

**SERVING INDIVIDUALS
WITH CO-OCCURRING DEVELOPMENTAL
DISABILITIES AND MENTAL ILLNESSES:**

SYSTEMS BARRIERS AND STRATEGIES FOR REFORM



National Association of State Mental Health Program Directors (NASMHPD)

66 Canal Center Plaza, Suite 302, Alexandria, VA 22314

(703) 739-9333 (phone) / (703) 548-9517 (fax)

www.nasmhpd.org

October 2004

Executive Summary

Individuals with co-occurring developmental disabilities and mental illnesses are a particularly vulnerable population of people served by state mental health agencies and state agencies providing developmental disabilities services. While their numbers are relatively small, these individuals pose major service delivery and funding challenges, requiring a coordinated array of treatment interventions and supports that necessitate the collaborative involvement of providers of both the public mental health system and the developmental disabilities service system.

Developed out of different historical trends, existing services and systems tend to be organized as though individuals have either mental illnesses or developmental disabilities – but not both. (Shriver, 2001) In most states, people with these co-occurring disorders face barriers to services related to a lack of coordination and collaboration across service systems, as well as gaps in research, clinical expertise, and access to appropriate programs.

Although little data is available to describe the population of people with co-occurring developmental disabilities and mental illnesses and the services they receive, stakeholders in both service systems agree that community-based services often are unavailable or inadequate. One indicator of the system's inability to respond appropriately to the needs of this population is that individuals with co-occurring developmental disabilities receiving services in state psychiatric hospitals have significantly longer lengths of stay. They are also more likely to be placed in restraints during their hospital stay.

This report documents the first step in a collaborative dialogue between state mental health and developmental disabilities agencies and multiple stakeholders in the states to assess the successes and failures of current practice in serving people with co-occurring conditions in an effort to develop a productive partnership for systems change. The report identifies barriers to services in existing service systems, describes components of an "ideal" system of care, and makes recommendations for systems change.

Introduction

Individuals with co-occurring developmental disabilities and mental illnesses are a particularly vulnerable population of people served by state mental health agencies and state agencies providing developmental disabilities services. Although relatively few such individuals receive services in either system, they pose major service delivery and funding challenges to service providers and administrators. Many in this population require a coordinated array of treatment interventions and supports that necessitate the collaborative involvement of providers of both the public mental health system and the developmental disabilities service system.

Despite these needs, services are often organized as though individuals have either mental illnesses or developmental disabilities – but not both.¹ In most states, this population faces barriers to services related to a lack of coordination and collaboration across service systems, as well as gaps in research, clinical expertise, and access to appropriate programs.

The systems designed to serve individuals with mental illnesses and those with developmental disabilities arose in response to different perceived needs, and their philosophies and training approaches have remained on separate tracks over time. When confronted with clients whose needs cross systems boundaries, service providers and administrators in both systems can feel unprepared to respond. State mental health agencies and providers often perceive people with developmental disabilities as having needs that require expertise and extensive resources not typically found in the mental health system. State developmental disabilities agencies and providers, on the other hand, often perceive the behavioral problems exhibited by this population as falling outside the scope of their expertise. And while those who receive services in both systems have come to speak and advocate effectively for themselves, mental health consumers and self-advocates with developmental disabilities seldom interact; they acknowledge a lack of understanding of the clinical and policy issues important to each community. In short, there is little in the existing service system structure to encourage coordination and provision of individualized services for those who need them.

Although a few states, providers, and national associations have begun to explore the clinical and programmatic needs of this population in more depth, there has been little research or dialogue about systems reforms to promote improved access and quality of

¹ Eunice Kennedy Shriver, Executive Vice President of the Joseph P. Kennedy Jr. Foundation, in a presentation to participants at a November 29, 2001, to December 1, 2001, workshop convened by the National Institute of Neurological Disorders and Stroke, the National Institute of Child Health and Human Development, the National Institute of Mental Health, the National Institute of Health Office of Rare Diseases, and the Kennedy Foundation. The conference was entitled “Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities: Research Challenges and Opportunities”. For information generally on the conference, please see: http://www.ninds.nih.gov/news_and_events/proceedings/Emotional_Behavioral_Health_2001.htm. For Mrs. Shriver’s statement, please see: http://www.ninds.nih.gov/news_and_events/Emotional_Behavioral_Health_2001_Remarks.doc.

care. Similarly, while promising practices have been developed in the many local pockets of excellence effectively serving this population, these state-of-the-art systems generally are not initiated or replicated by states and are not yet reflected in state-wide policy or systems reform. A national focus on this population has been even more limited than state efforts in the past.

The need for national attention and improvement of services to this population was highlighted by the U.S. Supreme Court's landmark decision in *L.C. v. Olmstead*.² That case involved two women with both mental retardation and mental illness who were residing in a state hospital in Georgia. The women were considered by the hospital's own experts to be ready for discharge to a community program, but they remained confined in state institutions pending the availability of such a placement. The United States Supreme Court ruling – that the Americans with Disabilities Act (ADA) generally guarantees individuals with disabilities the right to receive public services in the most integrated setting appropriate for their needs – pushed many states to re-examine their efforts to provide accessible, effective community-based care for individuals with both developmental disabilities and mental illnesses, among other disabilities.

This report documents the first step in a collaborative dialogue between state mental health and developmental disabilities agencies and a select group of diverse stakeholders involved in both mental health and developmental disabilities policy on state and national levels. With this report, we hope to assess the successes and failures of current practice in serving people with co-occurring conditions in an effort to develop a productive partnership for systems change. Specifically, the report attempts to: (1) describe key characteristics of the population of people with mental illnesses and developmental disabilities served by the public health system; (2) identify barriers to services; (3) begin to articulate essential components of an “ideal” system of care; and (4) identify next steps for both service systems to improve both access to and the quality of services for this population.

Preparation of the Report

This report was prepared from the proceedings of an experts' meeting titled *Co-Occurring Mental Illness and Developmental Disabilities: Systems Barriers and Strategies for Reform*, which was held April 11, 2003 in Alexandria, Virginia.

The meeting, hosted by the National Association of State Mental Health Program Directors (NASMHPD) and funded by the Center for Mental Health Services (CMHS), convened state and local mental health and developmental disabilities administrators, providers, advocates, and consumers of public mental health and developmental disabilities services for a 1-day retreat to discuss service delivery to people with co-occurring developmental disabilities and mental illness. A list of experts participating in the meeting is included in this report at Appendix A.

The meeting had the following goals:

² *L.C. v. Olmstead*, 527 U.S. 581 (1999).

- Define and describe the population of people with both development disabilities and mental illness in each system.
- Describe existing service delivery systems and assess their effectiveness in providing appropriate services.
- Identify barriers to effective service delivery, including but not limited to language and cultural barriers and financing.
- Identify principles for an effective service delivery system.
- Propose strategies for next steps and continued stakeholder collaboration.

In addition to the dialogue at the meeting, this report was also informed by literature on the clinical, programmatic, and policy issues related to serving people with mental illnesses and developmental disabilities. A comprehensive, but not exhaustive, compilation of articles was provided to meeting participants prior to the meeting and served as a basis for much of this report. A bibliography of literature reviewed in preparation of this report is included at Appendix B.

Drafts of this report were prepared by a technical writer and NASMHPD staff and were distributed for review and comment to all meeting participants. This report is a product of NASMHPD and does not necessarily reflect opinions held by all NASMHPD members or the experts participating in the April 11 meeting.

NASMHPD is committed to making information about people with co-occurring developmental disabilities and mental illness accessible to a broad range of audiences. However, since this report is intended primarily to facilitate collaboration among policymakers and administrators in the United States, it is presented here in English. NASMHPD understands that many people affected by developmental disabilities and mental illness may not read English or other languages and that future initiatives may need to be presented in other languages or non-verbal formats to ensure accessibility by all stakeholders.

Understanding the Population

Estimates of the number of people who have co-occurring developmental disabilities and mental illness vary widely. In part, this is because many individuals with both conditions are not accurately diagnosed or treated. The lack of data may also be attributable to the fact that several service systems are involved in providing services and supports, and their data is not easily shared or integrated. This problem is exacerbated by the lack of communication and coordination across service systems, even when the service systems are administered by the same agency.

The wide variance in prevalence estimates also reflects differences in the ways terms such as “mental illness” and “developmental disability” are defined. The term “developmental disabilities” includes a broad range of both cognitive (including mental retardation) and non-cognitive disabilities, and its statutory definition varies from state to state. Similarly, the term “mental illness” may mean “serious mental illness,” as defined by federal regulations or state statutes, or may encompass a very broad range of mental disorders.

For example, the National Association for the Dually Diagnosed (NADD) estimates that 20-35 percent of all people with mental retardation have a mental illness; the number of people who meet the federal definition for having a serious mental illness is likely to be much smaller.³ The Department of Mental Health and Substance Abuse Services and the Department of Mental Retardation in Pennsylvania have estimated the prevalence of serious mental illness among people with mental retardation to be 8-10 percent, as compared to the prevalence of serious mental illness in the general population of 5 percent. (Pennsylvania Department of Public Welfare, 2002)

Another reason that prevalence rates for this population are unreliable is that individuals with developmental disabilities rarely are assessed for mental illness and, even when they are, their disorders are often undiagnosed because their symptoms are mistakenly attributed to mental retardation or other conditions related to their developmental disability diagnosis. As a result, many people with co-occurring developmental disabilities and mental illness are not diagnosed and do not begin receiving services until they exhibit behavioral problems or disruptive “acting out.” This is sometimes called diagnostic overshadowing, which “refers to instances in which the presence of mental retardation decreases the diagnostic significance of accompanying emotional and behavioral disorders.”⁴ One meeting participant noted that the population is often stereotyped and defined by administrators essentially as “those people who create the most problems for us” – those who cannot be managed at home, in group homes, or in

³ “Cooperation Between Mental Health and Mental Retardation/Developmental Disability Systems”. *NADD Bulletin*, vol. 5, no. 6. (Nov/Dec 2002) and vol. 6, no. 1 (Jan/Feb 2003), available at <http://www.thenadd.org/cgi-bin/checkmember.pl?page=content/bulletins/v5n6a1> and <http://www.thenadd.org/cgi-bin/checkmember.pl?page=content/bulletins/v6n1a1>. See also Fletcher, R., Beasley, J., and Jacobson, J. “Support service systems for people with dual diagnosis in the USA”. In Bouras, N. (ed.), *Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation*. Cambridge, UK: University Press (1999).

⁴ Reiss, S., and Szysko, J., “People with a Dual Diagnosis: America’s Powerless Population,” p. 289-290.

institutions. Therefore, “the debilitating effects of mental health disorders appear less significant than they really are when viewed in the context of the debilitating effects of mental retardation.”⁵

The negative consequences of relying on disruptive behavior to identify mental illnesses among individuals with developmental disabilities are significant. Mental disorders may be misdiagnosed as behavioral issues, resulting in the use of inappropriate and ineffective interventions. Many individuals with co-occurring conditions, especially those with major depression, never exhibit such behaviors at all and, as a result, fail to attract the attention of clinicians or administrators. These individuals are unlikely to receive appropriate mental health services and efforts to integrate them into community settings may repeatedly fail. Individuals with co-occurring developmental disabilities and mental illness who are admitted to hospitals for inpatient services are at significant risk for long-term institutionalization.⁶

These problems are exacerbated by the very real difficulties inherent in diagnosing mental illnesses among people with developmental disabilities, especially cognitive disabilities that may pose communications barriers, and by the lack of training among professionals to differentiate between psychiatric and behavioral problems. Behaviors triggered by the conditions of congregate living or by medications and their side effects further complicate diagnosis.

Identifying individuals with developmental disabilities in the mental health system: Hawaii’s approach

As part of a settlement agreement reached in response to litigation under the Civil Rights for Institutionalized Persons Act (CRIPA), United States v. State of Hawaii, Hawaii is required to take specific steps to identify individuals with developmental disabilities within the mental health system. The Hawaii State Hospital Remedial Plan for Compliance directs that a Mental Illness/Developmental Disabilities Coordinator shall be responsible for identifying individuals with developmental disabilities who have been admitted to the hospital as patients. The functions of the coordinator include: development and implementation of individualized treatment and habilitation programs; provision of direct services; serving as the liaison to the Developmental Disabilities Division, liaison to community developmental disability providers, and advocate to ensure that discharges occur as soon as inpatient level of care is no longer necessary; Evaluation and refinement of services; Development and implementation of a process to identify patients who have developmental disabilities, identify their needs for habilitation services and ensure the provision of those services; and serve as a resource for treatment teams. The coordinator reports to the Director of Psychology and must meet the qualifications for a Qualified Mental Retardation Professional.

The coordinator is a part time position unless there are not more than 10 patients identified at the hospital. Since the plan took effect in February 2002, the coordinator has identified 18 individuals, out of the 166 patients at the hospital, with significant levels of developmental disabilities and several others who were known to have developmental disabilities but were placed in vulnerable situations, such as being housed in units with sexual predators or with patients who have sociopathic personalities. As a result, the position was made full time on staff at the hospital.

⁵ Ibid, p. 290.

⁶ 2003 presentation, available upon request from NASMHPD, by Lucille Schacht, PhD and Kathleen Monihan, B.S., both of NASMHPD Research Institute, Inc., entitled “Persons Served with Developmental Disabilities in State Psychiatric Hospitals: 2002”.

The Hawaii Adult Mental Health Division also has formed a work group with the Developmental Disabilities Division to accomplish a number of goals related to the state's dually diagnosed population through the revision of a Memorandum of Understanding. The agreement will work to identify consumers in the community who have mental retardation needs, specifically. It will also form a plan to address the needs of individuals with mental retardation in the mental health system and individuals with mental illnesses in the developmental disabilities system so as to most efficiently meet the needs of both groups affected by co-occurring mental illness and developmental disabilities needs.

Contact: Thomas Hester, M.D., Chief, Hawaii Adult Mental Health Division
Phone (808) 586-4688

Developmental Disabilities in State Psychiatric Hospitals

In an analysis of state psychiatric hospital data prepared for the April 11 meeting (attached to this report as Exhibit C), the NASMHPD Research Institute, Inc. (NRI) estimated that 5.5 percent of all episodes of care provided in state psychiatric hospitals during a 6-month period in 2002 were for individuals with a developmental disability. Among those served who had both a developmental disability and a mental illness,⁷ 30 percent had schizophrenia, 18 percent had affective disorders, and 18 percent had personality disorders. Seventeen percent of individuals with developmental disabilities served in state psychiatric hospitals also had a co-occurring substance use disorder – significantly lower than the rate of co-occurring substance use disorders among state hospital populations as a whole (43 percent).

Although 80 percent of individuals with developmental disabilities in state psychiatric hospitals have a co-occurring diagnosis of mental illness, only 7 percent are served in units specializing in treatment for both conditions.

Although 80 percent of individuals with developmental disabilities in state psychiatric hospitals have a co-occurring diagnosis of mental illness, only 7 percent are served in units specializing in treatment for both conditions. More than half (54 percent) of the individuals with developmental disabilities receiving services in state psychiatric hospitals are served in general psychiatry units. Twenty percent receive treatment in units designed especially for people with developmental disabilities, mental retardation, or traumatic brain injury.

The NRI's analysis of state hospital data showed other significant differences among people with developmental disabilities and others served in state psychiatric hospitals. Individuals with developmental disabilities were less likely to have lived in a private

⁷ Nineteen percent of those individuals with developmental disabilities served in state psychiatric hospitals during the relevant time period did not have a diagnosis of mental illness. That percentage roughly correlates with the percentage of people with developmental disabilities served in hospital units claiming a specialty in serving developmental disabilities, mental retardation, and/or traumatic brain injury (TBI), although there is no data clearly identifying these two populations as being comprised of the same individuals. For more detailed information regarding this, or other portions of the NRI survey, please contact Dr. Schacht or Ms. Monihan.

residence and more likely to have lived in an institutional setting prior to their hospital admission. They were much less likely to have been married at any time in their lives. During their hospital stays, they were somewhat more likely to be restrained or secluded, although the average number of hours spent in seclusion or restraint was slightly lower for people with developmental disabilities than for the hospital population as a whole.⁸

The most significant difference between individuals with developmental disabilities in state hospitals and the rest of the hospital inpatient population is that those with developmental disabilities, on average, have much longer lengths of stay.

The most significant difference between individuals with developmental disabilities in state hospitals and the rest of the hospital inpatient population is that those with developmental disabilities, on average, have much longer lengths of stay. Only 49 percent of individuals with developmental disabilities were discharged within the 6-month period in 2002 reviewed for this report, as compared to 72 percent of the general hospital inpatient population.

Of those who were discharged, the average length of stay was 266 days, as compared to 88 days for other hospital inpatients. These very long lengths of stay are partially accounted for by a small group of individuals who are hospitalized for long periods of time. Among individuals with developmental disabilities in state hospitals, 27 percent were hospitalized for 91 days or longer, as compared to 14 percent among the general hospital inpatient population.

Consistent with these actual experiences, hospital staff generally *expect* individuals with developmental disabilities to have longer lengths of stay than other patients. While 51 percent of psychiatric hospital inpatients are admitted to acute-care units – with expected stays of 30 days or less – only 31 percent of inpatients with developmental disabilities are admitted to these units.

There are many possible reasons that people with co-occurring developmental disabilities and mental illness experience significantly longer lengths of stay in state hospitals. Perhaps the most important is the lack of appropriate community placements. Most participants in the April, 2003 meeting agreed that this was a significant barrier to discharge, as evidenced by the fact that the plaintiffs in the Olmstead case were subject to long hospitalizations because no appropriate community placements were available. Another important reason for long periods of hospitalization for individuals with co-occurring developmental disabilities and mental illness may be ineffective inpatient services due to inadequate evidence-based research for services to this population, lack of trained staff, and insufficient resources.

⁸ In other words, the number of episodes of seclusion and restraint among this population is higher than average, but the duration of each episode is somewhat shorter. The NRI data and analysis suggests that, if a 30-bed unit were filled with inpatients with developmental disabilities, in a typical month one person would be secluded for a total of 11 hours and one or two patients would be restrained for a total of 17 hours.

Culture, Language and Stigma

Service systems serving individuals with mental illnesses differ significantly from those serving individuals with developmental disabilities in several important ways. In general, mental health systems are structured according to a model of treatment, while developmental disability systems use an approach that emphasizes the concept of supports. At the heart of these differences is the idea that mental health systems provide treatment to individuals so that they can recover from their illnesses, while developmental disability systems focus on providing supports to achieve independent living by individuals with developmental disabilities despite the continued existence of their disabilities.

The differences between these service system paradigms have many implications:

Mental Health System: Treatment Approach	Developmental Disability System: Support Approach
Recovery: Most mental health systems are designed to support the core assumption that people with mental illnesses can, and do, recover.	Self-Determination: Most developmental disability systems are designed to provide an array of services and supports to enable people with developmental disabilities to live as independently as possible by meeting the special needs that accompany their condition.
Psychiatric Intervention: Because mental illness is viewed as a disease and is cyclical in nature, medical interventions – especially psychiatric drugs – generally are considered appropriate and often necessary to achieve and maintain the ultimate goal of recovery.	Behavioral Supports: Developmental disabilities are viewed as a condition of living rather than as a disease. Improvement in functioning is a result of appropriate environmental and social supports. As a result, problematic behavior related to cognitive disabilities is addressed using support strategies that are based on functional assessments and an emphasis on teaching the individual new skills.
Rehabilitation: Because the onset of most serious mental illnesses typically is in late adolescence or early adulthood, the focus of many mental health programs is to re-teach critical social and employment skills that may have been lost as a result of episodes of illnesses.	Habilitation: Because developmental disabilities occur during a developmental period, service systems provide habilitation services to teach skills that individuals with developmental disabilities may never have learned.
Consumers: Modern mental health systems generally view individuals who receive mental health services as “consumers” in the sense that they are (or should be) active participants in developing and implementing their treatment plans. The focus of the mental health consumer movement traditionally has been on individual rights, including the right to refuse treatment.	Self-advocates: Individuals with developmental disabilities increasingly are active as “self-advocates,” creating, leading, or implementing disability advocacy efforts on behalf of themselves or others. The focus of this advocacy traditionally has been on community integration and access to services and supports.

These differences – both substantive and semantic – provide significant reasons for the lack of communication and coordination across mental health and developmental disabilities systems. Participants in the April 2003 meeting agreed, however, that in many cases these cultural and philosophical differences are more perceived than real. For example, although the concept of recovery is central to most state-of-the-art mental health service systems, this model acknowledges that (1) recovery in the community generally is possible only with a broad range of appropriate supports such as housing, employment, and income support; and (2) some kind of continuing care usually is necessary to ensure successful recovery. These are essentially the same principles that characterize the concepts of independent living and self-determination for developmental disabilities service systems. Thus, although individuals may not “recover” from a developmental disability, the kinds of services and supports needed to facilitate meaningful community living are the same for both individuals with mental illnesses and those with developmental disabilities.

In addition, distinctions related to differences in funding strategies and approaches to deinstitutionalization are often perceived to have resulted in different advocacy priorities for the mental health developmental disabilities communities. Because the systems have evolved in different ways and at different paces, the substantive focus of reform has also been described differently: the developmental disabilities community has emphasized community integration, while the mental health community has emphasized individual and patient rights. Despite these differences in emphasis, however, the core goals of both advocacy communities are the same: to promote self-determination and participant-driven services.

Differences in culture, language, and perception impede communication across service systems, contribute to misunderstandings and tensions in the development of treatment/service plans for individuals served by both service systems, and isolate individuals with both conditions from the mainstream of either service system.

Nonetheless, these differences in culture, language, and perception impede communication across service systems, contribute to misunderstandings and tensions in the development of treatment/service plans for individuals served by both service systems, and isolate individuals with both conditions from the mainstream of either service system.

These differences are deeply rooted not only in the education and training of professionals, but in the stigma that is pervasive across service systems and among families, consumers and self-advocates. Mental health consumers may be quick to take offense at any implication that they are intellectually or cognitively impaired, while developmental disabilities self-advocates may be adamant that they’re not “crazy.” Similarly, service providers trained in either mental health or developmental disabilities services often devalue the strengths and capabilities of individuals in the other service system. Participants in the April, 2003 meeting agreed that, while the labels applied to individuals ultimately may be less important than the services actually delivered to them,

pervasive stigma significantly harms the ability of the two service systems to communicate and provide services effectively.

In some cases, stigma is exacerbated by imprecise terminology that makes dialogue about serving people with co-occurring developmental disabilities and mental illness difficult. For example, many mental health professionals and consumers use the words “developmental disability” and “mental retardation” interchangeably, unaware that mental retardation is only one of many kinds of developmental disabilities and that the use of the label of mental retardation is considered offensive by many people with developmental disabilities, whether or not they have cognitive impairments. Similarly, many developmental disabilities professionals and self-advocates do not use the “people first” language valued by mental health consumers and may not fully understand the concept or implications of “serious mental illness” as a brain disease.

Meeting participants agreed that breaking down stigma is a critical priority. However, they also noted that the reality of existing stigma requires very careful use of language and a re-thinking of appropriate interventions so that individuals feel comfortable with their diagnoses, providers, and treatment/support plans.

Meeting participants were quick to point out that broader issues of cultural competency are also very relevant to people with mental illnesses and developmental disabilities. Services must be responsive not only to co-occurring conditions but also to ethnic and cultural considerations. For example, certain labels might prevent people from particular backgrounds from seeking treatment or services, and certain treatment approaches might offend an individual’s deeply held personal or religious beliefs.

Barriers to Service

Cultural differences and stigma contribute to a fragmented approach to services in which neither the mental health nor the developmental disabilities systems assume critical responsibility for a population of people that both systems should serve. A lack of coordination across service systems, clinical and staffing issues, and weaknesses in existing service mental health and developmental disabilities service systems also pose significant barriers to effective services.

A Self-Assessment

In preparation for the April 2003 meeting, NASMHPD and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) jointly surveyed their members about the coordination of services for individuals with both mental illnesses and developmental disabilities in their states. The survey's goal was to provide an overview of existing services and a self-assessment of their effectiveness, as well as to identify barriers to services and areas for improved interagency collaboration.

Among states responding to the survey,⁹ most reported that they have initiatives in place to support collaboration across mental health and developmental disabilities agencies:

- 36 percent have a written interagency agreement;
- 74 percent have a task force to address co-occurring mental illness and developmental disabilities, although these task forces are not necessarily interagency and may meet only on an ad hoc basis to discuss individual cases;
- 68 percent have an interagency agreement – either formal or informal – regarding payment and service coordination;
- 62 percent offer some kind of cross-system training or technical assistance; and
- 63 percent collaborate across agencies for discharge planning from state psychiatric hospitals.

Despite these efforts at collaboration, however, states responding to the survey indicated an almost universal frustration with services to people with co-occurring developmental disabilities and mental illness. In ranking the effectiveness of their states in providing access to services, service quality and appropriateness, and collaboration across state agencies (from 1 to 5, with 5 being most effective), agency directors overwhelmingly assigned their states only a 2 or 3. (See graphs below.) Few respondents felt their systems were doing an excellent job, and, in the case of access to services, no one did. This self-assessment revealed a surprising symmetry between the responses of mental health and developmental disabilities directors; only minimal differences emerged from these rankings.

⁹ Thirty-seven mental health directors and 35 directors of developmental disabilities services responded to this survey.

Fig. 1
Access to services in the
appropriate service system

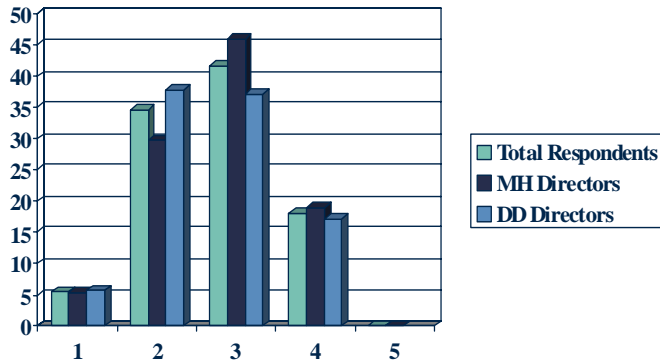


Fig. 2
Quality, appropriateness, and
effectiveness of services

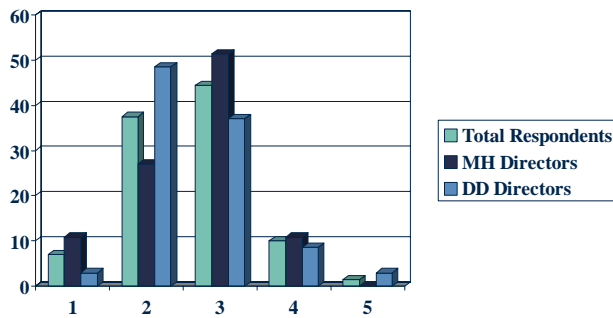
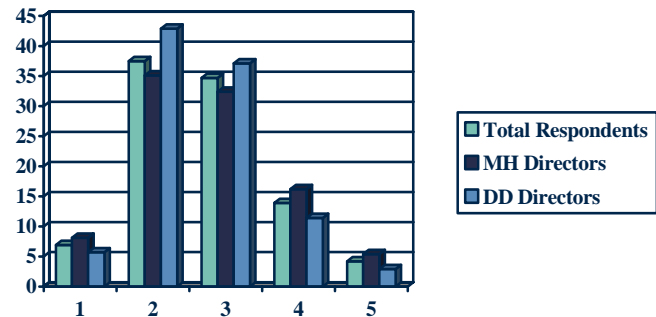
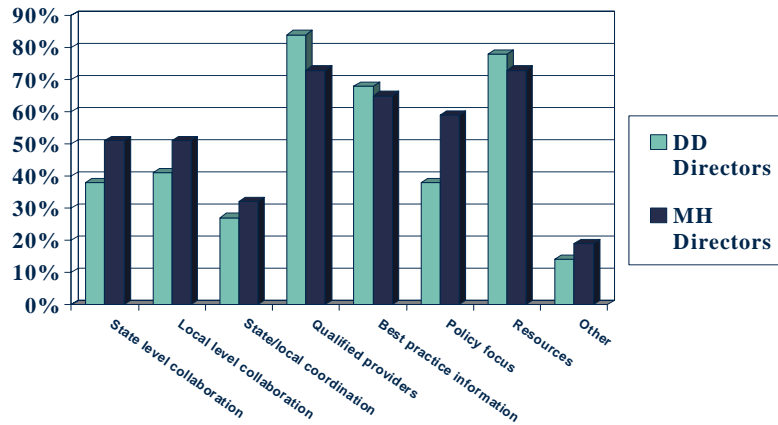


Fig. 3
Overall effectiveness
of collaboration



Reflecting a desire for greater collaboration across agencies, more than half (51 percent) of the respondents identified a lack of collaboration/coordination at the state level as a significant barrier to services and nearly half of the respondents (48 percent) identified “insufficient attention to policy development” as a significant barrier.

Fig. 4
Barriers to service provision



Lack of Coordination Across Service Systems

Meeting participants agreed that lack of coordination across service systems results in the perpetuation of stigma and poor service delivery for people with both mental health and developmental disabilities needs. There are many causes of this lack of coordination, including separate systems for financing services; a reluctance by mental health and developmental disabilities systems to allocate scarce resources for a high-needs population that could be served in another service system; established provider networks that are not cross-trained; and the evolution of advocacy movements that emphasize different priorities. In many cases, specific barriers to service may be both a cause and a result of the lack of coordination across systems

Administratively, more than two-thirds of the states have separate agencies for the administration of mental health and developmental disabilities services. Of the 16 states with combined agencies, 12 also include substance abuse. Meeting participants agreed that the administrative structure of these agencies was not particularly relevant to whether the services provided were effective and appropriate for individuals with co-occurring conditions, since even states with combined agencies develop internal bureaucracies that generally focus on different – and often competing – priorities. While it may be easier for a state with combined agencies to adopt policies supporting individuals with co-occurring conditions, any state can prioritize this population and work across service systems to achieve positive change.

Over the last 40 years, both the mental health and the developmental disabilities service systems have changed dramatically. Services that once were provided almost exclusively in institutional settings now are part of a broad, community-based service delivery system, and individuals who once would have spent their lives in state hospitals or schools now live independently or in small group homes in community settings. For both

service systems, self-determination and community integration have become critical – and attainable – goals.

The process of deinstitutionalization, however, has been significantly different for mental health and developmental disabilities and has, to a large extent, reflected the financing structures available to each service system. In mental health, where state general revenue funds continue to form the core of service funding, states have been slower to move dollars from institutional to community settings. Though the number of state hospital beds has fallen by almost 90 percent over the last 40 years, the increase in community spending as a percentage of overall state mental health agency spending has been much less dramatic.¹⁰

In the developmental disabilities system, however, states took advantage of broader access to Medicaid to close institutions and replace them with small group homes and community-based services. In particular, many states received home- and community-based services (HCBS) waivers under Medicaid to develop community-based services and supports for people with developmental disabilities. To obtain these waivers, states are required to demonstrate that the additional costs to the Medicaid program are offset by corresponding savings to Medicaid resulting from the reduced use of institutional beds (especially beds in Intermediate Care Facilities for the Mentally Retarded, known as ICF/MRs).¹¹ Because care provided in most institutional psychiatric settings for adults – psychiatric hospitals – is not reimbursable under Medicaid, HCBS waivers generally are not available to states to serve adults with mental illnesses.

State agencies often are reluctant to allocate their own scarce resources for a population that could be served in another system, especially when those individuals are relatively expensive to serve.

In addition, over the past several years state budgets supporting the mental health and developmental disabilities systems have been hard pressed to meet demand. Funding has not kept pace with the need for services and waiting lists have grown in states across the country. As a result, state agencies often are reluctant to allocate their own scarce resources for a population that could be served in another system, especially when those individuals are relatively expensive to serve. The fact that mental health and developmental disabilities advocacy communities may work at cross-purposes increases the political cost of serving this population.

Shared responsibility and funding are logical solutions, but restrictions on federal and state funding streams often create financing “silos” that make it difficult for agencies to

¹⁰ Community-based services expenditures (as opposed to hospital expenditures) constitute about 67 percent of overall state mental health agency expenditures, as compared to 33 percent in 1981 (the earliest year for which data are available). (NRI, 2002).

¹¹ Flexible statutory and regulatory language permit states to demonstrate cost-neutrality by showing that, absent the waiver, individuals with developmental disabilities receiving waiver services would require institutional care. The state does not have to demonstrate that the number of actual institutional beds would be reduced. For information generally on the ICF/MR program, see <http://www.cms.hhs.gov/medicaid/icfmr/default.asp>.

pool funding and complicate interagency cooperation. Some meeting participants suggested that systems reform should be pragmatic in its response to the current structure; for example, providers could diagnose patients more strategically to ensure that individuals with multiple diagnoses meet the technical requirements for eligibility for the most generous benefits packages. Most participants agreed, however, that such an approach could lead to misdiagnosis and treatment/service plans that did not address the actual needs of individuals. Reform is necessary to ensure that financing structures accommodate clinical and policy best practices – not the other way around.

Clinical and Staffing Barriers

Most people with co-occurring developmental disabilities and mental illness face significant clinical barriers to services. More than three-fourths of respondents (78 percent) in the joint NASMHPD/NASDDDS survey identified a shortage of qualified providers as a significant barrier, while two-thirds (67 percent) blamed inadequate information about clinical best practices. (See above graph.)

Participants in the April, 2003 meeting agreed that the absence of adequate integrated treatment/support models in most states and communities poses a significant barrier to services for many people with co-occurring developmental disabilities and mental illness. A few organizations – principally the National Association for the Dually Diagnosed (NADD) – have initiatives focused on improving clinical best practices for serving this population, and a growing body of literature suggests that many mental health treatment approaches – including psychiatric medication and psychotherapy – are effective for individuals with developmental disabilities. Experts generally agree that a biopsychosocial model of treatment incorporating psychiatric and psychological approaches with behavioral interventions is most appropriate.

Nonetheless, these models seldom are implemented at the provider level, partly because there is little services research, knowledge dissemination, or technical assistance to support implementation of the effective models for this population. In most areas, there remain significant differences in perspective among providers about how to develop and apply these models and a significant shortage of qualified, cross-trained staff.

Meeting participants observed that clinical and programmatic failures for people with both mental illnesses and developmental disabilities are often blamed on the individuals themselves and on their co-occurring condition. That is, mental health professionals are quick to point to an individual's developmental disability as a justification for treatment failures, while developmental disabilities service providers blame the individual's mental illness for his or her failure to acquire appropriate skills or meet established objectives.

Clinical and programmatic failures for people with both mental illnesses and developmental disabilities are often blamed on the individuals themselves and on their co-occurring conditions. A person's co-occurring diagnosis should never be used to justify the service systems' failure to provide effective treatment, services, and supports.

In fact, meeting participants emphasized, a person's co-occurring diagnosis should never be used to justify the service systems' failure to provide effective treatment, services, and supports. Rather, the plan of care must be designed and adapted to meet the individual's needs and to ensure successful community integration and recovery.

Weaknesses in Existing Service Delivery Systems

Meeting participants agreed that general weaknesses in the mental health and developmental disabilities service systems are a major factor contributing to a lack of effective services for individuals with both diagnoses. The mental health system, in particular, was criticized for its gaps in community-based services, emergency and crisis services, and criminal justice diversion programs.

Even with perfect coordination and financing, services to individuals with both mental illnesses and developmental disabilities cannot overcome the deficiencies and limitations apparent in each service system.

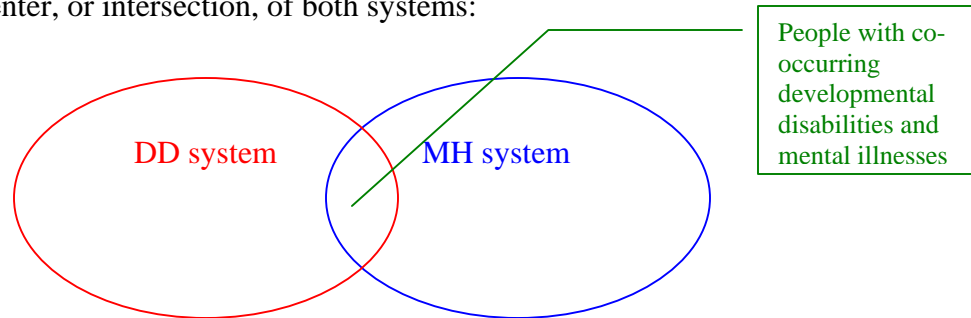
Administrators from both mental health and developmental disabilities agencies noted that, even with perfect coordination and financing, services to individuals with both mental illnesses and developmental disabilities cannot overcome the deficiencies and limitations apparent in each service system. As Reiss and Szysko described two decades ago,

Service delivery typically requires interdisciplinary staffing leading to a diagnosis of an emotional problem and a recommendation for treatment, a case manager who acts on the recommendation, state administrators who recognize the emotional aspects of mental retardation to be sufficiently important to fund appropriate services, and community clinics capable of providing the relevant services.¹²

¹² Reiss and Szysko, 1983, p. 401.

Values, Principles, and an Ideal System of Care

Individuals with co-occurring developmental disabilities and mental illness are often said to “fall through the cracks,” the inevitable victims of two distinct service systems with separate financing, provider networks, and advocacy organizations. Meeting participants, however, suggested a different paradigm -- one that places this very vulnerable population at the center, or intersection, of both systems:



Using this paradigm, individuals with co-occurring developmental disabilities and mental illness are integral parts of both service systems. Responsibility is shared by both systems, and the ability to serve this population effectively is directly relevant to the overall success or effectiveness of both systems.

One meeting participant suggested that individuals with co-occurring developmental disabilities and mental illness should serve the same function as a lighted match in a cave: if services to this most vulnerable and difficult to treat population are accessible and appropriate, it is an indication that the overall systems of care are strong. But if this population of people with the most critical needs is not adequately served, it is indication that the broader systems of care are in poor condition.

Meeting participants agreed that critical first steps in improving communication across the mental health and developmental disabilities service systems and improving service delivery to this population with co-occurring disorders are to: (1) articulate a set of shared values and principles; and (2) begin to identify components of an ideal system of care.

Meeting participants agreed that the following values and principles should drive any shared vision of a coordinated service delivery system:

- (1) Plans of care should be driven by the needs of each individual, rather than the systems providing or funding the services.
- (2) Consumers of services and self-advocates should be involved at all levels of decision-making, including developing their own plans of care and participating in broader policymaking initiatives.
- (3) Community integration and reducing stigma should be principal goals of system reform.

- (4) Coordinated service delivery systems should be culturally informed and responsive.
- (5) Coercion and violence should be eliminated in all settings in which services, supports, or treatment are provided.

Within the context of these shared values and principles, meeting participants agreed that an “ideal” system of care for individuals with co-occurring developmental disabilities and mental illness would include the following key characteristics:

Every person seeking health care services or entering the criminal justice system would receive a thorough screening and assessment by competent staff trained to identify mental illness, behavioral disorders, developmental disabilities, and substance use disorders. A comprehensive multi-modal, biosocial assessment would identify each individual’s strengths and the resources and supports available to them, as well as the individual’s needs. Each individual found to have a disorder would be referred for treatment, services, and/or supports. Routine re-assessments would be conducted to monitor changes in symptoms, diagnosis, and life experiences.

Every person who needs services or supports would be able to access them. Mental health and developmental disabilities providers would adopt a “no wrong door” approach to services, and all doors would lead to a centralized access point that ensures the delivery of services based on the individual’s needs. No one would be rejected for mental health services because they have a developmental disability, and no one with developmental disabilities would be denied access to supports that facilitate community integration because they have a mental illness.

Services would be “person-centered.” Currently, the range of services and supports available to an individual generally are determined by his or her diagnosis. Given widespread misdiagnosis and underdiagnosis among people with co-occurring developmental disabilities and mental illness and the complex, interrelated needs of this population, an ideal system would permit individualized treatment and service plans that transcend diagnosis to focus on the services each individual needs to recover from their mental illness and be fully integrated into the community.

Public financing would be available to implement person-centered treatment plans. Funding would be flexible enough to support integrating services from primary care, mental health, and developmental disabilities systems – as well as housing, employment, and income support programs – as appropriate for each individual and to facilitate cross-training of staff. As discussed in more detail above, a critical problem in serving individuals with both mental illnesses and developmental disabilities has been the funding “silos” that often drive system development and the range of services available to individuals. While the diversity of funding streams may, to some extent, be inevitable because of the varied services and supports needed to support community integration and recovery from mental illnesses, it is possible

and essential to provide flexibility in financing that makes the funding silos appear invisible to the consumer.

All people with co-occurring developmental disabilities and mental illness would receive specialized services from competent, cross-trained staff. Specialized training would be provided to teach staff how to identify needs; plan and coordinate services, supports and treatment; and measure outcomes for this population. Meeting participants agreed that staff needed to be trained to provide a holistic approach that combines behavior management techniques with mental health interventions. A very individualized approach to treatment and services would reflect the complexity of each individual's needs and closely monitor the impact of certain interventions, including the use of medications.

At a minimum, basic level, cross-training would include several components. Staff providing supports through the developmental disabilities service system must be able to identify mental illness and its manifestations, understand how the mental illness may affect the individual's behavior, know how to report relevant observations to mental health professionals, and continue to support the individual while she or he is working through the serious aspects of their illness. Equally important, staff must be able to assess the individual for symptoms of past trauma, understand how past trauma may manifest itself in the individual's behavior, and create a safe, therapeutic environment for recovery. Research has found that "as many as one-fourth to one third of women with mental retardation were abused. In some cases, women with mental retardation have been found to have PTSD as a result of sexual abuse."¹³

Similarly, mental health providers – especially clinical providers – must understand and respect the critical role that support staff play in facilitating successful community-based service delivery. Clinical providers must consult frequently with support staff, educate them and be willing to learn from them, and value their observations and contributions, especially when the individual is unable to self-report.

Where appropriate, family members would be trained to provide non-clinical supports.

Training providers: Ohio's approach

In Ohio, state and county agencies serving individuals with both mental retardation and mental illness observed that few practicing psychiatrists were willing or comfortable enough with their clinical skills to serve this population. Part of the reason for the shortage of appropriate psychiatrists is that there are few training experiences within psychiatry residency curricula specifically geared to serve people with this dual diagnosis.

To address this significant barrier to services, the state's mental health agency and mental retardation/developmental disabilities services agency have collaborated with agencies serving these populations in Montgomery County to jointly fund a Professorship of Mental Retardation/Developmental Disabilities at the Department of Psychiatry at Wright State University (WSU). After a national search, WSU hired Julie Gentile, M.D. to hold this position.

¹³ Ryan, R. "Posttraumatic stress disorder in persons with developmental disabilities". Unpublished manuscript. Boulder: Department of Psychiatry, University of Colorado Health Sciences Center (1993).

Dr. Gentile teaches the didactic aspects of the curriculum, supervises residents in clinical placements, and provides direct services to the dually diagnosed at the Montgomery County Board of MR/DD.

In addition, the same state agencies, the Ohio Developmental Disabilities Council, and a joint mental illness/mental retardation advisory board have collaborated to develop a Coordinating Center of Excellence for Dual Diagnosis. The Center initiated its activities in January 2004 and will focus on systems change by developing local provider teams and providing technical assistance and training to improve services to people with co-occurring developmental disabilities and mental illness.

Contact: Glenn McCleese (614)-387-0375.

To the extent possible, treatment and services would be based on the best available research evidence and their effectiveness in supporting each individual.

Meeting participants were hesitant to use the term “evidence-based practices,” observing that formal protocols and decision trees often don’t apply to the real world problems faced by people with co-occurring developmental disabilities and mental illness. Instead, meeting participants suggested that service delivery must incorporate research evidence but emphasize individual needs and outcomes. For example, when prescribing medications for this population, general research data about the drug’s effectiveness and risks is important but cannot substitute for working closely with and monitoring an individual to determine what is most effective. While this kind of flexibility does not conflict with the concept of “evidence-based practices,” meeting participants chose instead to emphasize a core concept that would be present in any ideal system: that treatment and services plans would be determined, with consumer involvement, by “data, not dogma,” that emphasizes individualized outcomes.

All staff would be trained to identify past trauma, understand its effects on people with co-occurring developmental disabilities and mental illness, ensure appropriate adjustments to treatment/service plans to address trauma issues, and avoid re-traumatization. Although little data exists about the prevalence of trauma histories among this population, some literature and anecdotal evidence provided by meeting participants suggests that most individuals with both mental illness and developmental disabilities have experienced sexual or other physical abuse.¹⁴ Successful treatment and service delivery must recognize and address trauma histories and avoid re-traumatizing through coercive or violent interventions such as seclusion, restraint, and forced medication.

Administrators would develop policies and procedures to adequately support caregivers. Caregivers for individuals with co-occurring developmental disabilities and mental illness need extensive supports that may exceed those required by caregivers for individuals with either a developmental disability or a mental illness. Examples of these supports include reliable, immediate emergency back-up, education and training, peer support, and respite.

¹⁴ Some meeting participants suggested that as many as 90 percent of individuals with both mental illnesses and developmental disabilities served in their systems were victims of past trauma.

Services would be provided in the least restrictive setting appropriate for each individual's needs. Although inpatient services would be available when required, appropriate community placements would be available to facilitate hospital and other institutional discharges as soon as possible. Mental health and developmental disabilities systems would work with police, jail and prison officials, and courts to implement effective jail diversion programs, provide treatment and services for individuals in jails and prisons, and ensure successful re-entry into communities. Mobile treatment teams would ensure access to and coordination of services and facilitate compliance with treatment plans.

Mental health and developmental disabilities systems would work collaboratively with each other and other service systems, especially primary care. The need to work closely with Medicaid agencies to secure stable, appropriate financing is described above. In addition, collaboration with primary care and public health networks, especially to promote prevention and early intervention efforts, is critical. All relevant service systems would participate in each other's planning efforts, and jointly develop policies to facilitate the delivery of effective, appropriate treatment, services, and supports for this population.

Working Together to Achieve the Vision

The vision described above is far from the reality faced by individuals with co-occurring developmental disabilities and mental illness. Federal and state policies fail to encourage mental health and developmental disabilities service systems to collaborate to ensure routine assessments, accurate diagnoses, integrated funding streams, and access to appropriate biopsychosocial interventions by cross-trained staff. As a result, individuals with dual diagnoses continue to experience treatment failures and be at significant risk for long-term institutionalization.

Meeting participants emphasized that partnerships across systems must take place at all levels -- national, regional, and local – and must embrace a range of stakeholders, including administrators, providers, advocates, consumers and families, and self-advocates.

State mental health and developmental disabilities agencies can and should play an integral role in initiating and modeling collaboration. First, agencies should formally acknowledge their shared responsibilities for serving this population, jointly assess the effectiveness of their existing approaches, and identify barriers to effective services. This paper is intended to begin that process.

State mental health and developmental disabilities agencies should formally acknowledge their shared responsibilities for serving this population, jointly assess the effectiveness of their existing approaches, and identify barriers to effective services.

Second, agencies should consider entering into cooperative agreements or developing interagency task forces that encourage collaboration across agencies. It is important that these agreements or task forces go beyond “divvying up” financing responsibilities to genuine collaboration that promotes accurate assessments and diagnoses, provides staff in both systems with appropriate cross-training, expands access to community services, and ensures that the individualized needs of each person requiring or receiving services are met.

And finally, agencies should actively facilitate a dialogue across disparate stakeholder groups to address stigma and the cultural and philosophical gaps between the mental health and developmental disabilities communities. In particular, state agencies can play a key role in educating advocacy groups and encouraging ongoing communication.

Learning From Each Other

Meeting participants agreed that collaboration across mental health and developmental disabilities agencies should be “strengths-based” and should work to improve both systems of care independently as well as collaboratively.

Addressing the concern that existing service gaps and inadequacies in both service systems leads to substandard care for individuals with dual diagnoses, meeting participants suggested that collaboration should include agencies learning from and incorporating the strengths of the agencies they partner with. For example, the mental health system has developed a sophisticated, effective approach to consumer and family psychoeducation that could be adapted to support people with developmental disabilities and their families. The developmental disabilities service system, on the other hand, generally has been more successful in advocacy and its efforts to close institutions and integrate people into the community.

This approach does not deny the important differences between the mental health and developmental disabilities systems, but rather acknowledges and respects the separate reform movements that have shaped the values, priorities, and infrastructure of both systems over the last four decades. The successes of each system are used to strengthen the other and build a more effective, collaborative approach for people requiring services from both systems.

Recommendations and Next Steps

Meeting participants emphasized that their groundbreaking dialogue is only the first step in a larger effort to better serve individuals with both mental illnesses and developmental disabilities. In particular, participants recommended that NASMHPD consider the following action steps:

(1) Continue the dialogue across systems. Several important topics were identified as priorities for future dialogue and initiatives, including the following:

- Articulate the level of interagency collaboration needed to effectively serve individuals with co-occurring developmental disabilities and mental illness. Meeting participants praised efforts by NASMHPD and the National Association of State Alcohol and Drug Abuse Directors (NASADAD) to move beyond abstract discussions of collaboration toward a concrete agreement about when collaboration, coordination, and/or integration of services are appropriate. Meeting participants suggested that the NASMHPD/NASADAD initiative might provide a model for future collaboration across mental health and developmental disabilities agencies.
- Facilitate an open dialogue about some key clinical and philosophical issues that remain as areas of perceived differences between mental health and developmental disabilities systems, including issues related to behavioral supports and coercion, the use of seclusion and restraint, and financing.
- Develop a common language to facilitate dialogue, including clarity in definitions and agreements among stakeholders about preferred terms.

(2) Develop a joint research and data agenda. Little is known about the population of people with co-occurring developmental disabilities and mental illness, complicating state planning efforts and attempts to prioritize this population for services. Meeting participants identified the following as priorities for data collection for this population:

- Prevalence of co-occurring developmental disabilities and mental illness – among the general population, among those receiving services through the mental health system, and among those receiving services through the developmental disabilities system;
- Incidence of trauma;
- Incidence of risky or dangerous behavior, especially sexual offending and self-injurious behaviors; and
- Incidence of incarceration; and

- Costs of providing services.

In addition to the above data needs, meeting participants identified several important research questions, including research regarding

- (3) Identify and disseminate clinical and programmatic models and promising practices.** Several communities and local systems of care have implemented effective programs to serve individuals with co-occurring developmental disabilities and mental illness. Identifying these programs and sharing information about their key characteristics provides an important starting point for states seeking to reform or improve services for this population.
- (5) Through NASMHPD’s Medical Directors’ Council, produce a Technical Report on the programmatic and clinical needs of this population and the policy reforms needed to meet those needs.** Appropriate use of psychiatric medications is an important priority for technical assistance through this report.
- (4) Identify and disseminate effective models of collaboration.** Collaboration across mental health and developmental disabilities service systems is needed.
- (5) Develop a universal assessment tool and guidelines for its use.** Working collaboratively with experts in mental health, developmental disabilities, and dual diagnoses, NASMHPD should convene a work group to develop a universal assessment tool, articulate guidelines for its use,
- (6) Recommend changes in federal programs.** NASMHPD and other mental health and developmental disabilities stakeholders should work collaboratively to develop a federal policy agenda and advocacy strategy to facilitate interagency collaboration and, where needed, the integration of funding streams to provide appropriate, coordinated services.

Conclusion

The meeting from which the information and recommendations contained in this report were drawn took place before release of the final report of the President's New Freedom Commission on Mental Health in July 2003.¹⁵ The Commission's work was conducted within the framework of the administration's broader New Freedom Initiative, which presents a vision of all Americans with disabilities having opportunities to live, work, learn, and participate fully in their communities.¹⁶

Although there was no explicit connection between the effort embodied in this report and the work of the President's Commission, the two are aligned in significant ways. While the Commission report makes scant reference to developmental disabilities, it does devote considerable space to recommendations encouraging cross-system collaboration at the local, state, and federal levels, improved screening and assessment, and accelerated research and knowledge dissemination. In the eyes of many, the Commission's central recommendation is for development of individualized plans of care, supported by sweeping changes in the mental health system's structure and practice. These and other recommendations echo those made in this paper with specific reference to the systems serving individuals with co-occurring developmental disabilities and mental illnesses.

As recommendations of the President's Commission move towards implementation in the next several years, those seeking reform of the systems serving individuals with these co-occurring disorders must look for opportunities to ensure consideration of the concerns raised in this paper. As improvement in services for people with developmental disabilities and mental illnesses will depend on collaboration across systems, it is clear that reformers will have to look beyond opportunities initiated within the mental health system. The thesis of this report is that improvements in services for individuals with co-occurring developmental disabilities and mental illnesses will come only when all systems on which they rely meet their obligations to this population.

This report represents a start to the process of shining a light on the issues that must be confronted by systems serving people with co-occurring developmental disabilities and mental illnesses. By taking up the challenges laid out in these pages, policy makers and systems administrators can begin to create the mechanisms needed to help individuals with these co-occurring conditions seize the opportunities promised in our society for fulfilling and productive lives.

¹⁵ New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. Available at: <http://www.mentalhealthcommission.gov/reports/reports.htm>.

¹⁶ *New Freedom Initiative*, The White House, February 1, 2001. Available at: <http://www.whitehouse.gov/news/freedominitiative/freedominitiative.pdf>.

APPENDIX A

Meeting Participants

Alexandria, Virginia

April 11, 2003

Carlos Brandenburg, Ph.D.

Administrator

Division of Mental Health and Developmental Disabilities

Department of Human Resources

505 East King Street, Room 602

Carson City, NV 89701-3790

(775) 684-5943

cbrandenburg@dhr.state.nv.us

Barbara Brent

Deputy Assistant Director

Division of Developmental Disabilities

Arizona Department of Economic Security

PO Box 6123

Phoenix, AZ 85005-6123

(602) 542-6853

bbrent@de.state.az.us

Cathy Campbell, J.D.

Director of Legal Services

Department of Mental Health and Mental Retardation

909 West 45th Street

P.O. Box 12668

Austin, TX 78711-2668

(512) 206-4591

cathycampbell@mhmr.state.tx.us

Michael D. Chambers

Board Member

National Association of County Behavioral Health Directors

Executive Director

MHMR Administrators Association of PA

17 North Front Street

Harrisburg, PA 17101

(717) 232-7554

mchamber@pacounties.org

Bob Clabby

Administrator
Developmental Disabilities Division
Wyoming Department of Health
186E Qwest Building
6101 Yellowstone Road
Cheyenne, WY 82002
(307) 777-7115
rclabb@state.wy.us

Jerry Deans

Assistant Commissioner
Division of Facility Management
Department of Mental Health, Mental Retardation, and Substance Abuse Services
P.O. Box 1797
Richmond, VA 23218
(804) 786-0383
gdeans@dmhmrsas.state.va.us

Jerry Dennis, M.D.

Medical Director
Department of Health Services
Division of Behavioral Health Services
2122 East Highland, Suite 100
Phoenix, AZ 85016
(602) 553-9002
jdennis@hs.state.az.us

Richard DiGeronimo

Public Health Advisor
SAMHSA
Center for Mental Health Services
5600 Fishers Lane Room 15C26
Rockville, MD 20857
(301) 443-2056
rdigeron@samhsa.gov

Robert J. Fletcher, DSW

Executive Director
The National Association for the Dually Diagnosed (NADD)
132 Fair Street
Kingston, NY 12401
(800) 331-5362
rfletcher@thenadd.org

Linda Flores

Executive Assistant to the Deputy Secretary
Office of Mental Health and Substance Abuse Services
Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105-2675
(717) 787-6443
liflores@state.pa.us

Robert M. Gettings

Executive Director
National Association of State Directors of Developmental Disabilities Services
113 Oronoco Street
Alexandria, VA 22314
(703) 683-4202
rgettings@nasdds.org

Robert W. Glover, Ph.D.

Executive Director
National Association of State Mental Health Program Directors
66 Canal Center Plaza, Suite 302
Alexandria, VA 22314
(703) 739-9333, x129
bob.glover@nasmhpd.org

Pablo Hernandez, M.D.

Administrator
Mental Health Division
Department of Health
P.O. Box 177
(or 831 South Highway 150)
Evanston, WY 82931-0177
(307) 789-3464, x354
pherna@state.wy.us

Thomas Hester, M.D.

Chief
Adult Mental Health Division
Department of Health
1250 Punchbowl Street
P.O. Box 3378
Honolulu, HI 96813
(808) 586-4688
twhester@amhd.health.state.hi.us

Lisa S. Hovermale, M.D.
Psychiatrist/Liaison, DDA/MHA
Spring Grove Hospital Center
Mitchell Building
55 Wade Avenue
Catonsville, MD 21228
(410) 402-8461
lhovermale@dhhm.state.md.us

Joyce Jorgenson
5 Sargent Camp Road
Harrisville, NH 03450
(603) 924-8368
joycejorgenson@earthlink.net

Michael Maples
Assistant Director
Behavioral Health Services
909 West 45th Street
P.O. Box 12668
Austin, TX 78711-2668
(512) 206-5968
michael.maples@mhm.state.tx.us

Noel A. Mazade, Ph.D.
Executive Director
NASMHPD Research Institute, Inc.
66 Canal Center Plaza, Suite 302
Alexandria, VA 22314
(703) 739-9333, x113
noel.mazade@nri-inc.org

Charles R. Moseley, Ed.D.
Director of Special Projects
National Association of State Directors of Developmental Disabilities Services
113 Oronoco Street
Alexandria, VA 22314
(703) 683-4202
cmoseley@nasdds.org

Liz Obermayer

Quality Consult/Self-Advocate
The Council
100 West Road, Suite 406
Towson, MD 21204
(410) 583-0060
lizobe@aol.com

Pope Simmons

Senior Vice President Government Relations
National Council for Community
Behavioral Healthcare
12300 Twinbrook Parkway, Suite 320
Rockville, MD 20852
(301) 984-6200
popes@nccbh.org

Kenneth Ritchey

Director
Ohio Department of Mental Retardation/Developmental Disabilities
1810 Sullivant Avenue
Columbus, OH 43223-1239
(614) 466-0129
ken.ritchey@dmr.state.oh.us

Lucille Schacht, Ph.D.

Director of Statistical Analyses/Director of Operations
NASMHPD Research Institute, Inc.
66 Canal Center Plaza, Suite 302
Alexandria, VA 22314
(703) 739-9333, x125
Lucille.Schacht@nri-inc.org

Christine P. Squibb

Director
Office of Consumer Affairs
Department of Mental Health
1706 East Elm Street
P.O. Box 687
Jefferson City, MO 65102-0687
mzsquic@mail.dmh.state.mo.us

Sue Swensen

Deputy Executive Director

The Arc/US

1010 Wayne Avenue, Suite 650

Silver Spring, MD 20910

(301) 565-3842

swenson@thearc.org

Nancy Thaler

Deputy Secretary for Mental Retardation

Office of Mental Retardation

Pennsylvania Department of Public Welfare

Health & Welfare Building, Room 512

PO Box 2675

Harrisburg, PA 17105-2675

(717) 787-3700

nthaler@state.pa.us

Facilitator:

A. Kathryn Power

Director

Department of Mental Health, Retardation, and Hospitals

14 Harrington Road, Barry Hall

Cranston, RI 02920

(401) 462-3201

kpower@mhrh.state.ri.us

Writer:

William Kanapaux

P.O. Box 3176

Albany, NY 12203

(518) 482-9711

kanapaux@NYCAP.rr.com

NASMHPD Staff:

William Emmet

Project Director

66 Canal Center Plaza, Suite 302

Alexandria, VA 22314

(703) 739-9333, x136

bill.emmet@nasmhpd.org

Shelby M. Hockenberry

Policy Associate

66 Canal Center Plaza, Suite 302

Alexandria, VA 22314

Jenifer Urff, J.D.

Senior Policy Counsel

C/o Donahue Institute

100 Venture Way, Suite 5

Hadley, MA 01035

(413) 587-2418

jurff@donahue.umassp.edu

APPENDIX B

Bibliography and Selected References

Benson, B. and Eddy, A. Biopsychosocial Treatment. In *Clinical Best Practices for Serving People with Developmental Disabilities and Mental Illness*. Ohio Department of Mental Health, Ohio Department of Mental Retardation and Developmental Disabilities Advisory Committee (2000).

Dual Diagnosis Task Force of the Public Policy Committee of the Canadian Mental Health Association, Ontario Division. Fact Sheet: *Dual Diagnosis: People with Developmental Disability and Mental Illness – Falling Through the Cracks*. June, 1998.

Eberlein, L. Guidelines for the Evaluation of Persons Dually Diagnosed with Mental Retardation and Mental Illness. In *Clinical Best Practices for Serving People with Developmental Disabilities and Mental Illness*. Ohio Department of Mental Health, Ohio Department of Mental Retardation and Developmental Disabilities Advisory Committee (2000).

Fletcher, R., Beasley, J., and Jacobson, J. Support service systems for people with dual diagnosis in the USA. In Bouras, N. (ed.), *Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation*. Cambridge, UK: University Press (1999), pp. 373–390.

Fodero, J. Forgotten: The Other Dually Diagnosed. Available at: <http://intotem.buffnet.net/mhw/30jf.html>.

Jacobson, J. and Holburn, S. The Foundation of Dual Diagnosis Partial and Supportive Services. In Jacobson, J., Mulick, J., and Holburn, S. (eds.), *Contemporary Dual Diagnosis: MH/MR Service Models, Volume II: Partial and Supportive Services*. Kingston, NY: National Association for the Dually Diagnosed (2002).

Jacobson, J. and Mulick, J. Introduction: Dual Diagnosis Residential and Day Services. In Jacobson, J., Mulick, J., and Holburn, S. (eds.), *Contemporary Dual Diagnosis: MH/MR Service Models, Volume I: Residential and Day Services*. Kingston, NY: National Association for the Dually Diagnosed (2002).

Jorgenson, J. Barriers and Strategies for Effective Services Delivery from a mother's perspective. Unpublished document (April, 2003).

Kessler, R. Psychiatry and Mental Retardation. American Psychiatric Association Consortium on Treatment Issues. Available at http://www.psych.org/pract_of_psych/disability.cfm

Ohio Department of Mental Health and The Ohio Department of Mental Retardation and Developmental Disabilities. Interagency Agreement. Available at http://odmrdd.state.oh.us/Includes/Press_Releases/MH_InterAgy_Agreement.pdf

Ohio Department of Mental Health, Ohio Department of Mental Retardation and Developmental Disabilities Advisory Committee. *Report and Recommendations: Clinical Best Practices for Serving People with Developmental Disabilities and Mental Illness*. 2002.

Pennsylvania Department of Public Welfare. Coordination of treatment and support for people with a diagnosis of serious mental illness who also have a diagnosis of mental retardation. Pennsylvania Department of Public Welfare Bulletin No. 00-02-16 (Dec. 17, 2002).

Pennsylvania Department of Public Welfare. Guidelines for Identifying Persons with Mental Retardation and Mental Illness for State Mental Health Hospital Discharge. Pennsylvania Department of Public Welfare Bulletin No. 00-00-04 (May 15, 2000).

Poindexter, A. (ed.), Cooperation Between Mental Health and Mental Retardation/Developmental Disability Systems. *NADD Bulletin*, vol. 5, no. 6. (Nov/Dec 2002) and vol. 6, no. 1 (Jan/Feb 2003).

Reiss, S. Fact Sheet: Mental Illness in Persons with Mental Retardation. Silver Spring, MD: The Arc (Sept. 1993).

Schacht, L. and Higgins, K. NRI Behavioral Healthcare Performance Measurement System Public Report: Diagnostic Profile of Clients Served. Alexandria, VA: NASMHPD Research Institute, Inc. (May, 2002)

Shriver, E. Presentation on behalf of the Joseph P. Kennedy Jr. Foundation, in a presentation to participants in a 2001 workshop convened by the National Institute of Neurological Disorders and Stroke, the National Institute of Child Health and Human Development, the National Institute of Mental Health, the National Institute of Health Office of Rare Diseases, and the Kennedy Foundation. For a summary of the proceedings, please see: <http://ohrp.osophs.dhhs.gov/nhrpac/mtg07-02/nhrpac11.pdf>

Wilkerson, D. A Best Practice Model for Delivering Dual Diagnosis Services. In *Clinical Best Practices for Serving People with Developmental Disabilities and Mental Illness*. Ohio Department of Mental Health, Ohio Department of Mental Retardation and Developmental Disabilities Advisory Committee (2000).