

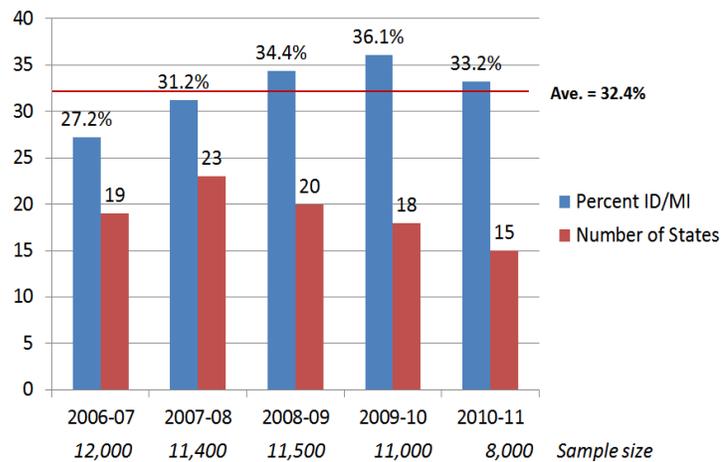
Including Individuals with Intellectual/Developmental Disabilities and Co-Occurring Mental Illness: Challenges that Must Be Addressed in Health Care Reform

The nation’s response to the service needs of individuals of all ages with co-occurring intellectual/developmental disabilities (IDD; e.g., autism) and mental illness (MI) is of concern. Nationally, State IDD and mental health (MH) authorities are responsible for funding and monitoring needed services, yet support and funding is uneven. An increasing number of publicly funded programs are hard pressed to provide the levels of assistance, therapy, primary care, long-term medical oversight and individualized supports that people with these co-occurring conditions need to live, work, and lead regular lives in the community. People with co-occurring IDD and MI are frequently referred to as a special population. It is important to recognize that this group makes up approximately one-third (32.9%) of the total number of individuals with IDD served by state developmental disability (DD) agencies nationwide.¹ The National Core Indicators data document the stability of this rate over time (see chart at right).

NADD is a not-for-profit membership association established for professionals, care providers, and families to promote understanding of and services for individuals who have developmental disabilities and mental health needs. The mission of NADD is to advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care. NADD has been influential in the development of appropriate community-based policies, programs, and opportunities in addressing the mental health needs of persons with IDD.

Similar data on these individuals served by state MH agencies are not known, but a prevalence rate of emotional disorders of up to 50% has been reported for children with intellectual disorders² and, anecdotally, individuals with mental disorders are known to have a high prevalence rate of co-occurring intellectual disorders. In view of the high prevalence of psychiatric disorders among people with IDD, this group should not be considered as a special population, but as a core constituency in both health and

Prevalence of IDD/MI:
National Core Indicators Data



¹ National Core Indicators Adult Consumer Survey 2011–12 Final Report (2013). National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute. Retrieved from www.nationalcoreindicators.org

² Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability, 36*(2), 137–143. doi:10.1080/13668250.2011.572548

human services settings.

Improvements in services for people with IDD/MI have been achieved by many states during the past decade by expanding supports furnished under the Center for Medicare & Medicaid Services, including Home & Community-Based Medicaid Waiver programs and state funding of improved crisis services and increased access to mental health services. While advances have been made in many areas, state DD and MH authorities and service systems continue to struggle in their attempts to provide effective and appropriate treatments and supports on a consistent and comprehensive basis. State efforts to establish and maintain coordinated systems of care for people with these co-occurring conditions have been significantly hampered by administrative and funding barriers that diffuse responsibilities and by the limited use of best practice models.. Furthermore, dramatic declines in state revenues resulting from the Great Recession of 2008, coupled with personnel reductions and a faltering economic recovery, have eroded the capacity of state agencies to maintain services. In many areas across the country, waiting lists have grown and access to needed supports has been delayed, deferred, or even discontinued.

Currently, several states and private providers are looking for ways to stretch available dollars by more effectively coordinating services and improving support outcomes. Some are pursuing home and community-based services available under the Section [1915\(c\) Medicaid waiver program](#) and the [1915\(i\) state plan option](#); both afford states the ability to cover a wide array of community-based residential supports. Other states are expanding access to self-directed personal care through the new [1915\(j\) state plan](#) services or by using the [1915\(k\) Community First Choice](#) personal care option to assist individuals with living in their homes. In addition, many state authorities are taking advantage of federal programs such as [Money Follows the Person \(MFP\)](#) and the [Balancing Incentive Payment \(BIP\)](#) programs, which provide increased federal financing to states moving people from institutions to home and community-based settings. The [Health Home](#), an optional Medicaid state plan service available under the Affordable Care Act, offers states a new strategy for improving the coordination of primary, acute, behavioral health, and long-term services and supports for individuals with two or more chronic conditions.

In addition to implementing these Medicaid state plan alternatives, some states are pursuing managed care as one of several strategies to decrease expenditures and improve service coordination. Managed care approaches have been used to organize the delivery of acute health care and behavioral health services for some time; however, the application of this model to long-term supports including Medicaid waiver-based programs (explained above) furnished to people with IDD is limited. Currently, only four states, (Arizona, Michigan, North Carolina, and Wisconsin) operate managed long-term care for persons with IDD including people with IDD and co-occurring MI. Kansas is in the process of moving the IDD population into managed care, and Louisiana and several others states are considering similar moves. Persons with IDD may receive mental health services through managed mental health programs such as Health Homes, as supported through the Affordable Care Act.

Managed care approaches are being used or considered by states for this population, although there are limited data documenting the impact on quality and efficacy of these approaches for

managing long-term services and supports for people with co-occurring IDD and MI as compared with traditional fee for service systems. Managed care proponents point out that the approach offers many benefits to states, enabling policymakers to more closely align program expenditures with treatment and service outcomes, improve administrative and operational efficiencies, and reduce costs over time. Changing the structure and functioning of state IDD and MH service systems, however, to adopt either public or privately administered managed care is a complex undertaking. States are responsible for administering their Medicaid programs including those offered through managed care organizations (MCOs) under [Section 1903\(m\) of the Social Security Act](#). A recent report on the implications of Medicaid managed care for people with disabilities prepared for the National Council on Disabilities underscores the importance of the state's role in managing Medicaid service delivery regardless of whether the plans are operated by the state or other public agencies, county governments, nonprofit organizations, or for-profit corporations. The authors recommend that states moving to managed care systems retain staff with knowledge and expertise of disability services, especially those with expertise in community long term services and supports, to provide both effective management and oversight and to ensure high quality of care through contracts and obligations with MCOs. The authors identify 24 policy-related issues and offer several recommendations for both federal and state policymakers.³

Managed care systems are designed to control expenses, predict expenditure stability, including frequently a reduction in the contract's expense goal, while maintaining quality and improving outcomes. Service costs and utilization are controlled through highly structured contracts among the state as the purchaser, the health plan(s), and the service providers. Contracts between the state agency and the MCOs should specify funding mechanisms, service delivery arrangements, and the nature of the relationships of the various parties. Specific contract provisions are implemented through separate but related administrative protocols described in operations and policy manuals. Written by the state, these documents should identify the obligations of the MCO with respect to the services and supports to be purchased and provided. In these documents, states must clearly identify the nature and scope of services to be furnished to people with co-occurring disabilities including service coordination (with emphasis on community-based services), provider qualifications, oversight, quality management, cost-effectiveness, and steps to ensure coordinated care occurs among state agencies, providers, and others.

The populations of people with co-occurring needs are very heterogeneous, and their support needs change over their lifetimes. Individuals with IDD and co-occurring MI require a flexible array of services to help them effectively reside in the community. States' managed care funding models need to be designed to promote this flexibility and to support providers' ability to structure services around the needs of the individual.

Regardless of whether a state is considering changes in service delivery through the introduction of managed care, with Medicaid expansion, by the introduction of new funding or resource allocation practices, or through internal departmental reorganization, the change methodology

³ National Council on Disabilities (March 2013). *Medicaid Managed Care for People with Disabilities*. Retrieved from <http://www.ncd.gov/publications/2013/20130315>

must embrace key program elements associated with high-performing services to both children and adults with co-occurring disabilities.

In terms of service provision, these program elements are put into operation through supports and interventions that address a person's needs for appropriate assessment, diagnosis, and treatment; flexible funding that is individualized to support meaningful outcomes in employment; socialization and community participation; family supports; unified coordination of services and supports across service providers and state agencies; ongoing technical assistance to build provider expertise; targeted cross-disciplinary training for clinicians, administrators, and direct support professionals; family-based education; effective interagency collaboration and coordination among state DD, MH/behavioral health (including mental health and substance abuse), child welfare, and corrections (including juvenile justice) agencies; responsive crisis intervention services; and ongoing data collection, performance measurement, and outcome assessment.

The lack of behavioral health and primary care providers with the specialized training to diagnose and treat this population results in preventable and expensive health care and treatment, repeated hospitalizations, problematic drug interactions and the overuse of psychotropic medications. To avoid these outcomes, states must carefully design their MCO contracts and requirements (as initially specified in states' requests for proposal) including how service priorities, gaps, expansions and desired outcomes shall be addressed (e.g., for individuals on waiting lists and underserved groups). A well trained and supported workforce is a critical contract requirement.

Recommendations

NADD recognizes the challenges that state policymakers face in responding to today's economic, political, and regulatory environments. State officials must address the continuing fiscal limitations resulting from the economic recession, respond to increasing numbers of people with co-occurring disorders waiting for services, and more effectively manage current service costs. NADD recommends that states consider the following principles as they develop plans to restructure their service systems to ensure that vulnerable people with co-occurring IDD and MI are taken into account in managed care requests for proposals and resulting funding contracts. These recommendations will help make certain that the treatment and support needs of individuals with IDD and co-occurring mental illness disorders are seamlessly met during the process of organizational changes:

1. *Community Living.* The primary goal and outcome of service delivery should be to enable people with co-occurring disabilities to have friends and to live, attend school, and/or work in the community, consistent with Title II of the Americans with Disabilities Act and the Supreme Court's Olmstead ruling.
2. *Knowledge and Expertise.* States considering systems change should involve the recipients of supports and services family members, and advocates in conjunction with key state officials, providers, and subject matter experts with experience providing and

funding high-quality services and supports to children and adults with co-occurring disabilities. All of these individuals should be included in the design of new services, supports, and funding options. Consideration should be given to including representatives of diverse cultural and linguistic groups.

3. *Person-Centered Services.* People with co-occurring disabilities should have services that are individualized and person-centered, according to their needs.
4. *Workforce Competencies and Training.* Provisions should be made to specify required qualifications and training expectations for staff members (which should include individuals with lived experiences and family members), who treat children and adults with co-occurring disabilities. These provisions should be based on external standards such as the [NADD Accreditation and Staffing Certification Guidelines](#). Training should emphasize specialized skills, especially diagnosis and treatment. Skill development is especially needed, in light of health care reform, for primary care and psychiatry physicians, physician assistants, nurse practitioners, mental health personnel, and other medical staff
5. *Readiness Review.* States should complete a readiness review to fully inform their consideration of new funding methodologies, support strategies, provider requirements, and quality and performance expectations for children and adults with co-occurring disabilities. Workforce development must be part of this review.
6. *Funding.* Funding priorities, rates, and mechanisms should be flexible and designed to reward the achievement of high-quality and cost-effective performance outcomes that support community-based placements, adequate direct care staff salaries, and braided governmental funding. .
7. *Support for Families.* The majority of people (children and adults) with IDD receiving public services live in the homes of family members. Services and supports including respite care, integrated care coordination, preventive behavioral supports, and crisis prevention and stabilization must be designed to address the needs of recipients of services across the lifespan and their family members. Training and skills development should be provided to staff, including those who provide peer support.
8. *Inter-Systems Service Coordination.* Efforts must ensure that the historically fragmented service delivery systems are integrated, result in effective services provision, and provide the service recipient (including the family) with the ability to advocate for needed services.
9. *Specifications in State Contracts with MCOs.* Specifications, using provider manuals and network plan documents, should include the amount, duration, timeliness, and scope of services furnished to children and adults with co-occurring disabilities based on functioning, symptoms, and timely access to needed services. States and MCO's should be encouraged to use monitoring teams that include persons receiving supports

and family members, as currently occurring in Maryland, Massachusetts, Pennsylvania and Wisconsin.

10. *Specifications for Public and Private Insurance Benefits and State Contracts with MCOs.* Private insurance emphasis on reactive symptom management is inadequate and costly for this co-occurring population because it typically results in overuse of medically unnecessary emergency room and inpatient placements. Instead, private and public insurance benefits should emphasize preventive services and positive behavioral supports as more effective and less costly approaches.
11. *Support to Develop Proven Models of Care and Treatment.* Enhanced research supporting the provision of evidence-based practices is necessary to help address the current inappropriate use of psychotropic medications, seclusion and restraint, the criminal justice system, emergency rooms and institutional-based long-term care for this population.
12. *Quality and Performance Expectations.* Quality and performance expectations should be consistent with current national efforts for persons receiving support, for peers, and the family movement. These outcomes should be publicly stated and measurable.