Step #7: *Invest in In-Home Supports*

In the 2008 *Blueprint*, Illinois was advised to concentrate on expanding home-based services as its primary tool for reducing the number of individuals waiting for services. Such action would be consistent with decisions made in most other states to invest in in-home supports. However, at 35.7 percent, Illinois consistently performs below the national average of 48.3 percent. In developing a strategy for addressing the waiting list for I/DD services consistent with what was recommended in 2008, two actions are offered:


Percent of People Receiving HCBS Services Who Live with a Family Member(2000-2010)

Larson et al., 2012

- ✓ Of the new capacity Illinois needs to add by 2022 (See Action Step 15), 60 percent should be allocated to the expansion of home-based services.
- ✓ Illinois should consider shifting home-based services to a stand-alone Medicaid HCBS waiver.

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[9] National Council on Disability Communications (2/12) to the Centers on Medicare and Medicaid Services: Guiding Principles: http://www.nasddds.org/pdf/managedcarencdprinciples 1.pdf. Recommendations:http://www.nasddds.org/pdf/cmsmanagedcarencdrecommendations 1.pdf.

Action Step #8: *Promote mutual support and association among self-advocates and families*

As in Illinois, service systems across the nation are challenged to accommodate increasing demands for services while enduring difficult fiscal times. One approach to addressing service demands efficiently involves establishing sustainable networks of mutual support for individuals with I/DD and their families to complement existing public services. The Illinois Association of Microboards and Cooperatives (IAMC) (http://www.iambc.org) utilizes such a model to complement the Medicaid-funded services people receive by connecting individuals and families to each other (their peers) for mutual support. These peer connections add to people's lives greater access to their communities and additional sources of support.

Several types of agencies are capable of establishing peer connection or cooperative initiatives, including self-advocacy groups, local Arc Chapters, and other family or advocacy oriented organizations. What is needed, however, is a funding mechanism to pay for development and later for staffing to organize and maintain the effort. Toward these ends, the Division should establish a service within its HCBS waiver to create a clear funding pathway for financing peer connection initiatives and formal cooperatives or federations where participants work together to manage the services they receive.

Action Step #9: *Strengthen community-based supports for people with extraordinary behavioral challenges*

A critical measure of the effectiveness of a community developmental disability service system is how well it supports individuals with especially challenging behavioral conditions. To the extent that the needs of such individuals can be appropriately addressed, their lives will be more stable and higher service costs will be avoided. Toward this end it is vital that individual needs be met without resorting to unnecessary placement out of the person's community residence or family home.

To improve its response to individuals with significant behavioral challenges, the Division should:

- ✓ Consider adding to its HCBS wavier services: (a) expenses related to consultation and materials pertaining to specialized environmental design; and (b) specialized residences meant to support people with extraordinary behavioral challenges.
- ✓ Accelerate its efforts to bolster its local crisis support response capacity. These efforts might include further adjustments to service reimbursement rates for behavioral responders.
- ✓ Conduct a study to examine psychotropic use patterns and take steps needed to assure that individuals are not being prescribed or administered such medications inappropriately.

Action Step #10: *Scale up the use of self-direction system-wide*

Self-advocates all over the country demand to control or "be the boss of" their own lives and in many states they can through the use of self-directed service options. The demand for self-directed services is present in Illinois as well. The Illinois Self-Advocacy Alliance, a statewide network of local self-advocacy groups, published a position statement on self-direction and is currently working with State staff to expand the self-directed service options within the current HCBS waiver for adults with developmental disabilities.

We encourage the Division to continue with the necessary planning to scale up self-direction across the entire service system with a new self-directed option within its HCBS waiver. Successful large scale implementation of self-direction will require that the Division:

- ✓ Build capacity for case management to align with self-directed principles.
- ✓ Develop specific performance measures related to self-direction.
- ✓ Adopt principles related to self-direction.
- ✓ Assure that uniform operational structures are in practice across the state.
- ✓ Assure that uniform processes are in place for self-direction.

In addition, if individuals are to choose a self-directed option, they must be made aware of its availability. Some available outreach options include:

- ✓ Incorporating discussion about self-direction into all service planning meetings.
- ✓ Modifying existing self-direction trainings for self-advocates and families.
- ✓ Engaging self-advocacy organizations to provide guidance on materials and messaging to self-advocates.

Action Step #11: *Accelerate opportunities for integrated employment*

Over the past two decades, states have adopted public policies intended to advance supported employment as the preferred employment service for people with I/DD. To further these efforts, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute for Community Inclusion at the University of Massachusetts Boston (ICI) launched the State Employment Leadership Network (SELN) in 2006. The SELN is a national initiative dedicated to improving employment outcomes for adolescents and adults with intellectual and other developmental disabilities.

The Network promotes connections among state members so state developmental disability service agencies can take better advantage of other resources and partner with sister service systems, sharing costs and maximizing resources. We encourage Illinois to become a SELN member to advance integrated employment outcomes for individuals with developmental disabilities. To make the most of SELN membership, DDD can:

- ✓ Institute Employment First policies at the state level.
- ✓ Assure that use of community based non-work options are tied to gaining community employment.
- ✓ Support self-advocacy and peer mentoring to promote community employment.
- ✓ Embed identified elements of best practice into state and local operations practices.

Action Area D: Serve People in the Most Integrated Setting

Action Step #12: *Adopt policies that help individuals and providers transition from ICFs/DD services to HCBS funded alternatives*

Once a person is placed in an ICF/DD, it is difficult to move to a more independent living arrangement or alternative funded by the HCBS waiver. ICF/DD funding is not easily portable and cannot follow the person into the HCBS waiver program. As a result, many people residing in ICFs/DD get stuck in these settings. Illinois should follow the lead set by other states and take action consistent with Ligas, findings of the Rate Committee, and the Division's *Strategic Plan FY 2011-2017* to help individuals transition from ICFs/DD services to HCBS funded alternatives. To achieve these strategic changes, the State should:

- ✓ Continue to support efforts tied to the Ligas Consent Decree to help people relocate from ICF/DD facilities to HCBS alternatives. This includes commitment to a strong person-centered planning process for assuring smooth transition for individuals, and access to the services they need.
- ✓ Take action to provide "transition fiscal support" for providers to help individuals relocate to HCBS options or to transform the provider's funding base from ICF/DD to the HCBS waiver.
- ✓ Assure that the HCBS waiver is an attractive option with respect to both the service array available to participants and the associated service reimbursement rates. There is no incentive to providers to switch if the perception is that the waiver has significant associated difficulties and/or if providers cannot offer needed services to individuals at a fair rate of reimbursement.
- ✓ Make better use of the Money Follows the Person Program.

Action Step #13: *Adopt policies to revitalize the commitment to Community Integrated Living Arrangements*

Over the years, there has been a steady increase in the size of residential CILAs as providers cope with the failure of state payments for services to keep pace with their costs. As a consequence, there are now many larger CILAs in operation. Moreover, larger facility sizes and anemic reimbursement rates have undercut the promise for flexibility in service design and the commitment to promote community integration.

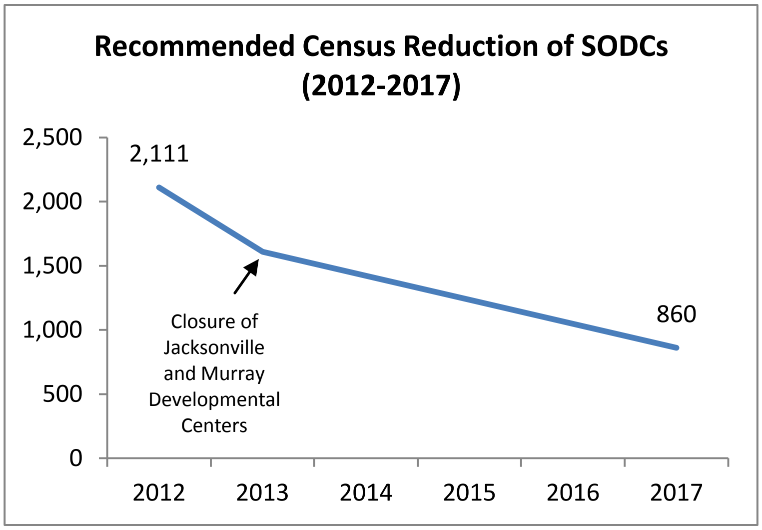
A commitment to change and gathering information to improve the rate structure are steps in the right direction. Building on these steps, the State should:

- ✓ Set policy to limit the size of new CILAs to no more than four beds. We understand that the State has elected to transition individuals leaving the Jacksonville and Murray SODCs to residences of no more than four people. This action is laudable and positions the Division to utilize the Money Follows the Person program to help finance transitions. It will also require that CILA rates be adjusted up to assure that these residences are fiscally viable. By doing so, however, the State establishes a contrast between those scheduled to depart these SODCs and others already receiving services who live in residences housing more than four people. Going forward, the State should apply its "no more than four" standard to the entire system, including any CILAs formed outside of the SODC transitions.
- ✓ Reconsider CILA reimbursement rates. The Division should revisit the formulas that are used to set CILA rates and the work of the Rate Committee to ensure that the operation of sites that serve four or fewer individuals can be an economically viable proposition for provider agencies. This should be undertaken as part of a larger scale rate study to consider the rate schedule for the entire system (See Action Step 6).
- ✓ Adopt a "four or less" residential standard statewide. Once rate setting formulas are revised, the State should establish a three-year time period for provider agencies that operate CILAs for more than four individuals to reconfigure their sites to meet the four-bed standard.

Action Step #14: *Reduce the number of people served at State Operated Developmental Centers to no more than the projected national average by 2017*

Illinois continues to serve individuals with I/DD in large state-run facilities at a much higher rate than the national average. By 2010, Illinois served 16.5 individuals per 100K in SODCs, compared to the national average of 10.1 people per 100K. Although Governor Quinn has recently announced the closure of the Jacksonville and Murray Developmental Centers, Illinois policy makers should enlarge plans to reduce the SODC census to the projected per 100K utilization national average in 2017 (6.7 per 100k).

Despite plans to close Jacksonville and Murray, state-run institutions will continue to command a significant share of state spending on behalf of people with I/DD. Additionally SODC closures do not automatically result in transition



of all residents to community alternatives. Moreover, cost savings from these closures are not reinvested in the community system. While the State has noted plans to ensure that any cost savings from the closure of facilities or transition of individuals out of facilities will be reinvested into the community system, Illinois should continue to set up defined processes and procedures which ensure that any saved funding be allocated to offering high quality community services.

Action Area E: Expand Community System Capacity

Action Step #15: *Expand system capacity at a steady pace by serving an additional 1,918 people each year between 2012 and 2022*

An important goal for Illinois' system is to have sufficient capacity to respond with reasonable promptness to the legitimate needs of people it is charged with serving. Yet, Illinois faces a major strategic challenge – keeping pace with the rising demand for services while simultaneously adding new capacity. There already is a substantial shortfall in Illinois' current system capacity to meet the expressed demand for services.

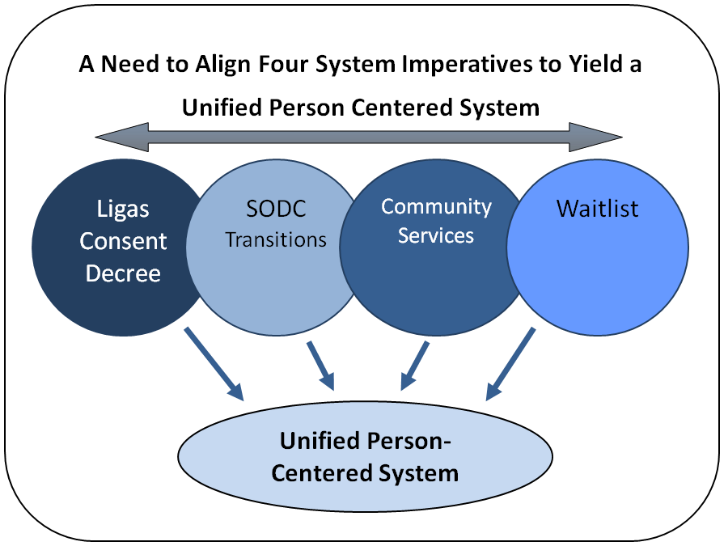
To assist in developing a sound strategy to address this demand, HSRI created two realistic scenarios to project service demand over a 10 year period. The State stands the best chance for eliminating its wait list, however, if it were to pursue a scenario requiring that an additional 1,918 people be served each year between 2012 and 2022. To achieve this goal, the State would obviously need to invest substantially more in I/DD services than it has.

Conclusion

Illinois is at the tipping point. Our review of the state's performance from 2007 until now reveals that in many ways little has changed. The state consistently produces sub-par performance on a variety of performance benchmarks. Notably, state policy makers have articulated a willingness to make necessary changes to correct inefficiencies and commit to establishing a person-centered service system. The Division of Developmental Disabilities' *Strategic Plan FY 2011-2017* furnishes a calculated guide for managing many of the changes in policy and practice that must occur. Other events bring momentum for change, such as the implementation of the Ligas Consent Decree, the Governor's decision to transition individuals from SODCs to community alternatives, and actions small and large within the Division to improve community services. Finally, service recipients and other advocates are increasingly calling for changes to promote community integration and self-direction.

The actions taken by policy makers and others in these coming months and years will be decisive. The State may either take action to establish a person-centered system, or stall the present momentum and muddle on. The future of the Illinois system hangs in the balance. People will either agree to change and will, or they will not.

To succeed, policy makers and other stakeholders must collaborate effectively to align efforts associated with four significant imperatives. These include: (a) implementing the terms of the Ligas Consent Decree, (b) transitioning individuals from SODCs to community alternatives, (c) improving multiple features of the existing community system, and (d) reducing the waitlist for services.



In this context, the 15 *Action Steps* presented earlier provide state leaders with definitive direction for addressing the challenges faced by the Illinois I/DD service system. By enacting the proposed steps and working towards a person-centered system, Illinois will increase system capacity, improve efficiency, and enhance the quality of life of thousands of people with I/DD their families.

In 2008, the thrust of the original *Blueprint for System Redesign* was to urge Illinois policy makers to push past prevailing circumstances and establish an action bias for change to assure that people with I/DD receive the supports they need to live in the community as other citizens do. The *Action Steps* presented here again call on Illinois policy makers to achieve this same goal. Illinois has reached its tipping point. It is time to take the steps needed to establish a person-centered system. As was the case in 2008, individuals with I/DD and their families will settle for nothing less.

Introduction

In 2007 the Illinois Council on Developmental Disabilities awarded a grant to the Human Services Research Institute to conduct a strategic review of the state's system for delivering services to people with intellectual and other developmental disabilities (I/DD). The effort was completed over two years and resulted in two primary reports.

- A *Gap Analysis: Services and Supports for People with Developmental Disabilities in Illinois* (published in 2008) provides an assessment of the 2007 performance of the Illinois service system against seven benchmarks. The assessment draws on previous studies of the system, consultation with national experts, comparisons of performance against other states, and results of interviews of numerous stakeholders in Illinois. [10]
- A *Blueprint for System Redesign in Illinois (2008)* provided an 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. Fifteen *Action Steps*, to be completed over seven years, were offered related to service delivery, system capacity and system infrastructure.[11]

In 2011, the Council asked HSRI to refresh the findings originally described in the *Gap Analysis*, review the progress made in Illinois since 2008 to implement the *Action Steps* recommended by the *Blueprint*, and offer additional recommendations as warranted.

Methods Applied

Prior to considering what *Action Steps* may be taken in Illinois going forward, it is essential to maintain perspective on the present circumstances that define the system and any overarching issues that influence policy. After all, the system is not being designed from scratch, nor is it static. Rather, its current status results from past decisions made over many years and that yield current policy preferences, service arrays, service use patterns and associated funding. Taken together, these system factors comprise the planning context or platform upon which the subsequent *Action Steps* must be built.

To gain a better understanding of the planning context, we followed the lead of the original *Gap Analysis* to review present contextual circumstances in Illinois during which the performance of the state's current service system was assessed against seven benchmarks.

To complete this work, we:

- **Reviewed the Division on Developmental Disabilities' *Strategic Plan FY 2011-2017*.**[12] This Plan was completed in July 2010 given a process that involved discussion among a variety of

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[10] Smith, G., J. M. Agosta, and J. Daignault. (2008). *Gap Analysis: Services and Supports for People with Developmental Disabilities in Illinois.* Tualatin: Human Services Research Institute

[11] Smith, G., J. M. Agosta, and J. Daignault. (2008). *Blueprint for System Redesign in Illinois.* Tualatin: Human Services Research Institute

[12] Division on Developmental Disabilities (2010*). Strategic Plan 2011-2017*. Springfield IL: DDD, Department of Human Services.

Illinois stakeholders concerned about services for people with I/DD. It presents objectives to re-orient Division priorities and resources to support a person-centered system of services. The Plan sets five strategic priorities for the Division:

1. Create person-centered services aligned and strengthened across the developmental disabilities system, such that they are provided in the most integrated setting appropriate to the needs of the individual throughout the lifespan, regardless of intensity or severity of need.
2. Restructure financing and rates to encourage high quality person-centered services.
3. Expand system capacity to accommodate increasing demand.
4. Actively build a strong, compassionate, and professionally trained work force.
5. Continue our commitment to measure system performance and engage in continuous quality improvement.

- **Reviewed state and national literature relevant to the Illinois long-term services system pertaining to developmental disabilities**. Project staff researched and compiled various relevant materials, focusing attention on services offered by the Division of Developmental Disabilities (DDD) within the Department of Human Services (DHS). A summary of the scope of responsibilities of the DDD is found on the following page.
- **Reviewed available state and national data.** We gathered information from the following sources:
  - Data available from the Research and Training Center on Community Living (RTCCL), Institute on Community Integration/University Center on Excellence in Intellectual and other developmental disabilities (ICI/UCEDD) at the University of Minnesota. The research team at RTCCL/ICI collects information by state on the numbers served and related expenditures associated with Medicaid-funded developmental disability programs, including Intermediate Care Facilities for the Mentally Retarded (ICFs/MR)[13,14] and Home and Community-Based Services (HCBS) waivers and other long-term care services. This resource provided us with data through 2010[15]and is cited in this report as (Larson, et al. 2012).

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[13] It is important to note that the term "intermediate care facility for the mentally retarded" is not in line with best practice terminology today. This report refers to these facilities as ICFs/DD (Intermediate Care Facilities for people with Developmental Disabilities).

[14] Periodically, in this report the word "retarded" or "retardation" may be found. We remind the reader that such language does not reflect present best practice. In October 2010, President Obama signed into law Rosa's Law, which changes references in federal law from *mental retardation* to *intellectual disability*, and references to *a mentally retarded individual* to *an individual with an intellectual disabilities*. Several states have moved in ways consistent with the federal law to remove "R-words" from its laws, service labels, operational language, rules, regulations and so forth. This report uses the term individuals with "intellectual and other developmental disabilities" for referring to individuals receiving services.

[15] Larson, S.A., Ryan, A., Salmi, P., and Smith, D. (2010). *Residential Services for Persons with Developmental Disabilities: Statues and trends through 2010.* Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

The Illinois Division of Developmental Disabilities

The Division of Developmental Disabilities has oversight for the Illinois system of programs and services specifically designed for individuals with developmental disabilities. With an annual budget of just over $1 billion, including state and federal funds, the Division provides direct services and funds services provided by private facilities and local, community agencies. Community services funded through Medicaid waivers for children and adults are provided through about 350 agencies and, for Home-based Services, through 4,100 employees who are hired directly by the person served. These services vary from 24-hour residential services to specialized therapies, personal support services, day programs, Individual Service and Support Advocacy (ISSA), and respite. Medicaid waiver services are to be provided in integrated community settings. Currently, over 16,500 people are served through the Division's Medicaid waiver program.

The Division has administrative oversight of about 300 private Intermediate Care Facilities for Individuals with Development Disabilities (ICFs/DD) and Skilled Nursing Facilities for Pediatrics (SNFs/Ped). These residential settings vary in size and location and provide specialized and generic training, treatment, health services, and related services. There are currently 6,530 people living in private ICFs/DD and similar type settings in Illinois.

The Division also manages the operations of residential services to 2,100 individuals with developmental disabilities who reside in eight state-operated developmental centers (SODCs).

In past years, the Division has supported nearly 15,000 children and adults with developmental disabilities through a wide-range of non-Medicaid grant programs offered through 160 community agencies. Many of the people served through these programs, for example people with mild intellectual disability and a co-occurring mental illness or people with an Autism Spectrum Disorder, need services to achieve personal goals and live successfully in their local community, but may not meet the federal Medicaid eligibility requirements.

Adapted from: *DDD strategic Plan FY 2011-2017*, p. 3-4.

- Data available through the National Core Indicators (www.nationalcoreindicators.org). The National Core Indicators (NCI) began in 1997 as a collaborative effort between the National Association of State Directors of Developmental Disabilities Services

(NASDDDS) and the Human Services Research Institute (HSRI). The goal of the program was to encourage and support NASDDDS' member agencies, state developmental disability authorities, to develop a standard set of performance measures that could be used by states to manage quality, and make cross-state comparisons and set benchmarks. Fifteen states initially stepped forward to work on the Core Indicators Project, as it was originally known, and pooled their resources to develop valid and reliable data collection protocols. Over time, NCI has become an integral piece of over half the states' quality management systems and aligns with basic requirements for assuring quality in HCBS Waivers.

NCI states and project partners continue to work toward the vision of utilizing NCI data not only to improve practice at the state level but also to add knowledge to the field, to influence state and national policy, and to inform strategic planning initiatives for NASDDDS. Currently, 29 states are participating in the NCI survey, including Illinois. It should be noted that this report only contains data from the 2009-10 Consumer Survey.[16] Illinois completed 382 Consumer Surveys.

- **Conducted interviews with five key informants knowledgeable about the Illinois developmental disabilities service system**. Project staff conducted five interviews of key informants, including three state officials, one person to offer information about micro-boards and human service cooperatives, and a team of self-advocates representing *The Alliance*.

To assess performance against the seven benchmarks, we utilized the information noted above, including comparisons of Illinois to national averages during FY2010.

Report Structure

This report is divided into three additional parts:

1. **Strategic Review: 2008 to the Present:** We provide an assessment of present performance of the Illinois service system for people with developmental disabilities against seven benchmarks.
2. **Strategic Path Forward: Call to Action**: We present a series of steps that we believe Illinois must take to improve performance and better position the state's service system. These actions are consistent with (but not exactly duplicative of) the steps recommended in the 2008 *Blueprint*. Actions are called for in five areas to:
    A. Establish clear and cohesive leadership for the developmental disabilities service system.
    B. Develop organizational infrastructure in support of the community services system.
    C. Improve the community response to individual support needs to promote person-centered outcomes important to individuals and families, including emphasis on self-

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[16] NCI State Report: Illinois 2009-2010. Human Services Research Institute. Cambridge, MA.

direction among people with developmental disabilities and partnerships among service recipients, their family members and others.

D. Serve people in the most integrated setting by reducing further the role that SODCs and ICFs/DD play within the Illinois service system.

E. Expand system capacity so that by 2022 all people who have emergency or critical unmet needs will be served with reasonable promptness.

3. **Conclusion:** We present a summary of our observations and parting remarks.

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Strategic Review: 2008 to the Present

A *gap analysis* compares an enterprise's actual, to its potential, or desired, performance. It is an assessment of the distance between what an enterprise is currently doing and what it seeks to do in the future. A gap analysis flows from benchmarking the level of performance achieved and other assessments of requirements as well as current system capabilities.

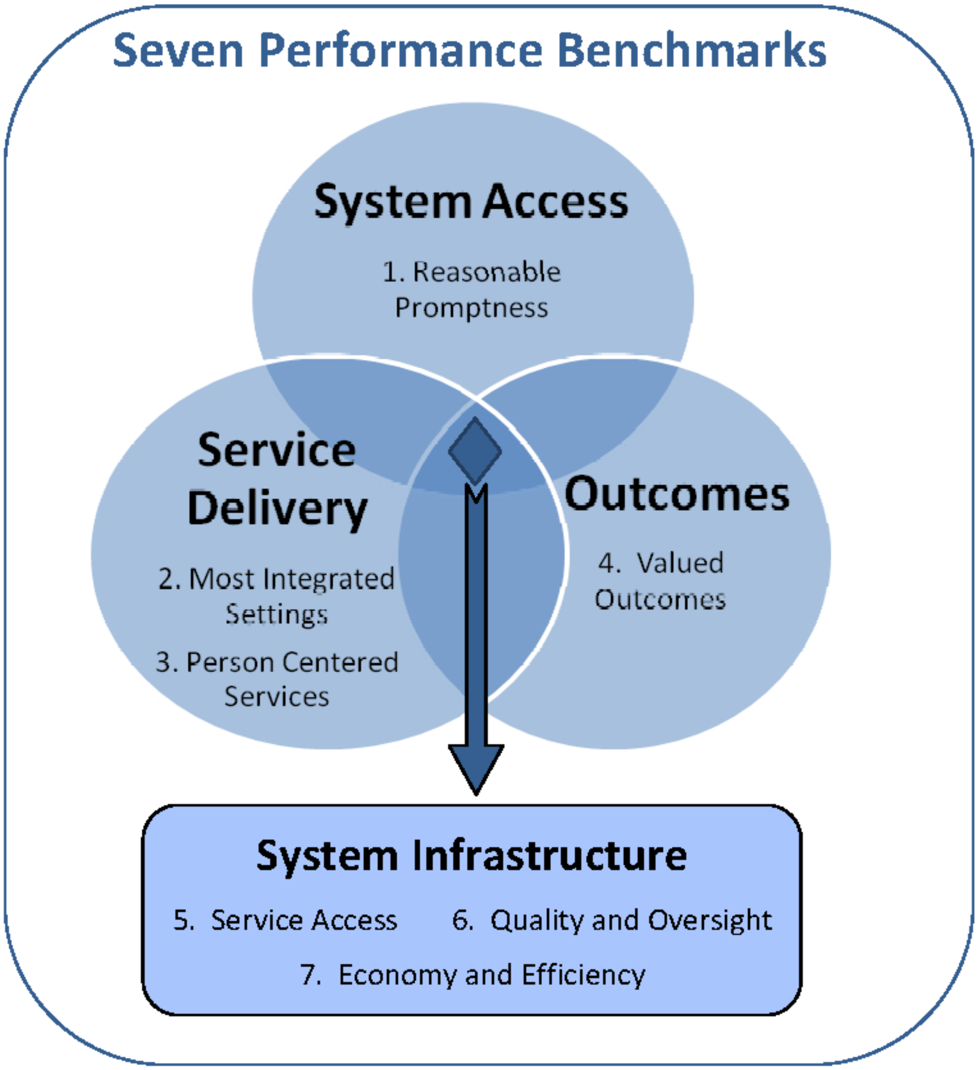
The gap analysis begins with defining the expectations for desired system performance. These expectations serve as the basis for appraising current performance. For the purpose of this gap analysis, we again made use of seven fundamental, top-level performance benchmarks against which to gauge the provision of publicly funded services and supports for people with intellectual and other developmental disabilities in Illinois. These benchmarks were derived from HSRI's nationally recognized work in developing quality assurance indicators (i.e., the "Quality Framework" for the Centers for Medicare and Medicaid Services, and the National Core Indicators utilized by 29 states). As illustrated by the graphic on the next page, the benchmarks are related to service access, service delivery, system efficiency, service quality and oversight and achievement of valued outcomes.

Seven Performance Benchmarks

1. **People with intellectual and other developmental disabilities have access to and receive necessary publicly-funded services and supports with reasonable promptness**. Publicly-funded systems should be capable of ensuring that those needing services receive them within a reasonable period of time. This requires sound system infrastructure in order to ensure a diverse and agile service delivery capacity. When services are not furnished promptly, individuals and families experience negative life outcomes.

2. **Services and supports are provided in the most integrated setting appropriate to the needs of the individual**. The U.S. Supreme Court's *Olmstead* decision has established the clear benchmark that publicly-funded services must be furnished in the most integrated setting possible, given the individual's needs. The decision mandates that states operate services so that individuals are not unnecessarily institutionalized or otherwise served in overly restrictive programs or settings.

3. **Services and supports are person-centered**. Person-centered service delivery means that services and supports are identified and authorized to address the specific needs of each person as a result of an individualized assessment and through a person-centered planning process. Person-centered service delivery requires flexibility in service selection and service delivery methods. Opportunities for individuals and families to direct and manage services are available. A person-centered system also meaningfully involves people with developmental disabilities in advising decision-makers.



4. **The provision of services results in the achievement of valued outcomes for people with intellectual and other developmental disabilities.** Services should promote such outcomes as personal independence, employment and community integration. Services that effectively address functional and other limitations that impede the achievement of personal outcomes by individuals must be available.
5. **There is an infrastructure that facilitates the ready access of people with developmental disabilities and families to services.** Infrastructure refers to the operational components that undergird and support the functioning of the direct services system. A well-designed infrastructure is essential to the effective operation of a complex system.
6. **Services must continuously meet essential quality standards and there must be confidence that quality oversight systems that function effectively and reliably.** Quality assurance systems must ensure that individuals are not exposed to abuse, neglect and

exploitation. Appropriate oversight must be in place to protect the health and welfare of vulnerable people.

7. **The system must have ample resources and promote economy and efficiency in the delivery of services and supports**. This means that the State must seek out the most cost effective services and supports, building on the supports that families and communities provide, and effectively utilizing federal funding. Systems that do not stress economy and efficiency are not sustainable.

These seven benchmarks provide the framework for the present analysis. In the following sections, information about Illinois' current performance vis-à-vis these benchmarks is presented. For each, information is presented to provide:

- Background pertaining to benchmark,
- The assessment made in 2007 of the State's performance,
- A review of current circumstances, and
- A summary assessment of progress made and performance in 2012.

Key Policy Factors Influencing Present Policy-Making

Review of the present system must take into account circumstances that influence the State's policy decisions and performance. Four primary factors include: (a) changing expectations over what constitutes "best practice" in service delivery, (b) enduring state revenue shortfalls, (c) implementation of the Ligas Consent Decree, and (d) discussion over design and implementation of the managed care initiative surrounding Chicago.

Changing Expectations

Expectations for what constitutes best practice are changing. Especially credible spokespeople for such change are people with developmental disabilities. After all, it is their life that the system affects, and they are the ultimate "end-users" of the services a system offers.

People with developmental disabilities nationally argue strongly for support systems that look decidedly different than the current service system 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 less than what is emerging as a national "self-advocate agenda" for system change. In Illinois, however, the opinions of people with developmental disabilities historically are too often set aside in favor of consideration for the opinions of other special interests. In 2008, as part of its work to compile the *Blueprint for System Redesign*, HSRI completed a *Systems Environmental*

Scan[17] that involved interviews of over 50 stakeholders, including people with developmental disabilities. One conclusion reached was that:

> *"…the opinions of one chief stakeholder, and in our view the most significant, are largely ignored. People with developmental disabilities have strong opinions about the issues in play, but for a variety of reasons their voices are often not heard or are discounted." (page 18)*

In response, with funding from the Illinois Council on Developmental Disabilities, self-advocates organized and developed a unified voice, as evidenced by the emergence of the *Illinois Self Advocacy Alliance*.[18] The Alliance is a statewide network of self-advocacy groups whose mission is to, "*Speak up for ourselves and each other while working together to make changes in our communities and in Illinois."*

The Alliance has made great strides in forming a strong self-advocacy network. There are currently 15 local groups throughout the state who are part of the Alliance. These groups, spread across the state, include representation from:

Advocates for Change	Joliet	Personal Power Players	Monticello
Community Awareness, Possibilities, and Supports (CAPS)	Decatur	Ray of Hope Self-Advocates	Chicago Heights
Change to Independence Altogether (CIA)	Bloomington-Normal	Self-Advocates of Lake County	Lake County
DSC Self-Advocacy Group	Champaign	Self Advocacy Council of Northern Illinois	McHendry County
Friendship House Group (Strike for a Better Change)	Ottawa	Sertoma United	Alsip
People 1st of Illinois	Statewide	Speak Out of Rock Island	Rock Island
People 1st of the Illinois Valley	LaSalle-Peru	The Network	Alton
People 1st of Peoria	Peoria		

Through this statewide network, self-advocates in Illinois are emerging as a cohesive constituency that demands say over the policy direction of the developmental disabilities service system. On the state level, the Alliance has organized around the "It's My Life Campaign for Self-Direction" to provide information about self-direction to self-advocates, family members and service providers. Moreover, the Alliance is working with State staff to expand the self-directed service option included in the Illinois HCBS waiver for adults with developmental disabilities.

At the local level, the Alliance conducts leadership training with local groups and provides hands-on support to help these groups with development and action planning. The Alliance also offers "challenge grants" to local groups to address issues specific to their communities.

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[17] Human Services Research Institute (2007). *Illinois System Environmental Scan*. Tualatin, OR: Human Services Research Institute

[18] http://selfadvocacyalliance.org/

Most notably, the Alliance is offering a “Peer Mentoring Program” to residents of SODCs to help prepare them to transition into community living alternatives.

Overall, the Alliance is raising expectations among self-advocates and others regarding the types of services and supports that should be made available to people with developmental disabilities to live the lives they want in the most integrated setting with the support they need.

State Budget Shortfalls

Since 2009 states, including Illinois, have experienced significant budget shortfalls. The crisis in the national economy left state budgets in their worst shape in decades, leaving nearly every state scrambling to balance its budget. Since 2008, cuts in budgets were enacted in at least 46 states, plus the District of Columbia. Cuts occurred in all major areas of state services, including public health, services to the elderly and people with disabilities, K-12 and early education, higher education, and state work forces. Illinois was one of 15 states to report cuts in all these areas.[19]

Medicaid, an essential funder of human services, was highly vulnerable to cuts. The program functions as a federal-state partnership where, for each “Medicaid dollar” a state spends, it is reimbursed a percentage by the federal government (known as the Federal Medical Assistance Percentage or “FMAP”). In 2008, Illinois was reimbursed 50 percent of each dollar spent.

Table 1: Projected Shortfalls Faced by Illinois From 2009-2012

Fiscal Year	**Shortfall When Budget Adopted**	**Mid year Shortfall**	**Total for Fiscal Year**	**Shortfall as Percent of that Fiscal Year’s General Fund Budget**	**National Average**	**Illinois’ Rank Compared to Other States** (lowest rank equal most affected)
2009	1.8 billion	$2.5 billion	$4.3 billion	15.1%	15.2%	39
2010	$9.3 billion	$5 billion	$14.3 billion	43.7%	29%	4
2011	$13.5 billion	$0	$13.5 billion	40.2%	19.9%	2
2012	$5.3 billion (projected)	Not available	$5.3 billion	16%	15.9%	12
Total	----	----	$37.4 billion	----	----	----

Source: Center on Budget and Policy Priorities http://www.cbpp.org/cms/index.cfm?fa=view&id=711

In February of 2009, President Obama signed legislation entitled the “American Recovery and Reinvestment Act of 2009.” Among many other facets, this Act provided a temporary increase in the share of the Medicaid program paid by the federal government. The provision took effect immediately and provided states with approximately $87 billion in assistance over nine calendar quarters (October 1, 2008 through December 31, 2010). During this time, Illinois’ match rate was increased from 50 percent to 61.88 percent for FYs 2009 and 2010; however, with the sunset of the Recovery Act, this match rate has returned to 50 percent.[20]

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[19] Johnson, N., Oliff, P. & Williams, E. (2010). *An update on state budget cuts*. Center on Budget and Policy Priorities. http://www.cbpp.org/cms/index.cfm?fa=view&id=1214

[20] http://www.statehealthfacts.org/comparetable.jsp?ind=184&cat=4

Studies illustrate that Illinois was hard hit by these economic times. Table 1 shows the revenue shortfalls from 2009-2012, illustrating that Illinois was especially hard hit in FYs 2010-2011.

More recently, the data suggest that state finances are slowly recovering, yet states still face additional challenges. For example, while Illinois' projected 2012 shortfall suggests improvement over the two previous years, the state still projected an additional mid-year budget gap of $507 million. Further, while not all states have reported projections for FY 2013, by January 2012, 29 states projected shortfalls totaling $44 billion. [21]

"The budget bureaucrats are cutting the heart out of important disability supports."

Tony Paulauski
The Arc of Illinois
February 2011

Not surprisingly, services for people with I/DD are caught up in the enduring budget crisis. In some states, family support or personal assistance programs have been cut, with increased emphasis placed on "shared" living (i.e. two or more individuals residing in a shared apartment or house) or day service options. Efforts to reduce waiting lists have also slowed. Provider payments have been delayed and/or reduced. Around the country, many provider organizations have laid off staff, and some have gone out of business altogether due to state budget cuts.

Citizens in Illinois have also felt the impacts of the present recession. State leaders implemented a variety of cost cutting measures, resulting in impacts such as cuts to services, reduced service reimbursement rates, and delays in pay to service providers. Service recipients and providers have complained throughout, fueling avid discussion among many over what types of services should be funded and to what extent.

If revenue remains depressed, as is expected in many states, additional spending and service cuts are likely. Going forward, policy makers will undoubtedly be required to make decisions with a strong regard for present and future budget limitations.

"We understand there is a budget crisis, but legislators should look at where the money goes."

Amber Smock
Access Living
April 2011

Ligas Consent Decree

On July 28, 2005, the *Ligas v. Hamos* lawsuit was filed on behalf of individuals with developmental disabilities residing in private, state-funded ICFs/DD of nine or more persons or who were at risk of being placed in such facilities. The Plaintiffs sought placement in community-based settings and receipt of community based services.

On June 15, 2011, the State entered into a Consent Decree to settle the lawsuit. The Decree will retain jurisdiction for at least nine years (or until finding of substantial compliance). The

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[21] http://www.cbpp.org/cms/index.cfm?fa=view&id=711

Decree identifies two groups of Class Members. Members include adults (ages 18 and older) with developmental disabilities who qualify for Medicaid Waiver services who either:

- Reside in a private ICFs/DD with nine or more residents and who affirmatively request Community-Based Services or placement in a Community-Based Setting; or
- Reside in a Family Home, and for whom the State has a "current record" of the person seeking Community-Based Services or placement in a Community-Based Setting.

The Decree is based on the following principles:

- People with disabilities will have a say and a choice about how and where services and supports will be provided.
- People who want services in the community will have this option.
- Person-centered planning will be used as the cornerstone in documenting individual needs and preferences.
- Services will not be limited to those which are currently available.

To comply with the Decree, the State must meet the following provisions:

- Services for individuals residing in private ICFs/DD. The DDD must move all individuals living in private ICFs/DD who have affirmatively requested Community-Based Settings to such settings over the next six years. Placements must be implemented for one-third of all such individuals every two years of this six-year period.
- Services for individuals residing in the family home. The DDD must serve 3,000 individuals on the waiting list for community-based services over the next six years (1,000 within the first two years and 500 per year over the next four years).
- Evaluations and Transition Service Plans will focus on individual desires and goals and will not be limited to existing services.
- The Department of Human Services will seek sufficient funds to develop and maintain the services described in the Decree.
- A court-appointed monitor will oversee compliance with the Decree and provide annual reports to the Court on the State's progress.

On December 15, 2011, the State filed its final plans to implement the provisions of the Consent Decree. The following sections are included in this plan.

- *Development and Maintenance of the Class Member List.* The DDD will compile an initial list of class members and continue to develop and maintain the list as additional individuals request to be added to or removed. There will be two Class Member Lists: those who live in private ICFs/DD who want community services; and those who live at home and have requested community services.
- *Outreach*. The DDD will ensure that individuals and their guardians receive accurate information about their options and continue to identify individuals in need of

residential or in-home supports and those who wish to move from private ICFs/DD. Outreach efforts will include written materials describing all components of the Ligas implementation, a Ligas website, and training for PAS agencies and others.

- *Development of Community Capacity.* The DDD will work with existing providers and recruit new providers to expand community service capacity to meet the requirements of the Decree and the needs of individuals seeking community-based services.
- *Community-Based Services/Placement for Individuals Residing in private ICFs/DD.* The first third of Class Members residing in private ICFs/DD will transition to community-based services by December 15, 2013. Similarly, the second third will transition by December 15, 2015 and the final third will transition by June 15, 2017. These moves will be monitored to assure successful transitions.
- *Transition Planning.* Transition Service Plans will be developed using a person-centered planning process to describe individual needs prior to the selection of service providers. Services will be offered in the most integrated manner consistent with individual choice and will not be limited to those services currently available.
- *Waiting List for Community Services and Placement.* The DDD will develop a process to select 3,000 Class Members residing at home on DDD's waiting list for community-based services and placements.
- *Community Crises.* The DDD will continue to serve individuals in crisis situations. These services will be above the 3,000 capacities being developed for Class Members residing at home.
- *Appeal Process.* The DDD will honor the right of individuals to appeal any denial, suspension, termination, or reduction of services, and inform Class Members of this right.
- *Resources Necessary for Implementation.* The DDD will seek additional budget resources to develop and maintain the services, supports and structures described in the Decree, consistent with the choices of individuals with developmental disabilities, including Class Members.
- *Interagency Agreements.* Interagency agreements necessary to carry out the provisions of the Decree are in place to secure matching Medicaid funds for developmental disabilities services.
- *Process for Plan Reporting and Modification.* Reports containing data and information regarding compliance activities and review and update of the Implementation Plan will be produced every six months by the DDD.

Implementation of Managed Care Strategies

In 2010, the Illinois Department of Healthcare and Family Services initiated a pilot managed care initiative in hopes of reducing health care costs while maintaining or improving services. The Department planned to implement its "Integrated Care Program" in three phases, scheduled for full implementation by 2015, and operate in DuPage, Kane, Kankakee, Lake, Will, and suburban Cook Counties (areas with zip codes that do not begin with "606").

The Department released a solicitation for proposals for two Health Maintenance Organizations (HMOs) to "enter into risk-based contracts for the Integrated Care Program, to provide the full spectrum of Medicaid Covered Services through an integrated care delivery system to Older Adults and Adults with Disabilities who are eligible for Medicaid but are not eligible for Medicare." The HMOs are required to cover the entire pilot "Contracting Area".[22]

In Illinois, the managed care pilot is being implemented in three phases. As depicted in the accompanying Figure 1, Phase 1 of the pilot is the transition of Medical and Behavioral health services into the managed care model. Services under Phase 1 are meant to offer medical and behavioral services to low income families and individuals already enrolled in the Medicaid program. Phase 1 is not meant to provide long-term services to Medicaid beneficiaries.

Figure 1 Managed Care Phases

Phase I
Medical and Behavioral Health
Phase II
LTSS Nursing Facilities and Physical Disabilities
Phase III
Developmental Disabilities
HCBS Waiver
ICFs/DD
SODCs

Phase 2 of the pilot brings in Long Term Supports and Services (LTSS) for individuals in nursing facilities and individuals with physical disabilities. Services under Phase 2 would include all services under Phase 1 plus any residential or other long-term services required by the individuals enrolled in Medicaid.

Phase 3 of the pilot focuses on all individuals with I/DD enrolled in Medicaid. The services for people with I/DD under the managed care program would include all of the medical services under Phase 1 plus management of the SODCs, private ICFs/DD and the HCBS waiver program.

Although the pilot is early in implementation, the program has already received careful scrutiny, yielding both praise and criticism. Those in favor of the managed care system believe that it has strong potential for helping the State address significant budget shortfalls and rising medical costs. Others, however, criticize the initiative because they fear the plan will not be able to respond effectively to the unique needs of individuals across service populations. Concern, for example, has been raised around the transition of I/DD services into the new system. Because people with I/DD typically need more specialized care, many worry that a managed care program aimed at reducing costs will in turn reduce service quality and choice for this population. Further, as reported in the Chicago Tribune[23], "many doctors and hospitals are refusing to join the new Medicaid program, which the state hopes will better coordinate care and lower costs for some of its neediest recipients. The providers' rationale: They dislike the bureaucratic hassles and cost-cutting measures associated with managed care." In turn,

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[22] http://www.hfs.illinois.gov/assets/icprfp.pdf

[23] http://www.chicagotribune.com/health/ct-met-medicaid-managed-care-20110826,0,6553592.story

the hesitancy among doctors and hospitals to join the plan may make it more difficult for people with I/DD, and other vulnerable citizens, to acquire the health care they need.

Benchmark Comparisons

What follows is an assessment of Illinois' performance in relation to seven performance benchmarks. For each, the benchmark is stated followed by background information, the summary finding in 2008 with associated documentation, and the new findings for 2012 with related discussion.

Performance Benchmark 1: People with developmental disabilities have access to and receive necessary publicly-funded services and supports with reasonable promptness.

Background

Most of the 5 million people with developmental disabilities in the United States are supported by their families, live independently with only intermittent publicly-funded support, or get along without any specialized, publicly-funded developmental disabilities services. Assuming a prevalence rate of developmental disabilities of about 1 - 1.6 percent, most public developmental disabilities service systems provide services and supports to a relatively small percentage (about 20-25 percent) of all individuals with developmental disabilities. Public systems focus principally on people who have significant functional limitations and require services over and above the supports that their families are able to provide or that they can obtain through generic human services programs.

Demand for publicly-funded developmental disabilities services, however, is growing nationwide. Generally, demand has been increasing at a rate greater than population growth alone. The demand for developmental disabilities services is dynamic. Each year, significant numbers of youth with developmental disabilities exit special education systems and need ongoing services and supports as young adults. Other people seek services because their families cannot continue to support them or they need extra assistance. Based on work completed elsewhere and national comparisons by the University of Minnesota Research and Training Center on Community Living, it is not uncommon to observe year-over-year increases in the expressed demand for developmental disabilities of 4 percent[24] or more.

States generally operate their developmental disabilities service systems under fixed capacity limits. System capacity is managed by capping dollars or "slots" (service openings), or a combination of both. Likewise, capacity is regulated by changes in funding from year to year.

Capped system capacity, coupled with rising demand for services, has resulted in individuals spilling over onto "waitlists." The number of people on a waitlist measures the gap between current system capacity and expressed service demand. This gap grows when the expansion of

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[24] Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2008). *Residential Services for People with Developmental Disabilities: Status and Trends Though 2007*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

system capacity does not keep pace with growth in service demand. The waitlist queue will lengthen even though there may have been some growth in system capacity.

Federal court decisions have clearly indicated that responding to service needs with reasonable promptness means that individuals enrolled in Medicaid who have emergency or crisis needs must receive Medicaid-funded services within 90 days. It follows then that people who have critical unmet needs should be able to count on receiving services within 6-9 months (Federal Medicaid Act 42 C.F.R. § 435.930(a)). If they do not receive the services required, their needs can rapidly turn into an emergency or crisis situation.

… people who have critical near-term needs should be able to count on receiving services within 6-9 months.

Findings in 2008: Illinois does not furnish services with reasonable promptness to its citizens with developmental disabilities.

In the original *Gap Analysis* report (Smith, et. al, 2008) an estimated 11,214 individuals with developmental disabilities were waiting for – but not receiving – Medicaid-financed services through the Prioritization of Urgency of Need For Services (PUNS) database. The PUNS was developed in Pennsylvania to compile information about unmet service needs.[25] It classifies individuals based on an assessment of how soon services must be provided. Individuals are classified as to whether the service need is an “emergency” (i.e., services are needed right away), “critical” (supports are needed within one year) or “planning” (services are needed within a 1-5 year time frame).

The classification of individuals by urgency of need takes into account both the needs of the individual and the caregiver’s situation (e.g., the capacity of the caregiver to support the person). For example, the “emergency need” classification includes people whose caregivers are no longer able to support them, who are at immediate risk of out-of-home placement and/or where there has been a significant deterioration in the person’s condition. The “critical” category includes persons with urgent needs due to the deteriorating condition of their caregivers or who live with aging caregivers over the age of 60. Some people with unmet needs currently receive services but require different or additional services. In addition, the measure gathers demographic data on the individual and current caregivers, as well as information on the services being received and those sought. Urgency of need is used to prioritize the authorization of services when openings are available.

Illinois makes available data compiled from its use of the PUNS on its state developmental disabilities services website. Go to: http://www.dhs.state.il.us/page.aspx?item=56036.

At the time of the 2008 report, the PUNS data (dated January 2008) indicated that:

- 1,971 (17.6%) were in the emergency need category;

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[25] http://www.temple.edu/thetrainingpartnership/resources/mrBulletins/gd/00-06-15%20Attachment%201.pdf

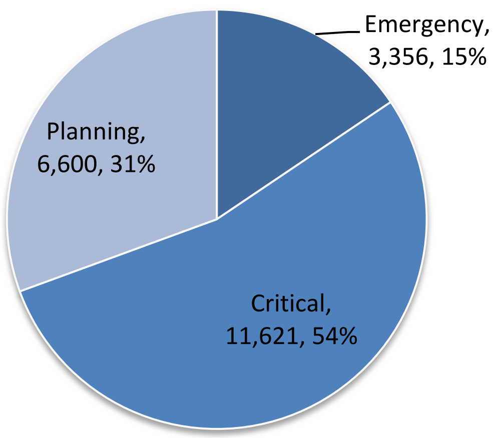
- Another 5,813 (51.8%) were in the critical need category; and
- 3,430 (30.6%) people had "planning needs."

Taking into account the individuals with emergency need (1,971) and those with critical needs (5,813) the report found that a growth in system capacity of 35 percent was needed to serve those individuals. Providing services to the 7,784 individuals with the most urgent need would have cost the state $225.2 million ($112.6 million in State funds) in 2008. This estimate was based on the 2008 HCBS waiver per person costs of $30,027 per year.

Current Status: Illinois is still not providing services to individuals with I/DD with reasonable promptness and maintains a large waitlist for I/DD services. In fact, the waitlist has nearly doubled since the previous *Gap Analysis* report.

Since the original report was written in 2008, the number of individuals registered through PUNS, waiting for services has more than doubled.[26] As of February 2012, 21,577 individuals were waiting for – but not receiving – services across the three categorizations (Emergency need, Critical need, Planning). Chart 1 shows the distribution of need by category type. As shown, 69 percent of those registered on PUNS have Emergency or Critical need (Emergency: 3,356; Critical: 11,621).

Chart 1: People on PUNS Waiting List (February 2012)



http://www.dhs.state.il.us/page.aspx?item=51905

Chart 2 offers a more detailed view of the types of services individuals are currently waiting for. It shows a duplicative count of all (emergency, critical or planning) individuals currently enlisted on PUNS. As seen, Personal Support, Transportation and Work/Activities have the highest numbers of individuals waiting, followed by therapies (Speech, Behavioral Support, Occupational) and out-of-home residential supports.

Using the same formula as the original report (total waiting for Emergency or Critical Services divided by the total served in 2010), a growth in service capacity of 58.4 percent would be

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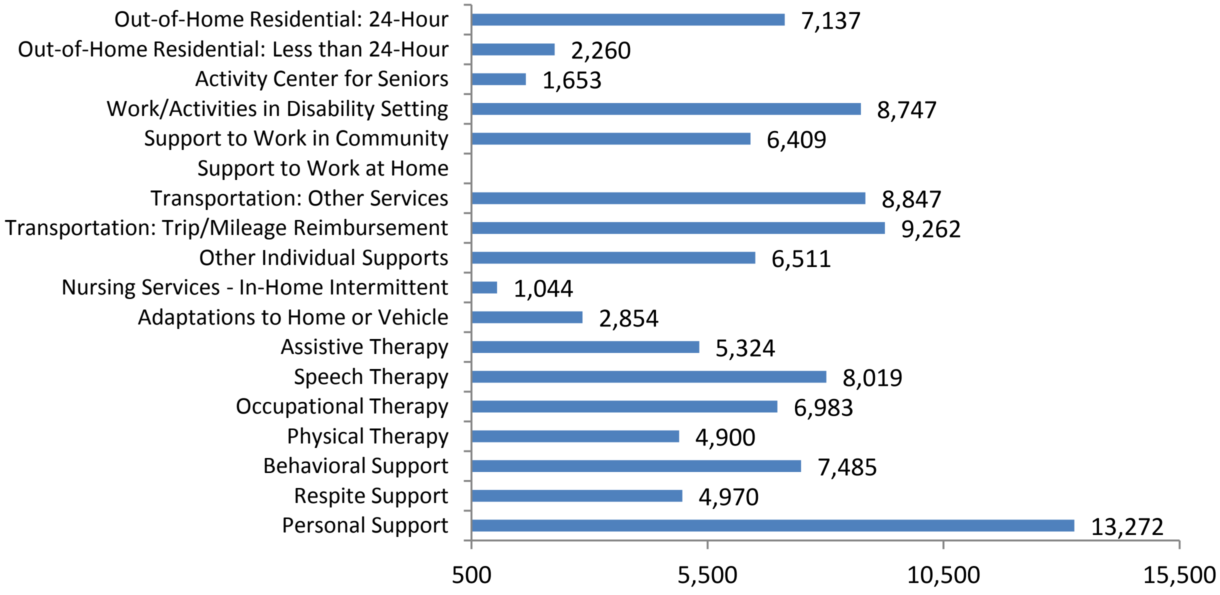
[26] Illinois makes available data compiled from its use of the PUNS on its state developmental disabilities services website. Go to: http://www.dhs.state.il.us/page.aspx?item=56036

Chart 2: Total Number of Individuals Waiting (by service type) on PUNS Waiting List (February 2012)



http://www.dhs.state.il.us/page.aspx?item=51905

needed to serve these individuals. Assuming the 2010 average HCBS cost per person of $31,002, this would cost an additional $464,316,954 ($231,232,843 in State funds).

In 2010 the State provided Medicaid funded I/DD services to 199 people per 100 thousand people in the general population. The national average was 220, leaving Illinois 10.5 percent short of the national marker. Given a state population then of 12.8 million, these findings suggest that Illinois would need to serve 2,688 people just to achieve the national service utilization rate.

In past work, we advised that states serving 200 per 100K have little to no waitlist for services. We have, however, steadily raised this marker due to demographic and other factors that have increased service demand. Presently, the data suggest that states that serve 300 people per 100K have a better chance of eliminating service waitlists. The outlined growth above of 3,356 individuals with Emergency needs and 11,621 individuals with Critical needs added to the already 25,520 people in service in 2010 would give the State a service rate of 315.1 per 100K, likely greatly reducing if not almost eliminating the waitlist for services.

It is important to note, however, that serving those currently classified as having Emergency or Critical needs as of February 2012 will not allow the state to stop growing system capacity. Individuals shown as being in the Planning phase through PUNS will at some point need services, and others will need services due to crisis. However, if the state does not make plans to serve many if not all of the individuals currently on PUNS, similar growth as seen between 2008 and 2012 will likely continue into the unforeseeable future.

Performance Benchmark 2: Services and Supports are provided in the most integrated setting appropriate to the needs of the individual.

Background

In its landmark *Olmstead v. LC & EW* decision, the United States Supreme Court affirmed that, under Title II of the Americans with Disabilities Act, states are obliged to operate programs for people with disabilities to ensure that individuals receive services in the most integrated setting appropriate to their needs. The decision established a benchmark for the operation of public programs for people with disabilities. As a practical matter, "most integrated setting" means that individuals are supported in community settings similar to the typical living arrangements of people without disabilities. The Olmstead decision sent the strong message that people should not be unnecessarily institutionalized. The decision also established affirmative expectations for the transition of persons from institutional settings to the community.

In developmental disabilities services, just over twenty years ago the substantial majority of individuals were served in large congregate settings (i.e., settings where seven or more persons are served). In 1987, only 27.3 percent of all persons who received residential services were supported in living arrangements for six or fewer persons. About one-half of all individuals were served in very large settings that serve sixteen or more individuals, including 95,000 persons who resided in very large, state-operated public institutions.

By 2010, 75.7 percent of all persons nationwide were supported in living arrangements for six or fewer people. In eleven states (AK, AZ, CO, DC, ME, MD, NV, NH, NM, RI, VT), 90 percent or more of individuals were served in small living arrangements. Nationwide, only 12.2 percent of all persons were served in very large settings with sixteen or more beds. The number of people served in very large public institutions fell to under 31,101 in 2010. The average community living arrangement supported 2.45 individuals versus 7.5 persons in 1987. The steady, marked decline in the use of large and very large residential settings over the past twenty years is the product of several factors, including litigation about the conditions in very large public facilities, the expansion of community services, and the community integration imperative.

Today, in the United States, the benchmark for supporting people with developmental disabilities in the most integrated setting is to employ settings where six and frequently fewer people share a living arrangement. Most states have reconfigured their service systems so that the substantial majority of individuals now are supported in settings that meet this benchmark.

Findings in 2008: Illinois relies on large congregate care facilities to serve people with developmental disabilities to an extraordinary extent. Opportunities for individuals to receive services in the most integrated setting are truncated.

The original *Gap Analysis* report found that in 2006:

- Illinois substantially lagged the nation and most other states in shifting the delivery of services to the most integrated setting.

- Only 37 percent of people with developmental disabilities in Illinois were supported in living arrangements for six or fewer persons, the benchmark standard at that time.
- People with developmental disabilities in Illinois were twice as likely to be served in very large settings (16 or more persons) than individuals in other states.
- There were approximately 1,100 individuals with developmental disabilities who were served in nursing homes and SNF/Peds facilities.
- Illinois alone accounted for about 10 percent of all persons nationwide served in very large facilities. Very large facilities in Illinois included the nine SODCs and many of the private-sector ICFs/DD.
- The rate at which Illinois served individuals in very large state-operated facilities was 64 percent higher than the nationwide average. In order for utilization in Illinois to have matched the nationwide average, the census of the SODCs would be about 1,050 people lower than it was in 2006.
- In 2006, Illinois ranked 7th among the states in terms of the number of people served in large state-operated facilities relative to state population.
- The pace of reduction in the number of persons residing in the Illinois SODCs has been slower than the rate nationwide. For example, between 1995 and 2006, the number of people served in very large public facilities nationwide declined by 40.6 percent. During the same period, the number served in the Illinois SODCs declined by 27.8 percent.
- In 2006, there were another 3,757 individuals who were served in very large non-state facilities. Most of these facilities were classified as private ICFs/DD. The number of persons served in these settings has gradually trended downward. Still, more people with developmental disabilities are served in large ICFs/DD in Illinois than in any other state. In 2006, Illinois accounted for one out of every six very large private ICF/DD beds nationwide.

Current Status: Illinois is still not providing services to individuals with I/DD in the most integrated settings. The State still relies heavily on the SODCs, private ICFs/DD and 24/7 community group homes for the majority of their service population.

To date, little has changed in comparison to the 2008 report. The State did however close the Howe Developmental Center in 2010 and has announced plans for closure of the Jacksonville Developmental Center in October 2011[27] and the Murray Developmental Center in February 2012[28]. While Howe was the ninth facility to close, eight large State Operated Developmental Centers (SODCs) are still open, as seen in Table 2.

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[27] http://www.sj-r.com/top-stories/x441967789/Quinn-again-proposes-closing-Jacksonville-Developmental-Center

[28] http://www2.illinois.gov/budget/Documents/Budget%20Book/FY%202013/FINAL%20Rebalancing%20Fact%20Sheet%20-%20FY2013%20Budget.pdf

Table 2: Large State-Operated Residential Facilities in Illinois (2010)

Large State ID/DD Facilities or Units Operating 1960-2010	Year Facility Opened	Year Closed	Residents with ID/DD on 6/30/10	All Residents on 6/30/10	Average Daily ID/DD Residents FY 10	Residents with ID/DD on 6/30/09	% +/- Change 6/30/09-6/30/10	Average per Diem Expenditures FY 10 ($)	FY 10 Admissions/ Readmissions	FY 10 Discharges	FY 10 Deaths
Alton Mental Health & Dev. Ctr. (Alton)	**1914**	**1994**									
Bowen Ctr. (Harrisburg)	**1966**	**1982**									
Choate Dev. Ctr. (Anna)	1873		161	163	160	DNF	DNF	611.67	28	32	2
Dixon Ctr. (Dixon)	**1918**	**1987**									
Elgin Mental Health & Dev. Ctr. (Elgin)	**1872**	**1994**									
Fox Dev. Ctr. (Dwight)	1965		124	124	125	125	-0.8	521.68	9	5	5
Galesburg Ctr. (Galesburg)	**1959**	**1985**									
Howe Dev. Ctr. (Tinley Park)	**1973**	**2010**	**0**	**0**	**262**	**265**	**-100.0**	**DNF**	**0**	**252**	**10**
Jacksonville Dev. Ctr. (Jacksonville)	1851		207	207	206	204	1.5	562.37	22	14	4
Kiley Dev. Ctr. (Waukegan)	1975		227	227	218	213	6.6	487.33	22	8	0
Lincoln Dev. Ctr. (Lincoln)	**1866**	**2002**									
Ludeman Dev. Ctr. (Park Forest)	1972		419	419	386	372	12.6	595.07	63	12	4
Mabley Dev. Ctr. (Dixon)	1987		93	93	88	84	10.7	506.53	11	3	0
Meyer Mental Health Ctr. (Decatur)	**1967**	**1993**									
Murray Dev. Ctr. (Centralia)	1964		296	296	296	291	1.7	525.44	23	14	3
Shapiro Dev. Ctr. (Kankakee)	1879		581	581	542	527	10.2	383.00	7	19	6
Singer Mental Health & Dev. Ctr. (Rockford)	**1966**	**2002**									
(Larson, et. al, 2012)											

Table 3: Residential Setting Sizes (2010)

Setting Size	Illinois (People Served)	% Illinois (2010)	% Illinois (2008)	% U.S. Average (2010)	% U.S. Average (2008)
>6	8,252	38%	37%	76%	71%
7-15	7,703	36%	32%	12%	14%
16 or more	5,545	26%	31%	12%	15%
	21,500				

(Larson, et al. 2012)

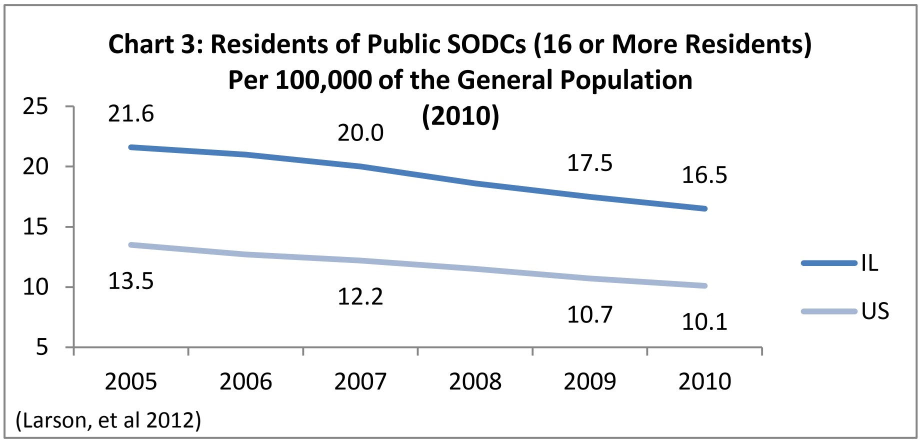
Even with the closure of Howe, the residential services offered in Illinois are still greatly different than those of the rest of the nation. As shown in Table 3, Illinois serves a significantly higher percentage of individuals in residential settings of both 7-15 and 16 or more individuals. In fact, Illinois serves over twice as many individuals in each setting as the 2010 national average. Further, the state serves 50.8 percent fewer individuals in settings of 1-6 (the most integrated setting size). As shown in Table 3, the decrease in the percentage of individuals living in settings of 16 or more translated into a small increase in the number served in settings of 6 or fewer, but a large growth in the number served in 7-15 settings.

Reliance on SODCs

Illinois' continued utilization of large, state-operated SODCs is not new. Table 2 reveals that:

- Jacksonville, presently scheduled for closure, was opened in 1851. Two other facilities, Choate and Shapiro were opened in 1873 and 1879 respectively. Clearly, Illinois has relied on facilities such as these for a very long time.
- Even as Howe was closing in 2010, resulting in the discharge 252 people, there was a net enrollment gain at the other SODCs. In the remaining eight SODCs, 131 people were either discharged or passed way compared to 185 who were enrolled, yielding a net gain of 54 across the SODC network. We understand that some number of these individuals were relocated from Howe, illustrating that the SODCs remain a strong part of the Illinois service system.

As shown in Chart 3, Illinois uses these settings at a higher rate than the national average. In 2010, the rate at which the State utilized residential options of state-operated facilities of 16 or more people was 63.3 percent higher than the national average. For the State to serve a number equal to the national average in 2010, an additional 815 individuals would have to be moved from these settings. Of further concern, the State reports that roughly 22.4 percent of



(Larson, et al 2012)

those receiving services in the SODCs have mild to moderate levels of intellectual or developmental disabilities.

Reliance on Private ICFs/DD

The SODCs are not the only unchanged factor in the residential services arena. As noted in the 2008 report, a significant number of individuals receiving residential services in Illinois do so through privately operated ICFs/DD settings. In 2010, 3,434 individuals lived in large 16-plus bed residential facilities operated by private service providers. Of those, 3,078 were in facilities classified as non-state operated ICFs/DD. This rate was 275 percent higher than the national average. Further, an additional 3,378 individuals lived in private ICF/DD settings of 15 or fewer. In all, the 6,456 individuals in private ICFs/DD make up 30.0 percent of Illinois residential service options, compared to only 12.0 percent nationally.

The Ligas Consent Decree of 2011 brings the possibility of significant change to the aforementioned issue of private ICFs/DD. As laid forth in the Decree:

> “Within six years of approval of the Decree, all individuals living in ICFs/DD as of the effective date of the Decree who have affirmatively requested Community-Based Settings will move to Community-Based Settings. Placements must be implemented for one-third of all such individuals every two years of this six-year period. For those individuals who wish to continue living in an ICF/DD, the Decree requires the State to honor that choice and to continue to provide adequate funding to meet the needs of such individuals.”

The Decree has allowed a much needed choice for individuals residing in private ICFs/DD to move into more integrated settings in the community. The State should embrace this option and continue efforts to move individuals into more integrated settings. Doing so will bring Illinois closer to the national trend of serving individuals in smaller, more integrated settings, and reduce its investment in high cost, low-outcome settings such as ICFs/DD.

Reliance on Large Out-of-Home HCBS Residences

Illinois serves a large portion of individuals in HCBS residential options referred to as Community Integrated Living Arrangements (CILAs). The CILAs are residences owned and operated by an individual or group who in turn is reimbursed for the cost of care by the State. Over the past several years, a significant movement toward smaller (four or fewer residents) community operated group homes or CILAs has been the national trend. Illinois, however, has not followed that trend and is still operating several large community centers. Due to data reporting limitations, information on the number of CILAs in

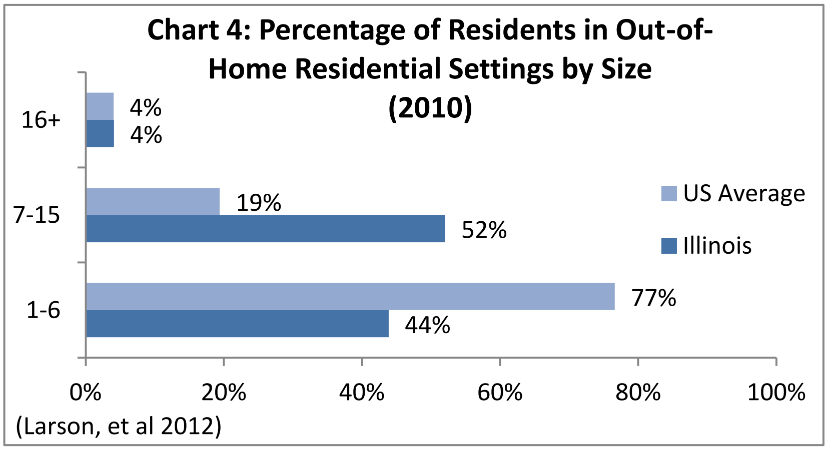


Chart 4: Percentage of Residents in Out-of-Home Residential Settings by Size (2010)

(Larson, et al 2012)

operation by number of individuals served is unavailable for the State. However, data on individuals by setting size is available. As seen in Chart 4, Illinois utilizes small 1-6 bed residential settings at a significantly lower rate than the nation as a whole. In Illinois, 44 percent of HCBS out-of-home residential options are available through 1-6 bed facilities, compared to 77 percent nationally. As can be seen, Illinois utilizes 7-15 bed residences as the primary option for individuals. In Illinois, more than half (52 percent) of HCBS out-of-home residential services were offered in settings of 7-15 beds compared to only 19 percent nationally.

Performance Benchmark 3: Services and Supports are person-centered

Background

Person-centered service delivery means that services and supports are identified and authorized to address the specific needs of each person as the result of an individualized assessment and through a person-centered planning process. Person-centered service delivery requires flexibility in service selection and service delivery methods. Opportunities for individuals and families to direct and manage services are available. A person-centered system also meaningfully involves people with developmental disabilities in advising decision-makers.

Person-centered service delivery systems have several key features, including:

- *Portability.* The funds that are available to support a person are not locked into specific service models. For example, funding for residential services is not tied to particular types of settings but may be used to purchase services and supports in a variety of settings.
- *Free Choice of Provider.* Individuals can freely select among all qualified providers and can readily change providers when dissatisfied with provider performance. This particular feature is a requirement of administering an HCBS waiver.
- *Flexibility.* Services and supports can be customized around the particular needs and preferences of the individual. Person-centered service delivery recognizes that there are alternative pathways to achieving individual goals.

In this context, person-centered planning serves as the critical, instrumental tool for identifying the best mix of paid services and unpaid supports that will assist each individual in securing valued outcomes while concurrently assuring health and welfare. A person-centered system also is characterized by continuously engaging people with disabilities and families in policy deliberations. Moreover, person-centered systems are inherently fluid, and promote the development of individualized support strategies rather than the operation of set service delivery models. Such practice is often best led by independent case managers or service coordinators.

An important development in the evolution of person-centered service delivery is the emergence of self-direction. Self-directed service delivery methods position the individual or families to manage a service budget, including distributing the budget among different types of supports and serving as the employer of service workers. Self-direction gives individuals and families a greater degree of control over services while concurrently encouraging them to seek out the most economical services.

Person-centered service delivery is inherently consumer-driven and market-based. It stands in contrast to systems that use slot-based contracting with service providers.

Findings in 2008: Illinois has not configured its developmental disabilities system to embrace person-centered service delivery. Services and funding are tied to "programs" and service provider agencies.

The *Gap Analysis* reported that Illinois had not configured its developmental disabilities service system to embrace person-centered service delivery. Historically, the Illinois community developmental disabilities service system was structured around grant-in-aid contracts between the state and service providers. The grant-in-aid system tied dollars to service providers. Over the years, Illinois gradually shifted the purchase of community services toward fee-for-service payment arrangements, in part to secure increased Medicaid funding for community services. This included enrolling more CILA residents in the HCBS waiver and shifting people who receive day training to the waiver. The grant-in-aid framework, however, had not been discarded entirely. Contracts between the State and service providers continued to be used to control total spending and, by default, available service openings. Fee-for-service billing was nested within these contracts, which mainly encompassed day training and CILA services. This type of arrangement impeded the free selection of providers by individuals. With respect to CILA services, choice was limited to providers with available openings.

The 2008 *Gap Analysis* also stated that the Illinois HCBS waiver for people with developmental disabilities covered a relatively wide range of services. Yet, the waiver was internally partitioned into sectors (e.g., CILA and home-based services) and each sector was slot controlled. This practice is not consistent with person-centered service delivery principles.

In the case of people who received ICF/DD services, their funding was not portable. It was locked into the ICF/DD program and could not be easily redeployed to purchase alternative services in the community. If a person left an ICF/DD, the person had no guarantee of receiving services elsewhere in the Illinois system.

Current Status: Illinois has committed to embedding person-centered practices throughout its system and is taking steps in this direction, but there is still much to do.

Since 2008, consider that:

- As reflected in the *DDD Strategic Plan FY 2011-2017*, the Division outlined a strong commitment to developing and implementing a person-centered service system. For example, by 2017, the State proposes that *all* people served by the Division will have a

Person-centered services: services and supports characterized by a comprehensive understanding of individuals ‘ strengths, desires, hopes, and aspirations and provided in a manner that reflects a sincere commitment to maximizing opportunities for individuals to function with as much independence and self-determination as possible.

A person-centered organizational change process requires a systematic review of all policy, procedure, and program design to align with the new service model.

Strategic Plan FY 2011-2017
Illinois Department of Human services
Division of Developmental Disabilities (July 2010)

person-centered plan and subsequent services that accurately reflect their needs, personal goals, and objectives.

- Illinois engaged in a major Medicaid conversion effort, shifting from state funded grant-in-aid contracts with service providers to primarily HCBS waiver funding. This allowed the State to capture additional federal Medicaid dollars to purchase community services.
- A provision in the Ligas Consent Decree dictates a clear focus on person-centered planning processes for Class Members transitioning to community-based residences,[29] and all parties responsible for relocating individuals from ICFs/DD to alternative residences have agreed to utilize a vibrant person-centered planning process.
- The State has indicated a commitment to utilizing a person-centered planning process entitled “Active Community Care Transition” (ACCT) planning, to relocate individuals from SODCs to community residential alternatives.
- According to State staff, the Division of Developmental Disabilities is currently embarking on developing and conducting a series of trainings for state staff, service coordinators, and service providers on person-centered planning.
- Notably, Governor Quinn in his February 2012 State of the Budget address espoused a definitive expectation that the service system will make dramatic changes to embrace person-centered principles and community-based supports, including moving “our most vulnerable citizens from institutions to community care.”

While these are steps in the right direction, there is still much to do. In this regard, we note the following concerns that impede progress:

- There is a lack of funding for Person-Centered Planning (PCP) made available through the HCBS waiver. Additionally, while a person-centered planning process (i.e., ACCT) will be provided to individuals leaving SODCs it is not, but should, be available to all SODC residents.

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[29] The Ligas Consent Decree states that: *“The process for developing a Transition Service Plan shall focus on Class Member’s personal vision, preferences, strengths and needs in home, community and work environments and shall reflect the value of supporting the Class Member with relationships, productive work, participation in community life, and personal decision-making*.” (Section VII. TRANSITION SERVICE PLANS, 13)

- Individuals who receive HCBS waiver funding have the right to choose their service provider, however, in practice, changing providers can be difficult.
- Case management is restricted to 25 hours per year per person, which limits the time available to effectively conduct the person-centered planning process. Further there is a lack of clarity around who is responsible for facilitating the person-centered planning process with service providers often undertaking the planning role despite a potential conflict of interest.
- Even with appropriate resources and accompanying person-centered planning practices, the current service array offers a limited and insufficiently funded menu of services and supports that inhibits delivery of customized services to achieve the very goals of a person-centered system.

Performance Benchmark 4: The provision of services results in the achievement of promoting valued outcomes for people with intellectual and other developmental disabilities.

Background

The delivery of developmental disabilities services should result in the achievement of valued outcomes for individuals and families. Such outcomes include independence, community integration, competitive employment, social connectedness, and safety from abuse, neglect and exploitation. Service systems should be held accountable for achieving these outcomes for individuals and routinely be measured against mission-critical performance benchmarks. Evidence suggests person-centered service delivery promotes better outcomes for individuals. When services and supports are customized around the needs and preferences of individuals and families, better outcomes are achieved.

The outcomes that a service system can achieve are affected by the services that the system offers, the allocation of resources within the system, and the extent to which a state promotes the achievement of valued outcomes. State policies play a critical role in securing valued outcomes for individuals. For example, integrated community employment is often noted by service recipients as a high priority personal outcome. This led Washington to become one of the first states to implement an “employment first” policy to emphasize employment options in its individual service planning process. This and other associated policy changes, resulted in 88 percent of adults with I/DD having some kind of integrated community jobs, the highest level nationwide. Likewise, in Vermont, state officials set policy to limit and eventually prohibit the use of state funds to pay for day services in congregate sheltered workshops. This policy change resulted in 54 percent of adults in integrated community jobs. Clearly, as service system leaders set direction to decrease facility-based work and non-work, integrated employment numbers grow.[30]

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[30] Butterworth, J., Smith, F., Cohen-Hall, A., Migliore, A. & Winsor, J. (2010). *State data: The national report on employment services and outcomes.* Boston MA: Institute for Community Integration, University of Massachusetts.

Similarly, the extent to which states support people in the most integrated setting varies considerably. Yet, there are several states that have achieved the outcome that nearly all persons are supported in small living arrangements or typical community housing.

Equally important is the extent to which services effectively address substantial functional and other limitations that impede the achievement of personal outcomes for individuals. In every state, there are individuals who have extraordinary medical and behavioral challenges. A measure of the effectiveness of a service delivery system is the extent to which these challenges are effectively addressed within the community without resorting to short or long-term institutionalization. Strategies for addressing such challenges include the operation of crisis networks and the development of centers that can provide clinical expertise to community agencies in addressing medical and behavioral challenges.

In many states, little systematic information is collected about the extent to which the delivery of publicly-funded developmental disabilities services results in the achievement of valued outcomes for individuals. However, today there is better technology available for states to track and measure the extent to which the delivery of services is having a positive impact. For example, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) sponsors the 29-state National Core Indicators (NCI) project that provides states with tools to measure consumer and system outcomes as well as benchmark performance.

Absent a focus on outcomes and system performance, it is virtually impossible for a state to gauge the impact of the delivery of developmental disabilities services. Information about outcomes is enormously valuable in focusing attention on potential areas for improvement. Data-based/data-driven system management is necessary to ensure the effective delivery of services.

Findings in 2008: Illinois lacked systems to track individual outcomes or comprehensively measure system performance. Consequently, the State also lacked mechanisms to systematically measure performance related to valued outcomes for individuals and for the system as a whole.

Without outcomes data, Illinois is unable to adequately gauge strengths and areas for improvement. To illustrate, in 2008:

- Illinois did not regularly and systematically compile information from individuals and families concerning their experiences or satisfaction with the services and supports they received.
- Illinois performance related to some outcomes was weak. For example, in 2004 only 13.2 percent of individuals receiving state-funded day services received supports to secure integrated employment. In that same year, almost twice as many individuals nationwide (23.7 percent) received such supports.

- Illinois lacked coherent strategies to address the needs of individuals with challenging conditions in the community. The lack of community capacity to address the needs of these individuals was frequently cited as a reason to continue to operate the SODCs.

Current Status: Since 2008, Illinois has made little progress to promote and measure valued outcomes for both individuals and the system as a whole. Concerns expressed in 2008 continue to be relevant.

As noted above, there is considerable evidence that person-centered service delivery promotes better outcomes for individuals. Notably, in its *DDD Strategic Plan FY 2011-2017*, Illinois articulates a vision and strategic priority to promote person-centered services across the developmental disability service system. This is a critical step forward. Meanwhile, stakeholders express concerns related to three major areas that indicate quality of life.

- **Living in one's own home or apartment.** When asked to define community living, representatives of three national self-advocacy organizations concluded, "In genuine community, people have names not labels, live in neighborhoods not on campuses, make their own choices, and enjoy privacy and genuine relationships of equality."[31] Illinois' residential service practices are in stark contrast to these ideals. As previously illustrated in Table 3, Illinois serves twice as many individuals in large residential settings of both 7-15 and 16 or more individuals than the 2010 national average. Additionally, Illinois is serving a growing number of people in settings of 7-15 beds.

- **Securing and maintaining integrated employment**. Integrated employment is an outcome valued by people receiving services. Integrated employment describes workplaces where a mix of people with and without disabilities is employed. Here, people with disabilities are afforded the same wages, benefits, opportunities to advance in their careers, contribute to society, and move out of poverty as their nondisabled peers. According to *The Riot*,[32] a national disability rights advocacy newsletter, self-advocates around the country clearly declare they want "real jobs for real pay."

  Self-advocates in Illinois are vocal about their desire for integrated employment as well. The Illinois Self-Advocacy Alliance has declared integrated employment as an issue that must be addressed. People with developmental disabilities want to have control of their own lives. Integrated employment is essential to meeting this expectation.

  Illinois performs poorly regarding the percentage of individuals receiving integrated employment services. The Institute for Community Inclusion's state comparison data on employment[33] illustrates integrated employment performance in Illinois' compared to other State I/DD agencies. While Illinois experienced growth in these services from 1988 to 1990

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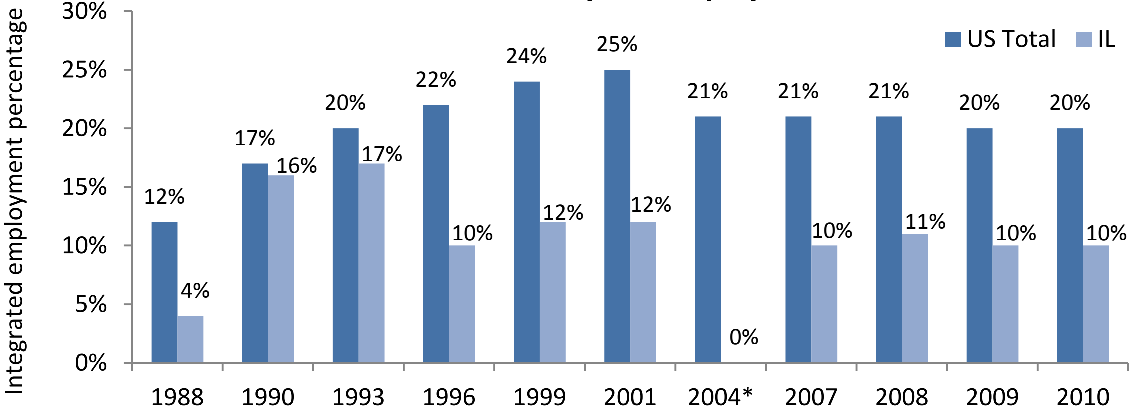
[31] Keeping the Promise: Self-Advocates Defining the Meaning of Community Living. http://www.acf.hhs.gov/programs/add/.

[32] *The Riot!* newsletter (July Issue 29 and October Issue 30). www.theriotrocks.org

[33] Institute for Community Inclusion State Comparison: State IDD Agencies, Illinois, US Total, Integrated employment percentage (www.statedata.info).*Blank spaces indicate that data is not available for that year.

(12 percent), this progress declined from 17 percent in 1993 to 10 percent in 1996. DDD has not recovered these services since, reporting between 10 and 12 percent of service recipients in integrated employment services from 1996 through 2010. This is roughly half the number reported by other State IDD agencies (See Chart 5).

Chart 5: Percentage of People Served in Integrated Employment Relative to Total Served in Day and Employment Services



* Data not reported in 2004

Institute for Community Inclusion State Comparison Data, State IDD Agencies

- **Opportunities for social connections**. Research shows that people who have close friendships report being happier and are physically and mentally healthier. Accordingly, our federal government, in its "Healthy People 2020"[34] initiative for health promotion and disease prevention, set a national objective to increase the proportion of adults with disabilities reporting sufficient emotional support. Where people live and work impacts the nature and depth of connections to others and thus their emotional and physical health. In Illinois, social connectedness to people other than family and staff is a challenge due to the prevalence of segregated congregate residential, day and employment services.

Taken together, Illinois performs poorly on three key outcomes that indicate quality of life (i.e., living in one's own home or apartment, integrated employment, social connectedness). When services and supports are targeted and customized around the needs and preferences of individuals and families, better outcomes are achieved.

Performance Benchmark 5: There is an infrastructure that facilitates the ready access of people with developmental disabilities and families to services.

Background

Within any system, investment in direct services must be complemented with a strong supportive infrastructure. Infrastructure refers to the operational components that undergird

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[34] U.S. Department of Health and Human Services, Healthy People: http/www.healthypeople.gov/hp2020.

and support the functioning of the direct services system. These components include intake and eligibility determination (gate keeping functions), service planning and authorization, service delivery monitoring and resolving problems in particular service access. Other components include contracting, reimbursing service providers, and the operation of management information systems (MIS) or information technology (IT) systems through which essential processes such as issuing provider payments and tracking service utilization and expenditures are performed.

A well-designed and adequately resourced infrastructure is essential to the effective operation of a complex service delivery system. A weak infrastructure can lead to delays in how quickly people receive services as well as result in other system management problems. The use of Medicaid to finance services puts a premium on a state's having a well-functioning infrastructure due to the scope of the federal requirements that must be met to secure federal financial participation in the costs of services.

Findings in 2008: Illinois' developmental disabilities service system infrastructure is fragmented and under-resourced. This poses barriers to people accessing services.

This finding is centered on observations pertaining to the state's efforts to establish a Single Point of Entry (SPOE) portal for people to access services and the status of its management information systems.

In 2008 we found that Illinois had limited IT capabilities to manage information systems. The state had developed systems to support the operation of the HCBS waiver program. The IT system, however, did not span the full range of developmental disabilities services, nor did it have the capability to fully support quality management functions. The operation of ample IT systems is vital to a developmental disabilities service system. Such systems are essential to manage complex systems efficiently. While IT is critical for managing system financing, it also has emerged as a vital tool to inform service authorizations, analyze service utilization, unify quality assurance and management functions, and provide information to guide quality improvement initiatives.

Like management information systems, the operation of a unified, comprehensive SPOE system is also a critical ingredient of developmental disability service systems. SPOEs serve as an identifiable portal through which people can seek services, and may also assure that individuals are aware of all available services and that individual service plans meet essential requirements. An independent comprehensive SPOE-based system is a key ingredient in promoting person-centered service delivery. In many states, SPOEs also play a critical role in arranging for services and interventions when individuals experience a crisis.

Effective "Single Point of Entry" systems provide individuals and families a clear pathway to access services and supports of all types. This includes uniform and consistent application of state eligibility criteria and service authorization policies, including case management.

In general, most states operate their developmental disabilities service systems through independent local/regional service coordination entities (i.e., entities that do not furnish direct services). These entities function as the SPOE into the developmental disabilities system and usually are responsible for ongoing case management and service coordination. SPOEs also authorize the delivery of services in accordance with state policies. SPOE responsibilities typically encompass the full range of developmental disabilities services, including Medicaid-financed services.

Over the years, Illinois has developed a network of Pre-Admission Screening (PAS) agents/Independent Support Coordination (ISC) agencies. PAS/ISC agencies gate keep the entry of individuals into Medicaid-funded services and perform certain other support coordination functions, such as operating the PUNS system. With respect to the HCBS waiver program, these entities also furnish "Individual Service and Support Advocacy" (ISSA) services. ISSA services include participation in the development of service plans, approval of individual service plans, advocacy on behalf of the participant and family, visiting individuals four times a year to monitor their health and welfare, and alerting DHS about issues that potentially require intervention. All waiver participants receive ISSA services. The amount of ISSA that may be furnished to a waiver participant, however, is limited to 25 hours per year unless an exception is approved by DHS. While the PAS/ISC network performs some of the same functions as SPOEs in other states, the network does not constitute a full-featured, comprehensive SPOE system.

Current Status: Since 2008, circumstances have not changed dramatically on two counts. Systems to support access to services continue to be fragmented and under resourced while IT systems remain insufficient.

Regarding SPOE and case management, as was the case previously, consider that:

- While there is commitment among many to a "person-centered planning" process, there is no service or funding available within the HCBS waiver dedicated to such planning.
- Within the HCBS waiver, responsibilities remain split among various entities. For participants who receive CILA and day training services, provider agencies have lead responsibility with respect to service planning and delivery. ISSA services provide a limited measure of external, independent oversight of the delivery of these services.
- For waiver-funded home-based services, individuals select a "service facilitator" to perform service coordination-type functions, such as assisting the individual to develop a service plan, choosing services and providers, monitoring service delivery and ensuring participant health and welfare. The facilitator is employed by a community-agency but not a PAS/ISC/ISSA agency. Subsequently, the costs of service facilitation are charged against the individual's home-based services budget.

- People who receive non-Medicaid funded services fall outside the orbit of the PAS/ISC network. They are assigned an independent service coordinator on an as-needed basis.
- ICFs/DD and SODCs furnish case management to their residents.

Overall, as was the case in 2008, the performance of SPOE/service coordination functions is divided by service type and funding stream, and is further fragmented within the HCBS waiver program. Further, while the PAS/ISC network serves as the portal to certain types of services, it is not a single portal arrangement. Finally, the limitation on the amount of ISSA services that may be furnished to waiver participants (i.e., 25 hours annually) also remains problematic.

Regarding its IT system, Illinois continues to maintain a problematic infrastructure. In 2008, those interviewed indicated that information pertaining to service utilization, associated costs and quality monitoring were insufficient. The same complaints are heard today.

It is difficult to determine, for example, the precise number of people receiving services while living home with their families or the number of CILAs operating across the state. Likewise, the State has not established a reliable database pertaining to "incident management." As a result, state leaders cannot effectively track the difficulties experienced by service recipients (e.g., hospital admissions, behavioral events resulting in significant staff response). Further, while the State notably participates in the National Core Indicators project to assess the outcomes of services provided to individuals and families across several domains (e.g., employment, service planning, community inclusion, choice) this data is insufficient. For Illinois to operate a full-featured, comprehensive SPOE/service coordination system with appropriate management information systems, the present system would need to be substantially altered.

Performance Benchmark 6: Services must continuously meet essential quality standards and there must be confidence that quality oversight systems function effectively and reliably.

Background

It is essential that a state operate effective quality assurance/quality management systems to ensure that people with developmental disabilities are safe and secure and the services they receive meet essential standards. Nationally, the shift of the delivery of services to the most integrated setting poses substantial challenges for the operation of effective quality assurance/management systems. In particular, the number of sites where services are delivered has grown dramatically over the past several years and significant numbers of people reside with their families. In 2009, people with developmental disabilities nationwide received residential services and supports at over 173,000 sites. In contrast, in 1999, residential services were delivered at approximately 113,000 sites. Many of the sites where residential services are now furnished are not licensed residences. Consequently, states have had to develop alternative oversight methods for services that are furnished in regular community housing.

Key to ensuring that individuals receive services that enhance their health and well-being is the presence of a trained cadre of case managers who function independently of service provision. Case managers are the system's eyes and ears and represent the first line of defense against the possibility of abuse, neglect and exploitation. They are also advocates for person-centered supports. In the majority of states, case management agencies are free-standing, rather than attached to provider organizations, thereby eliminating the possibility of a conflict of interest. Best practice also entails that case managers apply standardized monitoring procedures across the state so that data regarding performance can be aggregated at the state level.

State quality assurance systems are undergoing considerable change. In part, this change is being propelled by the ongoing growth of community services and supports. States are devoting more resources to quality management to keep pace with the growth of service systems. Some states are coping with this growth by sampling providers to gauge performance. The federal Centers for Medicare and Medicaid Services (CMS) have, furthermore, heightened their expectation of states with respect to the operation of comprehensive HCBS waiver quality management systems. States are now required to develop and implement a comprehensive Quality Improvement Strategy (QIS) that spans a wide range of HCBS waiver operations, including assuring the health and welfare of waiver participants. States are also expected to compile evidence about the operation of the QIS, including the extent to which problems are appropriately remediated.

Best practice in quality assurance/quality management now includes the operation of data systems that are capable of aggregating and analyzing information about the results of quality assurance processes to identify the extent to which problems are being discovered at the provider and system levels. Such data systems must have the capability to integrate quality information. For example, the results of routine monitoring of services should be linked to information gleaned from periodic provider agency quality reviews.

Findings in 2008: Stakeholders expressed wide-spread lack of confidence in the quality of services and the effectiveness of state quality management processes. Informants noted serious issues in several areas.

Note that in 2008:

- Provider agencies expressed deep concerns about their ability to meet basic quality standards due to low state payments for services, affecting their ability to recruit and retain workers.
- Independent observers expressed serious concerns about the extent of state oversight of services and follow-up to correct problems, many of which recur year after year.
- External quality monitoring performed by service coordinators was not routinely performed on behalf of people receiving state-funded services. For HCBS waiver participants, this monitoring was constricted to 25 hours per year per participant.

- The quality of community services was regarded as especially problematic despite similar problems with the quality of the care furnished in ICFs/DD and SODCs.
- DDD lacks "incident reporting and tracking" capacity so that state leaders have little idea of the difficulties experienced by service recipients across the state, including for example, aggregate data pertaining to hospital admissions or significant behavioral incidents.
- DDD had very limited capacity to pull together information about the quality of community services and apply such information to quality improvement strategies.
- Individuals with developmental disabilities, families, service providers and other stakeholders were not engaged with the State regarding its quality assurance/quality management processes.

Current Status: The state acknowledges difficulties surrounding service quality and oversight and has set strategic priorities for making improvements. Present circumstances, however, demonstrate that problems persist.

In response to issues such as those noted above, the Division established the Bureau of Quality Management. Among its responsibilities, the Bureau is meant to: (a) certify that providers and staff have proper licenses, certifications and training, (b) interview of individuals, guardians and agency staff to ensure needs are being met, and (c) review substantiated cases of abuse and neglect. Overall, the Bureau works to ensure that services are delivered appropriately and that the needs of service recipients are met.

Further, the *DDD Strategic Plan FY 2011-2017* demonstrates a commitment to improve matters by defining person-centered quality measures, monitoring performance, and using data and lessons learned to inform future policies and procedures. The State also intends to revise outdated rules and regulations, and ensure ongoing quality improvement. While these key intentions are a good start, present circumstances continue to raise concerns.

A push to promote person-centered approaches and practices suggest that quality assurance mechanisms must be developed to align with new thinking. Such systems must deliver services and supports that facilitate outcomes at the individual and aggregate levels while also implementing quality enhancement strategies. For example:

- Person-centered services must demonstrate a commitment to service excellence and personal outcomes. This commitment requires close monitoring by independent case managers to ascertain individual satisfaction and outcomes achievement. In Illinois, this service is provided – though to a limited degree – through Individual Service and Support Advocacy (ISSA) services. ISSAs have limited involvement in individual planning and, as previously noted, the 25 hour limit severely restricts monitoring essential to person-centered service provision and outcomes.

In turn, with time these circumstances may result in a gradual acquiescence among service recipients and their families to whatever services they receive regardless of quality. After all, if the ISSA case manger does raise concerns over the quality of services then one may conclude that their quality is sufficient. Additionally, given limited contact with the case manger opportunities to complain about service quality are minimized, further reinforcing acceptance of whatever is offered.

- Quality management strategies undertaken by person-centered organizations measure what is important to people, the impact on human needs and how well the program is meeting outcomes expected by individuals receiving services and supports. Further, these efforts include attention to instances of abuse, neglect and exploitation. Such strategies will need to be developed across service settings in Illinois.
- Person-centered systems must be able to collect information about the quality of community services and apply such information to quality improvement strategies to enhance the system. As noted in the previous section, Illinois has limited capacity to collect this information.

Performance Benchmark 7: The system must promote economy and efficiency in the delivery of services and supports.

Background

There is no doubt that supporting people with developmental disabilities requires a substantial financial commitment from the state. Developmental disabilities are life-long. People with developmental disabilities have significant functional impairments and many require day-by-day services and supports. Developmental disabilities services are among the most-costly long-term services. Therefore, it is important that a state employ effective financial management strategies and practices that promote economy and efficiency in the delivery of services.

There is significant variance among the states with respect to their level of financial effort in supporting services for people with developmental disabilities. State fiscal capacity varies due to underlying economic and other differences. However, all other things being equal, states where there is a relatively low level of financial effort in support of developmental disabilities services usually have large waiting lists for services. Service providers struggle to survive in the face of low payment rates that, in turn, result in major problems in meeting basic quality standards and in workforce stability.

Effective financial management of developmental disabilities services is complex and multi-faceted. Key facets include:

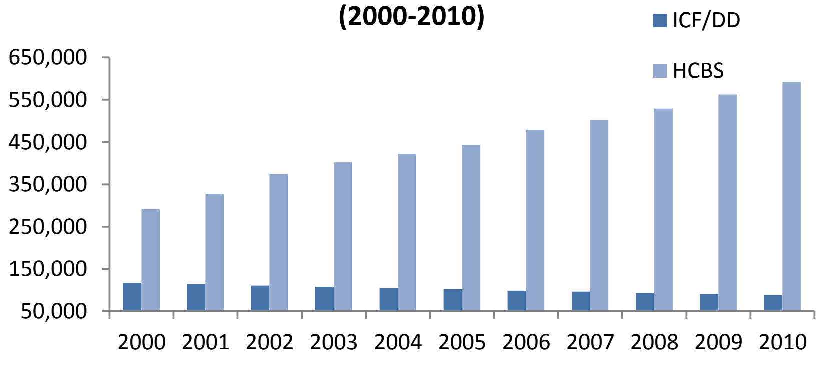
- *Managing the Application of Federal Medicaid Financing.* To the extent that a state can qualify services for federal Medicaid financing, it can stretch its own dollars to serve more people with developmental disabilities. In developmental disabilities services, Medicaid is the principal source of federal financial assistance to states to finance services. In general, maximizing federal Medicaid dollars is a practical necessity in all states. Medicaid financing can play a major role in underwriting the expansion of system capacity to meet service demand. However, Medicaid is a complex program that operates under federal parameters. It presents to states alternative pathways for securing federal dollars to pay for services. As a consequence, there are major differences among the states in their coverage of Medicaid services.

- *Promoting Economical Service Delivery*. It is in a state's best interest to channel service demand into lower cost, more economical service delivery alternatives. Some models of developmental disabilities service delivery are extremely costly due to regulatory and other requirements. For example, in 2010, the average nationwide cost of serving an individual in a public or private Intermediate ICF/DD was $146,999. In contrast, the average cost of supporting a person through the Medicaid HCBS waiver program was $44,396. In an environment of limited budgets, reliance on high cost service models obviously will shorten a state's ability to meet current and future service demand.
- *Purchase of service*. Because government is the principal purchaser of developmental disabilities services, state purchase of service policies and practices have major market place ramifications. The rates that a state pays for services affect the viability, quality and availability of services. For example, if state payments for personal assistance services are based on below market wage rates, then individuals will experience major difficulties in locating workers who are willing to provide supports. To the extent that state payments are not based on a realistic appraisal of legitimate provider costs, quality will suffer and there will be an insufficient supply of providers to support individuals.

Among the states, there have been several noteworthy trends and developments in the financial management of developmental disabilities services. With respect to Medicaid financing of developmental disabilities services, the trend for more than 20 years has been for states to concentrate on expanding HCBS waiver programs for people with developmental disabilities while concurrently reducing the utilization of more costly ICF/DD services.

Chart 6 shows the number of people served in ICFs/DD and through HCBS waivers for people with developmental disabilities across the country. As can be seen, ICF/DD utilization has been declining steadily over the past 5 years. A substantial proportion of the reduction in ICF/DD utilization is the result of the ongoing downsizing and closure of very

Chart 6: Service Recipients in HCBS and ICFs/DD Nationally (2000-2010)



(Larson, et al 2012)

large state-operated institutions. However, about 32 percent of the reduction in ICF/DD utilization stems from a decline in the number of persons served in non-state ICF/DD services. In contrast, the number of persons served in HCBS waiver programs has grown substantially. In 2010, 87.1 percent of the 679,630 people with developmental disabilities nationwide who received Medicaid-financed long-term services were served through HCBS waiver programs. As previously noted, the de-emphasis by states on ICF/DD services in favor of employing the HCBS waiver program is due in significant part to the very high costs of ICF/DD services and the relatively lower costs of waiver services.

The HCBS waiver program now is the principal source of federal financial assistance to states to underwrite the costs of specialized developmental disabilities services. On an expenditure basis, in 2010 federal-state spending for HCBS accounted for 67.1 percent of the $39.2 billion in Medicaid spending nationwide for specialized developmental disabilities long-term services.

Another important development is the de-emphasis by states of the delivery of 24/7 "comprehensive" residential services in favor of expanding supports services that complement rather than substitute for family caregiver and other supports that are available for individuals. Comprehensive residential services are very costly to deliver, whether in an ICF/MR or another type of community residence. Faced with rapidly rising demand for developmental disabilities services, most states simply cannot afford to respond by scaling up comprehensive services. Instead, many states have launched what are termed "supports waivers" that operate under fixed-dollar cost limits and pay for services that complement family care giving.

Findings in 2008: Illinois' financial level of effort in supporting services for people with developmental disabilities is subpar. The present system overemphasizes the use of costly service models.

As evidence, note that:

- In 2006, Illinois Medicaid spending per citizen for developmental disabilities services was 15.7 percent below the nationwide average.
- A larger proportion of individuals in Illinois who receive Medicaid long-term services are served in ICFs/DD (SODCs and ICFs/DD) than is typical nationwide or in most states. In 2006, 56.9 percent of individuals were supported through the HCBS waiver in Illinois versus 82.9 percent nationwide.
- Illinois expends a greater proportion of its Medicaid dollars on ICF/DD services than the nation as a whole or most other states. In 2006, 61.5 percent of the $1 billion in Illinois Medicaid spending for people with developmental disabilities underwrote ICF/MR (SODC and ICF/DD) services. In 2006, nationwide 59.5 percent of Medicaid spending for people with developmental disabilities paid for home and community-based waiver services.
- Illinois concentrates its funding for developmental disabilities services on higher cost services furnished in large congregate care facilities.

- The overall total cost of supporting a person in a SODC was somewhat higher than indicated on the chart (when all costs are taken into account, the 2006 per diem billing rate for the SODCs was $453/day or approximately $165,000 per year). Notably, this was the highest per person cost for SODCs since Illinois began reporting these data in 1977, but this cost began trending down the following year. Per person expenditures for CILA services are nominally lower than ICF/DD costs. Home-based services are the least costly. However, only a small proportion of individuals received home-based services. While CILA per person costs are appreciably lower than ICF/DD costs, they are much closer when the per person day program cost is added to the CILA cost.
- Illinois ICF/DD costs were appreciably below the nationwide average. Likewise, HCBS waiver per person expenditures were about 19 percent lower than the nationwide average. Additionally, weighted average per person expenditures were about 9 percent below the nationwide average.

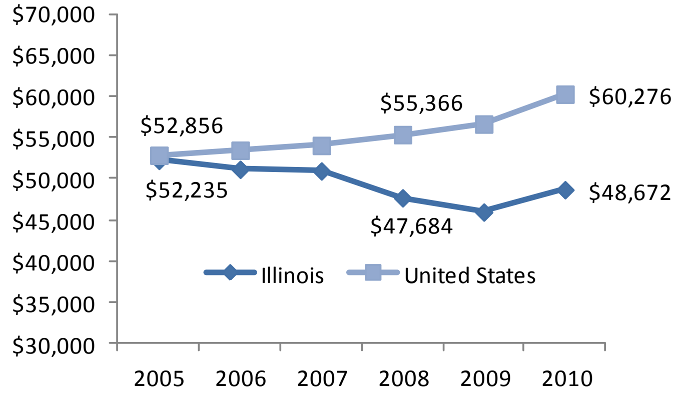
Current Status: Illinois' financial level of effort in supporting services for people with developmental disabilities continues to be subpar. The present system overemphasizes the use of costly service models and a disproportionate percentage of spending is allocated to SODCs and community ICFs/DD compared to HCBS waiver recipients.

Analysis of the current service delivery system finds that the State allocates an insufficient amount of resources into the system, and the resources being allocated are being used inefficiently. Put another way, as is illustrated below, the State has fewer dollars available for services, compared to other states, and dollars available are being used disproportionately to finance high cost service options.

Less Than Average Spending

On a per person basis, since 2005 Illinois' investment in services for people with I/DD has decreased while across the nation national average expenditures have grown. As illustrated by Chart 7, in 2005 the amount spent annually in Illinois per person was on par with the national average at about $52,000 per person. By 2010, however, Illinois expended $48,672 per person on average for HCBS and ICF/DD services while the national average was $60,276, or 12 percent more. In fact, given that 23,869 people received such services in 2010, Illinois would have needed to spend $277 million more just to reach the national average.

Chart 7: Combined Annual HCBS and ICF/DD Spending Per Service Recipient (2005-2010)



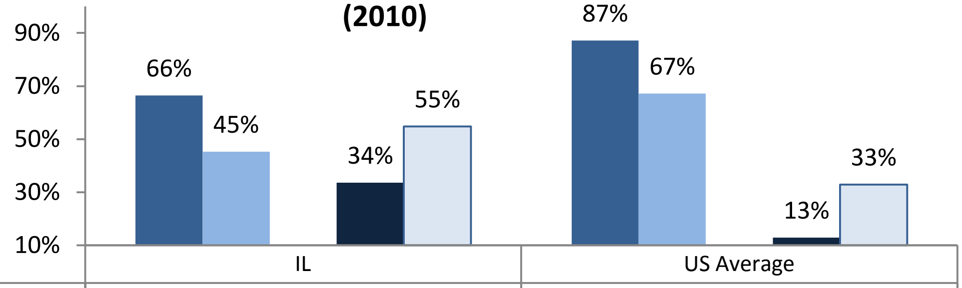
Larson et al.. 2012

Inefficient Use of Resources

The subpar investment in services is a difficult challenge to overcome. Making matters worse, the State spends its resources inefficiently, investing heavily on "high cost" options that other states have pushed away from. Chart 8 shows the proportion of Medicaid-financing for ICF/DD and HCBS services compared to the percentage of service recipients by service option. As shown, nationally the majority of service recipients and Medicaid funding is associated with the HCBS waiver program. In Illinois, however, this is not the case. Consider that:

- 66 percent of all Illinois service recipients receive services through the HCBS waiver program compared to 87 percent nationally. Conversely, 34 percent of Illinois service recipients live in ICFs/DD (including SODCs) compared to 13% nationally. In fact, only three other states (Iowa, North Dakota and Mississippi) make greater use of ICFs/DDs than Illinois.
- Regarding funding, in Illinois roughly 45 percent of the total budget is allocated to HCBS services, compared to 67 percent nationally. On the other hand, in Illinois 55% of the resources are dedicated to ICF/DD compared to 33 percent nationally.

Chart 8: Percentage of Individuals Utilizing ICF/DD or HCBS Services by Percentage of Spending Used to Fund Service Options (2010)



	IL	US Average
■ % of HCBS Recipients	66%	87%
■ % of HCBS Expenditures	45%	67%
■ % of ICF-MR Recpients	34%	13%
□ % of ICF-MR Spending	55%	33%

(Larson, et al 2012)

Put another way, for every 1 percent of service recipients receiving services through ICFs/DD, 1.6 percent of the budget is being allocated to those services. This compares to 0.7 percent of the total budget being allocated to every one percent of service recipients in HCBS services.

As the charts illustrates, Illinois allocates far more resources to public and private ICF/DD services than to HCBS services. The practice is inefficient because ICF/DD and SODC annual costs are significantly higher than HCBS services. Chart 9 shows the average annual cost of service across the three primary service structures within the states (SODCs, private ICFs/DD and HCBS services). As seen in the Chart, Illinois spends fewer dollars per service recipient across the board. This means that although the State allocates the greatest proportion of dollars to ICF/DD services, comparatively, they are still underfunding the services significantly.

Clearly, Illinois relies more heavily on ICFs/DD than do other states. The negative consequence of this pattern rests with the comparative costs of the available options. Put bluntly, over time a system strategy based in ICFs/DD costs more per person and in the aggregate than one centered on use of HCBS services. Consider that:

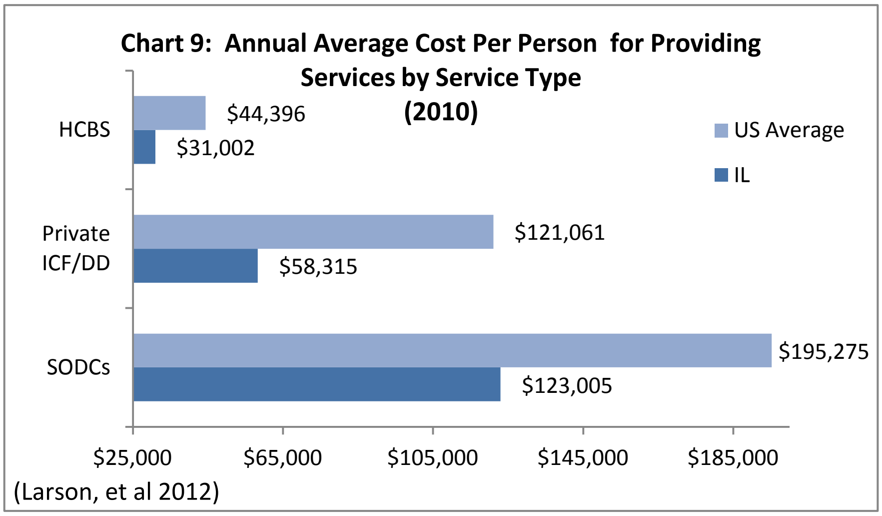


Chart 9: Annual Average Cost Per Person for Providing Services by Service Type (2010)

(Larson, et al 2012)

- The average cost of serving an individual in a private ICF/DD in Illinois in 2010 is $58,315 while the average HCBS waiver cost per person in Illinois is $31,002.
- The average cost per person cost for SODC services in 2010 was reported as $337 per day or roughly $123,000 annually, a decrease from the high-water mark set in 2006, and some $72,000 less than the national average.

  Yet, there is strong reason to believe that the individuals currently served in these centers could be supported as well or better in alternative community settings. First, consider that a formal study of individual level of need was not conducted for this project. Although such a study is outside the scope of this project, the University of Minnesota collects data on the severity of disability of those served in SODCs. As previously noted, Illinois reports that roughly 22.4 percent of those currently served in SODCs have mild to moderate levels of intellectual or developmental disabilities (Larson et. al, 2012). This raises questions to the appropriateness, cost and efficiency of providing SODC services to these individuals.

  Further, we emphasize that states are demonstrating that individuals can be effectively served through community options funded through a HCBS waiver. ICFs/DD and SODCs need not be part of the service array. In fact, by 2010 ten states and the District of Columbia had no SODCs with another 12 serving 150 or fewer people in such facilities. Moreover, Oregon and Alaska have no community ICFs/DD or institutions, and Oregon is the first state to serve all its citizens with I/DD within its HCBS waivers.

Plainly, Illinois spends less per person than the national average across all its services. As a result, even while there may be momentum to relocate people from SODCs to community alternatives, in pursuing such such policy the state must be concerned over the low HCBS service reimbursement rates. While many at SODCs may have mild to moderate support needs, others have complex needs that will require significant support, and so cost much more than typical average HCBS costs.

Summary of Findings and Call to Action

A summary review of the State's performance across the seven benchmarks reveals much to be concerned about. The data reveal that:

- Illinois does not provide services to individuals with I/DD with reasonable promptness and maintains a large waitlist for I/DD services. The waitlist nearly doubled since 2008, including 14,977 people waiting with critical or emergency needs (February 2012).
- Illinois continues to rely on large congregate care facilities to serve people with I/DD to an extraordinary extent and opportunities for individuals to receive services in the most integrated setting are abbreviated.
- While state leaders have expressed a commitment to person-centered practices, Illinois has not yet configured its service system to embrace person-centered approaches.
- Illinois still does not have systems in place to track individual outcomes or comprehensively measure system performance. Consequently, the State lacks capacity to systematically measure performance related to valued outcomes for individuals and for the system as a whole.
- Illinois' developmental disabilities service system infrastructure is fragmented and under-resourced. This poses barriers for people accessing services.
- While the State acknowledges difficulties surrounding service quality and oversight and has set strategic priorities for making improvements, present circumstances demonstrate that significant difficulties persist.
- Illinois' financial level of effort in supporting services for people with I/DD is insufficient. The present system overemphasizes the use of costly, outdated, service models. Including a disproportionate percentage of spending allocated to SODCs and private ICFs/DD compared to HCBS waiver services.

In many ways, one might surmise that little has changed since 2008. The system of services faces a number of challenges. Yet, many things have changed. Consider that:

- The DDD *Strategic Plan FY 2011-2017*, developed through a consensus building process involving multiple stakeholders, generated a plan that embraces the ideal of a person-centered system. Notably, the state legislature (i.e., SJR 15) adopted a resolution in 2011 to affirm that the progress of the Division in achieving its strategic goals will be measured by how it provides that Illinois citizens with developmental disabilities are served in the most integrated setting consistent with the protections under the Olmstead decision cited earlier. The resolution sets a clear expectation that all children and adults with I/DD living in Illinois will receive "high quality services guided by a person-centered plan that maximizes individual choice and flexibility in the most integrated setting possible regardless of intensity or severity of need."
- The Division has taken several deliberate steps to improve its service response and system efficiencies. For example, the Division:

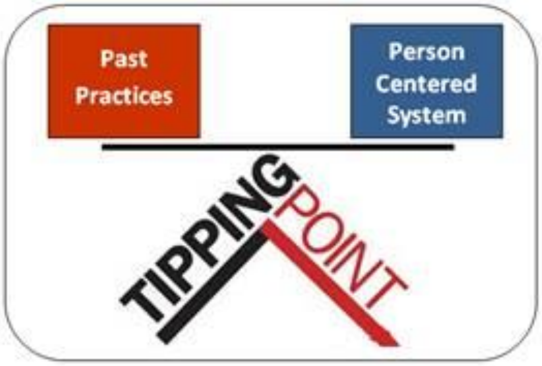
- Collaborated with others to close the Howe State Operated Developmental Center;
- Negotiated the Ligas Consent Decree;
- Implemented means for reducing state expenses by shifting financing for some services from "state funding only" to the HCBS waiver thereby gathering federal reimbursement for a share of the costs;
- Convened, with assistance from the ICDD, a Rates Committee that provided a thorough review of service reimbursement rates along with recommendations for improving how rates are calculated;
- Improved its response to people with behavioral challenges by increasing service reimbursement rates associated with behavior therapy and expanded statewide capacity by altering qualification requirements for individuals delivering this service;
- Began working with the Alliance to amend the present HCBS waiver to offer improved service options for self-direction; and
- Recognized the potential contribution of individual and family-led human service cooperatives by taking a first step toward creating means to fund staffing for these enterprises by permitting each to be licensed as CILAs, and so bill for staff time.

The Ligas Consent Decree was agreed upon and its terms acted upon, providing opportunity for people to relocate from residences in private ICFs/DD to alternative community options and requiring that 3,000 people on the wait list be enrolled in services over the next six years.

The Illinois Self-Advocacy Alliance was formed to bring together self-advocacy groups from across the state driven by a vision of self-advocates working together to "get the support we need and to live the life we want in the community."

Amplifying the significance of these events, Governor Pat Quinn has made a decided commitment to establish a person-centered system of services for people with I/DD. Aside from the Howe closure, Governor Quinn has instructed staff to close the Jacksonville and Murray SODCs. In his State of the Budget address in February 2012 he indicated his willingness to work toward improving the quality of life for people with developmental disabilities and mental health challenges, including funding to ensure transitions and coordinated care as individuals move from SODCs to community settings.

Illinois is at a tipping point. The decisions made and actions taken over these coming months and few years will be decisive. Given the present momentum, Illinois has the opportunity to reshape its system of services, shifting from one mired in an underachieving past to another that brings opportunity and the promise of a better life for its citizens with I/DD. We are passed the talk, however, it is time to act.



Proposed Action Steps

In its *DDD Strategic Plan FY 2011-2017*, the Division declares a vision for its work whereby:

> *All children and adults with developmental disabilities living in Illinois receive high quality services guided by a person-centered plan that maximizes individual choice and flexibility in the most integrated setting possible. All areas of the State have available a full array of services that meet the needs of children and adults with developmental disabilities living in their local communities regardless of intensity or severity of need. There is no waiting list for services.* (p. 5)

Complementing its vision, the Division also indicates a commitment to a number of guiding principles such as these:

- People with developmental disabilities will be actively involved in policy discussions and decisions and will be respected as partners in the process, making informed choices and decisions in order to support productive and fulfilling lives.
- Families and guardians will be listened to and respected, and we will strive to earn and keep their trust along with the trust of the public.
- As small, home and community-based options are increased and enhanced, we will look at new and creative ways to utilize resources across the service delivery system.
- Public resources will be used effectively and efficiently to help those we serve achieve their goals.
- The integration of habilitation, social, and clinical supports will be considered paramount when enhancing and developing services throughout the delivery system.

Adding to the momentum of the Division's *Strategic Plan* are expectations among growing numbers of people with I/DD (i.e., self-advocates) that the service system will be changed to embrace person-centered principles to emphasize self-direction and community integration. Joining in to add still further resolve for change are recent actions led by the Governor to close two additional SODCs (i.e., Jacksonville and Murray) and the pointed direction for change he declared in his February 2012 *State of the Budget* address to the legislature. In his address, Governor Quinn declared a commitment to changing the service system to enhance and promote the community service system along person-centered service principles.

These combined commitments and expectations signal an emerging new alliance for change. State policy makers are aligning with service recipients and other associated allies to call for change in how Illinois provides services to people with I/DD. Indeed, the momentum this alliance brings, coupled with actions already underway, places Illinois at the tipping point. In the coming months and years Illinois policy makers have the opportunity either to maintain present circumstances or even roll back the progress already made, or to push forward for change to establish a person-centered system.

Illinois at the Tipping Point

Governor Pat Quinn
Fiscal Year 2013 Budget Address
February 22, 2012

I'm committed to improving the quality of life for people with developmental disabilities and mental health challenges. Our budget includes funding to ensure smooth transitions and coordinated care as individuals go from costly institutions to supportive community settings…

Illinois lags behind the rest of the nation in the utilization of person-centered, community-based care which has been demonstrated to allow people with developmental disabilities to lead more active and independent lives...

We will comply with all court consent decrees.

We will provide individualized care.

And we will achieve savings for the people of Illinois.

www2.illinois.gov/gov/Pages/default.aspx

Illinois Self-Advocacy Alliance
Position Statement
on Self-Direction

2011

The *Declaration of Independence* states that all people have the right to life, liberty and the pursuit of happiness. This means ALL people, including people with disabilities. For us, this means being in control of our lives. We are experts about our own lives. We know we need help and support, but we also have ideas, dreams, and solutions on how to get the help we need. Other people have control over their lives, so why should we be any different?

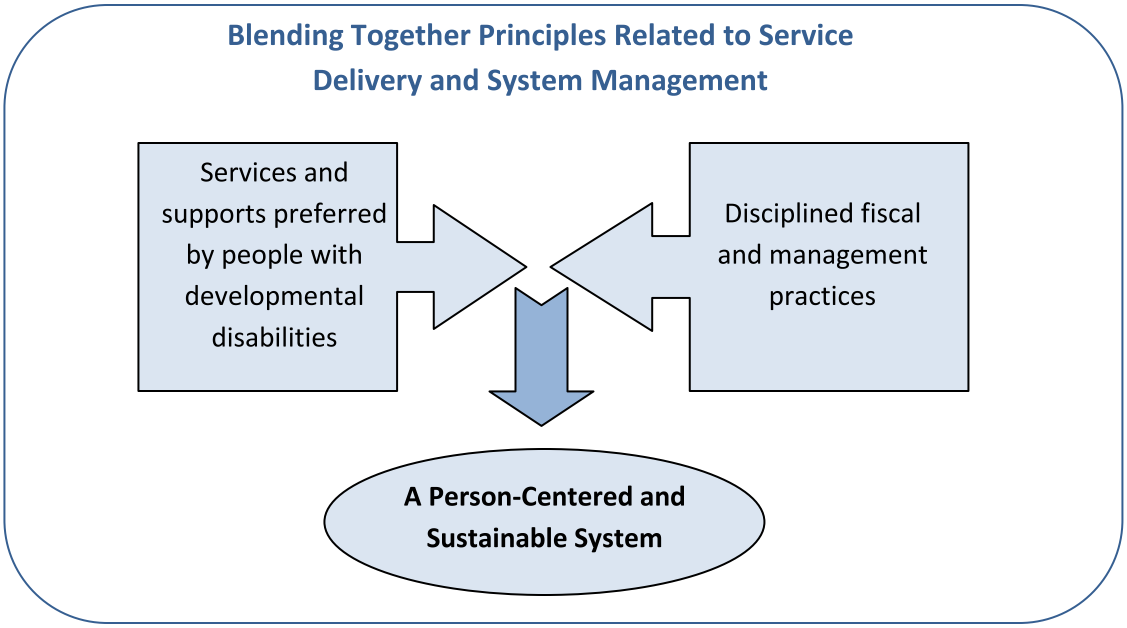
We want Illinois to create a disability service system where supports and services are controlled by us – the individuals who receive them. We want opportunities. We want freedom. We want choices.

www.selfadvocacyalliance.org

Call to Action

Given modest resources and troubled fiscal times, however, it is essential that actions taken in support of the desired system change also establish a system that is sustainable. A sustainable service system is one that is funded and structured to meet the needs of all those in need over time. It must be amply funded, but it must also make most efficient use of available public resources to yield high quality outcomes. Establishing a sustainable future for Illinois' developmental disability service system must begin with an overt commitment to provide high quality, person-centered supports to all citizens who need them. This is a commitment the Division has made, and now all policy actions must be aimed at fulfilling this goal.

In this context, aside from making the best use of available public resources, achieving this goal is also predicated on an important proposition – i.e., there are opportunities to improve efficiency and enlist new resources in support of people with developmental disabilities that must be vigorously pursued. Realizing these opportunities will require us to re-think what and how services are offered, and so will likely disrupt the present ways of doing things. Unless these opportunities are pursued, however, we will not be able to achieve the best outcomes possible for individuals and their families.



The proposed 15 *Action Steps* are grounded in principles that blend together <u>services preferred by people with developmental disabilities</u> with <u>disciplined fiscal and management practices</u>. Doing so provides the best opportunity for yielding a person-centered, sustainable future for developmental disability services in Illinois. Consistent with principles used to guide the Division's *Strategic Plan*, summary descriptions of the principles embedded within the *Action Steps* follow.

A person-centered, sustainable future requires:

- <u>Approaches that promote community integration and self-direction</u>. People with developmental disabilities themselves represent a primary, albeit too often neglected, group of stakeholders that must be effectively engaged. Beyond providing training resources to develop self-advocacy, policy makers must also provide opportunities for individuals to use self-advocacy skills to engage in discussions about service improvement.
- <u>Commitment to person-centered approaches</u> in which individuals can choose among qualified providers of any available service and also select where and with whom they live.

- A sustained, working partnership among service recipients, families, service providers and communities across the state. Making available well coordinated and efficient public services must be a primary goal. These services, however, must be complemented by other community supports that provide individuals and families the opportunities to offer mutual support.
- Sufficient resources. Illinois spends notably less overall than the national average given its state population. The state leadership must come to terms with these facts. Put plainly, not enough is spent on developmental disability services. Implementing the following *Action Steps* will require that Illinois step up its funding of services.
- Allocating resources more efficiently. Promoting efficiency will require a variety of complementary actions:
  - Accurate and reliable means of assessing individual support needs so that individuals are allocated resources that match their needs;
  - A range of valued services must be made available to individuals regardless of the amount of their individual budget;
  - Service planning must result in individuals receiving the supports they require and prefer, within the bounds of their allocated budgets and available community resources;
  - Shifting to service options that cost less and bring the highest value; and
  - Management of the developmental disabilities system as one cohesive system rather than its current division into discrete financial cost centers (e.g., HCBS, state operated developmental centers, private ICF/DD) and decision points.
- Encourages agility in service provision so that individuals can easily seek out providers who offer the highest quality services, and likewise, so that providers can alter their approach to be responsive to shifts in demand or changes in practice. In addition, agile systems must be able to develop and utilize sources of support outside the public sector, including those naturally available within communities and from individuals offering support to one another.
- A resilient system infrastructure. Within any system, investment in direct services must be complemented with a strong supportive infrastructure. This infrastructure should include a viable information management, service coordination network, an appropriate range of staff development opportunities, quality monitoring, effective response to crises, and equitable and reliable means of allocating resources on a person-centered basis.
- Collaboration. Health, education, human services, housing and transportation systems are terribly fragmented. Rather than offering cohesive responses to need, these systems too often sort needs into categories and assign responsibility for meeting needs to this or that public agency. As a result, people with lifelong disabilities and their families must negotiate across different service systems, cobbling together what they

can to meet their needs. Embracing collaboration – seeking new opportunities to weave together the resources of public agencies – is essential, especially in view of the economic crisis facing the state and the nation.

Fifteen Action Steps

Although not every area amenable for systems change is addressed, the 15 *Action Steps* that follow are related to one another and should be undertaken together and in tandem with system reforms already underway. Implementation of each *Action Step* will require more detailed planning than is presented here, planning that should be conducted as a collaborative enterprise that stresses transparency. The next section covers the recommended *Action Steps* organized by the these five topical areas and objectives:

A. <u>Establish clear and cohesive leadership</u> for the developmental disabilities service system.

B. <u>Develop system infrastructure</u> in support of the community services system.

C. <u>Improve the community response</u> to individual support needs to promote person-centered outcomes important to individuals and families, including emphasis on self-direction among people with developmental disabilities and partnerships among service recipients, their family members and others.

D. <u>Serve people in the most integrated setting</u> by reducing further the role that SODCs and ICFs/DD play within the Illinois service system.

E. <u>Expand community system capacity</u> so that by 2022 all people who have emergency or critical unmet needs will be served with reasonable promptness.

Implementing the proposed *Action Steps* offers an opportunity for Illinois to improve system performance while promoting sustainability. These *Action Steps* build on those offered in 2008, refreshing several actions but also introducing new ones.

For ease of review the 2008 and present *Action Steps* are shown alongside one another. As illustrated, the two sets of steps often overlap with identical or near identical phrasing used. In some instances, however, specific 2008 steps were not repeated as unique freestanding steps among the 2012 list. In such instances the thrust of the 2008 A*ction Step* was embedded within a 2012 *Action Step*. Likewise, sometimes a step nested within a 2008 *Action Step* is brought forward as a separate 2012 step. Examples include:

- 2008 *Step* 2 calling for Money Follows the Person legislation was modified and embedded within 2012 *Action Step* 12 on promoting transition from ICFs/DD;
- 2008 *Step* 4 regarding the CILA program was modified and embedded within 2012 *Step* 13;
- 2012 *Step* 11 on employment is a free standing step, but in 2008 was included within *Step* 15 regarding delivery of outcome-oriented services and supports.

Finally, new Action Steps are added to the 2012 list that were not included originally in 2008. Examples include *Step* 1 on leadership and policy direction, *Step* 2 on self-advocacy, *Step* 6 on managed care systems and *Step* 8 on mutual supports.

Summary of Action Steps Proposed in 2008

Step #1: Reduce the number of people served at its State Operated Developmental Centers (SODCs).

Step #2: Enact “Money Follows the Person” legislation.

Step #3: Adopt policies and offer financial incentives for providers of ICFs/DD to support individuals to transition to HCBS.

Step #4: Bar the development of new residences, funded through the CILA program, that serve more than six individuals. In addition, modify its payment policies.

Step #5: Boost funding for community services and promote improved conditions for workers.

Step #6: Build the capacity to support people with challenging conditions in the community.

Step #7: Take steps to strengthen oversight of its community services system.

Step #8: Grow system capacity.

Step #9: Expand home-based services.

Step #10: Establish adequately funded external service coordination system.

Step #11: Put into place a comprehensive single point of entry system.

Step #12: Restructure community services funding along person-centered lines.

Step #13: Adopt data-based, data driven rate determination methods for community services.

Step #14: Scale up the use of self-direction system-wide.

Step #15: Place increased emphasis on the delivery of outcome-oriented services and supports.

Step #16: Commit to measuring system performance and engage in continuous quality improvement.

Summary of Action Steps Proposed in 2012

Step #1: Commit to unified policy direction for developmental disability services throughout DHS to embrace person-centered practice.

Step #2: Invest in self advocacy.

Step #3: Establish a comprehensive Single Point of Entry system, including an adequately funded external independent service coordination system.

Step #4: Strengthen oversight of the community services system and improve the information management system

Step #5: Establish equitable resource allocation practices to set individualized budgets and advance person-centered services.

Step #6: Pursue implementation of managed care systems in ways to promote person-centered approaches.

Step #7: Invest in in-home supports

Step #8: Promote mutual support and association among self-advocates and families

Step #9: Strengthen community-based supports for people with extraordinary behavioral challenges.

Step #10: Scale up the use of self-direction system-wide.

Step #11: Accelerate opportunities for integrated employment.

Step #12: Adopt policies that help individuals and providers transition from ICFs/DD services to HCBS-funded alternatives.

Step #13: Adopt policies to revitalize the commitment to Community Integrated Living Arrangements.

Step #14: Reduce the number of people served at SODCs to no more than the projected national average by 2017.

Step #15: Expand system capacity at a steady pace by serving an additional 1,918 people each year between 2012 and 2022

Action Area A: Establish Clear and Cohesive Leadership

Action Step #1: Commit to unified policy direction for developmental disability services throughout DHS to embrace person-centered practice.

The Division of Developmental Disabilities, under the auspices of the Department of Human Services, announced in its *Strategic Plan FY 2011-2017* a firm commitment to establish a person-centered service system. The Plan sets strategic priorities and objectives for realizing this vision and describes a number of principles to guide the way. For example, the Plan sets objectives to assure that individuals are served in the most integrated setting appropriate to his or her needs, expand system capacity to accommodate increasing demand, promote valued employment outcomes for service recipients, adopt policies to reduce reliance on SODCs and private ICFs/DD, secure ample service reimbursement rates, and improve IT capacity.

Person-Centered Services:

Services and supports characterized by a comprehensive understanding of individuals' strengths, desires, hopes, and aspirations and provided in a manner that reflects a sincere commitment to maximizing opportunities for individuals to function with as much independence and self-determination as possible. (page 9)

DDD Strategic Plan FY 2011-2017)

While articulating this vision, the Division also acknowledges that present means of doing business are inconsistent with the desired new approach:

> *“Individuals with developmental disabilities and their families are more often than not frustrated by the current system of care and its philosophical underpinnings which seem to favor a rigid, bureaucratic approach to service delivery that puts the interests of rules and regulations ahead of the individual’s.” (page 11)*
>
> DDD Strategic Plan FY 2011-2017

For this Plan to succeed, much about the Illinois system will need to change, starting with a systematic review of policies, procedures and program design, and a willingness to make substantive changes to each. To this end, the *Action Steps* that follow help show the way.

Just as important, state policy makers will need to collaborate effectively. This includes leadership within the Governor’s office, the legislature, DHS/ DDD. Experience shows[35] that a primary reason that systems change efforts falter centers on a failure to articulate and communicate a clear and unambiguous vision for the future and take consistent policy action to advance the vision.

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[35] Kotter, John (1998). *Leading change: Why transformation efforts fail*. Harvard Business Review (March-April) Reprint No. 95204.

Indeed, over many years a consistent output of developmental disability policy making in Illinois has been ambiguity. Certainly, a number of documents, the present *Strategic Plan* being one of the most recent, illustrate Illinois' commitment to serving people with I/DD within a person-centered framework. Moreover, state leaders can point to several actions consistent with this intention.

Such commitment, however, is counterbalanced over time by the state's inability to initiate a unitary vision and action bias for progressive person-centered services over continued investment in traditional legacy services. Explained otherwise, while present circumstances are seasoned with notable improvements and good intentions, state leaders have provided over time an enduring mixed message to people with I/DD and their families.

Still, current expectations of self-advocates and commitments among policy makers place Illinois at the tipping point. Going forward, will Illinois policy makers follow through on their commitment to establish a person-centered system by:

- Restructuring to alter policies, procedures and programs to promote person-centered services?
- Providing ample resources to invest in infrastructure and service delivery?
- Reducing the number of individuals living in CILA housing to no more than four people?
- Continuing to reduce census at SODCs and reliance on other large congregate care facilities?
- Decreasing reliance on private ICFs/DD in favor of investment in HCBS?
- Adopting an "employment first" service response to offer individuals the opportunity for a community job in an integrated workplace?
- Increasing substantively investment in self-directed, community centered service options?
- Eliminating the disparity between wages paid to State employees and community-based direct service professionals?

Future policy direction for developmental disability services should consist of a cohesive and unitary response to these and other related questions. Toward this end, the response called for is not complicated.

- ✓ <u>Reaffirm a position in favor of person-centered services.</u> The DHS Secretary, in collaboration with the Governor's office, should consistently reaffirm a position in favor of person-centered services and direct leadership at the Division of Developmental Disabilities to take action consistent with this commitment without intrusion from other policy making offices.

  Put another way, primary decision making for system changes within the I/DD should center within DDD so that staff of other offices (e.g., the Governor's office, DHS) are not acting independently or out of line with the leadership and direction set by the Division. Certainly, Division staff will need to communicate and collaborate with DHS staff, the

Governor's Office and legislative leaders to orchestrate and align the span of changes that are required (e.g., downsizing of SODCs, altering the CILA program, complying with the terms of the Ligas Consent Decree). Care should be taken, however, to assure that all state leaders are in sync and working under unified direction provided by DDD.

- ✓ <u>Policy makers should work collaboratively.</u> Under the leadership of DDD, policy makers within DHS and the Governor's office should work collaboratively to align systems change actions to embrace person-centered principles. This would include, for example, transition planning and relocation to community alternatives for people leaving SODCs under the Governor's initiative or ICFs/DD under the Ligas Consent Decree. It also includes actions taken to improve practices associated with service planning, CILA services and other community services.

  While all involved may articulate a commitment to person-centered practices, the challenge is to work efficiently and effectively together to avoid "silos of practice" while embedding a consistent backbeat for person-centered policy and practice throughout the system.

Action Step #2: Invest in Self-Advocacy

Self-advocates want to live in the community with the supports they need. They also want to "be the boss of their own lives" and have a say regarding the policies and practices that affect their daily lives. To make these desires a reality, self-advocates must have a powerful voice in influencing change at the individual, local, state, and national level.

Illinois has made a clear commitment to involving people with developmental disabilities in shaping the services and supports available to them. As stated in the *DDD Strategic Plan FY 2011-2017*, Guiding Principle 1:

> *"People with developmental disabilities will be actively involved in policy discussions and decisions and will be respected as partners in the process, making informed choices and decisions in order to support productive and fulfilling lives." (page 6)*

Meaningful involvement of individuals with developmental disabilities requires providing necessary supports and preparation. Often individuals with I/DD have a difficult time making their voices heard and need support to follow conversation and develop opinions. To play a strong role, self-advocates must develop effective leadership skills and know something about the policies in play and the forces that shape them. They must be expressive about their want for self-determination, community integration and systems change. They must understand how they can be most effective in their own lives and in the policy arena. And they must have opportunity to act – individually and together.

One of the most effective ways for self-advocates to develop these necessary skills is by participating in effective self-advocacy groups. Beyond learning how to advocate for the services and supports they want, being a member of a self-advocacy group provides individuals with opportunities to achieve personal goals, offer one another mutual support, and contribute to their communities. From this foundation, they will be prepared to take action at multiple levels regarding critical issues that affect their daily lives.

To strengthen self-advocate voices and ensure meaningful participation of this key stakeholder group, DDD should:

- ✓ Support the statewide, independent self-advocacy organization that serves as the collective voice of people with I/DD in shaping public policy and practice. In the past, DDD had provided direct funding to support self-advocacy activities in the state. Unfortunately, in recent years this funding has been largely discontinued. DDD should rekindle its commitment by directing resources annually to further promote local and statewide self-advocacy groups.

  The Illinois Self-Advocacy Alliance (i.e., the Alliance) is the most visible self-advocacy organization in Illinois (http://selfadvocacyalliance.org/). Thus far, their primary funder has been the Illinois Council on Developmental Disabilities (ICDD). The Division should consider ways to fund Alliance activities as well.

  The Alliance is well positioned to provide trainings in the following areas:

  - *Peer Mentoring***.** The Alliance is currently implementing a peer mentoring project, funded by ICDD and DDD, aimed at providing training and information to individuals transitioning out of SODC's to community residences. As these and other transitions from SODC's are scheduled, the demand for this service will increase. The trainings utilize a peer-to-peer model with self-advocates providing the training to other self-advocates. This model compliments the person-centered planning process that will be utilized to facilitate transitions from SODC's into the community. We encourage the State to increase its investment in this important initiative, assuring that self-advocates become a strong part of the transition process.
  - *Supported Living Service.* The Alliance has been active in advocating for and shaping the expansion of the Supported Living Service in the Illinois HCBS waiver. They have already held several trainings and events to raise awareness regarding self-directed services for self-advocates.
  - *Self-determination.* To effectively utilize self-directed services, people with I/DD must have the opportunity to learn self-determination skills. Developing these skills are particularly important for individuals transitioning out of large institutional settings who have not had much experience making choices or speaking up for what they want in their lives. Consistent with its "It's My Life" initiative, the Alliance provides peer-to-peer trainings in this area. Information regarding the person-centered planning process that will be utilized to facilitate transition into the community could be included in these trainings.

- *Work incentives.* Over the next year, the Alliance has plans to begin organizing around employment, an issue that is continually raised within the developmental disabilities community. Through their established networks and contact with local self-advocacy groups, the Alliance could easily distribute information and educate self-advocates regarding work incentive programs available to help people with disabilities eliminate common barriers associated with working and keeping their benefits. Additionally, the Alliance could educate individuals about waiver funds allocated for the purchase of day services that can be used to purchase supported employment services.

- ✓ <u>Fund peer support services.</u> To offset costs, peer mentoring services should be included in the service array provided by the HCBS waiver. As mentioned above, the Alliance is a likely candidate to develop and implement peer support activities across the state. They are currently in the process of developing a structured peer support model to pilot with two local groups over the next year.
- ✓ <u>Increase the presence of self-advocates on advisory boards.</u> Self-advocates want to have a say about the decisions that affect their lives. Delivering on this goal, the state should include self-advocates in whatever decisions are being made that have a direct impact on the quality of their daily lives.
- ✓ <u>Promote the role of self-advocate leadership</u>. The collective goal among all should be to prepare self-advocates across the state to play leadership roles in their personal lives as well as guide change within the state's developmental disabilities service system locally and at a state level. The State should establish and fund a "Self-Advocate Liaison" position within DDD. Funding this

Potential HCBS Service Definition for Peer Support

Peer Support includes person-centered services that are offered to service recipients primarily by others who are or have been service recipients, or have a developmental disability.

Peer supporters themselves may require support from another to coordinate and manage their actions. Peer support is meant to assist with acquisition, retention or improvement in daily living skills and/or to improve or maintain the individual's opportunities and experiences in living, working socializing, recreating and staying healthy and safe. Activities may also be directed at maximizing use of natural supports and supports available from community serving organizations and businesses.

Activities included must be intended to achieve the identified goals or objectives as set forth in the individual support plan. The structured, scheduled activities provided by this service emphasize the opportunity for individuals to support each other in the use and expansion of the skills and strategies necessary to live successfully in the community.

Peer Support is a face-to-face intervention with the individual present. Services can be provided individually or in a group setting. The majority of contacts must occur in community locations where the person lives, works, attends school, and/or socializes.

position would provide self-advocates with significant visibility and access to high level decision makers, as well as opportunity for networking and forming partnerships. Overall, this position must receive ample support to conduct activities such as:

- Partner with self-advocates across the state, including local groups and statewide self-advocacy organizations, and provide meaningful linkages to the policymaking process.
- Provide leadership and promote coordination of self-advocacy groups and activities.
- Coordinate trainings, strategic planning, and other statewide activities intended to encourage people to be active self-advocates and to participate in government and civic activities that promote the rights of people with disabilities and encourage contributions to their communities.

Medicaid can be used to help fund this position and its associated activities. For example, the state might imagine that trainings offered to self-advocates teaches participants to be effective users of HCBS services, and so is Medicaid reimbursable. The state should move to include such training as a service under the HCBS waiver or claim it as an administrative expense for operating its waiver.[36]

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[36] Self-advocate Leadership Network (2006). *Using Medicaid to Fund Trainings for Self-Advocates*. Tualatin, OR: Human Services Research Institute

Action Area B: Develop Systems Infrastructure

Action Step # 3: Establish a comprehensive Single Point of Entry system, including an adequately funded external independent service coordination system.

Most states operate their developmental disabilities service systems by employing the Single-Point-of-Entry (SPOE) model. SPOE entities perform system intake, determine whether individuals are eligible for services, work with individuals and families to identify appropriate services and supports, and perform service coordination functions. SPOE entities also typically have the authority to authorize services and funding within state-specified parameters. In essence, SPOE systems establish a gateway into the system, and once enrolled provide individuals a means, through service planning and coordination, to receive services.

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In this regard, effective, *external* service coordination will be essential to the effective functioning of a person-centered service system. It is vital for ensuring that service plans are designed to meet the needs of individuals. Moreover, it is essential to efforts to assure service quality through ongoing monitoring of service plan implementation and the health and well being of service recipients.

As was described in the 2008 *Blueprint for System Redesign,* Illinois has incorporated some components of the SPOE model into the functions of the PAS/ISC agencies. The scope of PAS/ISC responsibilities, however, is not comprehensive. These agencies have limited responsibilities with respect to the flow of individuals into non-Medicaid services that are funded by the state. Since all individuals do not flow through the PAS/ISC agencies, it is not clear that individuals and families are fully informed of the full range of services and supports that may be available to them.

In response, the State should:

- ✓ Expand the responsibilities of the PAS/ISC agencies so that they function as true comprehensive SPOEs for entry of individuals into Medicaid-funded services. In the main, the expanded responsibilities of PAS/ISC agencies should include:
    - Performing intake for all state funded services, including the determination of eligibility and performing necessary assessments;
    - Counseling individuals and families concerning the services and supports for which they qualify, both within the developmental disabilities service system and other publicly-funded services (e.g., Medicaid and federal income assistance programs);
    - Facilitating the development of all HCBS waiver service plans;
    - Authorizing services;

  - Assisting individuals to access services;
  - Requiring ISSA service coordinators to perform direct contact monitoring of HCBS waiver participants served in community residences four times each year;

These responsibilities would be in addition to the more limited responsibilities that PAS/ISC agencies presently have with respect to the determination of eligibility for the HCBS waiver and determining the appropriateness of nursing home admissions. When linked to the enhancement of their service coordination functions, the foregoing expansion of PAS/ISC agency service coordination would provide Illinois with a strong, unified SPOE system.

- ✓ Increase the annual allowance for HCBS waiver ISSA services from 25 to 50 hours;
- ✓ Include performance benchmarks in contracts with PAS/ISC agencies to furnish ISSA services;
- ✓ Step up its funding of ISC agencies so that they have improved capability to support individuals who do not participate in the HCBS waiver, including assisting people who have unmet emergency and critical needs to access services outside the HCBS waiver until they can be enrolled in the waiver;
- ✓ Contract with an independent entity to perform quality audits of the performance of PAS/ISC agencies in furnishing service coordination.
- ✓ Consider use of the Balancing Incentive Program to establish a SPOE administered through the Centers for Medicare and Medicaid Services (CMS). This program would provide additional funding to support individuals relocating from ICFs/DD and nursing facilities to community alternatives.

BALANCING
INCENTIVE PROGRAM

The Balancing Incentive Program, set within Section 10202 of the Patient Protection and Affordable Care Act (Pub. L. 111-148), provides financial incentives to states to offer community Long Term services and Supports (LTSS) as an alternative to institutional care. Specifically, states that spend less than 50 percent of their long-term care dollars on community LTSS receive a two percent increase in the Federal match they receive from participation in the Medicaid program (i.e., Federal Medical Assistance Percentages or FMAP). States that spend less than 25 percent receive a five percent (5%) increase.

Illinois, using FY 2009 data (as is required) spends **27.8** percent[37] of their long-term care funding for all service populations (i.e., developmental disability, mental health, aging and physical disability) on Home and Community-Based (non-institutional) Services, and is therefore eligible for a 2% increase in FMAP if other program requirements are met. To meet the requirements, states must ensure their systems include, or will include, the following structural features as described by the legislation:

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[37] http://www.balancingincentiveprogram.org /sites/default/files/attachments/11-11-22/Percentage%20of%20LTSS%20Spending%20for%20HCBS%202009.pdf

- No Wrong Door—Single Entry Point System: Development of a statewide system to enable consumers to access all long-term services and supports through an agency, organization, coordinated network, or portal, in accordance with such standards as the state shall establish and that shall provide information regarding the availability of such services, how to apply for such services, referral for services and supports otherwise available in the community, and determinations of financial and functional eligibility for such services and supports, or assistance with assessment processes for financial and functional eligibility.
- Conflict-Free Case Management Services: Conflict-free case management services to develop a service plan, arrange for services and supports, support the beneficiary (and, if appropriate, the beneficiary's caregivers) in directing the provision of services and supports for the beneficiary, and conduct ongoing monitoring to assure that services and supports are delivered to meet the beneficiary's needs and achieve intended outcomes.
- Core Standardized Assessment Instruments: Development of core standardized assessment instruments for determining eligibility for non-institutionally-based long-term services and supports described in subsection (f)(1)(B), which shall be used in a uniform manner throughout the state, to determine a beneficiary's needs for training, support services, medical care, transportation, and other services, and develop an individual service plan to address such needs.

The legislation also requires states to meet certain target levels of community LTSS spending by October 1, 2015 (e.g., states that spend less than 50 percent of their long-term care dollars on community LTSS should hit the 50 percent target by this date).

Comprehensive information detailing the Balancing Incentive Program, and the process for applying can be found at the following website: http://www.balancingincentiveprogram.org.

Action Step 4: Take steps to strengthen oversight of the community services system and improve the information management system

A major shortcoming in Illinois is that neither stakeholders nor policy makers know how well the developmental disabilities service system is performing on behalf of individuals and families. Going forward, it is vital that the State establish standardized quality oversight practices and effective means for gathering and analyzing information on system performance.

Regarding service quality, it is said that what is tracked and reported is what improves. Illinois stakeholders of all types consistently express concern about the extent and effectiveness of state oversight of community services. As was explained in the 2008 *Blueprint for System Redesign*, the extent and frequency of oversight is generally regarded as inadequate. Further, as Illinois presses to implement a person-centered system, the Division will face greater challenges in assuring quality as flexibility in service delivery increases. As a consequence, the Division must take steps to increase its capabilities to oversee community services.

Outcomes important to individuals receiving services, and to all adults, include:

- Having a safe and welcoming place to live, meaningful things to do with their day and an ample amount of money to live, and
- To be as healthy as possible, to have relationships with others and to make important decisions about their life and supports.

Standardized quality management starts with setting system performance goals and prioritizing achievement of outcomes considered vital by people receiving services. Outcomes then drive development of appropriate structures and processes, rather than be driven by them. Standardized quality management entails not only targeted outcomes and performance measures, but also standardized practices for data collection, aggregation of data and analysis, reporting, and tracking data over time on progress to achieve outcomes at the local and statewide levels.

The Division should invest further in the recently formed Bureau of Quality Management, providing this office the means to track and report on outcomes and improve quality. Going forward, the Division, with support from the Bureau, should:

- ✓ Set goals, track and publicly report performance on what's important to individuals receiving services, such as on health status and outcomes, self-direction, integrated employment, living arrangements, reducing and eliminating unnecessary use of psychotropic medications, and personal relationships for people with I/DD.
- ✓ Use the information gathered to remediate problems, but also guide enforcement of corrections.
- ✓ Shorten the regular cycle of provider agency review from three to two years.
- ✓ Adopt a standardized risk assessment protocol that will be employed system wide to identify potential risks and risk mitigation strategies as part of the individual service plan development process.
- ✓ Maintain its membership within the National Core Indicators project to gather data on system performance across a number of topical domains important to individuals with I/DD and their families and spend additional time analyzing and understanding the data.
- ✓ Bring together information about quality within a broader quality improvement framework to furnish policy makers with comprehensive information about service system performance to support quality improvement initiatives.

These steps will entail a fundamental redesign of state oversight systems. This redesign should start as soon as possible. To this end, the Division should convene a stakeholder workgroup to develop the redesign, including identifying the resources necessary to implement the changes.

With respect to <u>information management</u>, it is essential that the state's information technology (IT) system be significantly improved. All states receiving Federal Medicaid-financing for I/DD services are required to collect data through a Medicaid Management Information System (MMIS) in accordance with the Title XIX (Medicaid) of the Social Security Act. Development of the MMIS is reimbursed by the administrative match through Medicaid at 90 percent federal match and maintenance of the system is reimbursed at 75 percent. The data collected through the MMIS, however, can vary among states. Required in the MMIS is a process for paying provider claims for services rendered, although other data elements collected and how claims data is collected is determined by each state.

Illinois uses an MMIS to gather data provider reimbursements as well as some limited demographic information. Table 4 shows the data elements collected through the State's MMIS and the data reports that can be generated with the limited information. As seen from the data elements targeted, there is limited data available to the Division to view the service system.

As important as the data *that is* collected is what *is not*. For example, data on the size of residential setting a provider may operate and/or the number of a residents at a given facility is not reported in Illinois' MMIS. This causes great issue in understanding the State's CILAs. Further, information about how individuals spend their days (i.e. what type of day services, how many other individuals are participating in the day services) is not collected in the current system.

Table 4:
Illinois MMIS Data Elements

Data Elements	**Report Types**
Female,	Grants for Alternative Non-Emergency Services,
Male,	High Risk Pools,
Unknown,	Homelessness Initiative,
Provider Name,	Independence Plus,
Amount Billed,	Medicaid Transformation Grants,
Non-Medical,	New Freedom Initiative,
Medical	Promising Practices,
	Real Choice,
	Improvement Act (TWWIA)

*http://www.dhs.state.il.us/page.aspx?item=32240

As the old adage goes, you cannot measure what you do not count. With the progressing complexity of the State's service system, Data Driven Decision Making (DDDM) becomes increasingly important. In response to present circumstances, DDD should:

- ✓ In cooperation with the Regional Medicaid Office, work to identify key pieces of information missing in the MMIS. This may include more detail on the providers offering services and how much of each service they offer, how many CILAs are currently in operation and how many individuals are residing at each facility, etc.
- ✓ Once an outline of missing elements has been developed, DDD and the Regional Medicaid office should work to develop a proposal for changing the current MMIS. DDD should consider applying for Medicaid match on this initiative so that all of the needed changes can occur at one time rather than making small changes over time. Even with Federal match, however, this project will still take significant resources and time from DDD.
- ✓ Establish the necessary IT systems to capture information concerning the results of monitoring, provider quality reviews and critical incident reporting.

Once these steps have been taken and a more fluid data system has been developed, DDD will be better equipped to review the nature of the service system, including its actions, outputs and outcomes. In turn, such analysis will help inform the policy decisions that must be made to establish a person-centered system.

Action Step #5: Establish equitable resource allocation practices to set individualized budgets and advance person-centered services.

In its *DDD Strategic Plan FY 2011-2017*, the Division illustrates its strong commitment going forward to person-centered services and associated financing to complement such services.

> *Strategic Priority 1: Create person-centered services aligned and strengthened across the developmental disabilities system, such that they are provided in the most integrated setting appropriate to the needs of the individual throughout the lifespan, regardless of intensity or severity of need. (page 11)*
>
> *Strategic Priority 2: Restructure financing and rates to encourage high-quality, person-centered services. (page 13)*

Key to achieving these priorities is action to establish individualized budgets for service recipients that are consistent with their assessed support needs. When individuals are allocated such budgets, a person-centered planning process can follow, although care must be taken to assure that the supports that are needed are available and can be secured for the amount in the budget.

More specifically, the Center for Medicare and Medicaid Services (CMS) defines the term *individual budget amount* to mean "a prospectively-determined amount of funds that the state makes available for the provision of waiver services to a participant" (Instructions: Version 3.5 HCBS Waiver Application). Often the allocated amount is fixed, though a range may be specified. Further, the individual is typically told what amount is allocated *before* developing a service plan (i.e., prospective planning), rather than after the plan is completed (i.e., retrospective planning).

States are acting to establish individualized budgets in response to a variety of pressures. Most notably, policy makers seek to achieve greater efficiency and equity. By doing so, they hope to make better use of resources while better positioning their service systems to take on current and future challenges. In addition, policy makers may also apply individual budgets to better position service recipients to direct their own lives and advance person-centered system themes.

To determine individualized budgets, Illinois policy makers must take at least these four steps:

- ✓ Implement independent accurate and reliable means for assessing individual support needs. Doing so allows policy makers to consider service recipients from those with the least need to those with the most, including capacity to identify those with extraordinary needs (e.g., medical or behavioral). We understand that in Illinois many individuals (e.g., those served by CILAs or in SODCs) are assessed using the Inventory for Client and Agency Planning (See: http://icaptool.com). The ICAP is used to measure both "adaptive and maladaptive behaviors" and gathers information to determine the type and amount of special assistance that people with disabilities may need. It is used in several states and by some (e.g., Wyoming, Indiana, South Dakota) to help set individualized budgets.

  The State may elect to build on its existing ICAP database to establish sound assessments for all service recipients. We caution, however, that when using assessment to allocate money it is imperative that the data collected are accurate, reliable and not compromised by the appearance of special interests. Presently, the ICAP data collected in Illinois fails this test because it may be collected by provider staff or others with a financial interest in the outcome. This is not to say that these data are confounded, but that they may be.

For best results, the State should seek to assess all its service recipients with an appropriate tool but also through independent assessors who can be counted on to provide fair, accurate and reliable information. Further, the ICAP may not be the tool that is best suited to provide the information that is needed as other choices are available.[38]

Thank you for everything that you've done … for all the services that there are…

But what you built, we don't want.“

Rebecca Coklev

- ✓ Reach agreement on the service array available and associated service definitions. We understand the State is seeking to renew its mainstay HCBS waiver. This waiver includes the services that will be available to service recipients along with their associated definitions. These services and definitions reflect much of what the State offers, but may also include new or revised services. Regardless, the State should take the opportunity, making amendments to the approved waiver as warranted, to assure that the array of services it offers is consistent with and sufficient for implementing a person-centered service system. The available array must not simply reproduce what has been, but must also look forward to offer services consistent with present and emerging best practice.

- ✓ Conduct an independent cost study to establish an appropriate service reimbursement rate schedule. In 2007, the Division formed an ad hoc Rate Committee of the Statewide Advisory Council.[39] The Committee was asked to review the rates and rate methodologies the Division employs to fund services to individuals with I/DD. The Committee met over two years, examining issues pertaining to the Illinois rate structure. Several cost centers were reviewed including, CILAs, day services, transportation, children's residential services, downsizing ICFs/DD, and wage and fringe benefits.

  The Committee did well to set forth principles for guiding a review of reimbursement rates and expectations of what might be done to establish adequate, fair and equitable rates for services across the state. The effort, however, was based primarily on a review of circumstances by various work groups. Group members gave great attention to their work, uncovered numerous issues, and offered reasonable recommendations in response. Still, inevitably, the work cannot be precisely applied to construct new rate schedules by service for two reasons. First, data illustrating actual costs experienced by providers for delivering services was not collected so that the study reflects more informed estimates of what a rate might be than actual costs. Second, the Committee, composed primarily of service providers and State staff, may have embedded in its work perspectives consistent with their underlying interests. An improved approach involves an independent third party to examine costs, consider system-level goals and establish appropriate rates.

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[38] Smith, G., Fortune, J., Taub, S. & Chiri, G. (2007) *Assessment Instruments and Community Mental Health Services Individual Budget & Rate Determination: Review and Analysis*. Tualatin OR: Human Services Research Institute.

[39] http://www.dhs.state.il.us/page.aspx?item=44698

To complete this task, we recommend building on the Committee's work to complete an *independent cost study of services.* In this approach, a model is constructed of the costs providers face in delivering a particular service. To construct the models, five primary cost areas are included for each service: (a) direct service staff wages; (b) direct service staff employment related expenses (ERE); (c) the productivity of direct service staff (i.e. the amount of time in each workday that direct staff time can be charged); (d) program support costs; and (e) administrative expenses. Any service could have additional components, but these five represent the basic outline of the cost model for every service.

In constructing the model for a specific service, the service definition is reviewed to determine specific requirements for that service. These requirements could include such elements as direct service staff qualifications, training and supervision requirements, the inclusion or exclusion of transportation within the service, staffing ratios, and whether the service is facility-based or home-based.

Once the outline of the cost model is determined, the model is populated with data that represents the costs/factors that providers face. We note that building a rate schedule entirely on review of historical costs may yield an unsatisfactory result because these costs have embedded in them many of the very legacy the State may be trying to eliminate. As a result multiple sources of information must be applied, including: (a) a provider cost survey; (b) special studies as warranted, including discussions with State staff and service providers; and (c) published sources such as information available on staffing costs provided by the Department of Labor.

Based on the findings, statewide rates may be established. The rate models would demonstrate for policy makers, providers and other stakeholders what specific costs are and are not included in the rate and the extent to which government funding covers the cost of services for people with I/DD. It should be understood, however, that the rates must eventually be squared with the overall state budget available for developmental disability services and the aggregate needs of service recipients. As a result, the rate schedule may not reflect the full cost to providers for delivering a particular service.

- ✓ <u>Reconcile assessments of support needs with an appropriate rate schedule to yield individualized budgets</u>. Once the first three steps are completed, action can be taken to consider an individuals' relative standing to others regarding their need for support, and match their need to the types and amount of services they may need. Given that a rate schedule for these services is available, an individualized budget allocation per service recipient may be generated. In doing so, this process may in turn require further adjustments to the rate schedule. Afterwards, the individual is informed of his or allocation in advance of a person-centered service planning meeting.

  We understand that some service recipients may have needs in excess of what their initial budget allocation could support. In response, the State must also establish means for identifying these individuals and addressing their needs as warranted. Overall, the intent is to assure that each individual is accorded sufficient resources to address their needs – no more and no less.

Action Step # 6: Pursue implementation of managed care systems in ways to promote person-centered approaches

Nationally, states are feeling pressure to adopt Medicaid managed care systems to reduce costs of long-term care, acute care or both. These systems may cut across multiple populations, including seniors and people with a variety of disabilities. For example, the North Carolina General Assembly recently enacted House Bill 916 to require a major restructuring of the management, financing and delivery system for services for individuals with mental illness, intellectual and other developmental disabilities, and substance abuse disorders. This restructuring will occur by July, 2013 and utilize a 1915 (b)/(c) Medicaid waiver[40] . Among the many requirements (or anticipated results) of the legislation is that 11 Local Management Entities will convert into managed care organizations, receive a capitation payment to manage the local service system and accept some measure of risk for maintaining full accountability for all aspects of HCBS waiver operations.

Consistent with this trend, Illinois is in the process of implementing a managed care system in several Chicago area counties. The State plans to implement its “Integrated Care Program” in three phases, scheduled for full implementation by 2015. The system will cover medical services as well as long-term services and supports across multiple populations, including I/DD.

The primary promise of managed care is administrative and fiscal efficiency, resulting in reduced per person costs. This promise, however, often prompts concern among service recipients, their families and service providers. They fear restrictions in choice of services, service cuts, reductions in reimbursement rates and an overall diminished quality of life. It is true that changing to a managed care system will alter budget allocations and service practices, but actions can be taken to offset potential shortcomings of the approach. The challenge is to implement means for advancing person-centered practices while also applying fiscal discipline within a managed care framework. Toward this end, as Illinois policy makers continue the managed care roll out and expand the practice, they should embrace the National Council on Disability’s guiding principles and recommendations for implementing managed care provided in Table 5.[41]

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[40] Medicaid is the major source of public funding for long-term services and supports provided in home and community settings for people with I/DD. A popular means for doing so involves use of a1915(c) HCBS waiver. When approved by the Center for Medicaid and Medicare Services (CMS), this type of waiver typically allows states to avoid certain requirements of the Social Security Act to target a particular group (e.g., people with developmental disabilities and/or people living in particular parts of the state). Other types of waivers are possible. CMS explains that a 1915(b) waiver permits States to make mandatory the enrollment of beneficiaries in Medicaid managed care plans, use local entities to manage services, deliver additional services generated through savings and restrict providers using selective contracting.

Upon CMS approval States may utilize these two authorities together within a combination 1915(b)/(c) waiver. When both are used, the State uses the 1915(b) authority to mandate enrollment in a Medicaid managed care plan and limit freedom of choice and/or selectively contract with providers, and uses the 1915(c) authority to target eligibility for the program and provide home and community-based services. By using both authorities, States can provide long-term services and supports in a managed care environment. States can implement 1915(b) and 1915(c) waivers concurrently as long as all Federal requirements for both programs are met.

[41] National Council on Disability Communications (2/12) to the Centers on Medicare and Medicaid Services :
Guiding Principles: http://www.nasddds.org/pdf/managedcarencdprinciples 1.pdf.
Recommendations:http://www.nasddds.org/pdf/cmsmanagedcarencdrecommendations 1.pdf.

Table 5: Guiding Principles for Enrolling People with Disabilities in Managed Care Plans National Council on Disabilities

1. The central organizing goal of system reform must be to assist individuals with disabilities to live full, healthy, participatory lives in the community
2. Managed care systems must be designed to support and implement person-centered practices, consumer choice, and consumer-direction
3. For non-elderly adults with disabilities employment is a critical pathway toward independence and community integration. Working age enrollees must receive the supports necessary to secure and retain competitive employment.
4. Families should receive the assistance they need to effectively support and advocate on behalf of people with disabilities.
5. States must ensure that key disability stakeholders -- including individuals with disabilities, family members, support agency representatives, and advocates -- are fully engaged in designing, implementing and monitoring the outcomes and effectiveness of Medicaid managed care services and service delivery systems.
6. The service delivery system must be capable of addressing the diverse needs of all plan enrollees on an individualized basis, including children, adolescents and adults with physical disabilities, intellectual and developmental disabilities, traumatic brain injuries, mental illnesses, substance use disorders, and other types of severe, chronic disabilities
7. States should complete a readiness assessment before deciding when and how various sub-groups of people with disabilities should be enrolled in managed care plans. A state's phase-in schedule in turn should be based on the results of this assessment.
8. The network of providers enrolled by each managed care organization should include those who furnish health care, behavioral health and, where applicable, long term supports. The network must encompass both providers of institutional and home and community-based supports. Each network should have sufficient numbers of qualified providers in each specialty area to allow participants to choose among alternatives.
9. States planning to enroll recipients of long-term services and supports in managed care plans should be required by CMS to include providers of institutional programs as well as providers of home and community-based supports within the plan's scope of services. This requirement should be built into the "terms and conditions" governing waiver approvals.
10. The existing reservoir of disability-specific expertise, both within and outside of state government, should be fully engaged in designing service delivery and financing strategies and in performing key roles within the restructured system.
11. Responsibility for day-to-day oversight of the managed care delivery system must be assigned to highly qualified state and federal governmental personnel with the decision-making authority necessary to proactively administer the plan in the public interest.
12. The federal government and the states should actively promote innovation in long-term services and supports for people with disabilities.
13. CMS should rigorously enforce the ACA "maintenance of effort" provisions in granting health and long-term service reform waivers. The agency should require that any savings achieved through reduced reliance on high-cost institutional care, reductions in unnecessary hospital admissions and improved coordination and delivery of services be used to extend services and supports to unserved and underserved individuals with disabilities
14. Within a well-balanced service system, the delivery of primary and specialty health services must be effectively coordinated with any long-term services and supports that an individual might require.
15. Participants in managed care plans must have access to the durable medical equipment and assistive technology they need to function independently and live in the least restrictive setting.
16. The state must have in place a comprehensive quality management system that not only ensures the health and safety of vulnerable beneficiaries but also measures the effectiveness of services in assisting individuals to achieve personal goals.
17. All health care services and supports must be furnished in ADA compliant settings
18. Enrollees should be permitted to retain existing physicians and other health practitioners who are willing to adhere to plan rules and payment schedules.
19. Enrollees with disabilities should be fully informed of their rights and obligations under the plan as well as the steps necessary to access needed services.
20. Grievance and appeal procedures should be established that take into account physical, intellectual, behavioral and sensory barriers to safeguarding individual rights under the provisions of the managed care plan as well as all applicable federal and state statutes.

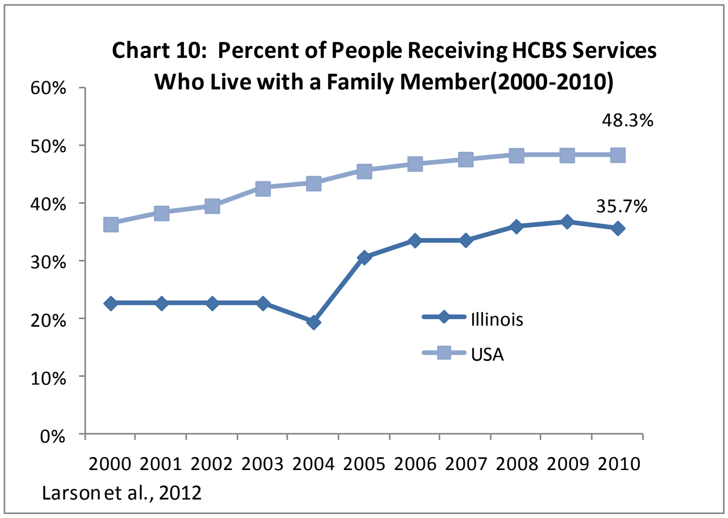
Action Area C: Improve the Community Response

The State, in its *Strategic Plan*, demonstrates commitment to improving the community response to the needs of individuals with I/DD and their families; however, many would agree there are significant shortcomings that must be addressed immediately. These deficiencies affect the substance of the services that individuals receive, as well as the infrastructure needed to support these services.

From the perspective of service delivery, more could be done to promote self-direction for individuals with I/DD, to increase their opportunity for community integrated employment, and to establish means for them and their families to offer one another mutual support. Regarding infrastructure, the Department must take action to strengthen the community system infrastructure. *Action Steps* 8 through 12 below address these areas for reform.

Action Step # 7: Invest in In-Home Supports

In the 2008 *Blueprint*, Illinois was advised to concentrate on expanding home-based services as its primary tool for addressing unmet service demand. Such action would be consistent with decisions made in most other states to invest in in-home supports.



As illustrated by Chart 10, in 2010, 48.3 percent of all those receiving HCBS services nationally live at home with a family member. In some states (e.g., Arizona, California Hawaii, Louisiana, North Carolina) the percentage tops 60 percent. This compares to 35.7 percent in Illinois. The chart also shows that Illinois has consistently performed under the national average.

In great part this trend is driven by the realization across states that focusing on in-home services, where individuals continue residence with a family member, is a less costly strategy than expanding licensed residential services. Put bluntly, states simply cannot afford to address increasing service demand primarily through out-of-home residential options.

We understand that individuals may want to leave their family home as other adults typically do or that parents may also look forward to that day. After all, parents age and the time comes when they may no longer be able to shoulder day-to-day responsibilities for providing support at home. Yet, in these fiscal times, states are hard pressed to address needs within their tightened budgets, and so states increasingly rely on continued residence at home.

In Illinois, home-based services have also proven to be an effective, economical means to support individuals with I/DD. Through home-based services, services and supports are furnished to supplement and complement the supports that families furnish day-by-day to individuals. Families also have expressed a high level of satisfaction with home-based services.

In developing a strategy for addressing the waiting list for I/DD services consistent with what was recommended in 2008, two actions are offered:

- ✓ Of the new capacity Illinois needs to add by 2022 (See Action Step 15), 60 percent should be allocated to the expansion of home-based services. Such action would add approximately 11,500 individuals to the HCBS waiver who live home with a family member. As a result, by 2022 about half of those receiving HCBS from the Division would be living home with family, which is the present national average. Shifting the mix of waiver services toward the provision of home-based services would also reduce the aggregate cost for serving these individuals because in-home supports are generally less expensive, on average, than out-of-home residential alternatives.

  When undertaking this strategy the State should take into account the needs of aging family caregivers and adults with I/DD who want to leave the family home. In doing so the state might fashion policy to emphasize continued residence at home - with supports – to young adults thereby focusing out-of-home residential opportunities on individuals with aging caregivers or older adults wanting to leave home.

  Illinois should allocate the remaining funds to strengthen options related to supporting individuals in alternative living arrangements outside the family home such as in CILA homes, supervised apartments or in their own homes.

- ✓ Illinois should consider shifting home-based services to a stand-alone Medicaid HCBS waiver. Currently, there are over 20 states that operate separate “supports waivers” that provide roughly the same type of services as Illinois’ home-based services. Supports waivers operate side-by-side with the traditional “comprehensive waivers” that provide extensive services, including licensed residential services furnished outside the family home. To contrast, supports waivers do not offer residential services and are characterized by a relatively low dollar cap on the total amount of HCBS services that may be authorized on behalf of a beneficiary. As a result, the per waiver participant cost in comprehensive waivers is substantially greater than in supports waivers.

  Setting up a distinct home-based services supports waiver would also provide the opportunity for Illinois to make other changes to home-based services that would prove beneficial. For example, a graduated funding limit for home-based services might be substituted for the current single funding limit to permit additional services to be authorized when necessary to meet the needs of the individual or address changes in family circumstances. In addition, consideration should be given to incorporating full-featured self-direction of home-based services, including adding the coverage such as “individual goods and services,” to provide an extra measure of flexibility for individuals and families to purchase non-traditional services and supports.

Action Step # 8 Promote mutual support and association among self-advocates and families

As in Illinois, service systems across the nation are challenged to accommodate increasing demands for services while enduring difficult fiscal times. Making matters worse, states often continue to invest in out-dated and costly service approaches (e.g., institutional services, sheltered workshops) that carry low value for the money spent and are financially unsustainable in the long term. These circumstances inevitably lead to service waitlists and tension among stakeholders with allegiances to contrasting service approaches (e.g., institution vs. community). In the face of these challenges, states continue to support a “services first and only” approach, funded primarily through Medicaid. Lost in this response are opportunities for promoting a spirit of personal reliance and contribution, mutual support and community connection.

A more favorable response requires that policy makers at all levels complement existing public services by establishing sustainable networks of mutual support so that individuals with I/DD and their families may:

- Make efficient and effective use of public services, such as those funded by Medicaid;
- Work cooperatively to achieve common goals;
- Utilize supports available from local businesses or community serving organizations;
- Provide supports to one another, as in an exchange network or peer support group; and
- Contribute in meaningful ways to the community.

The Illinois Association of Microboards and Cooperatives (IAMC) http://www.iambc.org) has acted in ways consistent with these objectives since 2007 when it was established as a project of the ICDD. They later incorporated in June 2009. The IAMC recognizes that people with I/DD and their families use both public and informal supports and assists families to develop either microboards or cooperatives. Microboards are small, non-profit organizations created to provide natural and/or paid supports and services to a single individual who has a disability. A cooperative is a group of individuals who join together, become incorporated and register with the state to become a certified service provider. As a result, the cooperative members are able to direct and control their support and service needs for the benefit of each co-op member.

IAMC
Illinois Association of Microboards and Cooperatives

Utilizing both microboards and cooperatives, the IAMC connects families to the public services they qualify for, but emphasizes developing and utilizing informal supports that are available from neighbors or friends, or from community businesses or other community organizations. These informal supports are often free, and are usually based upon relationships in the community.

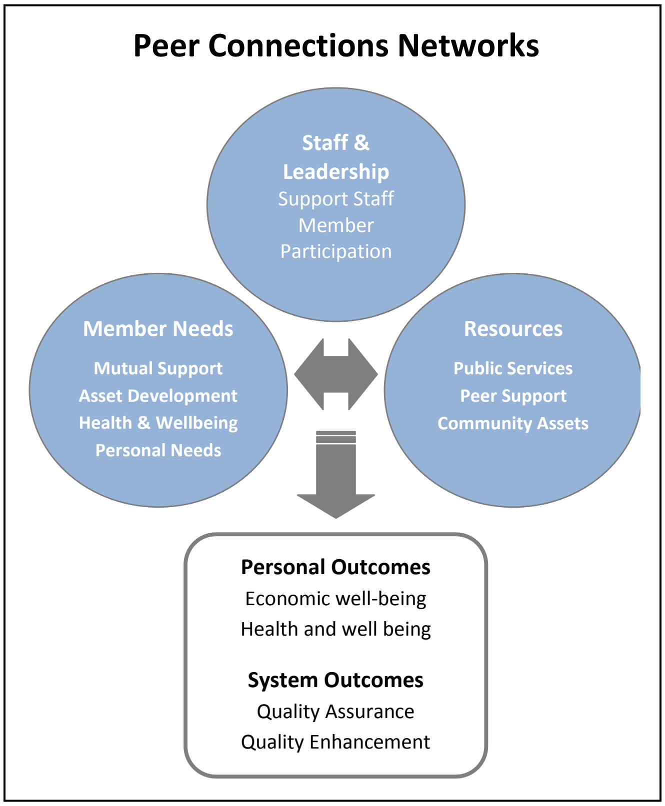
Currently, the Association supports seven cooperatives serving approximately 110 families and 31 microboards with roughly 40 microboards in development. IAMC's primary activities are to connect families with one another to utilize community assets in ways consistent with this *Action Step*.

Illinois must do more to invest in this supports model. Providing access to such supports will complement the Medicaid-funded services people receive, stretching those dollars further by adding to people's lives greater access to their communities and additional sources of support.

Toward these ends and complementing ICDD's efforts, the Division should create a clear funding pathway for financing development and staffing of peer connection and formal cooperatives or federations where participants work together to manage the services they receive. Working with IAMC, the Division should work across the state to establish:

- ✓ Peer Connection Networks. To complement traditional Medicaid-funded services, individuals and families should be encouraged to participate in local Peer Connection Networks to give and receive mutual support. These Networks are not meant to take the place of HCBS services. Rather they are intended to generate additional, complementary supports within communities across Illinois.

  In a Peer Connection Network, participants unite voluntarily to address common needs through mutual support and/or joint action. Networks can be composed of individuals with disabilities, family members or both. A staff person is typically required to advise and organize the Network, though it should ultimately be shaped by the needs and preferences of its members.



  Peer Connection Networks blend together three essential sources of support:

  - *Disability-oriented public services*: Individuals with developmental disabilities may be receiving support services already through a community services network funded by DDD. These actions may also be complemented by other public services (e.g., ride sharing programs sponsored by local transit agencies). These services often provide significant support, but usually are insufficient to address all of the unmet support needs among individuals with lifelong disabilities.

- *Peer support*: Peer support associations are created to link people through a voluntary exchange of support. Such support can include simple forms of assistance that individuals offer one another (e.g., temporary respite, a car ride, emotional support, information). Peer support may also be organized more formally through a "time bank." A time bank organizes participants within an exchange network where everyone's contributions are valued equally and tracked. At the Time Exchange of the North Shore (in Massachusetts), an hour of help offered equals one service credit. The hours of time a participant gives to others are credited to his or her account by computer, and hours of help the person receives are "debited" from the account. After each service exchange, the participants notify the office of how many hours were given. Quarterly statements are sent to all members. Participants e-mail each other with service offers ("I am able to provide transportation") and requests ("I need a ride to my Doctor next Wednesday"), exchange information, such as placing an ad for services or placing service requests. In this fashion, individuals reach out to others across an area to provide mutual support (http://www.lynntimebank.org/).
- *Community assets*: The network can also collaborate with community assets, such as faith-based and other community service organizations (e.g., churches, civic or hobby clubs, recreational centers). Local chambers of commerce and community businesses may also prove helpful.

✓ Human Service Cooperatives. In the current service system, families are counted on in a number of ways to manage the supports provided to the family member with disabilities. By working together, participants can form a strong alliance within a cooperative. Within the context of a self-directed service option, the cooperative itself may operate as a provider agency, performing any number of functions collectively for its members, including:

- Recruiting direct support staff;
- Acting as an employer of record;
- Monitoring paid staff and assuring that supports are properly delivered and accounted for;
- Purchasing services, durable equipment or other needed supports; and
- Acting as a fiscal intermediary to ensure that providers are paid, but also to offer providers workers' compensation and other benefits.

Working on their own, such responsibilities can prove burdensome over time. If families and individuals work together, however, many of the associated responsibilities taken on by families may be more efficiently and effectively managed. This can be accomplished by promoting partnerships within the public and private sectors – for example by forming a "Human Services Cooperative (HSC)."

HSCs are recognized by the Federated Human Service Cooperative, an organization whose goal is to "assist in the creation of Human Services Cooperatives" (http://www.federatedhsc.coop). This national entity certifies local cooperatives that are directed by individuals and families who use disability services to provide supports which benefit its membership. Once certified, a cooperative essentially operates as a provider agency, delivering services based on policies formulated by member owners. This type of cooperative typically is built on partnerships developed between agencies and community-service organizations in the public and private sector. These partnerships create a responsive network to offer self-directed services to address member needs. Several local HSCs have been successfully implemented in Illinois, Arizona and Tennessee:

Several types of agencies are capable of establishing peer connection or cooperative initiatives, including self-advocacy groups, local Arc Chapters, and other family or advocacy-oriented organizations. IAMC, however, has taken a lead in establishing these kinds of networks and can be relied on to help push forward. What is needed is a funding mechanism to pay for development and later for staffing to organize and maintain the effort. We understand that the Division has made available CILA funding to entities interested in establishing peer support networks and cooperatives. Yet CILA, given licensing requirements, associated regulations, and rates of reimbursement is not suited to this service approach.

More preferable is for the Division to establish a service within its HCBS waiver that is especially fashioned to this service. The accompanying graphic provides a potential service definition to target this service and staff that would be needed.

Potential HCBS Service Definition for
Peer Support Network Organizing

Peer Support Network Organizing provides assistance and resources to service recipients living at home with family members or on their own, or their caregivers (e.g., family members, but not direct support staff employed by provider agencies) who work together to meet common service-related goals for individuals.

The network may be designated as a corporation or may be less formally structured. The structured, scheduled activities provided by this service emphasize the opportunity for individuals and their caregivers to support each other in the use and expansion of the skills and strategies necessary for individuals to live successfully in the community. Activities may also be directed at maximizing use of natural supports and supports available from community serving organizations and businesses.

Activities included must be intended to achieve the identified goals or objectives as set forth in the individual support plan. This service can be a face-to-face intervention with the service recipient and his/her caregiver present or provided to advance goals of members of the network without individuals or caregivers present.

Action Step # 9: Strengthen community-based supports for people with extraordinary behavioral challenges

A critical measure of the effectiveness of a community developmental disability service system is how well it supports individuals with especially challenging behavioral conditions. To the extent that the needs of such individuals can be appropriately addressed, their lives will be more stable and higher service costs will be avoided. Toward this end, it is vital that individual needs be met without resorting to unnecessary placement out of the person's community residence or family home.

Some states (e.g., Maine, Oregon and Vermont) recognized the need to respond quickly and expertly to the needs of individuals with challenging conditions in their home communities and avoid placement within developmental centers – placements that in some cases become permanent because of lack of community capacity.

For DDD to act decisively to reduce its reliance on SODCs and otherwise respond to behavioral crises in the community, it is essential that community capacity be established to respond to such behavior. In this regard, we understand that the Division increased service reimbursement rates for behavioral intervention, expanded the qualifications associated with behavioral interventionists to increase their number, and created local crisis management teams to support providers and families. These actions resulted in a greater use of behavior therapy and an improved response to crises across the state, but these actions have been insufficient.

To improve its response to individuals with significant behavioral challenges, the Division should:

- ✓ Consider adding to its HCBS wavier services to cover:
  - Expenses related to consultation and materials pertaining to specialized environmental design. Through careful planning and design it is possible to recreate homes that in part address individual needs in ways to reduce the potential of behavioral events. The right physical environment can change the relationship between a person and people providing support, reducing conflict while enhancing opportunity for positive interaction.[42] See Creative Housing Solutions: http://gbcchs.com.
  - Specialized residences meant to support people with extraordinary behavioral challenges.
- ✓ Accelerate its efforts to bolster its local crisis support response capacity. These efforts might include further adjustments to service reimbursement rates for behavioral responders. Moreover, the Division should build capacity to provide at least these three forms of support:

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[42] See Creative Housing Solutions: http://gbcchs.com

  - *Emergency* – Situations where, because of an individual's challenging behavioral issues, there is a need for: (a) immediate specialized services; or (b) crisis/respite service for family members or staff.
  - *At Risk* – Situations where a specific or time-limited problem resulting from behaviors or situational factors disrupts an individual's optimal functioning in his or her place of residence or habilitation program and causes the person to be at risk of losing his or her services.
  - *Short-Term Assistance* –Situations where 24-hour linkage and referral services are needed for ongoing services by the family or primary caregiver to address an individual's behavior or situation.

  To respond to situations such as these, local teams will need to offer a mix of supports, including assessment, positive behavioral support planning, staff or family training, respite services and referral to companion service systems.

- ✓ Conduct a study of psychotropic use for behavior. Data available from the National Core Indicators project reveals that about 50% of service recipients nationally take medications for mood disorders, anxiety, behavior problems or psychotic disorders. While this percentage is lower in Illinois, NCI findings for the State show that about 60% of those residing in community residences take such medication. Usage rates such as these may be appropriate, but raise questions regarding the use statewide of what amounts to "chemical restraint" for behavior. The Division is encouraged to examine psychotropic use patterns and take steps needed to assure that individuals are not being prescribed or administered such medications inappropriately.

Throughout, it is essential to consider that behavioral difficulties are not always best responded to with behavioral intervention directed at the individual. It is not unusual to determine that behavioral difficulties can be tracked back to causative factors that may be addressed through other means. For example, an individual may suffer from health related difficulties (e.g., chronic pain) that yield troubling behavior. Likewise, a lack of communication skills or environmental obstacles may regularly trigger frustration and so problem behavior.

Finally, staff or family members may respond to individual needs or make unreasonable demands on the individual, prompting undesired behavior. Most notably, we observe a great many "silly rules" pressed on individuals by staff members that foster conflict and so problem behavior. Examples include arbitrary early bed times and restrictions of all sorts, such as on phone use, television viewing, dating, leisure activity or diet.

As a result, it is imperative that Illinois build capacity to address behavioral challenges among service recipients. It is equally essential that the Division continue to establish person-centered practices and make available associated staff and family training. Doing so will reduce the tension and conflict that often leads to challenging behavior.

Action Step #10: Scale up the use of self-direction system-wide

Self-advocates all over the country demand to control or "be the boss of" their own lives and in many states they can through the use of self-directed service options. Through self-direction, individuals and families have the authority to exercise decision making power over the services and supports that they receive, manage an individual budget for services, and hire or fire support workers. The federal Centers for Medicare and Medicaid Services (CMS) strongly encourages states to incorporate opportunities for self-direction into Waivers for people with disabilities, including people with I/DD.

In this context, we recognize the unique challenges that must be overcome when applying "self-determination" principles to I/DD services. Due to the nature of various disabilities, some individuals may not be able to exert full authority over all aspects of their services. For instance, owing to a significant intellectual disability, some may not be able to recruit and manage staff, manage their own budgets or complete other activities related to directing one's own services. In such instances, family members typically play a strong role within a "self-directed" framework. How this issue plays out person to person and family to family varies greatly, and sometimes results in tension between the individual with I/DD and his or her family. The idea always is to place the individual with I/DD in the lead to match his/her capabilities, but to honor the impact of the disability and the role family members will play. Further, this issue amplifies the need for effective, independent service coordination and application of person-centered principles.

Still, the demand for self-directed services is strong in Illinois as well. While family members will undoubtedly play a role in the design and application of "self-directed" policy, we focus our emphasis on the role self-advocates will play. After all, as they remind us consistently: "it's my life." The Illinois Self-Advocacy Alliance published a position statement on self-direction and is currently working with State staff to expand the self-directed service options within the current HCBS waiver for adults with developmental disabilities.

We encourage the Division to continue with the necessary planning to scale up self-direction across the entire service system with a new self-directed option within its HCBS waiver. Successful large scale implementation of self-direction will require that the Division:

- ✓ <u>Build capacity for case management to align with self-directed principles</u>. One characteristic of successful self-directed and person-centered service systems is the role of independent service coordinators or case managers to help individuals craft person-centered plans of support. In Illinois, service coordination is provided by Individual Service and Support Advocacy (ISSA) staff, but they have insufficient authority for playing this role effectively. Often it is provider staff that serve as "service coordinators and planners." This pattern constitutes an obvious conflict of interest that must be addressed. Illinois should build capacity within the ISSA network to offer individuals sufficient support so that they may effectively self-direct their services. This will, at the least, require additional resources so that ISSA staff can effectively participate. This will also require changes in regulations to allow for more than 25 hours of support annually per person.

- ✓ Develop specific performance measures related to self-direction. Performance should be tracked across the state and reported publicly through reports and the Division's webpage.
- ✓ Adopt principles related to self-direction. For example, a self-directed system must value:
  - *Individual authority to plan and pursue their own vision* - Individuals have the authority to indicate what they want, and be listened to and honored by others.
  - *Individual authority to direct services* – Control rests in the hands of individuals (not with programs or professionals) regarding what happens, what services or supports are received, and who provides them.
  - *Community membership* – Individuals are supported to develop and sustain their social relationships including friendships, romances, family connections and religious affiliations.

Illinois Self-Advocacy Alliance
Position Statement on Self-Direction

The *Declaration of Independence* states that all people have the right to life, liberty and the pursuit of happiness. This means ALL people, including people with disabilities. For us, this means being in control of our lives. We are experts about our own lives. We know we need help and support, but we also have ideas, dreams, and solutions on how to get the help we need. Other people have control over their lives, so why should we be any different?

We want Illinois to create a disability service system where supports and services are controlled by us – the individuals who receive them. We want opportunities. We want freedom. We want choices.

If we were in control of our own supports and services, we would…

- Stop funding institutions, and fund community services, like personal assistance and homes in our community instead
- Have meaningful work in the community so we are not bored and can have financial opportunity—real work for real pay!
- Develop opportunities for friendship, relationships, and social connections
- Improve transportation so that it runs on evenings and weekends

www.selfadvocacyalliance.org

  - *Collaborative support delivery* – Individuals are supported to negotiate across several service silos, to effectively weave together their needed resources.
  - *Meaningful leadership roles for individuals* – Meaningful leadership roles for individuals are valued and assured at all levels of the service system.
  - *Flexibility in support delivery* – People's needs change. A self-directed model can bend to accommodate change, and recognizes there are many paths to achieving individual goals.
  - *Access to satisfactory support options* – The system of supports includes an array of choices that are real, available and appropriate to the needs and desires of the person.
  - *Commitment to excellence and personal outcomes* – Self-direction assures a sustained commitment to service excellence and individual outcomes.

- ✓ Assure that uniform operational structures are in practice across the state. These include:
  - *A fair and accurate assessment of support needs* – Essential is an assessment measure providing sufficient information to differentiate among individuals accurately and reliably regarding their support needs.
  - *A fair and ample individualized budget* – With a personal assessment-based budget, individuals can consider their needs in relation to the size of the budget and the supports available to make well planned decisions about which services to choose.
  - *Fair and affordable service reimbursement rates for providers* – Budgets must be ample to purchase selected services, and providers must be reimbursed sufficiently for the services delivered.
  - *Timely pay for providers* – As a wide range of supports are developed, providers should be able to expect reimbursement for services rendered in an appropriate time frame and with reasonable requests for documentation.
  - *Means for informing and training individuals* – A self-directed model does not presume that individuals can play a leadership role within this system without training and support.
  - *Person-centered planning* – A self-directed system provides a structure for consistent and productive person-centered planning practices.
  - *A stable and qualified workforce* - A well-trained, stable workforce is central to assuring the quality of services.
  - *Quality assurance* – Effective quality assurance systems must ensure individuals are safe and secure, and services meet essential standards. Quality, for individuals, also focuses on personal autonomy, authority over resources, satisfaction and personal outcomes.

  - *Public transparency* – Self-directed models are open to public and legislative criticism concerning appropriate use (and potential abuse) of public funds. Therefore, it is imperative that the system maintain a mechanism for assuring ongoing transparency.

- ✓ <u>Assure that uniform processes are in place for self-direction</u>. These include:
  - *Individuals feel welcome and heard* – Individuals should feel welcomed, listened to, supported in their decisions, and not pre-judged.
  - *The exchange of information is adequate, yet not burdensome* – Individuals need user-friendly information, offered without hassle. Service providers' requests for information should be sufficient but not overly burdensome.
  - *Practices are culturally competent* – Self-directed services are culturally competent in anticipating and responding to people across cultures, geography, traditions and beliefs.
  - *Individuals control their budget allocation* – The individual is positioned to control a service budget, managing both the service budget and service workers.
  - *Planning is person-centered* – Person-centered planning identifies the best mix of supports to assist each individual in securing valued outcomes while assuring health and welfare.
  - *Individuals choose and manage supports and providers* – Individuals choose from an array of supports, select among qualified providers, and can change providers when dissatisfied.
  - *Money and services/supports are portable* – Funds available for support are not locked into specific service models or locations. They are connected to the individual.
  - *Supports are flexible to meet changing needs* – Service and support planning, delivery and funding is flexible to respond to changes in circumstance and need across the lifespan.
  - *Supports are available in a crisis* – Potential crises are anticipated, and effective community-based responses are available.
  - *Informal community resources are utilized* – Self-directed models ripple outward from the individual, starting close and informal and branching out to more formal service options.
  - *Peer support/mentoring is available* – Self-directed models assure the availability of peer support and mentoring options.
  - *Quality of supports is measured* – Qualitative and quantitative mechanisms must be in place to assess satisfaction with services/supports, both individually and in the aggregate.

- *The public is kept informed* – Clear and simple public reports regarding individual needs and outcomes (in aggregate), and assurances for service quality are easily accessible.

In addition, if individuals are to choose a self-directed option, they must be made aware of its availability. Some available outreach options include:

- ✓ Incorporating discussion about self-direction into all service planning meetings.
- ✓ Modifying existing self-direction trainings for self-advocates and families.
- ✓ Engaging self-advocacy organizations to provide guidance on materials and messaging to self-advocates.

Action Step #11: Accelerate opportunities for integrated employment

People with developmental disabilities often express a desire to work in a "real job." Self-Advocates Becoming Empowered (SABE), a national advocacy organization for people with developmental disabilities, plainly states, "We have been prepared enough. Get us real jobs. Close sheltered workshops (www.sabeusa.org)" SABE's resolve stems from an enduring disappointment in the lack of opportunity that people with developmental disabilities are afforded to work at real jobs in integrated settings at competitive wages.

Over the past two decades, states are slowly responding to this disappointment by adopting public policies intended to advance supported employment as the preferred employment service for people with I/DD. In a 2008 report funded by ICDD, the employment policies of several states (i.e., Washington, Vermont, Oregon, Tennessee, and Florida) were highlighted as promising practices that promote supported employment.[43] Their efforts have paved the way for such policies to be advanced in other states.

To further these efforts, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute for Community Inclusion at the University of Massachusetts Boston (ICI) launched the State Employment Leadership Network (SELN) in 2006. The SELN is a national initiative dedicated to improving employment outcomes for adolescents and adults with intellectual and other developmental disabilities.

The Network promotes connections among state members so state development disability service agencies can take better advantage of other resources and partner with sister service systems, sharing costs and maximizing resources. In particular, SELN offers opportunity to: (a) maximize resources such as funding and employment services; (b) develop more effective employment systems and partnerships; (c) use data to guide program management at the local and state level; (d), improve employment-related staff competencies; and (e) share resources for systems change across states.

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[43] Arndt, C., Mayer, M., & McLaughlin, B. (2008). *Retooling Employment: A Systems Analysis Including Promising Practices for Advancing Supported Employment for Citizens of Illinois with Developmental Disabilities.* Springfield, IL: Illinois Council on Developmental Disabilities.

Recent research on the policies, practices and outcomes of SELN members supports the need for a comprehensive system of support for integrated employment.[44] Between 2004 and 2009, SELN states reported a 23 percent increase in the number of individuals in integrated employment compared to a seven percent increase in non-SELN states during the same time period.

We encourage Illinois to become a SELN member to advance integrated employment outcomes for individuals with developmental disabilities. To make the most of SELN membership, DDD can:

- ✓ <u>Institute Employment First policies at the state level</u>. Very often the first employment options offered to people with developmental disabilities include segregated or sheltered environments. To contrast, *employment first* policies are based on the presumption that people with developmental disabilities should work and that integrated employment at competitive wages is the *first or preferred* option considered for service recipients. Individuals may choose a service option other than employment, but the organizing framework of the service approach presumes employability and establishes an expectation of successful employment. An Employment First policy stance provides a fundamental and necessary underpinning to a service system that seeks to increase employment outcomes for people with developmental disabilities.

  Colorado, Florida, Oklahoma, Pennsylvania, Tennessee, and Washington State have been identified as states with significant policies or directives in place that encourage employment.[45] In 2010, Washington State reported that 87.5 percent of those in service received integrated employment services, a national high.

- ✓ <u>Assure that use of community based non-work options are tied to gaining community employment</u>. Complementing integrated work, many states now also encourage “community-based non work” (CBNW). The Institute for Community Inclusion defines CBNW as including all services that are focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities. Volunteering and community service activities fall into this CBNW category as these kinds of community contributions are proven avenues through which individuals with disabilities can gain skills, explore career paths and develop the social networks necessary to gain meaningful employment or postsecondary education. Still, CBNW does not include paid employment, and it can be applied in ways that do little or nothing to promote later employment for participants. Care must be taken to assure that individuals do not become trapped within CBNW settings that do little more than

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[44] Winsor, J., Kennedy-Lizotte, R., Butterworth, J., Cohen Hall, A. (2012). *State Employment First Policies and the Elements Needed for State Success in Promoting Integrated Employment Outcomes*. Boston MA: National Association of State Directors of Developmental Disabilities Services and the Institute for Community Inclusion at UMass.

[45] Cohen Hall, Allison, Winsor, J, and Hoff, D. (March, 2009). *Q&As on State Employment First Policies*. Boston MA: Institute for Community Inclusion, UMass/Boston

offer free labor to work sites, and offer little opportunity for the individual to move on to paid employment.

- ✓ <u>Support self-advocacy and peer mentoring to promote community employment</u>. The Alliance has demonstrated the effectiveness of peer mentoring in supporting individuals with I/DD to make critical life choices (e.g., transitioning from an SODC to community-based placements). Peer support/mentoring is also useful to employment. Illinois should work with the Alliance to gear peer support/mentoring efforts towards employment as well. Peer support/mentoring is an important support mechanism for individuals with developmental disabilities who are considering employment or want to make changes to their employment.
- ✓ <u>Embed the following elements into state and local operations practices</u>:
    - Funding mechanisms and contracts with providers that emphasize employment as the preferred outcome, including a service array and associated rate schedule that reimburses providers amply for employment services.
    - Service reimbursement rates that encourage service providers to expand integrated employment activities, such as establishing a higher rate of payment for integrated employment than for other day services.
    - A sustained and significant investment in employment training and technical assistance.
    - Make available to individuals with developmental disabilities access to careers whereby an increased emphasis on the initial time that a direct service provider spends with the individual is spent to assist with the identification of career goals.
    - Provide for longer term supports to assist an individual with employment retention. At the same time, to support employment retention, develop natural and business-based supports.
    - Natural supports include supports to be provided by individuals, such as co-workers and employers, who are not hired by a human services organization.
    - Utilize assistive technology. Since the early 1970's, assistive technology or rehabilitation technology has emerged and opened unlimited employment opportunities for people with disabilities. Individuals who at one time faced enormous barriers concerning accessibility, communication, and mobility can now optimize their intellectual and physical capabilities through use of technology.

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Action Area D: Serve People in the Most Integrated Setting

Action Step #12: Adopt policies that help individuals and providers transition from ICFs/DD services to HCBS funded alternatives

From its inception, the Medicaid program was structured so that individuals are more likely to have an institutional service – rather than a community option presented.[46] Institutional options include nursing facilities and large public congregate-care facilities such as SODCs. Typically, these large centers for people with I/DD are funded as ICFs/DD. In 1981, Congress granted states authority to establish small-private ICFs/DD housing of no fewer than four people. These smaller facilities must abide by ICF/DD rules such as a service emphasis on habilitation rather than support to live a life as is typical for the general population. In most states ICFs/DD are managed separately from community-based services, both in financial management and services. Once a person is placed in an ICF/DD it is difficult later to move to a more independent living arrangement or another alternative funded by the HCBS waiver. This is because the HCBS waiver typically is capped with regard to the number served and often has a waitlist. As a result, people already served in an ICF/DD cannot easily be reassigned to the HCBS system. The difficulty would seem easy to resolve if the person receiving services could take

Rate Committee
Downsizing Work Group

Background. The ICFs/DD Downsizing Work Group has reviewed the rate methodology described in 89 Ill. Admin. Code 140.560 f). This rule addresses the circumstances under which the Director of the Division of Developmental Disabilities (DDD) may enter into a formal Downsizing Agreement, or contract, with an ICFs/DD provider to reduce the number of licensed beds by a minimum of at least 20% and up to and including the complete closure of the facility. The rule and the rate methodology provide for agreement on the total number of beds to be reduced and for setting of benchmarks, or increments, along the way toward the ending number of beds and for the period of time over which the targeted number of beds is to be reached. …

Overall Recommendation. The ICFs/DD Work Group supports the use of a downsizing rate methodology to encourage and facilitate the shift away from large institutional residential settings and services toward smaller community-based residential settings and other community based services. The Work Group recommends that rule changes, downsizing rate methodology changes, and downsizing agreement changes be made...

Interim Report (April, 2009)
ICFs/DD Downsizing Work Group
http://www.dhs.state.il.us/page.aspx?item=44150

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[46] Crisp, S., Eiken, S., Gerst, K. & Justice, D. (2003) *Money Follows the Person and Balancing Long-Term Care Systems: State Examples*. Bethesda: U.S. Department of Health and Human Services; Centers for Medicare and Medicaid Services; Disabled and Elderly Health Programs Division.

the ICF/DD money used to pay for his or her services and bring it to the HCBS waiver system. ICF/DD funding, however, is not easily portable and cannot follow the person into a HCBS waiver program.

In response to consumer demands and legal challenges,[47] states are taking steps to transition individuals who want to live in community settings, from ICFs/DD to settings in the community funded through a HCBS waiver. As described earlier, the Ligas Consent Decree in Illinois gives residents of ICFs/DD the choice to move into small community-based settings with the necessary supports. When individuals relocate, however, the beds they vacate are not always taken off-line. Beds may be re-filled as long as an eligible person comes forward and seeks ICF/DD services. In this way, even as individuals transition from ICF/DD services to HCBS, ICFs/DD may maintain their census.

Generally, success in other states to reduce reliance on ICFs/DD is rooted in: (a) legislative actions that set policy for system reform and create fiscal mechanisms to move funding from nursing homes or ICFs/DD to HCBS funded services, and (b) the opportunity for individuals to decline nursing facility or ICFs/DD residential placement and choose community services. Overall, the intent is to encourage increased use of community services and lessen the reliance on nursing facilities and ICFs/DD.

The Ligas Consent Decree surely provides a push in this direction. Further, the findings and recommendations of the Division's Rate Committee also lends insight into how this intent may be achieved. A work group of that Committee – the ICFs/DD Downsizing Work Group – focused on this topic, providing several recommendations to encourage ICF/DD downsizing.[48] Finally, in its *Strategic Plan FY 2011-2017* the Division set as a goal under its first strategic priority on person-centered services to:

> *1.12: Adopt policies that support the transition of people that live in private ICFs/DD to the most integrated setting (p.13 of the Strategic Plan).*

Illinois should follow the lead set by other states and take action consistent with Ligas, findings of the Rate Committee, and the Division's *Strategic Plan* to help individuals transition from

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[47] In Florida, a 1999 court settlement (*Cramer v. Bush)* identified a class of 2,096 people living in private ICFs/MR. The settlement indicated that any of the individuals could, depending on their choice, continue residence in an ICF/MR or request relocation to an alternative service funded by the HCBS waiver. In 2007, in Ohio *Martin v. Strickland* resulted in a settlement 2007 that provided funding for 1,500 additional individuals who are in an institution and who choose to move, or those who will be at risk of being institutionalized but who would choose to be served in a community setting to receive home and community based services through an Individual Options HCBS waiver. The settlement also required surveys of those residing in ICFs/DD and Nursing Facilities to assist in evaluating the need for additional community based services.

In 2005 in Illinois in *Ligas v. Maram*, advocates filed a lawsuit claiming that the State is violating the Americans with Disabilities Act (ADA) by not accommodating ICF/DD residents who would prefer to be supported in more integrated living arrangements. The resulting Consent Decree (*Ligas v. Hamos*) in 2011 gives residents of ICFs/DD the choice to move into small community-based settings with the necessary supports. The agreement also requires that an additional 3,000 people with developmental disabilities currently living at home without services be provided with community services.

[48] http://www.dhs.state.il.us/page.aspx?item=44150

ICFs/DD services to HCBS funded alternatives. In concert with assistance to offering individuals community services first, is the need to lend assistance to ICF/DD providers for transition to offering Medicaid HCBS. To achieve these strategic changes, the State should:

- ✓ Continue to support efforts tied to the Ligas Consent Decree to help people relocate from ICF/DD facilities to HCBS alternatives. This includes commitment to a strong person-centered planning process for assuring smooth transition for individuals, and access to the services they need.

- ✓ Take action to provide "transition fiscal support" for providers to help individuals relocate to HCBS options or to transform the provider's funding base from ICF/DD to the HCBS waiver. When a switch to HCBS funding occurs, the change often requires a change in thinking regarding programmatic responsibilities, administration, staffing patterns, costs and reimbursement. As a result, providers will likely not be paid the same amount as under the ICF/DD option. After all, the intent is to make the system more efficient, and so to lower the average cost per person for delivering services, while also promoting use of best practice community services. In doing so, however, note that for some number of individuals the cost of community services may be equal to or greater than costs in an ICF/DD. Aggregate cost savings may be achieved because some number of people may be "over-served" in an ICF/DD.

  Still, during transition periods providers have costs that remain, may incur higher costs per person as a facility's census decreases, and may also have additional costs for helping people to relocate to new residences. In this context, we note that the Rate Committee's Downsizing Work Group made several recommendations for the State to consider.

  Building on the downsizing protocols already in place, the Work Group designated three types of cost: (a) capital (e.g., fixed costs such as mortgage, vehicles, maintenance), (b) support (e.g., food, laundry, housekeeping), and (c) program (e.g., direct care staff, specialized staff, therapists). Subsequently, several recommendations were made to help providers absorb the costs of downsizing and/or transition from ICF/DD to HCBS funding. These recommendations included means to:

  - Adjust the rate methodology for each of the three primary components (i.e., capital, programming, support services) of the ICFs/DD rate to eliminate fiscal barriers to downsizing. For example, payment to providers is based on the number of residents in a home. During transition, when an ICF/DD has fewer residents, providers cannot bill for the openings in the home. This leads to loss of revenue and/or an incentive to fill the openings. A solution is to compensate providers for vacancies during a transition period.

  - Embed safeguards into the enhanced rate methodology to keep the downsizing process from stalling (e.g., placing time limits on enhanced rates tied to meeting downsizing benchmarks).

  - ▪ Make base and start up HCBS funds readily available to ICF/DD providers that are closing or converting ICFs/DD buildings to HCBS or developing new HCBS services.
  - ▪ Waive the provider tax requirement to encourage downsizing. Illinois has a unique means for "taxing" providers according to the number of residents. The tax is, in turn, used as Medicaid match. During transition of an individual even while vacancies exist, tax assessments are tied to the date that homes were initially assessed, typically without vacancies. As a result, providers again face a fiscal loss for participating in transition, creating an associated disincentive for such transition. The solution is to waive the Provider Tax fund for any ICFs/DD provider agreeing to terminate all beds at the point the downsizing to close reaches 25% or more reduction in licensed beds. (This would require a DHFS rule change and may also require statutory changes.)

- ✓ <u>Assure that the HCBS waiver is an attractive option with respect to both the service array available to participants and the associated service reimbursement rates</u>. There is no incentive to providers to switch if the perception is that the waiver has significant associated difficulties and/or if providers cannot offer needed services to individuals at a fair rate of reimbursement.

- ✓ <u>Make use of the Money Follows the Person (MFP) Program</u>. In the Deficit Reduction Act of 2005, Congress set aside $1.75 billion for a new MFP program to assist states in accelerating the transition of people from institutional settings to the most integrated setting. Thirty-one states received awards initially. This funding provides states with enhanced federal matching funds to pay for community supports for those who transition to the community.

  Illinois was awarded a MFP Demonstration Grant in 2007. Through MFP, Illinois was awarded $55.7 million in the form of enhanced Medicaid reimbursements for the five-year period, 2007-2011 (http://www.dhs.state.il.us/page.aspx?item=51575). We acknowledge that: (a) the MFP program in Illinois is primarily targeted to individuals seeking to relocate from nursing homes, and (b) relocation is required to a residence of four or fewer people, which excludes most CILA community homes. Still, the Division should not overlook the potential for utilizing the MFP program to relocate individuals from ICFs/DD to HCBS waiver alternatives.

  For example, relocation from SODCs provides opportunity to establish community residences for these individuals to serve four or fewer people. Though CILA rates for these homes will need to be adjusted upwards for them succeed, doing so would help create a platform to work from going forward, but also provide opportunity to utilize MFP funding.

Regardless of the policy path taken, it is important to acknowledge that transition from an ICF/DD to HCBS, while beneficial in the long haul, has budgetary ramifications. People who leave ICFs/DD may be replaced by other individuals. Unless this circumstance is avoided, there will be no reduction in ICF/DD expenditures and HCBS waiver funding will have to increase to accommodate the individuals who elect to transition from ICFs/DD to HCBS. In essence, success depends on phasing out ICF/DD capacity as the transition unfolds.

Action Step #13: Adopt policies to revitalize the commitment to Community Integrated Living Arrangements

In 1988, Governor Thompson signed into law the Community Integrated Living Arrangements (CILA) Licensure and Certification act (PL 86-922). The law created a statutory basis for changing the State's residential service system for people with developmental disabilities. The law was meant to assure that combinations of support and services will be made available that are flexible enough to be individually tailored to promote community integration while offering residence in community homes of eight or fewer residents.[49]

Over the years, however, the promise of this the original Act has eroded away. There has been a steady increase in the size of residential CILAs, which has been one way that providers have coped with the failure of state payments for services to keep pace with their costs. As a consequence, there are now many larger CILAs in operation. Moreover, larger facility sizes and anemic reimbursement rates have also undercut the promise for flexibility in service design and the commitment to promote community integration.

Going forward, in its *Strategic Plan FY 2011-2017*, the Division of Developmental Disabilities expresses its commitment to address these issues by setting goals to: establish a person-centered system of services; (b) assure that the number of people living in six beds or less will be significantly increased to match national averages; (c) increase pay for direct support staff; and (d) establish adequate rates of reimbursement for services.

We note too that the findings and recommendations of the Division's Rate Committee are also relevant. Two work groups of that Committee, the CILA Rate Work Group and the Wage and Fringe Benefit Work Group, centered on topics related to improving the fiscal environment for CILAs.[50] The Work groups reviewed prevailing reimbursement patterns and conducted systematic analyses of what changes need to be made to make the CILA rates "adequate, fair, and equitable." The groups identified cost changes that could be tied to alterations in the base formula to establish a rate (e.g., staffing ratios), staff hourly wages, and fringe benefits allowances.

A commitment to change and gathering information to improve the rate structure are steps in the right direction. Building on these steps, the State should:

- ✓ Set policy to limit the size of new CILAs to no more than four beds. We understand that the State has elected to transition individuals leaving the Jacksonville and Murray SODCs to residences of no more than four people. This action is laudable and positions the Division to utilize the Money Follows the Person program to help finance transitions. It

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[49] Division of Developmental Disabilities (1990) *State Plan: Community Integrated Living Arrangements*. Springfield IL: Division of Developmental Disabilities.

[50] CILA Rate Work Group report: http://www.dhs.state.il.us/page.aspx?item=44659
Wage and Fringe Benefit Work Group report: http://www.dhs.state.il.us/page.aspx?item=44310

will also require that CILA rates be adjusted up to assure that these residences are fiscally viable. By doing so, however, the State establishes a contrast between those scheduled to depart these SODCs and others already receiving services who live in residences housing more than four people. Going forward, the State should apply its "no more than four" standard to the entire system, including any CILAs formed outside of the SODC transitions.

- ✓ Reconsider CILA reimbursement rates. The Division should revisit the formulas that are used to set CILA rates and the work of the Rate Committee to ensure that the operation of sites that serve four or fewer individuals can be an economically viable proposition for provider agencies. This should be undertaken as part of a larger scale rate study to consider the rate schedule for the entire system (See *Action Step* 6).
- ✓ Adopt a "four or fewer" residential standard statewide. Once rate setting formulas are revised, the State should establish a three-year time period for provider agencies that operate CILAs for more than four individuals to reconfigure their sites to meet the four-bed standard.

A renewed commitment to the original promise of the CILA program will have fiscal implications. The State simply needs to invest more in its mainstay community response. Moreover, even as rates may be improved, the State must also assure that the CILA program that has evolved to its present standing is transformed to become the flexible, person-centered service response it was meant to be.

Action Step 14: Reduce the number of people served at State Operated Developmental Centers to no more than the projected national average by 2017

The substantial majority of states have significantly reduced or eliminated use of large state-operated facilities and nursing homes to serve individuals with developmental disabilities. Over the past 30 years, Illinois has modestly followed the national trend by reducing the use of its SODCs. In 1977, 6,394 individuals resided in Illinois' SODCs, and by 2010 that number was 2,111 (a decrease of 67 percent). Still, the State's actions have not kept pace with the national pace overall. By 2010, Illinois served 16.5 individuals per 100K in SODCs, compared to the national average of 10.1 people per 100K.

Although steps have been taken to reduce the census in the SODCs, Illinois policy makers should enlarge its plans to reduce the census of the SODCs to the projected per 100K utilization national average in 2017. Review of the national trends regarding census reduction of similar facilities from 2005-2009, reveals that by 2017 the national utilization average will be 6.7 people per 100K in state population. To achieve this goal, 1,251 people currently residing in Illinois' SODCs will need transfer to community residences. This entails moving 250 people per year over the next five years (2012 – 2017), a decrease of 40.7 percent.

In late 2011, Governor Pat Quinn announced plans to transition 600 residents from SODCs into community services by 2014. Following through, on January 19, 2012 Governor Quinn announced the closure of the Jacksonville Developmental Center, a center that in June 2010 housed 207 residents. Further, on February 22, 2012 Governor Quinn announced the closure of the Murray Developmental Center, a facility housing 296 residents. The census for the two facilities totals 503 people.

While these steps are notable, consider that:

- Illinois history shows that SODC closures do not automatically result in transition of all residents to community alternatives. Many (some say as high as two thirds) are relocated to other SODCs. Currently, state leaders hope that the great majority of Jacksonville and Murray residents will transition to CILAs but how many remains an open question.
- Even if all 503 residents transitioned to community settings or if the Governor pressed past these two sites to successfully relocate 600 residents into community alternatives, the result would still leave the state in excess of the national utilization average by approximately 600 people.

As a result, this *Action Step* calls on the State to extend its efforts past the initial goal set by the Governor so that by 2017 the census at the SODCs will amount to no more than 860 people (See Chart 11). It is also essential that the State minimize, even eliminate, new admissions to the SODCs. Doing so will require the State to instill across the state an expectation and capacity for managing behavioral or other crises within the community services network.

In this context we recognize that the State expects to apply a person-centered planning process entitled “Active Community Care Transition” (ACCT) planning to relocate individuals from SODCs to community residential alternatives. This process should be made available to all SODC residents to call attention to the needs of these residents and establish a stronger framework for their potential relocation to the community.

> **[the State should] extend its efforts past the initial goal set by the Governor so that by 2017 the census at the SODCs will amount to no more than 860 people. In this context it is also essential that the State minimize, even eliminate, new admissions to the SODCs.**

This calculation for serving 860 or fewer people in SODCs by 2017 is based on:

- A starting census of 2,111 which is based on 2010 reported data. This amounts to 16.5 per 100K state population. The present census may be slightly higher or lower than this figure.
- The closure of the Jacksonville and Murray Developmental Centers by 2013 (although not all in residence will likely be transitioning to community alternatives).
- Review of the national trends regarding census reduction of similar facilities from 2005-2009, revealing that by 2017 the national utilization average will be 6.7 people per 100K state population.

- Application of these findings to indicate that to reach the projected national utilization rate, Illinois would need to reduce its census to 860 by 2017. Using the 2010 census count of 2,111 this amounts to 1,251 people over the next five years.

Again, Chart 11 illustrates the steady anticipated decline in SODC over this period. Success will depend on the State's commitment to reduce its reliance on these residential settings.

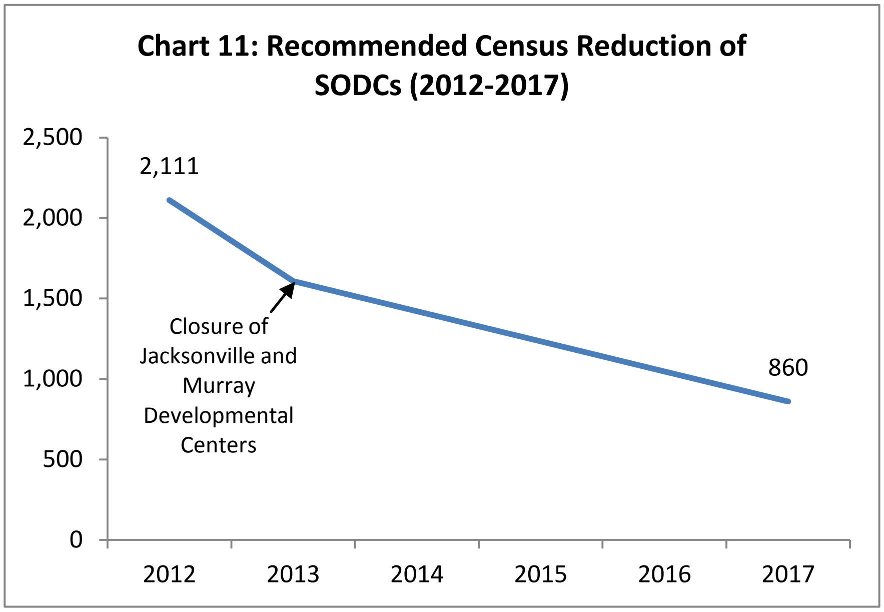
Chart 11: Recommended Census Reduction of SODCs (2012-2017)

Per diem rates for individuals residing in Illinois' SODCs have fluctuated up and down around a consistent overall upward trend. As of 2010, the average annual cost, not including capital expenses, of supporting an individual in a facility was $123,005. Despite past census reductions, state-run institutions continue to command a significant share of state spending on behalf of people with intellectual and other developmental disabilities.

Regardless of the reduction goal chosen, whether the closure schedule anticipated as announced by Governor Quinn or 8.1 percent per year recommended here to reach the pace of national average, under either scenario, the amount of money that would become available for reinvestment due to downsizing is likely to be modest. The faster the pace of downsizing, however, the less overall transition cost there will be. Further, the State has noted plans to ensure that any cost savings from closure of facilities or transition of individuals out of facilities will be reinvested into the community system. The State should continue down this path and set up defined processes and procedures which ensure that any saved funding be allocated to offering the best community services available for the I/DD population.

Action Area E: Expand Community System Capacity

Action Step #15: Expand system capacity at a steady pace by serving an additional 1,918 people each year between 2012 and 2022

An important goal for Illinois' system is to have sufficient capacity to respond with reasonable promptness to the legitimate needs of the people it is charged with serving. Yet, Illinois faces a major challenge – keeping pace with the rising demand for developmental disability services while simultaneously adding new capacity. There already is a substantial shortfall in Illinois' current system capacity to meet the expressed demand for services. Yet to develop a sound strategy to address demand for services, a realistic projection of service demand is necessary.

Projected Service Demand in Illinois

Total service demand is the sum of people who are receiving services and people who seek services and have emergency or critical unmet needs. To forecast the rate of demand for services in Illinois, HSRI assumes that demand will grow at a somewhat faster pace than state population alone, a rate of increase of two percent each year above the rate of population growth. This is a conservative assumption. Other states experience higher year-to-year rates of increase in service demand, and so, a "Population Plus 2%" assumption is reasonable.

Two scenarios were developed:

1. The first is keyed to the present rate by which the Division has added individuals to its Medicaid funded service system. This rate amounts to four percent per year over the past five years and we presume that this pace will continue. We acknowledge that this growth (four percent per year on average) did not typically involve adding new people into services, but resulted from moving individuals from state-only funding to HCBS waiver funding. Nonetheless, the State has shown the ability to increase their waiver population at this rate, so that this scenario presumes a continuation of the trend even though it will necessarily require additional funds to support it.
2. The second presumes a service use increase to achieve a total number served amounting to 330 people per 100K. This number was chosen because present state service use patterns across the nation suggest that once this level is reached states have little or no wait list. In previous work, HSRI advised a 200 or 250 person per 100K target. Owing to demographic and other factors, however, we have revised the target to 330 people per 100K.

Both scenarios factor in that:

- Illinois' general population will continue to grow. Projections offered by the United States Census Bureau indicate that Illinois population will grow to 13,280,998 by 2022, a growth rate of 2.22 percent between 2012 and 2022.

- Growth in demand will exceed population growth alone. The specific demand for developmental disability services is influenced by several factors. At a minimum, demand will grow at about the same rate as the general population. However, there is considerable evidence from other states that the demand for services is growing at a rate that exceeds the rate of general population growth. For example, California has experienced yearly increases in service demand that are two to four percent above the rate of population growth. Connecticut is another state experiencing growth in service demand despite efforts to reduce the State's waiting list for community services.
- Growth under both projections calls for action above and beyond the Ligas Consent Decree. The Ligas Decree calls for expansion of service capacity as follows:

> "The DDD will serve 3,000 individuals on the Waiting List for Community-Based Services or placement in a Community-Based Setting, as defined in the Decree, over the next six years (1,000 within the first two years and 500 each year the next four years) with home-based support services or in community-based residential settings. At the end of the six year period, all Class members on the Waiting List shall move off the Waiting List at a reasonable pace."

Both projection scenarios reveal, that to address the waitlist effectively, the State must grow its service capacity to a level in excess of what the Decree calls for. Although the Decree establishes significant purpose and momentum to building capacity, abiding by the terms of the Decree alone will not be sufficient.

Projection #1: Service Use Rate Continuing Past Trends.

In 2010, Illinois reports serving 198.9 people per 100K in general population. Review of the State's growth in service utilization shows an average rate of growth of four percent each year. Data from 2005-2010 was reviewed and analyzed to determine this growth rate. Under this projection, it is assumed Illinois will continue to grow at this rate. In doing so, the State is projected to serve 308 people per 100K in general population by 2022. This equates to services offered to 40,859 people by 2022.

Because the State has maintained this growth rate, this Projection does not assume a growth rate two percent above population. This Projection assumes adding roughly nine persons per 100K in general population to the service system each year.

Projection #2: Service Use Rate Adequate to Significantly Reduce or Eliminate the Waitlist.

Under this scenario, the target is set higher. As described earlier, Illinois currently has 14,977 people on the waitlist who indicate an emergency or critical need for services. HSRI's experience indicates that states serving 330 people per 100K in general population typically have little to no waitlist. However, given Illinois' past growth rate in the waitlist and projected growth in population, this number was increased to 365 people per 100K. This increase accounts for a growth rate two percent above population, past trends in waitlist growth and projections of future State population.

This projection requires a steady growth rate to achieve the goal of 365 per 100K by 2022. By 2022, this rate would yield an additional 19,183 people in service. This would eliminate those currently on the waitlist under the emergency or critical categories as well as offer additional HCBS waiver slots to new service recipients. Over the 10 year period, this growth rate would require adding 1,918 new people into services each year.

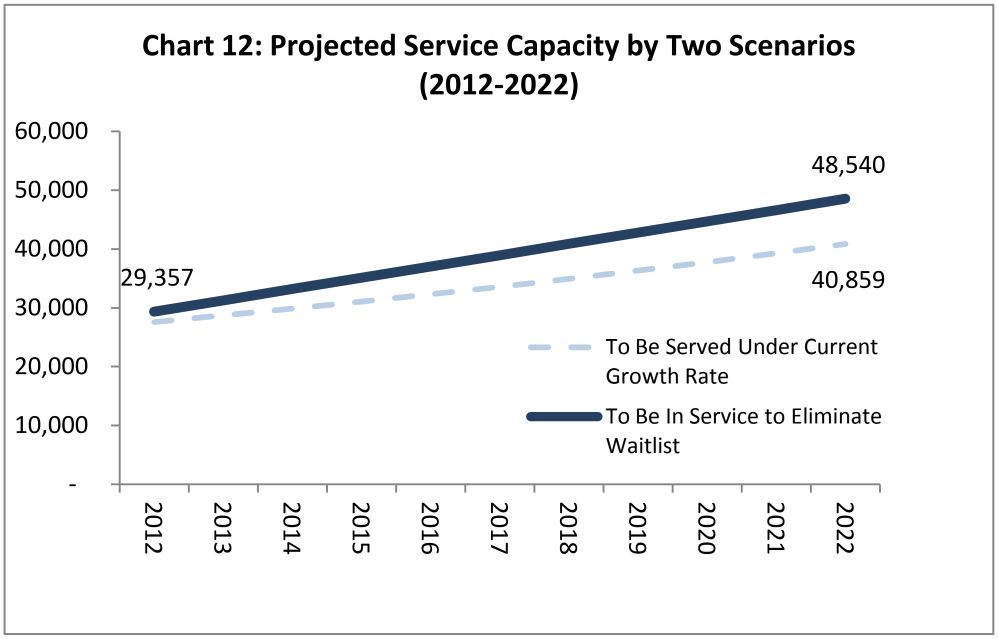

Chart 12 shows the service utilization growth needed under both projections.

Although both trend lines appear to get the state to a similar place, only the growth line for Projection #2 adequately address the state's waitlist. It is recommended that the State strives to accomplish a goal of reaching 365 people in services by 2022. Again, this requires a growth of 1,918 people into the HCBS waiver service system each year.

Resources Needed to Meet Projected Service Demand

There is no doubt that additional dollars will be needed for Illinois to address current unmet service demand as well as keep pace with projected additional demand through 2022. We emphasize that these resources should not be gathered from reductions in current HCBS waiver services. Federal Medicaid dollars can underwrite 50.0 percent of these additional outlays.

To estimate the dollars that might be necessary, we assume that Illinois will employ the Medicaid HCBS waiver authority exclusively to expand system capacity. The baseline figure used under this scenario is $31,002 per person[51] (the average HCBS expenditure of 2010).

Table 6 illustrates cost scenarios by two service utilization standards, the first being at a rate of growth constant with past state trends, and the second at a rate to significantly reduce or eliminate the waitlist. As shown:

- Given a service use rate growing at four percent per year, resources must be allocated to serve an additional 13,256 people by 2022. According to our calculations, this would run an additional $50.29 million annually by then. Given the state's Medicaid matching ration (50 percent) the cost to Illinois would be 50 percent of this amount, or $25.14. Again, in the State's past growth of four percent per year, funding was merely shifted from state-only money to the HCBS waiver program, allowing the State to receive

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[51] Prouty et al. (2008)

Medicaid match instead of paying for services out of general revenue. It is our understanding that the State is no longer shifting funding streams to grow the waiver program. Because of this, the four percent growth under this projection will require new money and investment into the system rather than shifting old money.

- Given a service use rate keyed to eliminating the waitlist, resources must be allocated to serve an additional 19,183 people by 2022. This scenario recommends adding 1,918 new service recipients into the HCBS waiver system each year. Because of this, the total new money added each year will be the same. The cost here would be $61.38 million annually by 2022. The cost in state general revenue would be $30.69 million added into the service system each year. This projection requires a total investment totaling $675.16 million over the 10 year period in total funds, and $337.58 million in state general revenue.

Note again that by utilizing the Medicaid HCBS authority the State shares the total expense with the federal government, bearing only 50 percent of the costs. In fact, thought of this way, the federal 50 percent match is already available, but cannot presently be accessed because the State has not yet allocated its share of matching funds.

Cumulative Resources Needed to Meet Service Demand Under Two Projections

Table 6

Utilization Pattern	Year	Additional Capacity Needed	Total Served with Additional Service Recpients	Total Cost (HCBS Waiver) $32,001 per person	Cost in Illinois General Revenue	Compounding Investment of General Revenue
4% Annual Growth	2011-12	1,062	27,603	$33.97	$16.99	N/A
	2012-13	1,104	28,707	$35.33	$17.67	$34.65
	2013-14	1,148	29,855	$36.75	$18.37	$36.04
	2014-15	1,194	31,049	$38.22	$19.11	$37.48
	2015-16	1,242	32,291	$39.74	$19.87	$38.98
	2016-17	1,292	33,583	$41.33	$20.67	$40.54
	2017-18	1,343	34,926	$42.99	$21.49	$42.16
	2018-19	1,397	36,323	$44.71	$22.35	$43.85
	2019-20	1,453	37,776	$46.50	$23.25	$45.60
	2020-21	1,511	39,287	$48.35	$24.18	$47.42
	2021-22	1,571	40,859	$50.29	$25.14	$49.32
Reduction of Waitlist	2011-12	1,918	29,357	$61.38	$30.69	N/A
	2012-13	1,918	31,275	$61.38	$30.69	$61.38
	2013-14	1,918	33,194	$61.38	$30.69	$92.07
	2014-15	1,918	35,112	$61.38	$30.69	$122.76
	2015-16	1,918	37,030	$61.38	$30.69	$153.44
	2016-17	1,918	38,948	$61.38	$30.69	$184.13
	2017-18	1,918	40,867	$61.38	$30.69	$214.82
	2018-19	1,918	42,785	$61.38	$30.69	$245.51
	2019-20	1,918	44,703	$61.38	$30.69	$276.20
	2020-21	1,918	46,622	$61.38	$30.69	$306.89
	2021-22	1,918	48,540	$61.38	$30.69	$337.58

Notes:

1. Estimated costs do not include corrections for potential inflation
2. 50.0% of estimated Total costs will be federally reimbursed through use of Medicaid
3. Larson, et al. (2012)

Conclusion

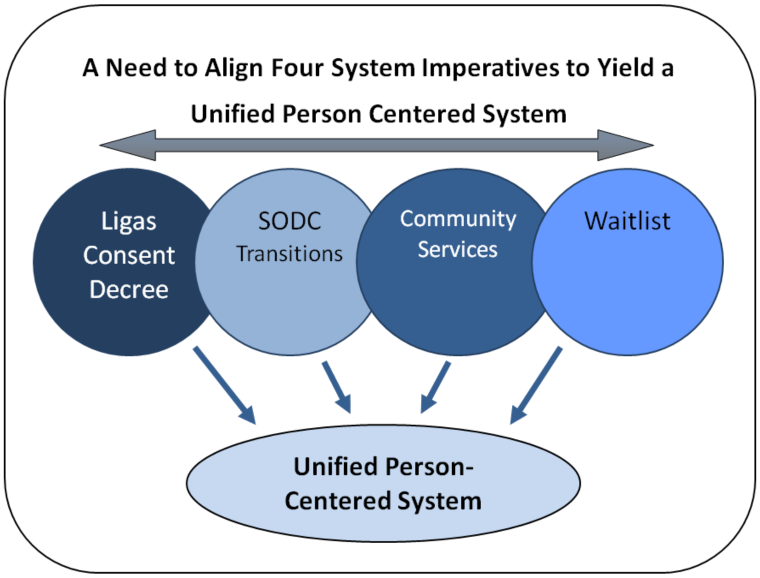
> **"The tipping point is that magic moment when an idea, trend, or social behavior crosses a threshold, tips, and spreads like wildfire."**
>
> *Malcolm Gladwell*

Inevitably, a service system produces what it is designed to produce. The enduring tendency of the Illinois service system for people with intellectual and other developmental disabilities is to produce subpar performance seasoned with periodic proclamations for change, pockets of innovation and tension among stakeholders. Consistent with these themes, our review of the state's performance from 2007 until now reveals that in many ways little has changed. Plainly, there is work to do in Illinois.

Yet viewed another way, many things have changed. Notably, State policy makers have articulated a willingness to make necessary changes to correct inefficiencies and commit to establishing a person-centered service system. The Division's *Strategic Plan FY 2011-2017* furnishes a calculated guide for managing many of the changes in policy and practice that must occur. Other events bring momentum for change, such as the implementation of the Ligas Consent Decree, the Governor's decision to transition individuals from SODCs to community alternatives, and actions small and large within the Division to improve community services. Finally, service recipients and other advocates are increasingly calling for changes to promote community integration and self-direction. The presence of and positions taken by the Alliance reflect heightened expectations taking hold across the State.

Illinois is at the tipping point. The actions taken by policy makers and others in these coming months and years will be decisive. The State may either take action to establish a person-centered system, or stall the present momentum and muddle on. The future of the Illinois system hangs in the balance. People will either agree to change and will, or they will not.

To succeed, policy makers and other stakeholders must collaborate effectively to align efforts associated with four significant imperatives. These include: (a) implementing the terms of the Ligas Consent Decree, (b) transitioning individuals from SODCs to community alternatives, (c) improving multiple features of the existing community system, and (d) reducing the waitlist for services.



There are a great number of points where these four imperatives intersect with one another. Although, it may be easiest to manage each separately, a significant challenge to policy makers is to weave the four together to establish a unified path toward a person-centered system. For example, the process for developing person-centered support plans for service recipients should follow a common course across the system. Likewise, ample independent case management must be established and provided to all – not some – service recipients. Reasonable and equitable service reimbursement rates must be fashioned and set to support a person-centered system for all service recipients. The Division must improve its means for gathering and aggregating data across the entire system. And throughout the change process there must be unified direction and matching policy directives led by the Division. In essence, the system must be managed not in parts, but as a single cohesive structure.

In this context the 15 *Action Steps* presented earlier call upon the state leadership and stakeholders to make changes related to these five objectives:

A. Establish clear and cohesive leadership for the developmental disabilities service system.

B. Develop organizational infrastructure in support of the community services system.

C. Improve the community response to individual support needs to promote person-centered outcomes important to individuals and families, including emphasis on self-direction among people with developmental disabilities and partnerships among service recipients, their family members and others.

D. Serve people in the most integrated setting by reducing further the role that SODCs and ICFs/DD play within the Illinois service system.

E. Expand system capacity so that by 2022 all people who have emergency or critical unmet needs will be served with reasonable promptness.

The actions associated with each of these areas provide State leaders with definitive direction for addressing the challenges faced by the Illinois I/DD service system. These *Steps*, however, are inter-related and should be regarded as a unified, intertwined series of actions that build and depend on one another. And, yes, the state will need to invest more in services for people with I/DD. Its investment to date has been insufficient and compares poorly to what other states spend. By enacting the proposed steps, Illinois will increase system capacity, improve efficiency, and enhance the quality of life of thousands of people with I/DD their families.

The state will need to invest more in services for people with I/DD. After all, its investment to date has been insufficient and compares poorly to what other states spend.

Across the nation, people with I/DD argue strongly for support systems that look decidedly different than the current service system in Illinois. Two decades ago, Dirk Wasano, a long time resident of a developmental center in Hawaii who eventually was given the opportunity to relocate to the community, observed that:

> *"In the 1960s and earlier we were treated like plants. You fed us, clothed us, kept us warm, and wheeled us out to feel the sun.*
>
> *In the 1970s and 80s you discovered we could be taught—we could learn—and we were treated like pets. You taught us all types of tricks and we stood by your side.*
>
> *But now…. Here we are. We are not plants. We are not your pets.*
>
> *We are people like you and we want to be treated as real people. We want the same opportunities as anybody."*

The work of the Alliance and other self-advocates throughout Illinois illustrate that they agree with national self-advocates and Mr. Wasano. In 2008, the thrust of the original *Blueprint for System Redesign* was to urge Illinois policy makers to push past prevailing circumstances and establish an action bias for change to assure that people with I/DD receive the supports they need to live in the community as other citizens do. The *Action Steps* presented here again call on Illinois policy makers to achieve this same goal. Illinois has reached its tipping point. It is time to take the steps needed to establish a person-centered system. As was the case in 2008, individuals with I/DD and their families will settle for nothing less.