blueprint

for System Redesign in Illinois

January 2008

Human Services Research Institute

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Prepared in partnership with
the Illinois Council on Developmental Disabilities

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A Blueprint for System Redesign in Illinois

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About the Authors

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

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

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

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

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

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In Memoriam
Gary Smith

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

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

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

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

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

Please spend a moment to remember Gary Smith.

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Table of Contents

Charts and Tables

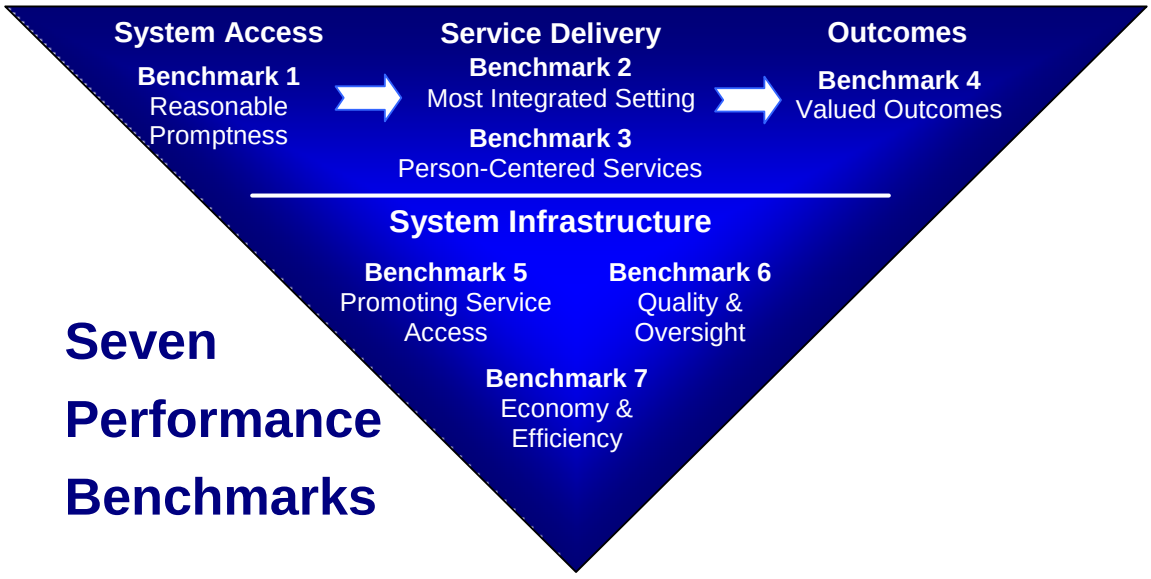
Executive Summary

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

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

Blueprint Framework

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



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

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

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

Six Action Plan Focus Areas

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

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

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

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

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

Funding and Financing

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

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

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

Action Steps by Area

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

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

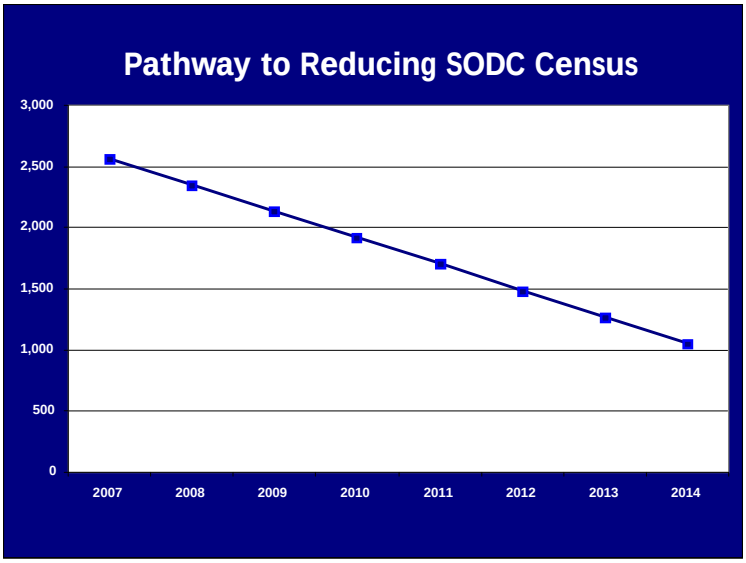
defray meeting and other expenses and support the meaningful participation of people with disabilities and families. The Steering Committee should have ongoing, *independent* staff support during the duration of the *Blueprint* period. The Steering Committee should be required to prepare periodic reports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

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

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

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

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



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

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

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

supporting individuals in the most integrated setting.

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

Action Area 2: Strengthen community services.

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

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

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

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

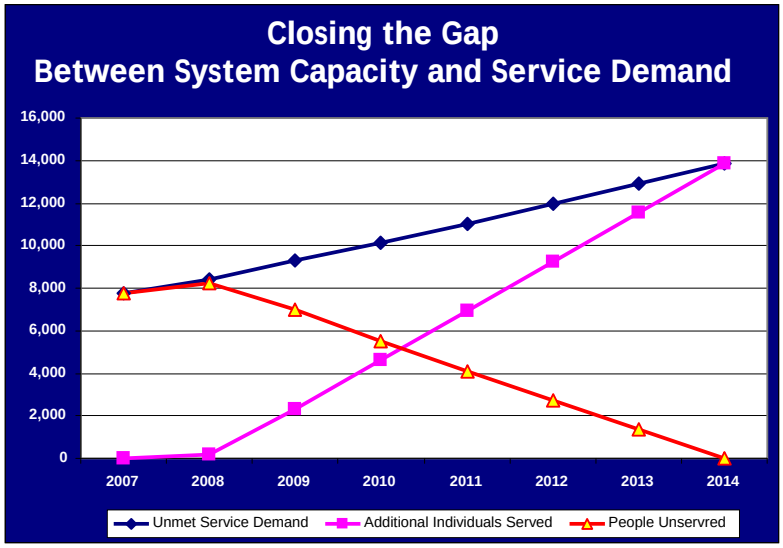
Action Step #7. Illinois should take several steps to strengthen oversight of its community services system.

Action Area 3: Expand community capacity.

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

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

Two action steps for addressing service demand are offered:



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

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

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

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

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

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

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

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

Action Area 5: Redesign services and funding.

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

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

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

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

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

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

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

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

Action Area 6: Measure performance and quality improvement.

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

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

Conclusion

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

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

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

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

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

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

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

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

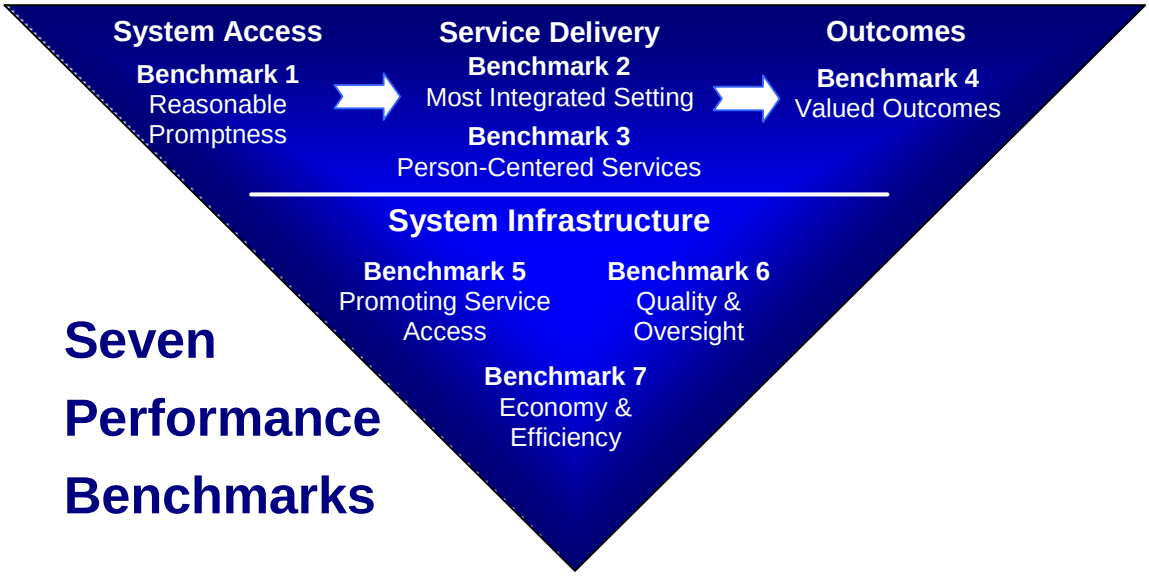
I. Introduction

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

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

Blueprint Framework

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



1. ***People with developmental disabilities have access to and receive necessary publicly-funded services and supports with reasonable promptness***. Publicly-funded systems should operate in a fashion so that individuals who have been assessed as needing essential services receive such services and supports within a reasonable period of time. This requires a sound system infrastructure to underpin 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. The decision mandates that states operate services so that individuals are not unnecessarily institutionalized.

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 preferred outcomes for people with developmental disabilities***. Services should promote such outcomes as personal independence, employment and community integration. Effective person-centered services must be available to address functional and other limitations that impede the achievement of such outcomes by individuals.

5. ***There is an infrastructure that facilitates the ready access of people with developmental disabilities and families to services.*** As a general matter, access to services and supports is facilitated through the operation of a comprehensive single-point-of-entry system. There must be an effective and adequately resourced independent service coordination system in place.

6. ***Services must continuously meet essential quality standards and there must be confidence that quality oversight systems function effectively and reliably***. Quality assurance systems must ensure that individuals are not exposed to abuse, neglect and exploitation. There must be appropriate oversight to protect the health and welfare of vulnerable persons.

7. ***The system must promote economy and efficiency in the delivery of services and supports***. This means emphasizing the use of lower cost 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.

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

Organization of the Blueprint

The *Blueprint* has the following major sections:

- ***Strategic Overview***. This section provides a top-level overview of the areas upon which Illinois should focus its attention in order to improve the performance of its developmental disabilities service system. It also discusses cross-cutting funding and financing issues.
- ***Action Plan Focus Areas***. The *Blueprint* has six major focus areas:
  - √ Embrace the principle of supporting people with developmental disabilities in the most integrated setting
  - √ Strengthen community services
  - √ Expand system capacity

√ Redesign service coordination and single point of entry

√ Redesign services and funding

√ Measure performance and engage in quality improvement

In each focus area, specific action steps are identified that Illinois can undertake in the near and mid-term to better align its developmental disabilities service delivery system to the performance benchmarks that frame the *Blueprint*.

- ***Implementation Sequence***. This part of the *Blueprint* outlines the proposed sequence for the implementation of the action steps identified in the *Blueprint*.

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II. Strategic Overview

The HSRI *Gap Analysis* revealed that Illinois needs to improve its performance in supporting its citizens with developmental disabilities. The present service system does not have adequate resources to meet the needs of all people who urgently require services or ensure the consistent provision of high quality services. Illinois significantly lags other states in shifting services out of large congregate care facilities to supporting people in the most integrated setting.

Fundamental system redesign is necessary in order for Illinois to improve its performance. Absent redesign, system performance will not change appreciably and arguably will deteriorate over time. System redesign is a complex, challenging endeavor, especially in large service delivery systems. The *Blueprint* contains many action steps to improve performance in Illinois. This section provides a strategic overview of the *Blueprint* and outlines the relationship of the action steps to one another.

This section also stresses the importance of engaging stakeholders throughout the seven-year *Blueprint* period in all system redesign activities. Finally, it discusses the implications of the Blueprint on the funding and financing of developmental disabilities services in Illinois.

Top-Level Overview of Six Blueprint Action Areas

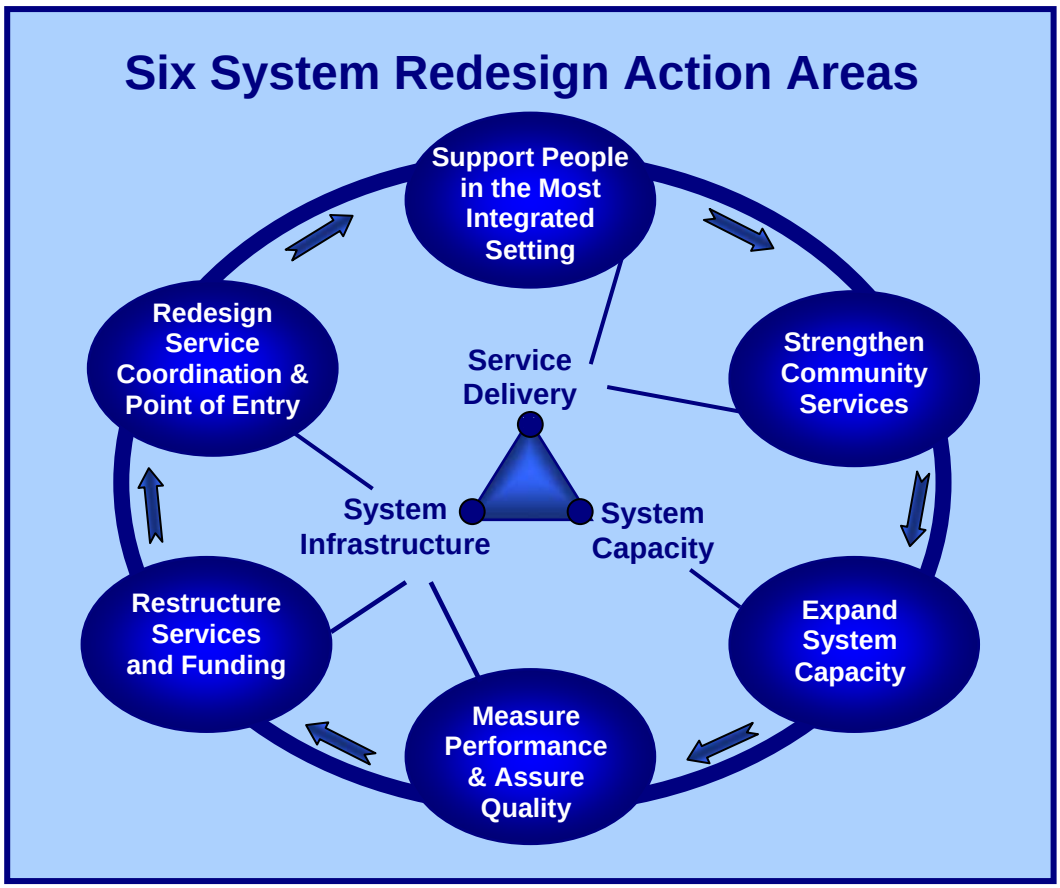
To improve the performance of its developmental disabilities service system, Illinois should concentrate its attention on six major system redesign action areas. As illustrated by the accompanying graphic on the following page, these six areas pertain to three primary system considerations related to service delivery, system capacity and system infrastructure. Further, these areas are intertwined and should be regarded as a unified series of actions that build and depend on one another.

During the Blueprint period, Illinois should concentrate its attention on six system redesign action areas.

For example, the state can take independent action to reduce reliance on large congregate care options such as SODCs. More effective, however, is to take such action together with others to build system capacity and improve community service systems. By doing so, pressure to utilize large congregate care options is relieved and demand is more readily channeled to preferred community service alternatives. Likewise, community capacity can be expanded to address the needs of those on waitlists simply by adding more services of the type that are already available. Yet, a more effective approach is to build capacity while also improving the community system and investing in services that promote cost efficiencies.

The following six system redesign action areas are discussed in more detail in the remaining sections of the *Blueprint*:

- **Embrace the principle of supporting people in the most integrated setting** by reducing the role that large congregate care facilities play in the Illinois service system. As discussed in the *Gap Analysis*, Illinois has a long way to go to meet the standards set forth in the U.S. Supreme Court's *Olmstead* decision. During the *Blueprint* period, the number of persons served in the State-Operated Developmental Centers (SODCs) should – at a minimum – be brought into



alignment with the rate at which such facilities are utilized nationwide. Also, Illinois should rethink the role that SODCs play in the service delivery system. With respect to large ICFs/DD and other larger facilities, Illinois should set in motion action steps to actively encourage the conversion of such facilities to furnishing residential supports in the most integrated setting. Finally, Illinois should enact ***Money Follows the Person*** legislation so that individuals have the choice to transition to the community. However, the pace at which Illinois can reduce its present over reliance on large congregate care facilities will hinge on addressing major shortcomings in the delivery and oversight of community services.

- **Strengthen community services**. There is wide-spread evidence that there are major problems in the delivery of services for people with developmental disabilities in the community. These problems are a major source of concern for all Illinois constituencies. Unless and until these problems are forthrightly acknowledged and resolutely addressed, they will substantially impede progress in improving system performance at all levels. In the main, addressing these problems will require three action steps: (a) improving working conditions for community staff (e.g., pay, benefits, training, career advancement) to ensure that Illinois has an adequate, competent work force to support people with developmental disabilities; (b) building capacity in the community to effectively address the needs of people with challenging conditions; and, (c) strengthening the oversight of community services. The final action step is intertwined with redesign of the service coordination and single point of entry functions.
- **Expand system capacity** so that by 2014 all people who have emergency or critical needs are served with reasonable promptness. How much system capacity will need to grow to catch up and keep pace with service demand is discussed in

Section V. Closing the gap between system capacity and service demand will require substantially boosting funding for community services. Illinois will need to make careful choices about the types of services and supports that are selected to meet service demand. The strategy or strategies that are selected to expand capacity will materially affect the amount of funding necessary to ensure that people with developmental disabilities are served with reasonable promptness.

- **Redesign service coordination and single point of entry**. To make sure that people with developmental disabilities are linked to the services that best meet their needs and have an independent source of assistance when they need it, Illinois needs to put into place an effective comprehensive service coordination system and implement a true single-point-of-entry structure.
- **Redesign services and funding**. Illinois needs to take several steps to restructure community services and funding to promote person-centered service delivery. Embracing the principles of person-centered service delivery will improve the capacity to match services to individual needs/preferences. There are four central action steps that should be pursued in this area: (a) restructuring funding to emphasize flexibility and portability; (b) adopting data-based rate determination methods; (c) accelerating the implementation of self-directed service delivery options; and, (d) emphasizing the delivery of outcome oriented services such as supported employment.
- **Measure performance and engage in quality improvement.** Illinois needs to design and implement information technology (I/T) and data acquisition systems that are capable of supporting performance measurement and quality improvement activities. Solid, reliable data that informs performance measurement is essential to determine whether services are effective and to identify where to devote attention to secure better system performance through quality improvement along with better outcomes for people with developmental disabilities.

Improving Illinois system performance requires pursuing a multi-faceted and intertwined set of action steps. System redesign is a complex endeavor. The seven-year time horizon for the *Blueprint* was purposely selected in recognition that many of the system redesign action steps will take time and resources to put into motion. Since there are many action steps identified, the question inevitably arises about how the steps should be sequenced. In the final section of the *Blueprint*, the action steps are recompiled and a general implementation sequence is provided. The *Blueprint*, however, does not offer a detailed work plan for implementing the action steps.

Still, it is important to emphasize that the *Blueprint* action steps are based on practices and policies that have been successfully implemented in other states. Indeed, many of the steps that are recommended here have been previously identified in other studies of the Illinois developmental disabilities service system, most notably in the "Gettings" report.[1] It is entirely feasible for Illinois to implement each of these steps. Inaction will have serious negative consequences for people with developmental disabilities. By not taking these steps, policy makers can expect that the state will: (a) continue spending

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

[1] Gettings, R. M., Cooper, R. & Chmura, M. (2003). *Financing Services to Individuals with Developmental Disabilities in the State of Illinois.* Alexandria, Virginia: National Association of Directors of Developmental Disabilities Services, Inc.

substantial sums to maintain large facilities, such as the SODCs, that people increasingly do not want[2] and that run afoul of oversight authorities, (b) find it increasingly difficult to accommodate new applicants for services so that wait lists will continue to grow, and (c) continue to oversee a community system that is increasingly challenged to address the needs of people already receiving services. In addition, forestalling action will likely make action later more costly and difficult to undertake. The time to act is now.

Implementing the *Blueprint*

The *Blueprint* lays out a complex, intertwined action agenda for system redesign in Illinois. System redesign is an exciting opportunity for a state to commit itself to achieving excellence in service system performance. Redesign also sparks major concerns about its potential impact on people with developmental disabilities, families, committed professionals, and other stakeholders. These concerns are entirely legitimate, and if not addressed can fuel strong resistance to system redesign. In addition, experience shows[3] that systems managers seeking to make change can inadvertently make matters worse by:

- √ Failing to articulate and communicate a clear and unambiguous vision for the future that appeals to most key stakeholders, and to take consistent policy action that advances the vision;
- √ Failing to establish a strong sense of urgency around the redesign effort that illustrates the consequences of inaction and the benefits of taking action;
- √ Failing to engage stakeholders in the redesign effort and forging a coalition among them for redesign;
- √ Failing to remove policy, financing or other structural barriers that may impede system redesign;
- √ Failing to plan systematically for redesign and to implement the plan step by step, building short-term successes along the way; and
- √ Failing to anchor the redesign to organizational cultures within agencies across the state and encourage learning communities among stakeholders to support the effort.

Most obviously, a successful redesign strategy involves purposeful action to avoid pitfalls such as these. In fact, several of the Action Steps that follow take these potential hazards into account. Steps may, for example, promote collaborative

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[2] We recognize that judgment over what people may "want" can be a contentious issue. Self-advocacy groups, however, persistently indicate that they prefer normalized community life with support rather than service delivery requiring residence in large facilities. SABE, for example, is a leading national self-advocacy organization and has clear positions on this matter, calling for outright closing of institutions (http://www.sabeusa.org). Likewise, family advocacy groups very often take positions to favor community support systems, including "family support" service options, over facility-based service responses. Reflecting these preferences, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 states as its purpose to assure that "individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life." Consistent with these themes, states have steadily divested from congregate services in favor or more person-centered modes.

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

problem solving, remove policy barriers or improve systems infrastructure. Such action will inevitably improve service delivery, but also help build confidence in the community system and fuel momentum among stakeholders for additional change.

Aside from implementing the specific steps contained in the *Blueprint*, however, the Department of Human Services (DHS)/Division of Developmental Disabilities (DDD) can improve its chances for success by:

1. ***Launching the redesign effort with Executive and Legislative branch sponsorship and working the redesign process through a collaborative process***. The success of system redesign will hinge on enlisting the collaboration of several stakeholders and constituencies from the start and sustaining their engagement throughout. In this context, because system redesign has both fiscal and legislative implications, policy makers must also be actively involved in the redesign process.

   In this context, we strongly recommend that redesign be launched by enlisting Executive and Legislative branch sponsorship. In advance, a Redesign Steering Committee should be appointed that includes leadership with decision-making authority. Care should be taken, however, assure that the Committee is composed of participants who are committed to achieving the objectives set out by the *Blueprint,* and that the Committee process not be used to forestall needed action. Instead, the Steering Committee should be clearly charged with helping state officials to push forward by working out implementation details and generating support for planned system changes. To ease the way, this Steering Committee should have its own budget to defray meeting and other expenses and support the meaningful participation of people with disabilities and families. The Steering Committee should have ongoing, *independent* staff support during the duration of the *Blueprint* period. The Steering Committee should be required to prepare periodic reports about its activities and these reports should be widely disseminated across constituencies.

2. ***Engaging people with developmental disabilities, the primary constituents of the system, in the redesign effort.*** People with developmental disabilities themselves represent a primary, albeit too often neglected stakeholder that must also be effectively engaged. As described within our first report, *Illinois Environmental Scan Project Brief*, the opinions of these individuals are too seldom taken into account when developing policy and practice. More recently, DDD indicates within its *2007-2011 Strategic Plan* that it seeks to forge a "strategic partnership" with these individuals. We recognize that DDD is already taking steps to develop and advance such partnership. For instance, DDD seeks to include self-advocates on policy-oriented task forces or committees. It also funds efforts by *Illinois Voices* to educate people with developmental disabilities and others about self-advocacy.

   We encourage such action. We note, however, that beyond providing training on self-advocacy, more needs to be done to help individuals to translate such training into collective opinion, common cause and action to improve services. Toward this end, we further recommend that DDD establish a position within its office that is staffed by a person with developmental disabilities to provide continual input into Division policy decisions. DDD should also encourage service providers to include self-advocates on their boards of directors. Most important, however, DDD should continue to direct funds annually toward training for self-advocates, and to help participants organize more effectively to convey their views regarding state and local policy and practice.

   In this context, several other states provide funds to self-advocacy

organizations, including Alabama, Oregon, New York, Pennsylvania, New Jersey, Massachusetts and others. To amplify their investment, in some states multiple sources of support are tied together. This may include teaming with the Illinois Council on Developmental Disabilities, utilizing VISTA/Americorps programs (e.g., Oregon, Missouri, New York, Utah) or by creative use of Medicaid to fund training (e.g., Minnesota, Wisconsin). In all such instances, participating agencies must take care to avoid conflicts of interest and assure that the voice of self-advocates stays free and unencumbered by agency policy preferences.

3. **Taking specific actions to help reduce potential resistance from stakeholders.** The Blueprint illustrates the steps that must be taken to achieve significant, and needed, system change in Illinois. For various reasons, such change may spur strong resistance from particular stakeholders, such as parents of individuals currently residing in SODCs, labor unions or administrators of community based ICFs/DD. The individuals being re-located may also be anxious about moving. Where concerns like these are not taken into account, the process can go awry and fuel resistance to future relocation efforts. In fact, in Illinois, re-location from SODCs in the past has not been managed with sufficient appreciation of these concerns.

   To promote success, it is essential that the opinions of these stakeholders not be discounted, but that their concerns be heard and addressed to the extent possible. For example:

   √ Individual residents being re-located may themselves have concerns over moving from an SODC or a large community ICF/DD into an alternative community setting. They may feel hesitant about being separated from friends or staff, or anxious about their new surroundings. Moreover, while they want to be re-located, they may feel conflicted about the move if family members object. Concerns like these may be addressed systematically by:

   - Involving individuals in the planning and re-location process from the start. Individual relocation plans should be compiled to assure that the relocation process takes full account of the individual's needs and preferences. In this regard, care should be taken to honor the individual's preferences, helping him or her to work through any potential differences of opinion with family members.
   - Individuals should have say over where they are moving to and the service provider they choose to support them. In addition, if they must share a room with another, individuals should be able to choose their roommate or at the least agree to a proposed roommate.
   - Where possible, individuals may be re-located with friends and/or staff to maintain friendships and reduce anxiety about meeting new people.
   - Creating opportunity for the individual to visit his or her new residence and gradually become acclimated to the new surroundings.
   - Assuring smooth transition in essential daily living routines and training protocols between facility staff and community staff.
   - Where possible, to involve family members with the individual to participate in the relocation process.

   √ Family members may have concerns over the uncertainties of the relocation of the loved one from an SODC or a large community ICF/DD into an alternative community setting. Many of these concerns may be addressed

systematically by:

- Providing family members the opportunity to gain an informed understanding of the new community service options. This may include printed information, but also presentations to show what has been successfully achieved elsewhere, "Provider Fairs" where family members can visit with several service providers in one place, or personal visits with particular providers to see local services in action.
- Providing opportunity for family members to meet with others whose loved ones were relocated previously. In Louisiana and Arkansas, for example, seasoned family members work with families whose loved ones are relocating to help ease their fears but also to work systematically with them to assure that needed community services are in place. Similarly, self-advocates in Washington have established a "Welcome Wagon" whereby newcomers to the community and their parents are formally welcomed and extended a helping hand.
- Implementing a strong person-centered planning process that engages family members and results in a service plan that satisfactorily addresses the needs of the individual. No amount of information, presentations or warm welcomes can substitute for this essential requirement of the system transformation process. Indeed, several of the Action Steps to follow are meant to strengthen the community system to assure that individuals re-located from large facilities into community alternatives receive quality services appropriate to their needs.

√ Workers, with many represented by a labor union, may have concerns over job loss or displacement. While workers may support many features of the *Blueprint*, gaining their support may be challenging, given that it calls for relocating individuals from certain settings in favor of others and likely will result in short-term sacrifices among workers. In part, these concerns can be addressed by:

- Committing to treat displaced workers fairly, and creating new job opportunities for workers within new community settings. Several states, for example, have relocated workers along with individuals into the community system or provided employment opportunities elsewhere in the state.
- Keeping workers involved with individuals, to help with planning the re-location and resolving any difficulties later. Often, workers and individuals forge close bonds and workers want to stay involved. To the extent possible, workers should have opportunity to participate in the re-location process, helping to plan for needed services or otherwise helping community staff to meet the individual's needs. In addition, it may be reassuring to the individuals and their families if these staff accompanied the individual on visits to prospective community residences.

√ Others, such as community ICF/DD administrators, have a stake in the present system, and may be uneasy about making changes to how their service agency is funded or delivers services. To the extent possible, their concerns should be heard and addressed. Most essential is to assure administrators that the individuals they serve will be satisfactorily accommodated within the new structures, and that the services they provide will be adequately funded.

Very often, within a systems change process, "resistance" is considered as

undesirable. Instead, it should be treated as "data" that can be used productively to improve the change process and address concerns. In this context, DHS/DDD staff should create opportunities for stakeholders involved with service delivery to voice their concerns and suggest means for resolving these concerns. Overall, success here requires effective communication between policy makers and those in the field charged with implementing the planned changes.

4. ***Establishing an unambiguous action-bias that is consistent with the redesign effort.*** Most likely, concerns or resistance from these and other sources can be accounted for and addressed before or during the transformation process. Still, no matter what is done in response some may object to the planned changes. Their objections, however, should not circumvent the process. Once DHS/DDD commits to redesign, it must assure that the actions it takes most often and most significantly promote the redesign effort. There may be instances where DHS/DDD must act in ways -- for the moment -- that are inconsistent with its commitment. Such decisions, however, should be carefully considered and increasingly rejected in favor of those that support redesign. By doing so, a clear and unambiguous path for redesign can emerge and an action-bias for change can take hold.

Overall, the *Blueprint* identifies major action steps but it is not a detailed implementation plan. The implementation of each action step will require considerable additional follow-up activities and more detailed planning. With guidance and oversight provided by a Redesign Steering Committee, implementation will proceed best, if it is conducted as a collaborative enterprise among constituencies that stresses full transparency and one where DHS/DDD routinely takes action consistent with the redesign.

Funding and Financing

Before turning to the six focus areas, it is useful to discuss the implications of the Blueprint on the funding and financing of developmental disabilities in Illinois.

Funding

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

There are only limited opportunities in Illinois to shift dollars among services to secure meaningful savings that can be redirected to expanding services and/or addressing problems such as low community worker pay. For example, while it is important that Illinois increase opportunities for people served in larger ICFs/DD to transition to the community if they wish, the costs of community residential supports for these individuals will be about the same as the cost of serving a person in an ICF/DD because Illinois ICF/DD payments are relatively low in comparison to payments for such services in other states.

In addition, we note that, since the publication of the *Gettings Report*, Illinois has taken steps to more highly leverage its state tax dollars to secure additional federal Medicaid dollars for community developmental disabilities services. As a result of this effort, there are fewer unleveraged dollars available in Illinois today that could support system expansion through refinancing additional community services. Unfortunately, recent Medicaid refinancing has not fully benefited the community developmental disabilities service system. This is because when the state receives federal Medicaid

reimbursement as match for its investment of state dollars, these funds are generally returned to the state treasury. As a result, while the state benefits from reduced state spending, the savings are not always re-invested in community services, resulting in little overall net gain for the that system. Most recently, DHDS/DDD indicated that federal matching funds tied to two new children's HCBS waivers (approved by CMS effective on July 1, 2007) will be re-invested into children's services beyond the first year of operation. Going forward, this precedent should be applied to Medicaid funding associated with any community service.

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

Financing

As a general matter, the additional spending that is necessary to implement most of the action steps contained in the *Blueprint* can be offset in part with federal Medicaid dollars. Certainly, expanding system capacity can and should be financed in large part through the expansion of HCBS waivers for people with developmental disabilities. Many of the costs associated with improving the service delivery system infrastructure also are apt candidates for Medicaid financing.

In the Deficit Reduction Act of 2005, Congress added §1915(i) to the Social Security Act. This provision provides states with an alternative to the long-standing HCBS waiver program to secure federal Medicaid dollars to underwrite the costs of home and community-based services. Under this alternative, a state may elect to cover certain home and community-based services under its Medicaid State plan rather than having to seek periodic federal approval of waivers or renewal of waivers to provide such services. Under this alternative, states are permitted to establish limits on the number of people who may receive these services. States also may continue to operate HCBS waivers.

This new Medicaid coverage alternative has certain drawbacks, principally with respect to the scope of services that a state may offer. In addition, this alternative does not permit a state to target home and community-based benefits by type of disability or condition (for example, benefits may not be limited solely to people who have developmental disabilities). On the other hand, this alternative sheds the HCBS waiver requirement that people with disabilities must require the level of care furnished in a Medicaid-reimbursable institution. Instead, eligibility for home and community services is based on functional limitation criteria that a state fashions. At this juncture, the federal Centers for Medicare & Medicaid Services (CMS) has not issued formal guidance to states concerning the benefit.

In the near-term, this new Medicaid coverage opportunity does not offer Illinois any significant advantage over continuing to employ the HCBS waiver program to underwrite the costs of home and community services for people with developmental disabilities. Down the road, however, this alternative may warrant consideration as a tool to finance cross-disability service delivery strategies, especially in the arenas of integrated employment and personal assistance.

There are other Medicaid financing alternatives to the HCBS waiver program that also are available. One such alternative includes what are termed 1915(b)/1915(c) combination waivers that permit a state to shift the delivery of developmental disabilities services to a managed care framework and integrate the delivery of Medicaid long-term care and other services. Wisconsin has used this alternative to implement its Family Care program. In Wisconsin, community agencies have been

established to manage the entry of individuals into long-term services (including developmental disabilities services) and channel people to the most appropriate services. Michigan also employs a combination waiver to channel funding to local entities for the delivery of developmental disabilities services.

Yet another alternative is employing the broader federal Section 1115 waiver authority to implement a broader restructuring of the delivery of services. For example, Vermont has employed this waiver authority to reconfigure long-term services for seniors and people with disabilities. In Vermont, individuals now have an entitlement to home and community services and admission to nursing facilities has been restricted.

Each of these alternative waiver authorities has attractive features. Either may serve as a vehicle to unify the delivery and funding of Medicaid services for people with developmental disabilities. However, there are major challenges associated with using either authority, including major operational design issues. More importantly, each alternative has major implications with respect to the flow of federal Medicaid dollars. For example, the Section 1115 authority imposes a "budget neutrality" requirement that limits the amount of federal Medicaid dollars that a state may receive. This requirement means that this authority should not be used unless a state is reasonably confident that the present level of Medicaid funding is sufficient to underwrite current services. If applied to an under-funded system, the Section 1115 authority can have negative consequences. Both of these authorities are more properly applied to systems that are stable and do not have large pent-up service demand.

At present, the best option for Illinois is to expand its HCBS waiver capacity and improve its operations. Illinois should ensure that the design of the waiver aligns with the goals and objectives it has set for the service system. Additionally, the financial gains achieved through expansion of the waiver and/or refinancing current services should be reinvested in the community system. Later, once Illinois has addressed some of the underlying problems in its developmental disabilities service system, other options may be considered.

III. Supporting People in the Most Integrated Setting

Background

The HSRI *Gap Analysis* revealed that a disproportionate number of Illinois citizens with developmental disabilities are served in large and very large congregate care facilities. In 2006, 62.8 percent of all persons in Illinois who received residential services were served in facilities that did not meet the most integrated setting benchmark – i.e., living arrangements that support six or fewer persons.[4] About one-half of these individuals were located in very large facilities that served 16 or more persons, including 2,763 persons who were served at the nine very large State Operated Developmental Centers (SODCs). Illinois lags substantially behind nearly all other states in fostering the provision of services in the most integrated setting.

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

Action Steps

Action Step #1. Illinois should reduce the number of people served at its State Operated Developmental Centers (SODCs) to no more than the present nationwide utilization rate for these types of facilities. This reduction in SODC utilization should be accompanied by the closure of five SODCs.

In 2006, Illinois served 67% more individuals at its State Operated Developmental Centers (SODCs) than the nationwide norm for utilization of such facilities. The Illinois utilization rate for SODC services was 21.0 individuals per 100,000 persons in the general population; the nationwide utilization rate was 12.6 individuals per 100,000 in the general population.

The substantial majority of other states have significantly reduced their utilization of very large state-operated facilities. For example, Michigan only operates one such facility that serves 175 individuals. In 2007, Indiana closed Fort Wayne Developmental Center, its last remaining state-operated institution. Minnesota operates only one very large facility that served 44 persons in 2006. Relative to state population, Wisconsin serves fewer than one-half the number of people in very large facilities as Illinois. In 2006, there were nine states that did not operate very large state-operated facilities.

Continuing this trend is New Jersey. In its May 2007 plan entitled *Path to Progress*, New Jersey announced that it intends to reduce the census of its developmental centers by 1,850 people over the next eight years. During this period, the census at its centers will drop from about 3,000 to 1,200 people by 2015.

There are several reasons why large public facilities are playing a diminished role in developmental disabilities service systems. Community service systems have improved capabilities to support people with challenging conditions. Large facilities also are extremely costly to operate, averaging $167,000 per resident nationwide in 2006. In

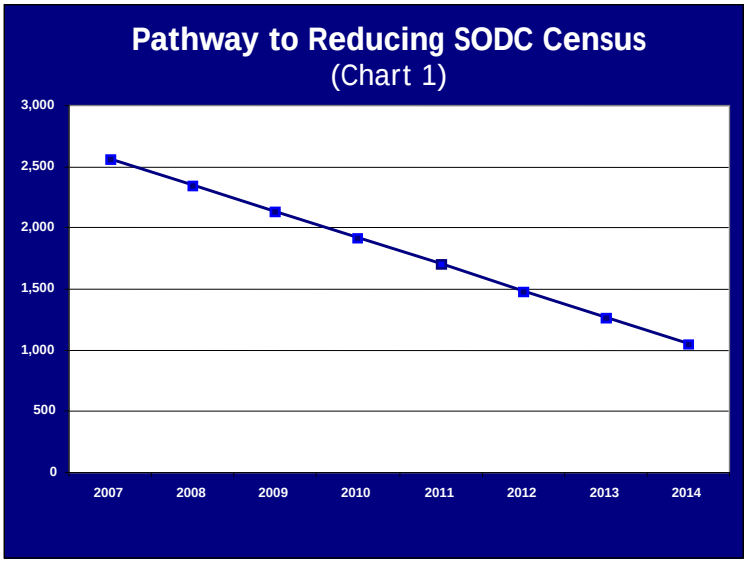
[4] Robert Prouty, Gary Smith, and K. Charlie Lakin (eds.) (2007, in press). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living. The utilization figures throughout this section are generally drawn from this report.

many states, such facilities continue to encounter serious problems in meeting federal quality of care requirements. Compliance with federal requirements is an ongoing source of the continuing increase in the costs of operating these facilities. In some states, the role of state-operated facilities is shifting to furnishing high intensity, short-term services to small population segments (e.g., individuals who have clinically complex conditions and/or require forensic services). The role of large state-operated facilities in providing long-term residential services has been substantially reduced in most states.

The persistence of the operation of large facilities in many states is explained in part by material shortcomings in the capabilities of community service systems. However, it is clear that both political and economic considerations also figure into the continuing of operation of such facilities.

Illinois will make substantial progress in supporting people with developmental disabilities in the most integrated setting by reducing the number of people served at the SODCs to the nationwide norm. The fact that most other states rely far less than Illinois on such facilities should serve as a signal that Illinois need not maintain its present SODC capacity. Clearly, Illinois continues to struggle in meeting federal quality of care problems, as witness the recent events at Howe Developmental Center and other facilities. The SODCs presently command a disproportionate share of the Illinois developmental disabilities budget. The per person costs of supporting people in the SODCs will continue to ratchet upward in order to maintain compliance with federal requirements. Reducing the number of persons served at the SODCs and operating a smaller number of such facilities is not only feasible but also a central strategy for avoiding higher costs in the future.

Illinois should close five SODCs during the Blueprint period to hold down costs.



Illinois should reduce the number of people served at its SODCs to no more than the predicted nationwide norm in 2014. This action would entail reducing the number of people served at the SODCs from 2,563 individuals in 2007 to 1,051 persons in 2014.

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

Overall, such action would result in a 59 percent census reduction. If census reduction is not accompanied by the closure of some SODCs, the per diem costs of operating the SODCs will ratchet upwards as fixed overhead costs are spread over fewer and fewer residents. This will result in Illinois experiencing difficulty in freeing up sufficient SODC dollars to pay for the community placement of SODC residents. To avoid this outcome, Illinois must close some SODCs along the way rather than linearly scale back the operation of the existing SODCs. The final number of SODCs targeted for closure is based on the overall relative reduction in total SODC census. The closure of the recommended number of SODCs during the *Blueprint* period will ensure that census reduction is at least budget neutral (i.e., community placement costs are offset by reductions in SODC operating budgets).

From a fiscal perspective, the reduction of SODC census accompanied by facility closure will yield significant dollars that can be reinvested in the community system to expand services to support other individuals and/or make strategic infrastructure investments. In particular, the proposed action would yield approximately a $33 million net decrease in total outlays by 2014.[5] During the period that SODC census is being reduced, however, the amount of dollars that would become available for reinvestment would be more modest.

The *Blueprint* does not identify specific SODCs for closure. The selection of SODCs for closure should be based on several factors, including geographic considerations, facility age, and physical plant condition. It also will be important that Illinois more sharply define the role that the SODCs will play going forward. Over time, the SODCs likely should concentrate on serving well-defined target populations and play a diminished role in furnishing long-term services. For example, the residual facilities in Michigan and Minnesota (as well as some other states) are largely devoted to providing short-stay services for people with very challenging behavioral disorders.

The transition of individuals from the SODCs to the community should incorporate the following best practices:

- √ Full-featured person-centered planning to identify the best mix of community services to support the person in the community. Person-centered planning should include family members and others who know the individual well;
- √ Management of planning/transition process by a team of state personnel who are intimately familiar with community services;
- √ The placement of individuals only to community living arrangements that meet the most integrated setting benchmark;
- √ Free and informed choice by the individual of the provider agency that will furnish services and supports in the community; and,
- √ Intensive monitoring of community placements for the first twelve months following SODC discharge.

Community placements will be more durable and stable to the extent that they are individualized and planned carefully.

Whichever pathway Illinois selects, it will encounter problems unless the state concurrently addresses the major problems that affect community services. This issue is addressed in the next part of the *Blueprint*. Unless these problems are addressed effectively, there will be continuing pressures to admit people to the SODCs. It is worth noting that securing a significant reduction in the SODC admission rate would contribute significantly to census reduction during the *Blueprint* period.

[5] This figure is conservatively estimated. It assumes that the costs of supporting an SODC resident in the community will be 85 percent of the SODC per diem cost.

With the implementation of the changes, there is no reason that Illinois cannot reduce its SODC census to reflect the utilization rates that most states have already achieved.

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

In Illinois, ICFs/DD constitute a distinct funding/service "silo." Once a person is placed in an ICF/DD, it is virtually impossible for the individual to secure an alternative living arrangement. People in ICFs/DD are not among the priority populations who are considered for enrollment to the HCBS waiver or for services in a CILA setting. Even though the cost of supporting a person through the HCBS waiver is comparable to ICF/DD services, ICF/DD funding is not portable and cannot follow the person into the HCBS waiver. As a consequence, individuals are locked into ICFs/DD. The absence of a mechanism in Illinois to accommodate ICF/DD residents who would prefer an alternative community living arrangement is at odds with the basic tenets of the U.S. Supreme Court's *Olmstead* decision. This situation prompted the filing of the *Ligas v. Maram* lawsuit that claims that Illinois is violating the Americans with Disabilities Act (ADA) by not accommodating ICF/DD residents who would prefer to be supported in an alternative and more integrated living arrangement.

Elsewhere, some states are taking steps to support the transition of individuals from ICFs/DD to more integrated settings in the community. For example, in the recent settlement of the *Martin v. Strickland* lawsuit, Ohio has agreed to accommodate ICF/MR residents who wish to move to a more integrated setting in the community. Over the past three years, Wisconsin has taken major steps to accommodate non-state ICF/MR residents who can be served in more integrated settings in the community. Louisiana is working with the operators of large ICFs/DD to transition their operations to supporting individuals in smaller community settings funded through a new HCBS waiver.

In the Deficit Reduction Act of 2005, Congress – at the urging of the Bush Administration – set aside $1.75 billion in "Money Follows the Person" (MFP) funding over a five-year period to assist states in accelerating the transition of people from institutional settings to the most integrated setting. This funding provides states with enhanced federal matching funds to pay for community supports for persons who transition to the community. Illinois is one of 31 states to receive a federal Centers for Medicare & Medicaid Services (CMS) award to expand opportunities for people to secure alternative services in the most integrated setting.

Illinois received an award of $55.7 million over five years to support the transition of 3,357 people from institutions to the community. However, only 3 percent (105 people) of these persons are expected to be individuals with developmental disabilities. The Illinois MFP proposal mainly targets older persons (1,517 of the total or 45 percent), people with physical and other non-developmental disabilities (1,000 or 30%), and persons with mental illnesses who are served in nursing facilities and other types of institutional settings. Several other states (especially Texas and Iowa) plan to use MFP funding to a greater extent than Illinois to help people transition from non-state ICFs/DD. The MFP demonstration will enhance Illinois' capability to successfully transition individuals to the community

Still, Illinois can build on this momentum and fashion its own "Money Follows the Person" initiative by enacting permanent legislation to actively support individuals who want to transition from an ICF/DD to an alternative living arrangement that is available under the HCBS waiver by guaranteeing them a waiver "slot" or opening. Texas

enacted this type of legislation in the late 1990s. The Texas legislation applies not only to individuals in ICFs/DD but also to people with all types of disabilities who are served in nursing facilities. In fact, Texas MFP federal award is expected to aid the state in transitioning about 1,200 people from large ICFs/DD to the community over the next five years. MFP legislation would contribute to breaking down the walls in Illinois that result in individuals being held captive by the ICF/DD funding stream and aid in opening up the Illinois system by giving individuals real choices. Such legislation also would permit Illinois to resolve the *Ligas v. Maram* litigation in a positive fashion.

It is important to acknowledge that this legislation has budgetary ramifications. People who leave ICFs/DD may be replaced by other individuals. Consequently, there would be no reduction in ICF/DD expenditures and HCBS waiver funding would have to increase to accommodate individuals who elect to transition to other alternatives. Note, however, that if HCBS system capacity is expanded and services improved, as recommended in Section V below, people may not seek placement in ICFs/DD, opting instead for a chance to enroll in the waiver program.

It is difficult to predict how many individuals might avail themselves of the opportunities afforded by the enactment of MFP legislation. A *conservative* estimate is that about 5 percent of ICF/DD residents might seek to transition to alternative community living arrangements over a multi-year period under this type of legislation. This number could increase were the state to mount an aggressive "in-reach" program to identify individuals who would be apt candidates for transition to the community. About $17 million in additional HCBS waiver funding would be necessary to accommodate the transition of 350 individuals (about 5 percent of the people presently served in non-state ICFs/DD). It is recommended that $3 million in additional funding be made available in 2008 to launch Money Follows the Person in Illinois.

The enactment of permanent Money Follows the Person legislation would expand opportunities for people to secure alternative services in the most integrated setting.

To avoid the result that individuals who want to transition from ICFs/DD compete with other individuals for HCBS waiver openings, Illinois should set aside or reserve waiver slots to accommodate such individuals. Illinois also should provide additional funding to its PAS/ISC agencies to facilitate the transition of individuals from ICFs/DD to alternative community living arrangements.

Action Step #3. Illinois should adopt policies that encourage organizations that operate large ICFs/DD to transition to supporting individuals in the most integrated setting.

The large concentration of ICFs/DD in Illinois is an historical artifact. Illinois saw ICF/DD services as a means to secure federal Medicaid funding to cover the costs of residential services. Illinois lagged other states in using the HCBS waiver program to fund other types of community living arrangements. As a consequence, Illinois has an especially large concentration of ICFs/DD. These facilities are operated by agencies that developed these facilities at the urging of the state.

For better or worse, Illinois cannot roll back the clock. Instead, Illinois must pursue strategies to rebalance its developmental disabilities service system in collaboration with the organizations that operate ICFs/DD. DHS/DDD has been working along these lines with some agencies that are interested in converting their facilities to alternative community living arrangements. These efforts should be stepped up.

Other states have launched rebalancing initiatives. For example, as previously mentioned, Louisiana is working with the operators of large, private ICFs/MR to facilitate the conversion of several facilities to smaller living arrangements. Over the years, Minnesota has worked collaboratively with ICF/DD providers to downsize and, ultimately, close their facilities.

Illinois can take three concrete steps to remove current financial obstacles to the conversion or downsizing of ICFs/DD:

1. Modify the manner in which the ICF/DD provider tax is calculated. Currently, the tax is based on the number of beds that were operated in the previous year. Consequently, when a provider is downsizing and/or converting a facility, the agency faces the prospect of paying a tax on beds that are no longer occupied.
2. Provide targeted fiscal incentives to agencies that agree to convert their facilities.
3. Revise ICF/DD payment policies to accommodate the downsizing and/or closure of facilities by adopting a budget-based rather than cost-based method of calculating facility payments for ICFs/DD that have committed to convert to smaller settings.

More broadly, Illinois should actively solicit proposals from agencies that operate ICFs/DD to convert such facilities to smaller settings. Starting in 2009, DHS/DDD should dedicate 1-2 staff positions to work directly with agencies interested in conversion.

Action Step #4. Illinois should bar the development of new CILAs that serve more than six individuals and take necessary steps to modify its payment policies to facilitate the downsizing of 7-8 bed facilities to six beds or less.

Community Integrated Living Arrangements (CILAs) are meant to be a combination of supports and services that are individually tailored to meet the needs of adults with developmental disabilities. Individuals may live in his or her own home, in a family home, or in a community residence. Over the years, however, there has been a steady increase in the size of residential CILAs. Upsizing facilities 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.

Going forward, Illinois should limit the size of new CILAs to no more than six beds, the benchmark for the most integrated setting. This policy change will entail revisiting the formulas that are used to set CILA rates to ensure that the operation of sites that serve six or fewer individuals is an economically viable proposition for provider agencies. Once rate setting formulas are revised, Illinois should establish a three-year time horizon for provider agencies that operate CILAs for more than six individuals to reconfigure their sites to meet the six-bed standard. We acknowledge that legislative proposals have been made to limit CILAs to supporting four or fewer persons. This legislation has merit and would aid in moving Illinois into the mainstream of states that stress the delivery of support in living arrangements that are more typical of the types enjoyed by persons who do not have disabilities.

This change would have fiscal implications. As a consequence, it is recommended that DHS/DDD develop estimates of the costs of this change and incorporate the projected costs in its 2009 budget request.

Summary

During the *Blueprint* period, Illinois should take several steps to rebalance its developmental disabilities system to improve opportunities for people to receive services and supports in the most integrated setting. It is entirely feasible for Illinois to bring the number of persons served at the SODCs into alignment with nationwide norms for the operation of such facilities. Neither of the two pathways outlined in this report for reducing SODC census is extreme. Both pathways would entail relatively modest year-over-year levels of community placement of SODC residents.

Three additional action steps have been outlined that would contribute to rebalancing ICF/DD and CILA services that would move Illinois toward a system where individuals have greater freedom to transition to the most integrated setting and/or enable the reconfiguration of facilities into smaller settings.

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IV. Strengthening Community Services

Background

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

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

Action Steps

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

Community agencies in Illinois are plagued by high rates of turnover among direct support professionals. High worker turnover translates very directly into major problems in assuring that services meet essential quality standards. It also poses real problems in ensuring that people with developmental disabilities receive services and supports that enable them to achieve critical outcomes in their lives. An unstable workforce increases the underlying costs of services in the form of increased use of overtime, higher workers' compensation expenses, and training costs. Unfortunately, these problems are not unique to Illinois. Adding capacity to serve people with reasonable promptness will be difficult to accomplish unless community agencies are able to hire more workers and retain the ones that they have for longer periods.

A skilled, stable workforce is the cornerstone of an effective community services system.

High worker turnover is attributable in part to the inability of provider agencies to pay competitive wages. The capacity of agencies to compete for and retain workers is directly affected by the level of state payments for community services. In Illinois, payments for community services have not been regularly adjusted year-over-year to reflect changes in the "cost of doing business." As wages increase in the general labor market, community agencies encounter more and more difficulties in hiring and retaining competent workers.

Compounding matters, providers may not be able to offer workers a satisfactory range of benefits (e.g., health insurance, vacation or holiday pay) or sustained training or education. Overall, conditions like these add to low worker satisfaction, which in turn helps fuel further turnover.

One response to this issue is to focus workforce development activities on education and training for staff so that they develop the underlying values and skills to perform well. By doing so, worker satisfaction can improve so that turnover is reduced. In this context, the Illinois Council on Developmental Disabilities recently invested in a three-year project to help create the supportive infrastructure that is vital to assist people with developmental disabilities and providers to find and retain competent workers.

Even so, the wages paid workers must be factored in. At present, there is little in the way of up-to-date, systematic information to gauge the extent to which community worker wages should be boosted so that community agencies can be reasonably competitive in the market place. While some advocate that community wages be benchmarked against state employee wages, the better approach is to benchmark wages against comparable types of jobs in the general labor market, providing as warranted for geographic modifiers to reflect local labor market conditions.

Illinois should conduct a full-scale study of community worker wages and boost funding as necessary to ensure that workers can be paid competitive wages.

Determining an appropriate level of compensation for community workers is not simple. To lay the proper foundation for making such a determination, a comprehensive study of current wages and benefits is necessary along with an analysis of general and local labor market conditions. For example, Wyoming undertook a comprehensive study of this type. The study revealed that community worker wages needed to be boosted by about 20 percent to be competitive with other employers. Based on this study, the Wyoming legislature appropriated the necessary funds to increase wages; a follow-up study determined that the increase in wages resulted in a substantial decline in community workforce turnover.

It is recommended that Illinois take three steps to improve conditions for community workers:

1. Build on the momentum generated through the Council's effort to identify and implement effective strategies for recruiting and retaining workers, and training these workers. DDD should study the specific activities undertaken by this effort, and their effects, and seek to expand on them and/or promote their application across the state.
2. In the short-term, community agency "top line" payment rates should be increased to catch up with underlying changes in the cost of doing business in Illinois. It has been two years since these top line rates have been increased. A catch-up funding increase would reduce strains on community services and avoid further deterioration in wages.
3. A full-scale study of community wages and benefits should be initiated this year and targeted for completion during 2008. We recognize that similar studies may have been completed in the past, such as one completed by the Illinois Association of Rehabilitation Facilities of its membership. These past studies likely contain considerable useful information that may be built on or expanded. The present study should examine current community wages and benefits in relationship to comparable positions in the general labor market. It also should examine the extent of local/regional variations in worker pay. The study should be designed so that it provides policymakers with reliable, concrete information concerning the extent to which community wages and benefits are (or are not) competitive. It should identify how much wages and benefits would need to be increased to be competitive. Finally, the study also should suggest how wages and benefits can be indexed going forward so that they can be kept in alignment and competitive with general labor market levels.

Should the recommended study of wages and benefits reveal that a substantial boost in funding is necessary for community wages and benefits to be competitive, then a multi-year funding strategy should be implemented that provides the necessary additional dollars to boost wages and benefits to competitive levels within no more than three years. Again, this increased funding can be financed in part with federal Medicaid dollars.

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

A critical measure of the effectiveness of a community developmental disabilities service system is how well it supports individuals who have especially challenging behavioral or medical conditions. The capacity to meet the needs of these individuals without resorting to long-term institutionalization is vital. To the extent that the needs of these persons can be appropriately addressed in the community, their lives will be more stable and the high costs of institutionalization will be avoided.

Illinois presently lacks a well-structured capacity in the community to respond to the needs of these persons. As a consequence, *de facto* the SODCs play the role of serving individuals whose needs cannot be met in the community due to their challenging conditions. Indeed, this is one of the rationales for maintaining the operation of the SODCs. So long as the capacity is not present in the community to address the needs of people with challenging conditions, Illinois will face ongoing pressures to admit people to the SODCs.

States that have closed their large public facilities or substantially reduced their capacity have had to confront the question of how to meet the needs of individuals whose challenging conditions would have led to institutionalization. Some of these states (e.g., Maine and Vermont) recognized that reducing institutionalization required the development of capacity in the community to respond quickly and expertly to the needs of individuals with challenging conditions. For example, Vermont sponsored the development of a crisis network that can respond to the needs of these individuals in a variety of ways. Establishing this crisis network cleared the way for Vermont to close its only public institution. Maine found itself caught in a revolving door situation, with individuals in crisis cycling into and out of its public institution. Maine created the capacity in the community to meet the needs of these persons. This enabled Maine to proceed with its closure of Pineland Center, its only large public institution.

Obviously, the Illinois developmental disabilities service system is larger and more complex than the Vermont and Maine systems. However, the fundamental design principles that under gird the approaches in these states to address the needs of individuals with challenging behaviors are relevant. These principles include:

- √ Developing solid skills among direct support staff and others involved with service delivery to prevent challenging behavioral patterns from developing, and to respond effectively to them before they grow worse;
- √ Developing “person-centered organizations” that are organized to routinely provide person-centered supports to individuals in ways that do not inadvertently prompt challenging behavior, or provide an environmental context where such behavior is more likely to emerge;
- √ Establishing on-call capacity to rapidly provide technical assistance to providers that experience problems addressing the needs of those with challenging conditions;
- √ The capability to dispatch skilled personnel to community settings to identify effective practices to address a challenging condition and work with provider agency staff to implement such practices; and

√ The operation of short-stay crisis residences to provide intensive services to stabilize a person who is experiencing a crisis.

The foregoing capacities and capabilities form the core of an effective approach to serving individuals with challenging behavioral conditions. Such an approach features addressing the needs of the person in the community rather than displacing the person to an alternative setting.

Given the sheer size of Illinois (from a geographic and population standpoint), a regionalized approach to creating needed capabilities to serve individuals with challenging behavioral conditions is the most feasible. Three recommendations are offered:

1. Illinois should contract with one or more private-sector organizations to furnish specialized behavioral services on an as-needed basis for defined geographic regions. These Behavioral Support Organizations can be linked to regional provider networks already in place as well as provide ongoing training and education to community personnel in how to support people who present behavioral challenges.

Illinois should establish regionally-based Behavior Support Organizations to provide crisis intervention and other supports to community agencies.

2. DHS/DDD should craft a set of specifications for the operation of Behavioral Support Organizations, and during 2008, issue a Request for Information to solicit applications to operate such organizations. Assuming that one or more satisfactory responses to this solicitation are received, it is recommended that DHS/DDD contract for BSO services in one or two regions during 2009 to pilot the delivery of such services. If the pilot is successful, this approach to furnishing services could be extended statewide starting in 2011. To complete these actions DDD may seek to establish an independent Task Force on behavior or utilize its behavioral Crisis Team.

3. Illinois also should consider adding the coverage of specialized residences to its HCBS wavier or, in the alternative, design a separate waiver for people with challenging conditions. These steps would strengthen the community capacity to support these individuals.

In a similar vein, Illinois should undertake an in depth study of current system capabilities in meeting the needs of individuals who have extensive medical support needs. At present, little is known about how well the health care needs of individuals in the community are being addressed, although there is some evidence that there are problems in appropriately supporting individuals who have especially complex medical conditions. Some states (e.g., California and Pennsylvania) have launched major initiatives aimed at improving the quality of health care services for people with developmental disabilities in the community. These initiatives may suggest potential courses of action for Illinois.

Since Illinois presently lacks systematic information about the quality of health care services for people in the community, conducting an in-depth study of current capabilities is a necessary first step. It is recommended that this study be launched in 2009 and completed in 2010. DHS/DDD should establish a technical advisory group to guide the design of the study. Once the study is completed, DHS/DDD should collaborate with system stakeholders to identify action steps to improve system capabilities in supporting people with complex medical conditions.

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

Illinois stakeholders of all types express serious concerns about the extent and effectiveness of state oversight of community services. The extent and frequency of oversight is generally regarded as inadequate. These concerns have spawned reservations about the advisability of placing people from SODCs into the community. In some quarters, community services are portrayed as not "safe." As previously discussed, the quality of community services is intertwined with the capability of community agencies to recruit and retain a competent workforce. Absent a stable workforce, quality of care issues will persist.

Going forward, Illinois will face even greater challenges in assuring quality as the number of people who are served increases. As a consequence, it is vital that Illinois take steps to increase its capabilities to oversee community services.

Assuring quality revolves around four critical components:

√ Performing systematic risk assessment as part of the individual service plan development process and using the results of risk assessment to ensure that service plans appropriately address identified risks;

√ External, independent review and oversight of the implementation of service plans along with ongoing monitoring of the health and safety of individuals;

√ Effective discovery and remediation processes that identify potential service delivery problems and act quickly to correct shortcomings; and,

√ Systematic analysis of quality data in order to identify areas that warrant focused quality improvement initiatives to address systemic problems.

Assuring quality starts with building in quality at the service plan level. Monitoring, discovery, and remediation processes serve as necessary safeguards to ensure that people are healthy and safe in the community. A quality improvement focus provides an important vehicle for boosting performance systemwide.

To improve service quality, four steps are recommended:

1. **DHS/DDD should adopt a standardized risk assessment protocol that will be employed systemwide to identify potential risks and risk mitigation strategies as part of the individual service plan development process.** Several states (e.g., Oregon and Massachusetts) have developed such protocols and integrated them into their service plan development processes. An appropriate protocol should be selected in 2008 and introduced into the service plan development process starting in 2009.

2. **Illinois needs to take steps to strengthen the role that PAS/ISC agencies play in performing regular and routine monitoring of the implementation of service plans and individual health and safety.** This will require increased funding for ISSA services, a topic to which we return in

Illinois needs to take four fundamental steps to improve confidence in the quality of community services:

√ *Implement a standardized risk assessment protocol;*

√ *Step up the regular and routine monitoring of services;*

√ *Increase resources devoted to state oversight of community services*

√ *Appoint a Quality Council to identify opportunities for improvement*

Section VI. Illinois must recognize that the operation of an effective external service coordination system that has sufficient resources to perform regular and routine monitoring of services is central to assuring the quality of community services. In addition, Illinois must take steps to ensure that the results of monitoring are captured and systematically channeled to appropriate authorities for follow-up action when necessary.

3. **Illinois must bolster the resources that it devotes to state oversight of community services.** Presently, Illinois is following a three-year provider agency review cycle (conducting more frequent reviews when problems are unearthed). This cycle is not sufficiently frequent. HSRI recommends that the regular review cycle be shortened to two-years. It also is recommended that DHS/DDD continue and expand present efforts to design and implement information technology (I/T) systems that systematically capture information about the results of provider agency quality reviews and periodically disseminate aggregate information about the results of quality reviews. Finally, DHS/DDD must strengthen enforcement and remediation of problems. The present approach to remediation appears to be inadequate because problems are recurring from review-to-review.

   This step clearly will entail a fundamental redesign of state oversight systems. This redesign should start as soon as possible. To this end, DHS/DDD should convene a stakeholder workgroup this year to develop the redesign, including identifying the resources necessary to implement the redesign with the aim in mind of implementing the redesign in 2009. It also is recommended that the workgroup examine the state oversight systems that are in operation in Colorado and Massachusetts. The workgroup also may wish to consider approaches used in Florida and Pennsylvania to quality oversight that features the use of a private sector organization to perform various quality oversight functions.

4. **Illinois should knit together information about quality within a broader quality improvement framework.** This step is linked to the broader need for Illinois to put into place systems that will furnish policy makers, state officials, and stakeholders of all types with better, more comprehensive information about service system performance to support quality improvement initiatives. With respect to information about the quality of services, Illinois should point toward having the necessary I/T systems in place by 2009, or sooner, that will capture information concerning the results of monitoring, provider quality reviews and critical incident reporting. At the point such information becomes available, Illinois should follow the lead of other states and appoint a Quality Council that is charged with examining this information and identifying topics that warrant focused quality improvement initiatives.

Summary

It is vital that Illinois pursue the foregoing action steps in order to create a solid platform for the delivery of community services going forward. To the extent that Illinois ignores these mission-critical areas, the feasibility of reducing the state's over-reliance on large congregate care facilities and expanding system capacity to support people with unmet needs will be undermined.

V. Expanding System Capacity

Background

Illinois faces a major strategic challenge: keeping pace with the rising demand for developmental disabilities services. As discussed in the *Gap Analysis*, there already is a substantial shortfall in Illinois' current system capacity to meet the expressed demand for developmental disabilities services. There are 7,784 people who have urgent unmet emergency or critical service needs. This translates into a shortfall in system capacity of about 35 percent. In large part, this shortfall stems from Illinois' sub-par performance in funding developmental disabilities services.

The *Blueprint's* seven-year time horizon extends through 2014. An important goal for Illinois is that the developmental disabilities system have sufficient capacity to respond with reasonable promptness to the legitimate needs of people with developmental disabilities. A realistic projection of service demand is necessary to inform the selection of strategies that will enable Illinois to achieve this goal.

In this part of the *Blueprint*, service demand projections are presented. Two action steps for addressing service demand are also identified and described in detail.

Projected Service Demand in Illinois

Total service demand is the sum of "satisfied" demand (i.e., people who are receiving services) and "expressed but unmet demand" (i.e., people who have emergency or critical unmet needs). The demand for developmental disabilities services is influenced by several factors. At a minimum, demand will grow at about the same rate as the general population.

Satisfied demand
\+ *Unmet demand*
Total Service Demand

However, there is considerable evidence from other states that the demand for developmental disabilities services is growing at a rate that significantly exceeds the rate of general population growth. For example, California has experienced year-over-year increases in service demand that are 2-4% above the rate of population growth. In Texas, service demand is growing at the rate of about 3,000 individuals per year. Connecticut is another state that is experiencing continued growth in service demand despite a concerted effort to reduce the state's waiting list for community services. As discussed in the *Gap Analysis*, there are demographic and other factors that are causing developmental disabilities service demand to spiral upward.

It is difficult to pinpoint year-over-year service demand trends in Illinois. DHS/DDD has only recently started to compile information about unmet service needs through the operation of PUNS. In Illinois, the demand for developmental disabilities services is not high in comparison to many other states. The present Illinois service demand rate works out to 233 individuals who receive or need services per 100,000 persons in the general population. In comparison, the rate of demand in Texas is roughly 269 per 100,000 while in Florida it is about 263 per 100,000. It is not uncommon for state service demand rates to exceed 275 individuals per 100,000 persons in the state population. For example, the service demand rate in Minnesota is approximately 383 individuals per 100,000 persons in the population.

For the purposes of the *Blueprint*, two projections of Illinois service demand have been developed. The technical note at the end of this section contains a more detailed discussion concerning how these projections were developed.

Projection #1: No Change in Demand Rate

The most conservative assumption is that the present observed rate of service demand (233 individuals per 100,000 in the general population) will remain unchanged through the year 2014. That is, relative to state population, the present rate of demand will hold constant. In absolute terms, total demand will grow only as fast as Illinois state population (i.e., at 0.73 per cent per annum). Under this projection, unmet service demand would total about 9,176 people by 2014 absent any change in system capacity.

Projection #2: Demand Rate Grows by 2 Percent Annually

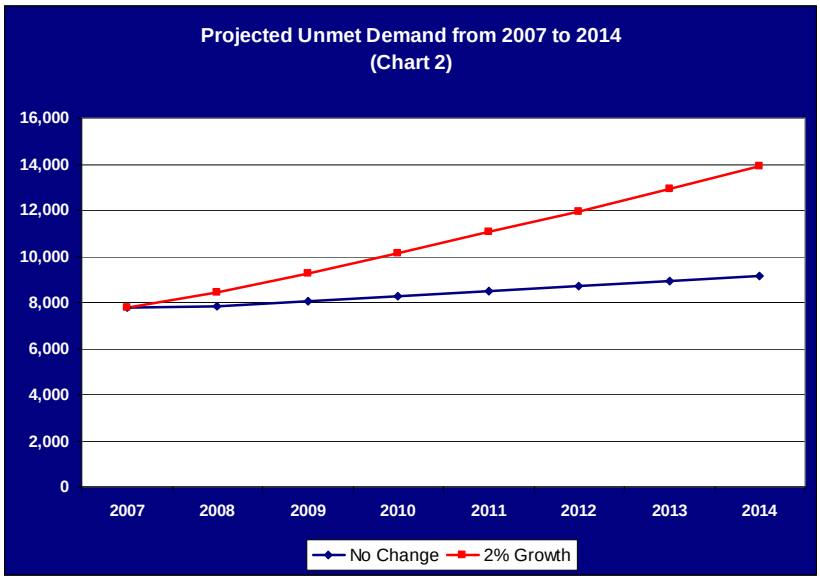
Under this scenario, it is assumed that the rate of demand for developmental disabilities services in Illinois will increase by 2 percent each year. That is, total demand will grow at a pace somewhat faster than state population alone. In light of the experiences in many other states, this is a relatively conservative assumption. For a variety of reasons, other states are experiencing higher year-over-year rates of increase in service demand. For instance, as systems develop new capacity, individuals who previously opted not to apply for services and be put on a wait-list, decide to come forward, resulting in a jump in demand.

Under this assumption, the rate of demand in Illinois would increase to approximately 267.8 individuals per 100,000 persons in the general population by 2014, about 14.8 percent greater than the current rate. This projected demand rate is consistent with the current observed rates of service demand in several other states.

The second projection is much more likely to play out than the first. Over time, one would expect service demand in Illinois to more closely approach observed demand in other states. As discussed in the *Gap Analysis*, the current PUNS data probably understates demand. Under this projection, unmet service demand will grow to about 13,891 people by 2014.

Projection of Unmet Need

Chart 2 shows the projected unmet need for services in Illinois through 2014 for both projections. The projections assume no change in the total number of people who presently receive services (i.e., 22,355 people). Both projections start at the present level of unmet need (7,784 individuals).



Assuming no change in the current observed rate of service demand, population growth alone would result in unmet need growing by 18 percent to 9,176 individuals by 2014. The relative shortfall in system capacity in 2014 would increase to 40.7 percent from the current level of 34.8 percent. Under this scenario, unmet need would be addressed only to the extent that there is turnover among individuals who presently receive

services. The movement into services of people who have unmet needs would be very slow.

Absent an increase in system capacity, the number of people with unmet needs is likely to reach 13,891 by 2014.

Under the more likely scenario that the rate of service demand would increase by two percent year-over-year, by 2014 there would be about 13,891 people with developmental disabilities with significant unmet needs or 78 percent more than currently. The number of people with unmet needs would grow by 800 to 900 per year. Under this scenario, the shortfall in system capacity would reach 61.6 percent by 2014. Absent expanded system capacity, individuals would have little or no prospect of having their needs addressed with reasonable promptness.

Resources Needed to Meet Projected Service Demand

To estimate the dollars that would be needed to respond fully to the needs of individuals with emergency and critical unmet needs going forward, estimates are based on the more realistic 2 percent per annum service demand growth scenario.

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 2014. ***Federal Medicaid dollars can underwrite one-half of these additional outlays***. To estimate how ma`ny dollars might be necessary, two alternative funding scenarios are used. Both scenarios assume that Illinois will employ Medicaid financing to expand system capacity. These scenarios are:

- **Current service mix**. Under this scenario, it is assumed that unmet service demand would be addressed by expanding system capacity in about the same proportion as the present mix of services. This scenario employs the current average per person cost of serving a person in Illinois ($46,519 per person) to estimate the cost of expanding system capacity forward. In applying this cost figure, however, note that current figures are based on averages distilled from the current patchwork of rates per person that may not accurately reflect the true costs of furnishing services (See Action Step 13).
- **HCBS Expansion Only**. It is assumed that Illinois would rely exclusively on expanding its HCBS waiver for people with developmental disabilities to address current unmet and future service demand going forward. The baseline figure used under this scenario is $30,027 per person.

Table 1 provides estimates of the additional resources that would be necessary to fully address service demand, assuming that service demand increases at the rate of two

Resources Needed to Meet Service Demand ($m) (Table 1)

Year	Additional Capacity Needed	Current Avg. Cost per Person ($46,519/person)	HCBS Only ($30,027/person)	ICF/DD Only ($73,122/person)
2007	7,784	$362.1	$233.7	$569.2
2008	8,429	$392.1	$253.1	$616.3
2009	9,279	$431.6	$278.6	$678.5
2010	10,152	$472.3	$304.8	$742.3
2011	11,049	$514.0	$331.8	$807.9
2012	11,971	$556.9	$359.5	$875.3
2013	12,918	$600.9	$387.9	$944.6
2014	13,891	$646.2	$417.1	$1,015.7

percent annually. The estimates are expressed in constant dollar terms. That is, no allowance for inflation has been built into the figures. The estimates also do not include additional funding enhancements (e.g., increasing payments to provider agencies to improve direct support worker wages) that are necessary to strengthen and stabilize community services.

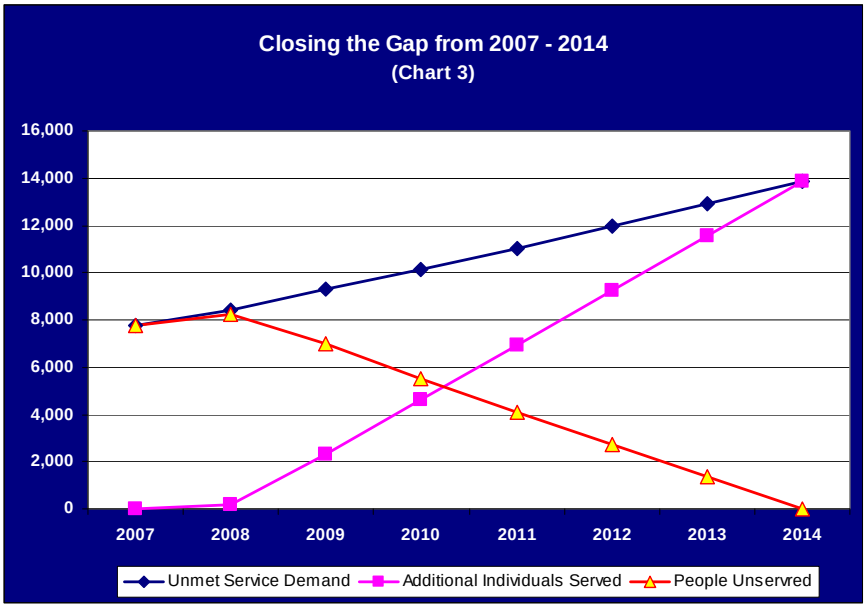
As can be seen, the projected amount of additional funds necessary to address service demand in 2014 ranges from $417.1 million to $1 billion. Since one-half of the costs of system expansion can be underwritten by federal Medicaid dollars, the amount of Illinois state tax dollars necessary to increase system capacity to fully-address unmet emergency and critical service demand would range from about $208 to $500 million. It would be substantially more economical for Illinois to address service demand by exclusively focusing on scaling up HCBS waiver services rather than a mixture of HCBS and ICF/DD services or through ICF/DD services alone. It also is worth noting that the funding necessary to eliminate unmet need is approximately equal to the difference between Illinois level of fiscal effort versus the nationwide norm.

Action Steps

Two action steps are recommended so that by 2014 Illinois has sufficient system capacity to meet projected service demand.

Action Step #8: Starting in 2009 and each year thereafter through 2014, Illinois should enroll an additional 2,316 individuals each year in its HCBS waiver.

To catch up with service demand, Illinois must expand system capacity to serve at least another 13,891 people by the year 2014. To close the gap between system capacity and service demand, system capacity must grow at a faster pace than service demand until the gap is closed. However, attempting to catch up with service demand all at once would be very challenging. In 2008, Illinois already plans to enroll 182 individuals presently on the PUNS database into its Children's Support waiver. In addition, starting in 2009 and each year thereafter through 2014, Illinois should enroll an additional 2,316 individuals each year in its HCBS waiver. By employing the HCBS waiver to finance this expansion in capacity, Illinois will be able to secure federal Medicaid dollars to underwrite one-half of the cost of this expansion.



As illustrated by Chart 3, expanding capacity to serve an additional 2,316 individuals each year starting in 2009 will enable system capacity to catch up with projected service demand by the year 2014. Moreover, there would be a steady reduction in the total number of individuals

who have unmet emergency and critical needs. For example, by 2010, the number of individuals with unmet needs will have been reduced to 5,520 from the current level of 7,784. By 2011, all individuals who currently have unmet needs will have been served and each year thereafter the length of time that individuals would have to wait for services would decline. By 2014, Illinois will have sufficient capacity to provide services to individuals with emergency or critical needs with reasonable promptness.

If system capacity is expanded at a slower rate during the period 2009 – 2014, Illinois will be unable to serve all individuals with reasonable promptness. For example, if system capacity is expanded to serve only an additional 7,784 individuals, there will be largely no net change in the total number of individuals with emergency or critical unmet needs. Though new people would be steadily added to services, people with developmental disabilities would experience waiting times of five years or more.

To implement this action step, $69.5 million in additional Medicaid funding will have to be added in 2009. This amount is calculated by multiplying the number of new people served per year (i.e., 2,316) by the present HCBS baseline average cost of $30,027 per person. Each year, another $69.5 million would have to be added to serve the next increment of 2,316 individuals. Again, federal Medicaid dollars would underwrite 50 percent of these additional expenditures so that the cost to the state would total about $35 million per year.[6]

Implementing this action step would entail scaling up the HCBS waiver from its present capacity of 14,000 persons to serving approximately 28,000 individuals by 2014. Doubling the size of the waiver would provide Illinois with HCBS waiver capacity relative to the size of its state population that is not dissimilar to the capacity other states already possess. By 2014, Illinois would serve 200 individuals in its waiver for every 100,000 persons in the general population. By way of comparison, Pennsylvania, a state that has about the same population as Illinois, currently serves 206 individuals per 100,000 in the population in its HCBS waivers for people with developmental disabilities.

Attacking and ultimately eliminating emergency and critical unmet need in Illinois also is critical to reducing the state's over-reliance on large congregate care facilities. Unmet service demand will spill over into institutional services. Relieving service demand through the expansion of community services will permit diverting demand away from large congregate care facilities.

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

Home-based services have proven to be an effective, economical means to support individuals with developmental disabilities in Illinois. 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.

Going forward, Illinois should concentrate on expanding home-based services as its primary tool for addressing unmet service demand. In crafting a strategy to eliminate its waiting list for developmental disabilities services, Oregon decided to concentrate its

[6] The projected costs of serving additional individuals do not include other Medicaid acute care costs. Currently, such costs average $5,923 per waiver participant each year. Assuming that 50 percent of the individuals who would be added to the waiver are already enrolled in Medicaid, the additional annual acute care Medicaid costs would be $7.5 million for each increment of 2,316 persons added to the waiver.

efforts on the expansion of similar non-residential services. Other states have taken a similar approach. Focusing on home-based services is a less costly strategy than expanding licensed residential services. At the same time, provision must be made for some measure of expansion of supported living and other residential services outside the family home, especially to accommodate individuals who are living with aging caregivers. Two recommendations are offered:

1. **Of the new capacity Illinois needs to add by 2014, 75 percent should be allocated to the expansion of home-based services**. During the *Blueprint* period, 3,250 new residential services opportunities would be created. Shifting the mix of waiver services toward the provision of home-based services would reduce the cost of the expansion of system capacity by approximately 19 percent.

   Illinois should allocate the remaining funds to strengthen options related to supporting individuals in alternative living arrangements outside the family home such as in supervised apartments or in their own homes. In addition, Illinois should expand and strengthen day-time service options so that individuals have greater opportunity to achieve employment goals, such as having a paying community job or owning one's own business.

2. **Illinois should consider shifting home-based services to a stand-alone Medicaid HCBS waiver**. Currently, there are 17 states (including Indiana, Missouri, and Pennsylvania) that operate separate "supports waivers" that provide roughly the same type of services as Illinois' home-based services. Supports waivers in these states operate side-by-side with the traditional "comprehensive waivers" that provide more 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.

   Aside from this cost advantage, changes in federal policies have also prompted these states to set up separate supports waivers. In specific, in 2001 the Centers for Medicare & Medicaid Services (CMS) issued a State Medicaid Director Letter #01-006 (a.k.a., *Olmstead* Letter #4). The letter addressed the question of whether a state could operate a single waiver but within the waiver restrict some waiver participants to the receipt of a limited package of waiver services. Overall, it barred such practice. In essence it was meant to prevent a state from administering what is termed a "waiver within a waiver" – a waiver that was internally partitioned to control the number of people who access certain types of waiver services. The letter made clear that, once a person is enrolled in a waiver, the person must be able to obtain any service available through the waiver, if they need it. Further, *Olmstead* Letter #4 made it clear that a state is at financial risk to provide the full range of waiver services that such individuals might require.

   As a result, we conclude that operating a separate supports waiver, rather than including a benefits package like home-based services within a single waiver as Illinois currently does, would: (a) assure that the state's waiver operations are consistent with *Olmstead* Letter #4, and (b) reduce budgetary risks for the state by enrolling some individuals into a supports waiver that can apply per person caps, as opposed to a comprehensive waiver with no such limits.

Setting up a distinct home-based services supports waiver also could provide the opportunity for Illinois to make other changes to home-based services that could 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 of "individual goods and services," to provide an extra measure of flexibility for individuals and families to purchase non-traditional services and supports.

Summary

Absent an aggressive, multi-year initiative to reduce and eliminate unmet emergency and critical unmet service demand, Illinois will find itself confronting a-widening gap between the capacity of the service system and service demand. Individuals and families will face longer wait times before they can receive services. Moreover, it will be very difficult for Illinois to reduce its over-reliance on large congregate care services so long as it is not fully meeting service demand in the community.

Technical Note

The service demand projections contained in this section start at the current base of "satisfied demand" (people who are presently receiving services) and "expressed but unmet demand" (people who are classified in the PUNS system as having emergency or critical unmet needs). In particular:

- √ At present, 22,355 people are served in the SODCs, ICFs/DD and the HCBS waiver program, and counted as "satisfied demand."
- √ Another 7,784 people have emergency or critical unmet needs.
- √ In absolute terms, the Illinois level of total service demand in 2007 is 30,139 individuals (22,355 people served plus 7,784 people with known, expressed unmet urgent needs).

Service demand rates are calculated when these numbers are considered in relation to the overall state population. For the purpose of calculating service demand, population projections are based on the July 1, 2006 baseline estimate of the Illinois population of 12,831,970 published by the U.S. Bureau of the Census. During the *Blueprint* period, the Illinois general population is expected to grow at the rate of 0.73 percent per annum, according to the Illinois Department of Commerce and Economic Opportunity. In projecting Illinois population through 2014, this rate of increase was applied to the U.S. Bureau of the Census July 2006 estimate.

In Illinois, the 2007 overall service demand rate is 233.17 individuals per 100,000 persons in the population. This rate is the sum of satisfied demand (172.9 individuals served per 100,000 persons in the general population) plus unmet demand (60.2 individuals per 100,000 persons).

Projected unmet demand using the "no change" in the rate of demand assumption is calculated by applying the current service demand rate to Illinois' project population each year and subtracting out the 22,355 individuals who currently receive services. For example, in 2014, total projected demand is estimated to be 31,414 individuals. (i.e., estimated population of 13,600,786 in 2014 times the present total demand rate of 233.17 people per 100,000 population to yield 31,713 people). Subtracting out the 22,355 people who currently receive services, unmet demand is the residual – 9,358 individuals. An additional 182 individuals are subtracted out in 2008 as the state begins operation of its Children's Support Waiver, yielding a final total of 9,176.

Projections of service demand employing the 2 percent year-over-year rate of demand growth assumption are calculated by increasing the base service demand rate by 2 percent each year and applying the calculated rate to projected state population for the year. For example, the service demand rate in 2011 is expected to be 252.39 individuals per 100,000 persons in the general population (includes 169.36 individuals served per 100,000 persons in the general population plus unmet demand 83.03 individuals per 100,000 persons). Applying this rate to the projected state population in 2011 of 13,307,225 yields an estimated total demand of 33,586. This includes the 22,355 now in service, the additional 182 individuals enrolled in 2008, and an additional 11,049 people with unmet needs. This total is 3,265 greater than 2007 demand. About one-quarter of this additional demand is attributable to projected population growth alone with the remainder attributable to an increased in the rate at which individuals and families are seeking services.

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VI. Redesigning Service Coordination and Single Point of Entry

Background

Effective, *external* service coordination is essential to the effective functioning of a developmental disabilities service system. External service coordination ensures that service plans reflect the needs and preferences of individuals. External service coordination also is a vital quality assurance component.

Additionally, in order to ensure that people with developmental disabilities are connected to the most appropriate services and supports, it is important that a state operate a single point of entry system through which all persons seeking service pass.

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

Action Steps

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

As discussed in the *Gap Analysis*, Illinois does not operate a comprehensive external service coordination system for people with developmental disabilities. The state provides minimal funding to purchase ISSA services from PAS/ISC agencies on behalf of individuals who participate in the HCBS waiver. In the case of people who receive residential services, service agencies have lead responsibility for developing service plans. Service facilitation services are available to people who receive home-based services. External service coordination is not routinely furnished to people who reside in ICFs/DD. In the case of people who receive state-funded services, PAS/ISC agencies furnish very limited service coordination due to limits on state funding.

The situation in Illinois stands in sharp contrast to developmental disabilities systems in other states where service coordination is an integral component of the delivery of community services. In most other states, external service coordination (i.e., service coordination that is furnished by entities which do not also furnish direct services to individuals) is the rule. External service coordination entities include the state developmental disabilities authority (e.g., Connecticut and New Mexico), county/regional developmental disabilities authorities (e.g., Minnesota and Pennsylvania), and private, specialized service coordination agencies (e.g., Florida and Louisiana). Typically, these entities perform system intake, work with individuals and families to develop service plans and assist them in locating service providers, and perform periodic monitoring of service plan implementation and health/safety.

With respect to individuals who participate in the Illinois HCBS waiver for people with developmental disabilities, ISSA services represent very limited external service coordination. ISSA services were launched in response to the federal waiver review in the late 1990s that found major deficiencies in the operation of the HCBS waiver. Prior to initiating ISSA services, Illinois did not have external service coordination in place. However, Illinois limits ISSA services that can be furnished to a waiver participant to a maximum of 25 hours each year. This limitation translates into a constricted set of ISSA services, including limited monitoring of services and involvement in service plan development and follow-up. The Illinois allowance for ISSA services is approximately

one-half the level that is the norm in other states for the performance of essential service coordination functions.

Illinois needs to ramp up a full-featured external service coordination system for people in the community.

An effectively functioning external service coordination system is essential to ensuring that people with developmental disabilities and families have access to an independent source of assistance. As discussed in the previous section, external service coordination is a cornerstone of quality assurance through the performance of ongoing monitoring of service plan implementation and health/welfare. Additionally, external service coordination is absolutely vital for ensuring that service plans are designed to meet the needs of individuals.

It is recommended that Illinois take the following five steps to put into place an effective external service coordination system for HCBS waiver services:

1. The allowance for HCBS waiver ISSA services should be increased from 25 to 50 hours, starting in 2008;
2. ISSA service coordinators should be assigned the responsibility of facilitating the development of all HCBS waiver service plans;
3. ISSA service coordinators should be required to perform direct contact monitoring of HCBS waiver participants served in community residences four times each year.
4. Contracts with PAS/ISC agencies to furnish ISSA services should include performance benchmarks; and,
5. DHS/DDD should contract with an independent entity to perform quality audits of the performance of PAS/ISC agencies in furnishing service coordination. These quality audits should include performing surveys of individuals and families concerning their level of satisfaction with the performance of ISSA services.

It also is recommended that Illinois step up its funding of ISC agencies so that they have improved capability to support individuals who do not participate in the HCBS waiver. Illinois should consider extending service coordination to persons who have unmet emergency and critical needs to assist those individuals in accessing services outside the HCBS waiver until they can be enrolled in the waiver. This expansion of service coordination could be financed by adding the coverage of Medicaid targeted case management services.

Action Step #11. Concurrently, Illinois should put into place a comprehensive single point of entry 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 usually also perform service coordination functions. SPOE entities also typically have the authority to authorize services and funding within state-specified parameters.

The SPOE model ensures uniform and consistent application of state eligibility criteria and service authorization policies. It also provides individuals and families with a clear pathway to access services and supports of all types.

Illinois has incorporated some components of the SPOE model into the functions of the PAS/ISC agencies. However, the scope of PAS/ISC agency responsibilities 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. Moreover, the lack of a comprehensive SPOE system has posed problems for Illinois in the past with respect to maximizing federal Medicaid funding of services.

It is recommended that Illinois expand the responsibilities of the PAS/ISC agencies so that they function as true comprehensive SPOEs for entry of individuals into publicly-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);
- √ Assisting individuals to access services; and,
- √ Service authorization.

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.

It is recommended that this expansion of PAS/ISC agency responsibilities be scheduled for implementation during 2010.

As an alternative, Illinois can consider substituting a public SPOE system for the present PAS/ISC agency network. This may prove more cost efficient. The pros and cons of switching to a public SPOE system should be weighed as part of the detailed implementation planning for this action step.

Summary

An adequately resourced, effectively functioning external service coordination system coupled with a SPOE system architecture is essential to ensure that people with developmental disabilities and families have access to services that will best meet their needs. The PAS/ISC agency platform can serve as the starting point for the implementation of such a system in Illinois.

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VII. Redesigning Services and Funding

Background

As discussed in the *Gap Analysis*, the current Illinois developmental disabilities system is not structured along person-centered lines. Individuals are slotted into programs and funding is tied to service agencies. Person-centered service delivery principles demand that funding be portable and flexible so that services and supports can be customized around each person's needs and preferences.

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

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

Action Steps

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

The needs of people with developmental disabilities can be met in a variety of ways. The essential principles of person-centered service delivery require that service plans be customized around the specific needs of each person. Person-centered service delivery requires a high degree of flexibility in how funds may be deployed.

However, historically, developmental disabilities service delivery systems have been organized along categorical program lines where individuals are slotted into specific types of services (e.g., day training) to which funding is attached. Categorical funding rules reduce flexibility in designing individual service plans and, frequently, create major obstacles in individuals changing from one type of service/support to another. Categorical funding is inherently rigid. At the same time, the use of categorical funding methods makes it easier for states to manage their budgets.

Illinois should develop and implement an IBA model to foster greater flexibility in the selection of services and improve funding portability.

Alternative approaches to structuring the funding of community services have emerged in recent years. These approaches attach a prospectively determined overall amount of funding to the individual. The funding amount (sometimes termed an individual

budget allocation or IBA) then serves as the financial framework within which a person's service plan is constructed. When an IBA model is employed, individuals and service planning teams can exercise decision making authority in the selection of services and supports to meet the needs of the person. An IBA model more readily supports varying the mix and volume of services during individual service planning. The use of an IBA model changes funding from a program/service basis to a focus on the individual. Since overall funding is capped, states retain the ability to manage their budgets.

As a general matter, IBA models assign resources to individuals based on their functional capabilities, characteristics and other factors. IBA models are designed to assign like amounts of resources to people with similar needs and life situations. Usually, such models employ information that is compiled by administering a standardized assessment instrument and are based on the observed usual and customary costs of supporting people who have similar needs. Some IBA models (e.g., the Wyoming DOORS model) generate person-by-person resource reallocations. Others generate IBAs that apply to groups of individuals in similar situations (e.g., a model that Connecticut has developed). All IBA models revolve around ensuring that people who have similar needs and life circumstances have the same level of resources available to them.

In the Illinois context, the development and adoption of an IBA model would contribute to breaking down the funding silos and rigidity that is present in the current system. Individuals and families would be able to more easily change service providers and types of services. Since spending would be limited by the amount of the IBA, Illinois could relax some of its purchase of service rules to permit more flexibility in the selection of services.

Designing and implementing an IBA model is complex. Since IBA models are driven by assessment information, it is necessary to select an appropriate assessment instrument and implement use of the instrument across the entire service system. It also is necessary to tie assessment data to expenditure data in order to properly identify usual and customary expenditures for people who have similar needs and circumstances. As a general matter, the design and implementation of a well-crafted IBA model takes about three years. It is recommended that Illinois begin the development of such a model in 2009 with the objective of full-scale implementation in 2012. However, an IBA model should only be implemented once Illinois has appropriately addressed base-funding levels for community services, especially with respect to community-worker wages.

The design and implementation of an IBA model also will facilitate the full-scale implementation of self-directed service delivery methods, as discussed below.

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

As discussed in the *Gap Analysis*, major concerns have emerged in Illinois concerning payment rates for community services. Some of these concerns revolve around the level of payments and are closely related to the adequacy of community worker wages. While various studies of Illinois payment rates have been conducted, these studies have not resulted in concrete action to revamp payment rates. In general, Illinois payment rates are rooted in historical payment levels rather than on explicit cost models linked to the real, verifiable costs of delivering services. Over the years, payment rates have been inconsistently adjusted to reflect changes in the cost of doing business.

A service system cannot achieve its fundamental goals and objectives unless a state's payment rates fairly and appropriately compensate providers for the reasonable cost of furnishing authorized services. Unless payment rates are appropriately determined, individuals and families will encounter problems securing services that are authorized in the service plan and insufficient providers will come forward to furnish services. *De facto*, in the face of inadequate payments, service quality suffers as does the confidence individuals have in the system. To contrast, systems with reasonable payments can help improve quality while boosting confidence. Families of individuals living in SODCs, for example, may feel more confident in moving their family member into the community if they felt the rates were adequate to support them.

At the same time, payment rates must encourage economy and efficiency in the delivery of services. Sound payment rate determination methods impose appropriate limitations on allowable costs, including provider agency overhead.

Illinois should revise and update its payment rates for all types of community services.

Illinois needs to revise and update its payment rates for all types of community services. The appropriate pathway for rebasing and restructuring payment rates is to design payment rates that are structured around service/cost models that are explicitly based on the level of direct support staffing that is necessary to deliver a service, observed industry costs for other types of expenses (e.g., program management costs), and external data sources that can serve as appropriate cost benchmarks (e.g., Bureau of Labor Standards wage information).

Arizona provides an example of a state that completely revamped its payments for community services by developing data-based, data-driven cost models that contain very explicit allowances for direct support staffing as well as build in appropriate productivity and other factors that are designed to ensure economy and efficiency. As a result, Arizona now has a rate determination system that is based on realistic cost models and that can be periodically updated and rebased to reflect changing conditions. The Arizona system also strongly emphasizes provider accountability. For example, providers that do not staff services in accordance with the rate model are subject to the recovery of funds.

Illinois should follow Arizona's lead and replace its present patchwork of rates with a well-designed rate determination system. Design of this system should begin in 2009 and targeted for completion by 2011. A new rate system can build on the information that is garnered from the study of community worker wages that previously has been recommended.

Payment rate redesign likely will reveal the need for additional funding over and above the amount necessary to pay community workers a competitive wage. To the extent that additional funds may be required, new rates can be phased in over a multi-year period by treating the new rates as benchmarks. For example, Arizona phased in its new rates over a three-four year period, starting at 92 percent of the benchmark rate. Presently, Arizona is making payments at 100 per cent of the benchmark rate.

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

Nationally, self-direction has caught hold as an alternative method for the delivery of home and community-based services. Through self-direction, individuals and families have the authority to exercise decision making authority over the services and supports that they receive, manage an individual budget, and hire/fire their support workers. The federal Centers for Medicare & Medicaid Services (CMS) recognizes that

self-direction is a legitimate alternative to provider-managed services and has strongly encouraged states to incorporate opportunities for self-direction into HCBS waivers for people with disabilities, including individuals with developmental disabilities. The past two years have seen numerous states modify their Medicaid waivers to include self-direction as an option that waiver participants may select. For example, Minnesota has incorporated a self-directed services option into all five of its HCBS waivers for people with disabilities. Individuals and families who direct their services generally express high levels of satisfaction.

Strategically, self-direction offers several advantages to a state. One major advantage is that self-direction can serve as a vehicle to expand the number of service providers beyond the current set of specialized agencies by adding non-specialized agencies and vendors. As a general matter, the use of self-directed service delivery methods is no more costly than provider-managed service delivery and frequently has proven to be less costly. Self-direction also directly engages individuals and families in managing funds/services and, thereby, creates positive incentives for them to access community resources and unpaid support to meet many of the needs of the individual.

As noted in the *Gap Analysis*, DHS/DDD had crafted plans to sponsor a 70-person self-direction pilot project that would have enabled adults to control residential services and other funding. Though state recently learned that it could not launch this pilot within its HCBS waiver, it remains committed to the idea.

We note that the state already supports about 16,000 individuals in its present home-based service option where principles of self-direction are promoted. The pilot would have given Illinois the opportunity to expand this experience.

Illinois should start the planning to scale up self-direction systemwide, targeting full statewide implementation by no later than 2011.

Illinois should continue with the necessary planning to scale up self-direction across the entire developmental disabilities service delivery system. Successful large scale implementation of self-direction will require designing effective education programs for individuals and families, building the necessary supporting infrastructure (e.g., financial management services), and modifying purchase of service policies.

Planning for full-scale, system-wide implementation of self-direction should start in 2008. This planning should be undertaken in consort with key stakeholders, including self-advocates and families. System-wide implementation should be phased-in, starting with one-two geographic areas in 2009. Statewide implementation should be targeted for 2011. In 2012, the amount of funds that individuals and families can self-direct can be tied back to the IBAs that are recommended under Action Step # 12.

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

Outcome-oriented services and supports are those that lead to real changes in people's lives that result in improved community integration and independence. Such services and supports lead to less dependence on the service system and greater opportunities for individuals to experience everyday community life. Outcome-oriented services and supports include supported employment, supported living, and supports for community participation through volunteering and similar activities. The hallmark of outcome oriented services and supports is promoting

opportunities for people to live, work and participate along side with people who do not have disabilities.

Illinois lags most other states in the delivery of outcome-oriented services and supports. For example, relatively few people with developmental disabilities in Illinois are engaged in supported employment. In other states, a much higher percentage of individuals have regular jobs in the community. Study-after-study has revealed that people with developmental disabilities value having a regular job in the community and benefit from being in a work place where their co-workers are people without disabilities.

Promoting outcome-oriented services and supports requires state leadership. On a pragmatic basis, successfully promoting such services requires a combination of system-level changes, technical assistance, and education/training. During the Blueprint period, Illinois should focus on the following:

√ **Employment**. In part, Illinois' poor performance in securing integrated employment for people with disabilities is due to the state's relatively low payment rates for employment services. Current rates are appreciably lower than the rates paid in other states to support community employment. More broadly, Illinois has tied down the bulk of its funding for community day services to day training programs. Improving the portability of day services funding also is necessary in order to enhance opportunities for people to secure integrated work. Finally, Illinois has suffered from a lack of strong state leadership in the arena of promoting employment opportunities for people with developmental disabilities.

Some of the previously recommended action steps (e.g., revamping payment rates) can contribute to overcoming some of the barriers to securing integrated employment for individuals. A near-term step that Illinois can take to step up its focus on employment would be to join the National Association of State Directors of Developmental Disabilities Services newly formed State Employment Leadership Network. The Network is designed to promote the interstate exchange of information about improving employment opportunities. The Network can serve as a strong resource for Illinois.

Stepping up employment in Illinois requires elevating employment to high priority status. Consequently, it is recommended that DHS/DDD establish a unit that is solely dedicated to improving employment opportunities for people with developmental disabilities. It also is recommended that, starting in 2010, $5 million in additional state grant funds be made available to community agencies to support the development of supported employment services. Lastly, it is recommended that Illinois establish the objective that by 2012 at least 30 percent of all adults who receive day time services are being supported in integrated jobs.

√ **Supported Living**. Supported living means the provision of services and supports to individuals in living arrangements that they own or control rather than confining services to provider owned and operated living arrangements. Supported living services promote community integration and independence.

Regarding control, previous action steps (e.g., Step 12 on individual budget allocation and Step 14 on self-direction) create a strong context for placing individuals in greater control of their lives. In addition, DHS/DDD should build on existing protocol and momentum in Illinois to promote home ownership for people with disabilities. Since 2002, the Homeownership Coalition has worked through state Independent Living Councils to help people with disabilities purchase their own homes. The Coalition works with the Illinois Housing Development Authority, banks and other authorities to help individuals make reasonable down payments

and secure favorable low interest loans.

√ **Supports for Community Participation**. In a similar vein, Illinois also should redesign adult day services so that people can be supported to participate in community activities outside the confines of facility-based programs.

Illinois' reliance on large, congregate-care service options imposes a "facility-first" culture across the system. As a result, individual lives play out day to day within a context that broadly gives priority to the demands of facility operations. Facility staffing patterns, operational requirements and funding constraints typically result in routines and rules that greatly dictate what happens to people during their day.

This is not to say that people are wholly isolated from their communities in Illinois, but to illustrate that the nature of large facility-based care diminishes the opportunities people may have to participate in their communities in ways they prefer with the supports they need. To contrast, in several other states strong action is taken to involve individuals with community life, including participation in faith based and other community oriented organizations.

Overall, community participation can be emphasized within a person centered planning process. More specifically, states can promote particular efforts to encourage such outcomes. Oregon funded a one-time grants program whereby local entities competed to provide unique local opportunities for community participation. In New Hampshire, the LifeArt Community Resource Center (www.mds-nh.org/mds/html/lifeart.htm) in Keene provides a "drop in" resource to people with developmental disabilities and others that fosters connections between individuals that bring together all the community. Pathfinders in a part of California employs self-advocate "Lifeguides" to help other self-advocates create a "Life Plan" for how they want to live their lives. Service coordinators subsequently make sure that services and supports are provided according to an individual's Plan. Equally of interest are "peer support" networks whereby self-advocates, with assistance, act as mentors or organizers to facilitate community participation among other self advocates.

Acting on previous recommendations can change individual living arrangements, but the underlying culture must be altered to promote community participation. DHS/DDD must take definitive action for change and, starting in 2010, make $5 million in additional state grant funds available to community agencies to advance this outcome.

Summary

The changes recommended under this action area will move Illinois toward scaling up the use of contemporary best practices in supporting people with developmental disabilities. The feasibility of implementing these changes hinges on Illinois taking the steps identified in the previous action areas to establish a solid service delivery platform.

VIII. Measuring Performance and Quality Improvement

Background

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

Action Step

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

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. The state lacks comprehensive information available concerning whether individuals and families are satisfied or dissatisfied with the services that they receive. Illinois does not measure the extent to which individuals are realizing valued outcomes as a result of the services that the state provides. As previously discussed, Illinois does not presently have systems that compile systematic information about the quality of community services.

Illinois also has not made a commitment to continuous quality improvement. While it is clear enough that there are major problems in the delivery of services of all types, such problems typically are being addressed on a reactive, ad hoc basis. Absent systematic performance measurement, Illinois will be trapped in a cycle of patching over problems rather than being in a position to proactively address system weaknesses through continuous quality improvement.

Moreover, if Illinois were to implement the steps we recommend, policy makers and others would be served best if they had available reliable and accurate information to monitor the significant changes undertaken and adapt policies as needed. Lacking such information, the changes would unfold without policy makers having a clear understanding of the new dynamics in play or their impacts.

To address this major shortcoming, Illinois will have to commit resources to establish information technology (I/T) systems that capture and integrate information about services for people with developmental disabilities. A full-capability I/T system (i.e., one that integrates information about individuals, services provided and expenditures, quality assurance, outcomes and other data) can cost several million dollars and take several years to design and implement. Illinois, however, will need to decide first what sort of system it requires, at what cost, and how it can most efficiently develop such a system over time.

To develop the preferred system, several steps must be followed:

√ **Reach consensus on the benchmarks that will brand the system and form a basis for the information that is collected**. The *Gap Analysis* provides seven top level performance benchmarks to consider. In addition, the *Blueprint* action steps offer markers that could be used to judge performance.

- √ **Develop an adequate platform for gathering needed information**. The model for a full featured I/T system is the Pennsylvania Home and Community Services Information System (HCSIS). HCSIS serves as a single platform that supports service planning and authorization processes while also capturing data about quality and outcomes. HCSIS is a state-of-the-art approach in the design of an I/T system that supports the operation of a complex human services delivery system.
- √ **Decide on how information will be collected**. An I/T system only serves as a means to perform processes and collect data. The more central consideration with respect to performance measurement and quality improvement is identifying the types of information to collect and how it might be collected. Illinois should focus on securing the following types of information:
  - Routine compilation of information about service quality related to the results of periodic service coordinator monitoring of individuals, including service plan implementation. Further, the system should support the integration of monitoring results with the results of provider quality reviews along with information compiled concerning critical incidents.
  - Direct information acquired through interviews with individuals and families about their experiences and satisfaction with the services that they or their family members receive. Such information can provide invaluable feedback concerning system and provider performance. Along these lines, the Pennsylvania Independent Monitoring for Quality (IM4Q) program can serve as a prototype. Through IM4Q, independent teams conduct interviews of people with developmental disabilities in order to collect systemic information about their service experiences. These teams include people with developmental disabilities and family members. Information compiled from these interviews is used to provide feedback to providers and service coordination entities about the quality of services that people receive. This information also is aggregated statewide and used to identify focus areas for quality improvement. Illinois should consider implementing a similar program.
  - Illinois also should consider adopting recognized personal outcome measures and collecting systematic information about the extent to which such outcomes are being realized. For example, Florida decided to adopt the personal outcome measures that have been developed by the national Council on Leadership and Quality. Florida has contracted with a private organization to collect systematic, provider-by-provider information concerning the extent to which individuals served by providers realize these outcomes. This information provides state officials and stakeholders with systematic information concerning system performance. It also provides important feedback to provider agencies concerning their performance relative to other providers.
- √ **Decide on how the information will be used to improve performance**. Collecting information about system performance is a necessary first step. Equally important is using this information to alter policies, change service practices, or improve performance of individual service agencies. Systems cannot be changed all at once. Collection of targeted information tied to predefined benchmarks and coupled to corrective action can, over time, yield steady system improvement.

We understand that DHS/DDD has already taken steps in this direction. Technical staff have begun building electronic platforms to compile information on individuals and providers with a common “client identifier” to allow tracking individuals across

various human service agencies. In addition, DDD expects to launch in August 2007 an online reporting format where residential and day program providers can log on to report vacancies and other service details. The site will also be accessible to staff of service coordination agencies and service users. DDD expects that the site will provide it with a centralized useful data base, but also offer information to a range of other interested users. DDD needs to maintain the present momentum to design and implement a useful I/T system, comparing its efforts along the way to the above described steps.

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IX. Implementation Sequence

Background

This *Blueprint* is underpinned by seven essential performance benchmarks that apply to services for people with developmental disabilities. Necessarily, the strategic approach taken requires that all aspects of the adult system be taken into account.

Aside from concrete actions to reduce the number of people living in SODCs or large community ICFs/DD, Illinois must concurrently build capacity to meet demand and do so while improving its community system. Without these complementing actions, Illinois will undercut its effort to downsize large facilities and may actually reinforce arguments to keep these facilities open. By strengthening the community system, Illinois can ease concerns over transitioning people from large facilities into the community, and stimulate demand for progressive community service options.

In the previous sections, 16 Action Steps were identified, several of which contain sub-steps. In this section, these 16 major steps are shown along a seven year timeline so that they can be seen in total and in relation to one another.

Sixteen Action Steps Over Seven Years

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

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

Going forward, what might Illinois do to address the needs of its citizens with developmental disabilities most efficiently and effectively? One crucial pivot point that defines the present conundrum concerns the notion of "choice." This concept is used to describe a necessary imperative within the system whereby people with developmental disabilities can have maximum opportunity to choose their living arrangements. This ideal is advanced based on principles that were set forth in the U.S. Supreme Court *Olmstead* decision. In Illinois, however, it is used to validate and sustain the continued investment in legacy systems. Inevitably, to avoid conflict among stakeholders, the system acquiesces to the idea of investing in the "full range of choices" for service recipients.

In our view, however, the *Olmstead* decision sets forth clear standards to limit the use of large congregate facilities as well as the imperative for states to manage its system so that the waiting list is addressed at a reasonable pace. *Olmstead* sets the standard that people with disabilities must be supported in the most integrated

setting. Simply put, the evidence reveals that other states have pushed in this direction more vigorously and with greater effect than has Illinois.

Clearly, present fiscal and policy trends in Illinois cannot suffice. Illinois must make changes in its present response to the needs of its citizens with developmental disabilities. Yet change, after all, imposes choices in policy. To guide the way, we crafted seven performance benchmarks that should underscore the provision of public-funded services. In brief, these benchmarks emphasize:

1. Access to services with reasonable promptness;
2. Services provided in the most integrated setting;
3. Person centered supports and services;
4. The presence of a supportive system infrastructure;
5. Services that result in achieving preferred personal outcomes;
6. Services that meet quality standards; and
7. A system that promotes economy and efficiency.

Given these benchmarks, 16 Action Steps were fashioned to help the state systematically realize each of the seven performance markers. As illustrated by the accompanying graphic depicting the Action Steps and their time line, there is much to do in a relatively short period of time. Four key elements to all of the actions recommended include a commitment from DHS/DDD to:

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

Review of the many steps recommended also reveals three types of actions:

- √ Discrete significant actions that are planned, implemented and completed within a fixed time period. Examples include:
  - Closing five SODCs (sub-step within Action Step 1)
  - Passing permanent “Money Follows the Person” legislation (Action Step 2)
  - Modify the manner by which the ICF/DD provider tax is calculated (sub-step within Action Step 3)
  - Increase “top line” payment rates for community providers (sub-step within Action Step 5)
  - Increase the allowance for HCBS waiver ISSA services from 25 to 50 hours per year (sub step within Action Step 10)
- √ Actions that develop a sound platform to work from, but lead to other larger actions. Examples include:
  - Establishing a Task Force to craft a set of specifications for the operation of Behavioral Support Organizations (sub-step within Action Step 6)
  - Adopt a standardized risk assessment protocol as part of individual service plans (sub-step within Action Step 7)
  - Put in place a single point of entry system (Action Step 11)
  - Create means for setting individual budget allocations (Action Step 12)

- Revamp and improve management and information systems and associated means of monitoring service quality (Action Step 16)
- Adopt a data-based means for setting rates for community services (Action Step 13)

√ Significant actions that endure, and must be undertaken year to year. Two primary examples include:

- Starting in 2009 and each year thereafter through 2014, add 2,316 people to the HCBS waiver (Action Step 8)
- Reduce the number of people served at the SODCs to no more than the national utilization rate for these types of facilities (Action Step 1)

The scope of the task at hand, and its associated costs, may appear daunting to some. Significant concrete actions must be taken and coupled with actions that create a favorable context for change. In turn, these actions will allow the state to reduce its reliance on large congregate care options, while building capacity for a future tied to the community.

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

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

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

Focus Area	Action Step
1	1. Reduce use of SODCs Close five SODCs 2. "Money follows the person" legislation 3. Policies for agencies to transition from ICF/DDs 4. Bar development of large CILAs and facilitate downsizing
2	5. Boost funding for community to pay competitive wages 6. Build capacity for challenging conditions. 7. Strengthen oversight of community services
3	8. Enroll 2,316 people per year in the HCBS waiver 9. Expand home based services. Consider supports waiver.
4	10. Establish adequately funded external service coordination 11. Establish single point of entry system.
5	12. Restructure community funding to promote flexibility & portability 13. Adopt data based rate determination 14. Self-determination 15. Emphasize outcome oriented services
6	16. Measure performance & promote improvement