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# Approaches to the Integration of Services for Individuals with Intellectual and Other Developmental Disabilities (I/DD)

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Today, there is a great deal of focus on integration of physical and behavioral health care services within the health care system overall, as well as within state Medicaid programs. Individuals with intellectual and other developmental disabilities (I/DD) often have multiple physical, behavioral, and long-term services and support (LTSS) needs. Many advocates of integration suggest that the consolidation of these services can provide an opportunity to improve care for individuals with I/DD.<sup>1</sup> Based on interviews conducted with I/DD staff in six states (Arizona, Kansas, Michigan, New York, Tennessee, and Vermont), this paper highlights approaches to integrating services within the Medicaid program for individuals with I/DD, and lessons learned from states with integration activities underway.

Prior to the creation of home and community-based services (HCBS) waivers through section 1915 (c) of the Social Security Act in 1981, individuals with I/DD could only receive coverage for comprehensive long-term care services through Medicaid in an institutional setting.<sup>2</sup> Today, few individuals with I/DD reside in institutions owing in part to the enactment of the Americans with Disabilities Act of 1990<sup>3</sup>, the Olmstead decision in 1999<sup>4</sup>, and the ongoing advocacy of I/DD consumers, families, and decision-makers. Most individuals with I/DD receive services and support in community-based settings, often under HCBS waivers with support and medical services from a wide range of providers. While states have long focused on person-centered and coordinated care for individuals with I/DD, there has been limited movement toward full integration of physical, behavioral, and LTSS care. Today, individuals with I/DD receive services from states in vastly different ways, and the level of coordination and integration varies tremendously depending on the state.

## Challenges to Integration

There are a number of challenges to integration for individuals with I/DD that must be considered as part of the program planning, development, and implementation process. First, states often have separate agencies responsible for the Medicaid program and the operation of an I/DD waiver, and services for individuals with I/DD are often not coordinated with the rest of the state's Medicaid program. Likewise, many LTSS providers work separately from physical and behavioral health care providers and do not coordinate on a regular basis. While most providers recognize the benefits of communication and coordination, it is not easily accomplished.

Furthermore, LTSS providers are less likely than other providers to have electronic health record (EHR) systems, and, where they do, the EHRs are typically not interoperable. One contributing factor as to why LTSS providers have fewer EHR systems is that LTSS providers are not eligible for financial incentives from the Office of the National Coordinator for Health Information Technology for the implementation of EHRs in primary care and hospital settings. Because the development and design of most EHR systems have focused on primary care and hospital settings, EHRs typically do not take into account data elements that reflect LTSS. Thus, in most circumstances, providers across medical and LTSS settings are not likely to be aware of other interactions that an individual with I/DD has had with the

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health care system. While providers committed to coordination and integration may communicate in the absence of integrated EHRs via telephone, email, or fax, to be effective, communication across providers must be comprehensive and consistent.

Finally, some individuals with I/DD and their families, advocates, and providers fear that integration with physical and mental health will result in a reduction in services, and a move to “medicalize” services, including narrower criteria for receiving HCBS to support functional needs that are particularly important to individuals with I/DD remaining and thriving in a community-based setting (e.g., housing, employment, and day supports). State approaches to integration must address stakeholder concerns and ease these fears.

Centers for Medicare & Medicaid Services (CMS) recently released a new HCBS rule to help clarify state plan and waiver authorities, providing states with clearer expectations for person-centered planning in the context of HCBS programs to encourage state innovation around integration.

## Approaches to Integration

As part of a greater push for integration in health care, some states have introduced new models of service delivery for persons with I/DD that attempt to move care along the continuum toward full integration, while preserving the important LTSS necessary for individuals with I/DD to continue to reside in the community and enjoy fulfilling lives. In moving toward integration, it is important to ensure that persons with I/DD are treated with respect and dignity; their rights are protected; available services foster independence and personal choice; services enable people to fully participate in family, community, and work life; and they receive outcome-based services and support.<sup>5</sup>

Below are three different approaches states are using to increase care integration for persons with I/DD, including:

1. Managed LTSS (Arizona)
2. Integration through addition of a case manager/coordinator (Tennessee, Vermont, and Michigan)
3. Comprehensive managed care for full array of services, including physical, behavioral health, and LTSS (New York and Kansas)

### Managed LTSS

**Arizona** has one of the nation’s oldest integrated programs for LTSS services. Arizona’s Department of Economic Security, Division of Developmental Services manages all LTSS with a capitated payment from the state Medicaid program. The Division is responsible for delivering all services for which individuals with I/DD are eligible under the state’s I/DD waiver, providing the agency with significant flexibility in terms of the delivery of LTSS, and health and behavioral health services. The Arizona results are impressive: There is no waiting list for services

for individuals who meet both financial and clinical eligibility for the I/DD waiver, high client satisfaction, and strong performance on national core indicators.<sup>6</sup>

### National Core Indicators

National Core Indicators (NCI) is a voluntary effort by public developmental disabilities agencies to measure and track performance to help states target human services spending to practices that work. NCI is a joint venture between the National Association of State Directors of Developmental Disabilities Services (NASDDDS), involved states, and the Human Services Research Institute. The core indicators are standard measures to assess the outcomes of services provided to individuals and families. Indicators are grouped into the following categories: individual outcomes, health, welfare, rights, system performance, staff stability, and family indicators. More details can be found at: [www.nationalcore-indicators.org/indicators/](http://www.nationalcore-indicators.org/indicators/). Currently, 39 states and the District of Columbia participate in NCI. The U.S. Department of Health and Human Services Administration on Intellectual and Developmental Disabilities has awarded NASDDDS a multiyear project to expand participation in NCI to all states.

### Integration Through Addition of a Case Manager or Coordinator

A number of states, including Tennessee, Vermont, and Michigan, have implemented programs aimed at improving integration for persons with I/DD through use of a dedicated case manager responsible for coordinating all care for an individual, regardless of the funding source for the services.

**Tennessee** delivers LTSS services separately from physical and behavioral health services for the I/DD population. Through its Select Community program, Tennessee introduced a coordinated care model for the full range of health care services, including LTSS, for a portion of the I/DD population. Participating individuals work with a nurse case manager, who manages an integrated plan of health care for the individual’s physical and behavioral health care needs across services and delivery settings. Each participant also works with an independent support coordinator, who manages the plan of care for the individual’s LTSS waiver services. The Select Community program utilizes structured coordination protocols to help facilitate this process and the communication across the case managers.

**Vermont** provides all individuals receiving services through the state’s Developmental Disabilities Services program with a case manager who is responsible for developing an individual support agreement to identify that individual’s service and support goals and improve care integration. This person-centered planning approach aims to be holistic and consider the many dimensions of the individual with I/DD’s life, resulting in an integrated support plan. State staff report that while the patient-centered planning approach and individual support agreements could—

and often should—include consideration of health concerns for individuals with medical conditions, the medical aspects of care are not consistently included in the plan as case managers tend to focus on LTSS services.

While medical and behavioral health providers may consult in an initial care plan and in treatment as needed, in most cases, agencies and medical or behavioral health professionals do not work from the same care plan. However, I/DD services providers appropriately document and follow-up on health care needs as part of each individual's support agreement. The health and wellness guidelines of the Department of Disability, Aging and Independent Living (DAIL) reinforce the importance and focus on health care. Registered nurses often participate in DAIL's quality reviews of provider agencies in an effort to ensure compliance with these guidelines. However, intermittent consultations between providers do not solve the problem of improving care coordination across all providers on an ongoing basis.

Vermont hopes to continue to bridge gaps in provider communication and service integration by including individuals with I/DD into the state's Medicaid accountable care organization (ACO) program. To achieve this goal, the Medicaid ACOs would facilitate development of care teams across disciplines to work together on assessment and care planning processes.

**Michigan** is working to develop a new system to better coordinate the care for dually eligible individuals, including those with I/DD. Its Care Bridge demonstration program is designed to increase coordination across LTSS, physical, and behavioral health care services.

Today, Michigan operates separate managed care systems for physical and behavioral health care. The state provides physical health services for the I/DD population through its standard physical health managed care organizations (MCOs), and provides LTSS and behavioral health services through its behavioral health plan, which operates as a prepaid inpatient health plan (PIHP). Through the PIHPs, each person with I/DD is paired with a designated case manager with expertise in working with I/DD. The case manager helps create a person-centered plan for the individual, which is focused primarily on the provision of LTSS and behavioral health services provided through the PIHP. Michigan's statewide Care Bridge program pairs the existing case managers with a Care Bridge care coordinator to manage care across all services, supports, settings, and plans.

### Comprehensive Managed Care

**New York** is undertaking a system transformation project designed to increase integration of services and person-centered care by moving its I/DD population into managed care through its People First 1915 (b) and (c) Medicaid waiver. The People First waiver, set to be implemented soon, subject to final

approval from CMS, includes two newly integrated managed care initiatives that may serve individuals with I/DD. These initiatives include Developmental Disabilities Individual Support and Care Coordination Organizations (DISCOs), which are nonprofit entities that will operate as specialized managed care plans for the I/DD population, and the Fully Integrated Duals Advantage plans, which are focused more broadly on the dually eligible population but may include individuals with I/DD on a voluntary basis.

The DISCOs will receive a capitated payment and will be responsible for assessing the needs of individuals with I/DD, providing covered services, and reporting quality outcomes. Using a phased approach, New York will first provide DISCOs with responsibility for LTSS. However, officials plan to have the DISCOs transition into comprehensive managed care plans that are responsible for providing the full range of services beginning in 2015. In addition to having all of the funding and management funneled through a centrally managed structure, New York plans to implement an accompanying health information technology (HIT) system that will enable real-time sharing of health and safety data across all providers, in an effort to improve person-centered planning, communication among providers, program satisfaction, and outcomes, as well as reduce costs.

**Kansas** transitioned 8,000 individuals with I/DD into comprehensive managed care in early 2014. Prior to the transition, Kansas conducted a research study that examined the utilization patterns and quality metrics of those with I/DD, and found significant opportunities to improve their health and well-being through better preventive measures. As part of its planning process, Kansas held more than 100 outreach events to hear from consumers, families, and guardians about the transition. During the process, Kansas overemphasized the savings related to the move to managed care (an estimated reduction in growth of 2 percent), leading stakeholders to worry that there would be a direct cut to services, despite state assurance that the reduction in cost would be applied to reducing waiting lists.

### Additional Options

While it currently serves frail, elderly individuals, the PACE model might also inform discussions about improving care coordination and integration for individuals with I/DD who don't meet current PACE requirements. The PACE model is a fully integrated care model that offers all medical, behavioral, and long-term services and support for its enrollees. PACE combines the intensity and personal touch of a provider with the coordination and efficiency of a health plan. The PACE interdisciplinary team delivers much of the care directly, enabling them to personally monitor participants' health and respond rapidly with any necessary changes. The PACE team is also responsible for managing and paying for services delivered by contract providers, such as hospitals, nursing homes, and specialists.

Some organizations are currently exploring ways to adapt PACE to serve younger individuals with disabilities, including individuals with I/DD. Notably, President Obama's most recent federal budget included a funding request for a pilot program for PACE organizations serving those under the age of 55.

## Recommended Strategies in Facilitating Reform of Programs That Serve the I/DD Population

States considering integration of care for the I/DD population can learn from the experiences of the states highlighted in this brief. As states approach integration, we recommend Medicaid directors consider what makes other managed care programs successful within their state, and take the following steps:

1. Enlist stakeholder support and buy-in.
2. Dedicate sufficient state staff time and resources to the project.
3. Encourage use of HIT to support change.

### Enlist Stakeholder Buy-In and Support

It is essential to build trust with individuals with I/DD, their families, caregivers, guardians, and advocates. Without a foundation of trust, any state attempts to explain why programmatic changes will improve care are likely to not be heard. To secure buy-in, states should engage stakeholders from the very beginning of the project and focus the discussion on how proposed changes will improve care and enhance services, not on the potential savings. Engaging stakeholders can be time-consuming, which is why a transparent and deliberate process is critical from start to finish.

### Dedicate Sufficient State Staff Time and Resources

It is also critical to recognize the amount of state staff time and attention the reform process takes. As a Michigan state staff member noted, "Getting big systems that have previously operated in parallel and haven't communicated well to work together takes time and takes energy." Intense engagement in the design process by organizational leadership will send a very strong message throughout the agency about the importance of this initiative and the need for engagement at all levels.

### Encourage Use of HIT to Support Change

While new HIT systems alone will not knit together a fragmented system, they will at least offer providers the opportunity to exchange information under appropriate confidentiality requirements and without requiring that they go through a cumbersome manual process. Technology cannot replace communication; it should be a means to improve communication, bidirectional information/data exchange, and integration of services. Until there are interoperable EHRs, states and providers

should put processes in place to consistently utilize "lower-tech" options of communication; including: telephone, fax, email, and in-person meetings.

## Conclusion

States have utilized a number of approaches aimed at improving care provided to the I/DD population. State Medicaid directors should work closely with their I/DD counterparts to understand the gaps in coverage in their state, and to determine the best approach to improve care delivery so that an individual with I/DD is cared for in a person-centered, holistic manner. The goal of providing comprehensive and coordinated services to the I/DD population should remain the same, whether the vehicle is an integrated standalone plan or in other broader integration reforms, such as duals demonstration projects, health home initiatives accountable care organizations, or more traditional managed care.

Giving one entity the responsibility for managing the funding and delivery of all services to the I/DD population could provide that organization with more flexibility, increase communication, and help eliminate duplication of services resulting in increased efficiency. However, without substantial efforts to ensure integration and coordination of services at the point of care, changes to the financial mechanisms may not result in improvements in the quality of care. While financial fragmentation is a key barrier, it is unrealistic to believe that simply consolidating funding under one entity, without any additional support for providers or delivery system changes, will improve the quality of care for individuals with I/DD. As states implement integration approaches, close attention should be paid to the extent to which service delivery changes actually accompany the financial reforms.

## Appendix

### List of Interviewees

1. Larry Latham, assistant director, Division of Developmental Disabilities, Arizona Department of Economic Security
2. Shawn Sullivan, secretary, Kansas Department for Aging and Disability Services
3. Linda Zeller, deputy director; Debra Tsutsui, director of planning and quality management; and Charlyss Ray, department specialist, Michigan Behavioral Health and Developmental Disabilities Administration, Michigan Department of Community Health
4. Gerald Huber, acting deputy commissioner; Katherine Bishop, director of the Person Centered Services Design Program; and Tamika Black, deputy director, New York State Office for People with Developmental Disabilities Administration

5. Camille George, director, Developmental Disabilities Services Division, Department of Disabilities, Aging and Independent Living, Vermont Agency of Human Services
6. Chas Mosely, associate executive director and Barbara Brent, director of state policy, National Association of State Directors of Developmental Disability Services
7. Shawn Bloom, executive director, National PACE Association
8. Barbara Coulter Edwards, director, Disabled and Elderly Health Programs Group, Center for Medicaid and CHIP Services, Centers for Medicare and Medicaid Services

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## Endnotes

1. Integration on its own does not equal improved quality of care. For integration to improve care provided to individuals with I/DD, it must be well-organized and well-managed and must include providers with expertise in serving the I/DD population.
2. Shirk, Cynthia. 2006. "Rebalancing Long-term Care: The Role of the Medicaid HCBS Waiver Program." *National Health Policy Forum*. Accessed March 15. [www.nhpf.org/library/background-papers/BP\\_HCBS.Waivers\\_03-03-06.pdf](http://www.nhpf.org/library/background-papers/BP_HCBS.Waivers_03-03-06.pdf)
3. United States Department of Justice Civil Rights Division. 2014. "Information and Technical Assistance on the Americans with Disabilities Act." Accessed March 15. [www.ada.gov](http://www.ada.gov)
4. United States Department of Justice Civil Rights Division. 2014. "Olmstead: Community Integration for Everyone." Accessed March 15. [www.ada.gov/olmstead/olmstead\\_about.htm](http://www.ada.gov/olmstead/olmstead_about.htm)
5. Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services. 2014. "NCI Indicators." Accessed March 15. [www.nationalcoreindicators.org/indicators](http://www.nationalcoreindicators.org/indicators)
6. While some states use the term "care manager" instead of "case manager," for consistency's sake, we use the term "case manager" throughout this brief.