Systems of Care for Individuals with Intellectual and Developmental Disabilities: A Survey of States

By Gretchen Engquist, PhD, Cyndy Johnson, and William Courtland Johnson, PhD   S E P T E M B E R   2 0 1 2

State agencies serving individuals with intellectual and developmental disabilities (I/DD) strive to provide efficient and effective systems of care. However, in many cases they have been slow to adopt innovations in the structure and financing of I/DD services as they deal with the more pressing concerns of severe budget reductions, litigation, and stakeholder opposition to change.

Although some states have embraced innovations such as self-directed services, many of these programs serve only a fraction of a state's I/DD population. To date, comprehensive system redesign has occurred on a statewide basis only in Arizona, Michigan, and Vermont. While Minnesota and Massachusetts offer managed long-term services and supports (LTSS) programs for persons with I/DD on a voluntary basis, enrollment is small; and Wisconsin offers "voluntary" enrollment, but access to waiver services is contingent upon enrollment in its managed LTSS program.

Until recently, states were reluctant to enroll their I/DD populations in managed care for either acute care services or LTSS. However, growing comfort with managed care models for complex populations and budget-related pressures have prompted some states to rethink their positions on managed care for I/DD populations. Other states are seeking ways to make their existing fee-for-service systems more cost effective, including the adoption of resource allocation models based on levels of assessed need outside of a managed care structure, emphasizing non-bricks and mortar service options, and strengthening supported employment.

While resources such as the University of Minnesota's *National Residential Information Systems Project* and the University of Colorado's *State of the States in Developmental Disabilities* track valuable information on publicly-funded services for people with I/DD, there are currently few resources to assist states in redesigning the delivery structure and financing of I/DD services. This policy brief describes the results of a survey of state I/DD agency directors regarding their current delivery systems and planned innovations for people with I/DD. The survey results

IN BRIEF

Innovations in the structure and financing of services for individuals with intellectual and developmental disabilities (I/DD) have been slow to take hold in Medicaid programs across the country. Barriers such as budget reductions, litigation, and stakeholder opposition to change hamper states' ability to focus on system redesign.

This brief describes the results of a survey of state I/DD directors regarding their current delivery systems and planned innovations for individuals with I/DD. The survey results can help inform state decision-makers as they move toward implementing innovative systems of care for I/DD populations.

can help inform state decision-makers in advancing systems redesign for this high-need population.

Surveys were emailed to state I/DD agency directors in February 2011. Questions covered current agency activities as well as planned innovations in service delivery and reimbursement for persons with I/DD. The survey touched on a variety of issues, but the results presented here specifically focus on:

- Pressing issues for I/DD agencies including initiatives for enhancing service provision and barriers to reform;

- Assessment and person-centered planning; and

- Waiting lists for home- and community-based services (HCBS).

Completed or partially-completed surveys were received from 25 states and the District of Columbia.[1]

Pressing Issues, Barriers to Reform, and New Initiatives

Pressing Issues

States were asked about the top challenges currently facing their I/DD programs. By a wide margin, states ranked budget issues as their most daunting problem. Twenty-one of the 26 state I/DD agencies responding ranked budget issues as their most pressing issue.[2]

Unsurprisingly, the overwhelming majority of responding states (80 percent) have had to adopt cost containment strategies in the wake of the recession, with reductions in provider reimbursement the most common cost-cutting measure. Other cost containment strategies included the elimination of dental services, agency hiring freezes, and increased departmental efficiency. In addition, 75 percent of respondents were planning or proposing additional cost containment measures, such as further administrative consolidation, additional rate reductions, and placing limits on specific services. Several states surveyed are seeking to improve the targeting of services by using validated, data-driven resource allocation tools such as the Supports Intensity Scale as a means of better assessing an individual's service needs.

Barriers to Reform

When asked about barriers to meaningful systems reform, every respondent except Wyoming and North Dakota cited budgetary issues ranging from a general lack of funds to concerns about federal reimbursement to the challenge of operating siloed programs with separate administration and funding streams. A number of states specifically stated that their anticipated levels of funding will be insufficient to reduce or eliminate waiting lists for the foreseeable future. Other important barriers include:

- **Agency administration and organizational issues**, including interagency conflicts; lack of state staffing resources; the sheer number of distinct programs; balancing CMS requirements with state and local requirements; and the complexity of serving individuals dually eligible for Medicare and Medicaid.

- **Information technology issues**, including lack of IT infrastructure; rural IT capacity; competition between I/DD-related IT priorities and other health care reform-related IT priorities.[3]

- **Stakeholder issues**, including provider lobbying strength; provider resistance against transitioning the traditional bricks and mortar-based service delivery system to community-based alternatives; stakeholder fragmentation; and guardianship resistance.

- **Environmental issues**, including economic climate dampening interest in initiatives; workforce shortages; turnover of direct care staff; low wage rates; and lack of provider capacity to meet HCBS service needs.

New Initiatives

Although states face budgetary and other barriers, nearly all state survey respondents indicated that they have implemented, or are in the process of implementing, a number of new initiatives. Of the 21 states with planned or implemented initiatives, 18 (86 percent) reported initiatives to improve the availability of transportation. After transportation, initiatives related to information technology (76 percent), supported employment (76 percent), and reimbursement (67 percent) were cited most frequently. At least half of the states also identified initiatives to:

- Improve state administration and oversight (57 percent);

- Revise their service package (62 percent);

- Improve the cost-effectiveness of service delivery (62 percent);

- Integrate medical and behavioral health services with LTSS (62 percent);

- Improve care planning (57 percent); and

- Reduce the size of waiting lists (52 percent).

Thirteen survey respondents indicated plans to close state institutional beds. The most common rationale for closing beds (states could select more than one reason) was to comply with a state agency-led initiative, a reason cited by nine of the 13 respondents. Five cited budget savings, while three or fewer chose one of the other reasons.

State responses indicated a great deal of interest in new programs made available through the Affordable Care Act. All but two states said that they would participate in the expanded Money Follows the Person program. In addition:

- Michigan plans to develop a section 2703 Medicaid Chronic Care Health Home Project;

- New Jersey intends to use the 1915(i) authority to support services for specific I/DD populations (e.g., children with intensive needs); and

- Minnesota intends to pursue the 1915(k) Community First Choice Option.

These efforts notwithstanding, many states described reforms that they would like to implement (improving supported

employment programs, increasing participation in self-direction, reducing or eliminating waiting lists, and improving IT infrastructure), but have not been able to because of previously described barriers. Examples of other reforms that states would like to implement include:

- Customizing the service delivery system for I/DD subpopulations, including persons with autism spectrum disorder, medically fragile, medically complex, and significantly behaviorally challenged;

- Implementing a uniform assessment process for the equitable distribution of resources among participants;

- Transferring responsibility for assessments from providers to independent assessors (either contractors or state staff) to ensure conflict-free assessment processes; and

- Automating service planning, approval, and change processes and providing participants/families with "real time" information.

▶ *The survey results indicate* that states recognize the need to innovate and improve their delivery systems for I/DD services. Despite many obstacles, states have found ways to move forward. The types of innovations planned by states will improve services for beneficiaries and help states to better manage their resources.

Standardized Assessments for Person-Centered Planning and Resource Allocation

Assessment Tools Used by States

States use a variety of instruments for allocating resources according to beneficiaries' assessed needs for services and supports. More than half of survey respondents use a standardized assessment tool to inform the service planning process (Table 1). The most commonly used tools are the:

- Inventory for Client and Agency Planning (ICAP);

- Developmental Disabilities Profile (DDP); and

- Supports Intensity Scale (SIS).

Three states -- Vermont, Minnesota, and New Jersey -- reported using customized assessment tools. New York recently selected the interRAI instrument (Resident Assessment Instrument) for its proposed Section 1115 "People First" waiver (New York currently uses the DDP, as do Kansas and Ohio). Georgia, New Mexico, Rhode Island, Louisiana, Oregon, North Carolina, and North Dakota have adopted or are in the process of adopting the SIS tool.

The SIS tool was created by the American Association of Intellectual and Developmental Disabilities (AAIDD) to gauge the intensity of support an individual needs based on

his or her ability to perform life activities combined with medical and/or behavioral support needs and other factors. At present, 18 states and 17 foreign countries have adopted the instrument and a number of others are actively considering doing so. The SIS tool works best when combined with other information such as whether unpaid supports are available or whether an individual requires close supervision owing to involvement in the criminal justice system. Other tools (e.g., Wyoming's DOORS instrument and South Dakota's Service-Based Rates) may also accomplish the same objective, with the overriding goal to allocate resources equitably and efficiently based on an objective assessment of individual needs.[4]

Most states have added supplemental questions to the SIS tool in three areas:

- Severe medical and psychiatric issues;

- Severe community safety risk; and

- Severe risk to self.

In a majority of states, assessments are conducted by the case manager/support coordinator. However, states using the SIS assessment typically designate internal assessment teams or contract with independent assessment contractors (in one state a support coordination provider agency conducts the assessment). The frequency of the assessment also varies. Most of states report conducting an annual reassessment or review, but some conduct them less frequently or only perform them when a beneficiary's condition warrants.

Selecting an Assessment Tool

When selecting an assessment tool, states should consider a number of factors:[5]

- The scope of the tool (i.e., national versus state-specific);

- The tool's reliability, validity, and standardization;

- The tool's comprehensiveness (i.e., applied to all services and supports or to specific waivers, populations, or services); and

- How the tool is administered and by whom (e.g., state agency, provider, third-party contractor, etc.).

In addition, states must decide how often beneficiaries should be reassessed, how the implementation process should unfold, and what to do when new beneficiaries are added.[6]

A key factor in the reliability of resource allocation tools is consistency in the manner in which they are administered and interpreted. This is especially important in states that

have a newly-adopted system for allocating resources inasmuch as some beneficiaries may experience a reduction in services and supports based on the assessment. If there are questions or inconsistencies about the accuracy of the results, the entire methodology will be thrown into doubt. To avoid this, states should first simulate the results of the tool, determine how funding patterns will be altered, and obtain feedback about the potential implications. It is also important to have alternative strategies in place for "outliers" who have unique support needs that the tool does not address.[7]

Dissatisfaction with Assessment Tools

Almost half of the states reported a desire to use a different tool to inform person-centered planning or assign resources to individuals, and/or they wanted to change the methodology they used to assign resources to individuals. Alabama and Maryland are evaluating the use of the SIS tool and Pennsylvania recently announced its intention to adopt it as well. The District of Columbia, Georgia (SIS state), Kansas, Michigan, Minnesota, Missouri (SIS state), Nebraska, Ohio, and South Carolina indicated a desire to change one or more instruments or methodologies, but did not indicate precisely how.

States expressed a number of frustrations regarding assessment options and processes:

- **High costs**: Some assessment tools are proprietary and have high fees that must be paid for each assessment performed. Also, assessments and reassessments are typically conducted by licensed professionals in the individual's residence, which adds to their cost.

- **SIS tool issues**: While the SIS is gaining increasing acceptance nationally, some states have expressed concern that the AAIDD–which developed the tool, conducts state pilot tests, and is the only source of SIS training–does not recognize the urgency of state needs. Moreover, AAIDD assessors are costly and states would like to see a greater availability of qualified vendors to conduct SIS assessments. New Mexico recently contracted with an independent entity whose assessors will be trained by AAIDD, suggesting that there has been movement to broaden qualified vendors other than AAIDD. There is also some concern that the SIS instrument needs to be periodically retooled and it is unclear whether AAIDD plans to undertake this task.

- **Assessments of children**: While most states do not cover young children in their waiver programs, there are exceptions (e.g., North Dakota). The SIS tool is only valid for individuals age 16 and over and there are no current assessment options for children under age five. (The child SIS now in BETA testing is valid for children age five and above.)

- **Natural supports:** States expressed their concern that none of the available tools appear to assess the nature and extent of the natural/informal supports available to beneficiaries. This is a significant concern since states do not have the budget to supplant natural supports.

▶ *The survey results indicate* that states are searching for, but largely have not found, standardized assessment tools that meet their needs. Ideally, individuals with I/DDs should receive the services and supports they need in accordance with their preferences and abilities. In reality individuals with similar needs are frequently allocated differing funding levels with no discernible rationale other than what are known as "system factors" (e.g., regional variation, case manager decisions, provider influence). Also "first-come, first-served" waiver policies keep individuals on waiting lists for years, while other individuals with lesser needs continue to receive services because they were there first. Consequently, service awards often appear arbitrary and unfair.[8] To address this issue, states must continue to develop and implement standardized assessments to evaluate individual support needs and protocols for allocating resources that are equitable and efficient.

Waivers and Wait Lists

Waiver Authority and Covered Services

There are a number of Medicaid waiver authorities available to states that could be used to provide services for individuals with I/DD. However, almost all survey respondents (22) utilize 1915(c) waiver authority to provide home- and community-based services to persons with I/DD (Table 2). Five states use (or plan to use) Section 1115 waiver authority (Arizona, New Jersey, New York, Rhode Island, and Vermont). States also reported using 1915(b) or (b)/(c) combination waivers for managed care. In general, it appears that states are moving to global waivers or are putting services for individuals with I/DD under 1115 demonstration waivers.

			Update

Table 1: Assessments Used to Inform Resource Allocation/Reimbursement

State	Assessment Used	Inform Resource Allocation	Who Performs	Update Required to Change Resources
Alabama	ICAP-but only for very limited components of rate setting, not currently used for global resource allocation	Yes	Case manager	No
Delaware	ICAP	Yes	Arbite Consulting, Inc.	No
Georgia	SIS as the basis of a formal resource allocation model (in the process of implementation)	Yes	Support coordinator	No
Kansas	DDP	Yes	Assessment contractor	Yes
Louisiana	SIS as the basis of a formal resource allocation model (in the process of implementation)	Yes	Support coordination provider agency	Yes
Montana	Montana Needs Assessment	Yes	Case manager	Yes
Nebraska	ICAP	Yes	State employees	Yes
New Jersey	Developmental Disabilities Resource Tool is used to identify resource needs and allocation for some waiver recipients	Yes	The New Jersey Institute of Technology's DD Planning Institute	Yes
New Mexico	SIS is the basis of a formal resource allocation model (in the process of implementation)	Yes	AAIDD[1]	Yes
New York	DDP2	Yes	Service provider	Yes
North Carolina	SIS is the basis of a formal resource allocation model in the Piedmont region	Yes	Managed care contractor	Yes
Ohio	Ohio Developmental Disabilities Profile	Yes	County Board Service and Support Administrator	Yes
Oregon	SIS is the basis of a formal resource allocation model	Yes	State employees configured as assessment team	Yes
Rhode Island	SIS is the basis of a formal resource allocation model	Yes	State employees configured as assessment team	Yes
Vermont	Tool developed by providers	Yes	Intake coordinator or supports coordinator at local provider	Yes
Wyoming	ICAP	Yes	Outside contractor	No

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[1] In July 2012 New Mexico contracted with an independent entity to perform SIS assessments. AAIDD will train the assessors.

Respondents expressed two sources of frustration relating to waiver authorities and the waiver application/renewal process: the inability to consolidate waiver programs and the lack of federal support for innovative waiver applications.

Multiple Waiver Programs: An inability to consolidate various waiver programs creates a multitude of negative consequences for states, including:

- Competition for staff and budgetary resources among waiver programs;
- An inability to pursue innovative strategies such as supporting caregivers as well as beneficiaries within the same waiver to maintain both at home as long as possible at the least cost;
- Difficulty addressing the increasingly complex medical needs and comorbid conditions of the aging I/DD population;
- Limitation of strategies available to meet the needs of individuals with dual diagnoses (i.e., comorbid I/DD and behavioral health diagnoses); and
- Inability to use limited state management resources efficiently because waivers often have different requirements and effective dates and encourage duplication.

Waiver Application Process: Some respondents observed that CMS is very supportive of state efforts. The majority recognized the need for a close partnership between CMS and states to clarify what is needed to move waivers forward. States sought flexibility from CMS in reviewing proposed innovations and encouraged CMS reviewers to acknowledge the need for states to seek cost-effective and efficient models to improve care delivery for the I/DD population.

States were asked about services offered through waivers, state plans, and state-only programs as well as reimbursement for those services. The most common waiver services include supported employment, respite, and assistive technology.

Not surprisingly, states offer fewer state plan services than waiver services to support persons with I/DD in the community. The most commonly cited state plan services that contribute to the care of individuals with I/DD living in the community include:

- Case management;
- Personal care;
- Transportation;
- Behavior supports;
- Rehabilitation; and
- Clinical services.

At least one-quarter of states listed assistive devices, partial hospitalization, psychosocial rehabilitation, and crisis services as state plan services.

Fewer than half the states offer state-only and/or local-only services, with some states offering just a few services and others a full continuum. The most common state/local-funded service is respite care, followed closely by case management.

Wait Lists

Due to budgetary and infrastructure constraints, most states have a fixed capacity for providing waiver services, which forces them to use waiting lists to limit access. Unfortunately, because of decreased rates of turnover among beneficiaries already receiving services, some state waiting lists have become quite lengthy and beneficiaries often wait years to access services.

Almost all states maintain a waiting list for I/DD waiver services, with the noteworthy exceptions of Arizona, California, the District of Columbia, Hawaii, Idaho, Massachusetts, Michigan, North Dakota, South Dakota, Rhode Island, and Vermont. About a third maintain more than one waiting list, with survey respondents citing a number of reasons for maintaining more than one waiting list, including:

- Maintaining a separate list for each waiver program (Ohio, Texas, and Wyoming);
- Keeping one list for residential services and another for home services so that beneficiaries can receive some waiver services while continuing to wait for openings in housing to become available (Missouri);
- Maintaining separate short-term and long-term lists (Georgia and Maryland); and
- Keeping one list for people transitioning from state institutions and another for non-priority applicants (Arkansas).

States vary in their approaches to managing wait lists. Slightly more than half of those states with a waiting list have priority categories for moving individuals off the wait list; others are first-come, first-served. Common strategies for maintaining wait lists include:

- **First-come, first-served**: In these states, parents often sign their child up for waiver services upon diagnosis of I/DD even though the child may not need the service for 20 years. States can spend valuable administrative resources managing a wait list with individuals who cannot access the service for years. One strategy is to

Table 2: Waiver Authority Used for I/DD Services						
STATE	1915 (B)	1915 (C)	1915(B)(C)	1915(I)	1915(K)	1115
Alabama		Yes				
Arizona						Yes
Arkansas		Yes				
Delaware		Yes				
District of Columbia		Yes				
Georgia		Yes				
Kansas		Yes				
Louisiana		Yes				
Maryland		Yes				
Michigan		Yes[9]	Yes			
Minnesota	Yes	Yes				
Missouri		Yes				
Montana		Yes				
Nebraska		Yes				
New Jersey						Yes[10]
New Mexico		Yes				
New York		Yes				Yes[11]
North Carolina		Yes	Yes[12]			
North Dakota		Yes				
Ohio		Yes				
Oregon		Yes				
Rhode Island						Yes
South Carolina		Yes				
Texas		Yes				
Vermont						Yes
Wyoming		Yes				
TOTALS	1	22	2	0	0	5

limit applications to individuals who would be eligible within three years.

- **Prioritize applicants**: The most common categories include individuals transitioning from: (1) an institutional placement; (2) crisis and/or emergencies; (3) school; or (4) child protective services.

- **Managed care**: Arizona's ALTCS managed long-term care program, which includes persons with I/DD, does not maintain a waiting list. And although Texas's STAR+PLUS managed long-term care program for elderly and physically disabled beneficiaries excludes beneficiaries with I/DD, it succeeded in eliminating the waiting list for waiver services by contracting with private managed care organizations (MCOs) to more effectively manage care and services. However, states adopting this approach must exercise caution when initially developing capitation rates because the impact of prioritizing the most severe cases can have a substantial impact on the financial viability of MCOs in the absence of appropriate risk adjustment for these higher need, higher cost beneficiaries. Moving the more severe cases off the waiting list first raises the case mix and resource needs of individuals served by MCOs.

The Human Service Research Institute (HSRI) recommends that individuals with I/DD who have emergency or crisis needs be able to access services within 90 days, and within six to nine months for those with critical near-term needs. However, to achieve this goal states must first have processes in place to track and trend the number of eligible applicants requesting services. For example, Illinois and Pennsylvania have adopted a tool known as the Prioritization of Urgency of Need for Services (PUNS), which stratifies applicants into one of three categories based on their individual needs as well as their caregiver's circumstances:

- Emergency (services needed as soon as possible or within the next six months);[13]

- Critical (services needed within one year (Illinois) or two years (Pennsylvania)); and

- Planning (services needed within five years).

As stated, having a tracking system is just the first step to ensuring access to services. States also need a workable process to make services available. Illustrating this point, although Illinois and Pennsylvania have tracking systems, their ability to provide services is not equal to the identified level of need. In 2010 Illinois reported there were more than 15,000 individuals with unmet needs in its two highest PUNS categories (118 per 100,000 population) and over 22,000 for all three PUNS categories (173 per 100,000

population while.[14] Pennsylvania had 15,888 persons on waiting lists in all three PUNS categories as of October 2011 (124 per 100,000 population).[15] Thus, states must adopt enhanced strategies for identifying and intervening with individuals who have emergent or critical service needs.[16] Additional best practices for managing wait lists include:

- **Determine financial eligibility**: Because waiver enrollment under 1915(c) cannot be retroactive (it can be under an 1115 waiver), a person moving off the wait list to a waiver program who has not been determined financially eligible may experience significant delay until the receipt of services.

- **Check for Medicaid claims**: Often neglected as a component of wait list management (and as protection in adverse actions), states fail to match their waiting lists to claims for state plan services, some of which support individuals living in the community with services such as personal care, home health aide, nursing, durable medical equipment, etc. A number of years ago, Ohio matched its waiting lists to Medicaid claims and found a significant number of those on the waiting list were accessing home-based services outside the waiver under the state plan (as they should). It is thus not true that all individuals on the waiting list are, in fact, unserved.

- ▶ *The survey results indicate* that states depend on Medicaid waivers to help individuals with I/DD live and function within their communities. However, many states do not have the financial capacity to provide waiver services for everyone who needs them. Finding ways to manage wait lists and increase access to waiver services must become a higher priority for states.

Conclusion

Surveyed states described their current delivery systems and planned innovations in care for individuals with I/DD. They continue to plan and implement innovations in service delivery despite such obstacles as budget shortfalls, lack of information technology infrastructure, and stakeholder resistance. They are eager to adopt uniform needs assessment tools that will determine the array of services and supports that individuals need based on their risk level. They also are looking for tools to help them manage waiting lists for services. States understand that they must become agents of change to assist individuals with I/DD and their families in securing the valued outcomes they desire – access, choice, and satisfaction.

Endnotes

[1] In some instances, states asked the authors to complete the survey for them based on the authors' knowledge of the state gained from previous consulting activities. One state declined to submit a written response owing to ongoing litigation. Survey responses were collected for: Alabama, Arizona, Arkansas, Delaware, District of Columbia, Georgia, Kansas, Louisiana, Maryland, Michigan, Minnesota, Missouri, Montana, Nebraska, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oregon, Rhode Island, South Carolina, Texas, Vermont, and Wyoming.

[2] These four states ranked Department of Justice inquiries, waiting lists for HCBS, and the loss of state staff as their most important issues.

[3] Specific IT-related issues include the inability to access all data for sources of care for I/DD individuals that states serve, including Medicaid State Plan claims and encounters, Medicare claims, and even a consolidated picture of the HCBS services they provide as a result of multiple legacy systems. Survey respondents report that their disparate programs often have separate financial and quality reporting systems. In fact, two states that reported having seven separate systems. IT development focusing on consolidating information on a single platform was cited as a challenge by most states responding to this question.

[4] A. Tribble, S. Wrigley, and B. Downing. *Utilizing an Enhanced Version of the Supports Intensity Scale with Direct Links to Individual Supports Planning.* Utah Department of Human Services, Services for People with Disabilities. May 2007.

[5] C. Moseley. *State Resource Allocation Strategies and Challenges.* Maryland Developmental Disabilities Administration, January 2008.

[6] Marc J. Tasse, PhD, "Resource Allocation and DD," University Center for Excellence on Developmental Disabilities, University of South Florida, May 2009.

[7] G. Smith and J. Fortune., *The Supports Intensity Scale and Resource Allocation.* American Association on Intellectual and Developmental Disabilities, June 2008.

[8] Ibid.

[9] Michigan uses the 1915 (c) authority for children and the 1915 (b)(c) authority for its Managed Specialty and Supports Services.

[10] New Jersey is nearing approval of a Comprehensive Waiver which brings virtually their entire Medicaid program under a single authority.

[11] New York has submitted an 1115 waiver proposal to CMS to develop an integrated program for people with developmental disabilities.

[12] North Carolina is in the midst of implementing a statewide 1915 (b)(c) managed care waiver for behavioral health and IDD that is currently operational only at Piedmont Behavioral Health.

[13] Pennsylvania further classifies the emergency category according to whether the individual needs out-of-home or residential services or whether the needed services are in-home supports.

[14] *Living in Illinois as a Young Adult with Developmental Disabilities.* Bridge2Hope. Available at: http://www.bridge2hope.com/Living%20in%20Illinois%20as%20a%20Young%20Adult.pdf.

[15] The Pennsylvania Waiting List Campaign. http://www.pawaitinglistcampaign.org/WL_County.html.

[16] Additional information about Illinois's PUNS initiative may be accessed at http://www.dhs.state.il.us/page.aspx?item=47620; information on Pennsylvania's program is available at http://www.temple.edu/thetrainingpartnership/resources/faq/faq_puns.shtml.