NASDDDS TECHNICAL REPORT

Survey on State Strategies for Supporting Individuals with Co-existing Conditions

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Introduction

In January 2004, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) launched a multi-part study of state strategies for supporting individuals with co-existing developmental disabilities and mental health or behavioral conditions. This paper reports the findings of one component of that study, a survey of state agency officials on the approaches used to support individuals with co-existing conditions. The questionnaire was designed to build upon the results of a previous survey of the directors of state developmental disabilities and mental health agencies conducted in March 2003 by NASDDDS in association with the National Association of State Mental Health Program Directors (NASMHPD).[1]

In July 2004, a letter was sent to the directors of all state developmental disabilities agencies, including Washington DC, requesting their participation in a short survey of state strategies for supporting individuals with co-existing conditions. The correspondence included an Internet link connecting respondents to an on-line questionnaire comprised of fifteen multiple-choice and short answer questions. Responses were received from forty-four of the fifty states, plus Washington D.C. representing eighty-six percent (86%) of the Association's membership. The survey was designed to gather information on several key areas related to the funding, operation, and scope of state financed programs for individuals with co-existing conditions. This paper reports survey results identifying commonalities and differences among states with respect to interagency collaboration, responsibility for payment and service provision, barriers inhibiting the delivery of supports and the program elements believed to be most directly associated with positive individual and program outcomes.

[1] See NASDDDS Project Technical Report, April 2003 by Chas Moseley

Working Together.

The presence of positive interagency collaboration is frequently identified as a necessary component of effective service design for persons with coexisting conditions. In the current study, the majority of the respondents, 28 of 43 states (65%), reported that their state's policy regarding individuals with co-existing conditions was developed and implemented through a collaborative process between the state developmental disabilities (DD) and mental health (MH) authorities.

Assessments of the effectiveness of the working relationship between the departmental authorities varied among the 44 states participating in the survey. The majority, 24 states (55%) described the relationship as effective, very effective or extremely effective, while the remaining 21 (45%) rated the relationship as not or not very effective.

State officials did not rate the effectiveness of the collaboration between state DD and Correctional authorities as favorably. In this case, the clear majority of state officials responding to the survey, 73% (31 of 43), described the relationship between DD and correctional agencies as not or not very effective. The response was not all one sided, however, relations between the two departments were identified as effective by 10 (22%) respondents and in one state, very effective.

The same question was asked regarding the nature of the working relationships between community DD and MH service providers. In this case, 24 of the 43 respondents (56%) described the working relationships between the two provider groups in their states as not or not very effective. Nineteen respondents (44%) indicated that collaborative efforts were effective or very effective (see Figure 1).

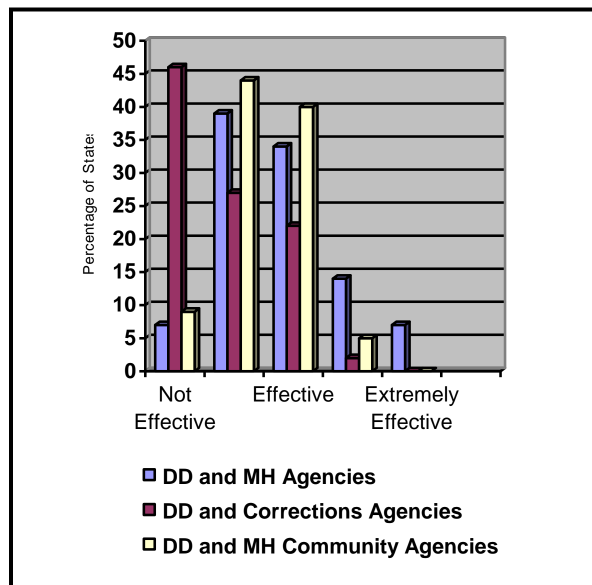

Figure 1. Interagency Collaboration Effectiveness

In summary, the results of the questions regarding interagency collaboration suggest that although relationships between state DD and MH agencies are generally productive, considerable effort needs to be directed toward improving collaboration between DD and correctional authorities.

Responsibility for Funding and Service Provision.

Two survey questions gathered information on the individual and shared responsibilities of state DD and MH authorities for funding and service provision.

Individuals with co-existing conditions may require services and supports from a number of different state agencies, each employing separate eligibility, funding, and program requirements. State policies and practices can vary significantly from one program to the next challenging each agency's best attempts to coordinate and deliver services in an effective manner. Although an individual may interact with several state supported programs, responsibility for both funding and service provision is typically shared or distributed between the DD and MH program authorities.

Who Pays? The survey findings suggest that responsibility for funding certain categories of service, such as long-term support, consistently resides with one agency or another, while the costs for other services are generally spread between the DD and MH authorities. The majority of the state officials responding to the survey, 30 of 43 (70%) reported that funding for long term services and supports was the responsibility of the DD agency alone. A little more than half of the states, 22 of 43 (51%), reported that the DD authority additionally was responsible for covering costs related to case management (including program planning, and service coordination). Not unexpectedly, responsibility for funding short-term psychiatric care rested with the state MH authority in 32 of 42 states responding (78%).

Payment responsibility for other services and supports, however, was less often centralized in a single state agency. Funding for clinical consultation and treatment, for example, appeared to be fairly evenly spread between the two state authorities (see Table 1). Crisis and emergency services were more apt to be funded by the DD

Activity Funded	Funding Responsibility							
	DD		MH		Shared		Either	
	n	%	n	%	n	%	n	%
Long-term Support	30	70	1	2	7	16	5	12
Case Management	22	51	1	2	9	21	11	26
Clinical Services	10	23	11	26	12	28	10	23
Crisis Response	14	33	6	14	12	28	11	26
Psychiatric	2	4	32	76	5	12	3	7
Quality Assurance	15	37	2	5	10	24	14	34

Table 1.
Departmental Funding Responsibility by Service Type

authority, 14 of 43 (33%) states responding, but payment responsibility for this service varied by state. The mental health authority was solely responsible for funding crisis services in six states (14%). The obligation was shared in 12 states (28%) and funded by either agency depending on the case in 11 states (26%). Quality assurance was funded by the DD authority in thirty-seven percent (37%) of the states, and distributed between the two agencies in thirty-four percent (34%) of the states.

Who Provides? Responsibility for providing services and supports to individuals with co-existing conditions generally followed funding liability. Long-term services were provided by the DD authority in 26 of 43 states (60%). The responsibility was shared in eight states (19%) and provided by either the DD or MH authority, also in eight states. The mental health authority was responsible for providing long-term support to individuals with coexisting conditions in one state (2%). The state DD agency was primarily responsible for providing case management and program planning services in 23 of 43 states. The mental health authority, by contrast, held this responsibility in only one state (2%). The obligation was shared in nine states (21%) and was assigned to either the DD or the MH agency depending on the situation in 10 states (23%). Table 2 illustrates the distribution of service provision responsibilities between state DD and state MH authorities by type for clinical services, crisis response, psychiatric services, and quality assurance.

Purchase of Services. A review of each state's responses to questions five and six suggests that state developmental disabilities and mental health authorities generally provide the services they fund, rather than purchasing services from one another. Figure 2 on the next page compares funding and service provision responsibilities by service type. The vertical axis indicates the percentage of

Activity Provided	Responsibility for Service Provision							
	DD		MH		Shared		Either	
	n	%	n	%	n	%	n	%
Long-term Support	26	60	1	2	8	19	8	19
Case Management	23	54	1	2	9	21	10	23
Clinical Services	9	21	8	20	17	40	9	21
Crisis Response	13	30	3	7	17	40	10	23
Psychiatric	1	2	32	75	8	17	2	5
Quality Assurance	15	35	2	5	13	30	13	30

Table 2.
Departmental Responsibility for Service Provision
By Service Type

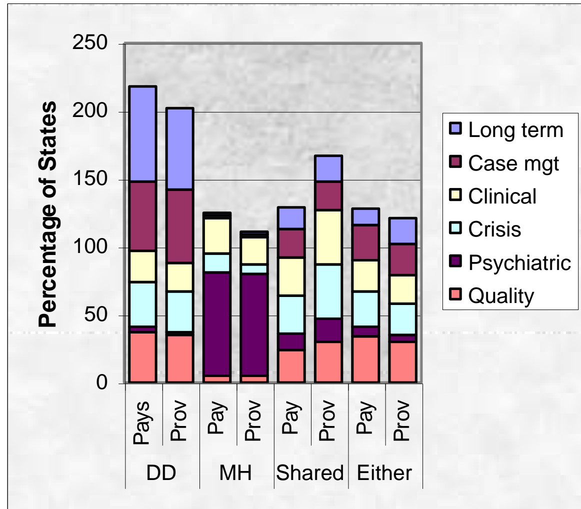

Figure 2. Responsibility by Department

states responsible for funding and providing each type of service; the colored bars indicate the service type. In most instances, state DD and MH authorities with responsibility for funding services, provided the services. Exceptions occurred in two areas. The mental health authority was cited as the entity responsible for funding crisis intervention and support in 14% of the states but for providing the service in only seven percent of the states. This appears to suggest that the state mental health authority is more apt to purchase or share in the cost of crisis services than to provide them directly. Similarly, with respect to clinical consultation and treatment, 40% of the respondents reported that responsibility for providing services was shared by state DD and MH authorities, but only 28% of respondents reported that responsibility for funding these services also was shared. The same percentage differences were reported with respect to crisis intervention and treatment: 40% and 28% respectively.

Barriers.

The survey of state directors of developmental disabilities and mental health agencies jointly conducted by NASDDDS and NASMHPD in 2003[2] identified the lack of qualified service providers as a major obstacle to the delivery of services to people with co-existing conditions. The current questionnaire sought more specific information on the impact of service provider availability related to: (a) long term support, (b) program planning and case management, (c) clinical consultation and treatment, (d) psychiatric or medication management,

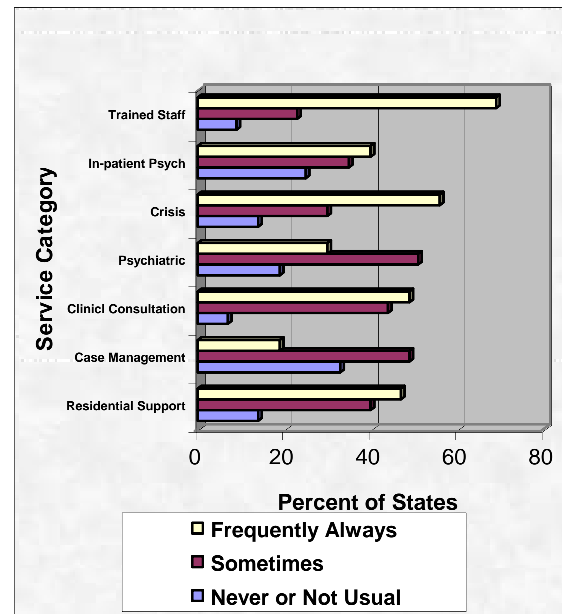

Figure 3. Percentages of States Experiencing Barriers to Service Delivery Due to Provider Availability

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[2] Ibid.

(e) crisis intervention, (f) short term inpatient psychiatric care, and (g) trained staff.

An insufficient number of qualified service providers in any of the above-mentioned areas could significantly impair service delivery (See Figure 3 on the previous page). The availability of trained staff was identified as frequently or always a barrier by 24 of 35 (69%) survey respondents. The accessibility of crisis intervention and support services was identified as a major barrier ranking second by 24 of 43 (56%) state officials responding to the survey. In third place was the availability of clinical consultation and treatment services, identified as frequently or always a barrier by 21 of 43 respondents (49%) and in fourth, the availability of long term residential supports, identified by 20 of 43 (47%) states. The inability to use funds in a flexible or unrestricted manner to meet the needs of individuals with co-existing conditions was described as frequently or always posing a barrier to service delivery by 18 of 43 (42%) survey respondents.

THE TOP FIVE MOST CHALLENGING BARRIERS

1. **Not Enough Providers**
2. **Provider Unwillingness**
3. **Lack of Coordination**
4. **System Structure**
5. **Lack of Targeted Funds**

Approaching the question of barriers in a slightly different way, respondents were asked to rank order the five most challenging barriers facing their state's efforts to support individuals with co-existing conditions. Their responses, summarized in the box above, include in descending order of priority: (a) an insufficient number of providers with expertise, (b) the unwillingness of providers to serve individuals with co-existing conditions, (c) an inability to coordinate activities with the department of mental health, (d) the structure of the existing service delivery system and, (e) the lack of designated funding for this group of individuals.

Crisis Services.

As noted above, fifty-six percent (56%) of the respondents identified the lack of effective crisis intervention and support services as a frequent or consistent impediment to the provision of supports to individuals with co-existing conditions. Crisis services are configured in different ways depending on the structure of each state's system of service delivery. In some parts of the country, for example, emergency services are provided through local county or regional programs. In other areas such supports are delivered on a statewide basis, often coordinated with regional or district offices of the state agency. Still other states rely on local, provider-based programs. In response to a question on the structure of the

state's crisis service system, 14 of 34 survey respondents (41%) reported that crisis support is furnished through a regional or county network. Ten states (29%) base their crisis response capacity at the local level in private agencies; two (6%) furnish crisis services through a statewide system or network and three (9%) use a combination of approaches. No organized crisis response capacity was reported to exist in five (15%) of states responding.

In general, existing crisis response services were considered to be effective or very effective in 56% of the states and not or not very effective in 44% of the responding states. Ratings of effectiveness varied according by crisis system structure. The two states organizing crisis response services at the state level rated their systems as effective and very effective. Of the 14 states with systems based at the county or regional level, 11 of the 13 states responding (one state did not report) or 85% described this approach as being effective or very effective. Turning to states with crisis response capacity based at the local or provider level, five of the nine states reporting described their systems as not very effective (56%) and four reported their systems to be effective (44%). To briefly summarize, the majority of states reported that their crisis intervention systems were organized at the county or regional level and 85% of those responding rated these system as effective or very effective.

What Works?

One question frequently asked by policy makers, program administrators and staff alike is: "what works?" Survey respondents were asked to identify the three program or funding elements that contributed the most to achieving effective service outcomes. The ability to individualize services was cited as the most important factor by the majority of state officials, 29 of 40 individuals responding (73%). The presence of responsive crisis or emergency services was ranked second by 30 of 42 respondents (71%). The existence of effective systems for support coordination and planning was named by 27 of 40 respondents (68%). A complete breakdown of the data is shown in Figure 4.

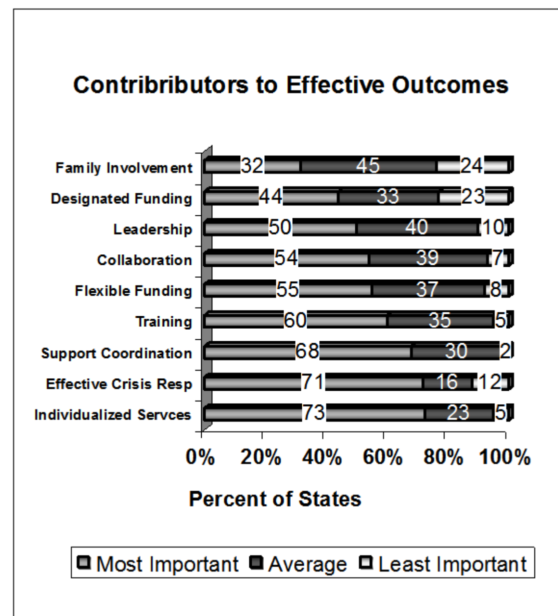

Figure 4. Program Elements Contributing to Successful Outcomes

A Typical State.

This paper reports on the results of a survey of officials of state developmental disabilities agencies on the nature of state funded services offered to individuals with co-existing developmental disabilities, mental illness, and/or behavioral conditions. The data in combination suggest that services to individuals with co-existing conditions in a "typical" state might exhibit a number of characteristics.

In a typical state, policy with respect to the organization and delivery of services is developed through an effective collaboration between the state authorities for developmental disabilities and mental health. Working relationships with department of corrections, by contrast, are not effective. Responsibility for funding and service provision is distributed between the DD and MH state authorities with each department covering the costs of the services it supports through its own budget. The state DD agency pays for long-term services and supports, program planning, case management/ service coordination. The state MH authority covers the costs of short-term in-patient psychiatric services. Responsibility for funding and providing clinical consultation and treatment as well as crisis intervention rests with either or both state programs. The quality of services provided to individuals with co-existing conditions is monitored and assessed by the DD authority alone or in collaboration with mental health officials, but the process used is not very effective.

The typical state suffers from a lack of service provider availability across a number of areas including staff with expertise, crisis intervention, and clinical consultation. Programmatically, the state is challenged by insufficient numbers of providers with expertise, the unwillingness of existing providers to support individuals with co-existing conditions, an inability to effectively coordinate services with the mental health authority, limitations imposed by the structure of the existing service delivery system, and the lack of funding designated to support this group of individuals.

Crisis intervention services are based at the county or regional level and the supports provided are generally effective. The lack of capacity in this area, however, can be a significant barrier to service provision. The achievement of positive treatment and support outcomes for individuals with co-existing conditions is most influenced by the ability to individualize the supports a person receives, the availability of capable and responsive emergency services and the presence of an effective system of support coordination and service planning.

Discussion.

Increasing numbers of individuals with developmental disabilities are receiving publicly financed services and supports in integrated community settings. Institutional populations declined by 48.7% between FY 1990 and FY 2003. During this same period, the number of individuals receiving Medicaid home and community based services increased by 910%, a net expansion of 362,600 beneficiaries. The trend toward placement in smaller settings during this period has been dramatic. In 1982, for example, 15,705 individuals were reported to be living in homes of three or fewer individuals. By 2003, the number had grown to an estimated 177, 260 individuals representing 44% of the total number of persons with DD receiving state financed residential services.[3] This dramatic shift in the base of service delivery from centralized facilities to dispersed community programs requires that states develop the capacity to support individuals with even the most intensive needs in local settings. Individuals with co-existing developmental disabilities and mental illness, and those with intensive behavioral conditions, have needs that challenge the ability of state agencies to operate and maintain community systems. This study surveyed state officials on the strategies used to support these individuals, identifying key elements associated with effective service design, and barriers to service delivery. Descriptive information was gathered from state officials on funding and support provision responsibility, the organization of crisis response services and quality oversight.

Achieving Positive Outcomes. State officials reported that the program elements most directly associated with the achievement of positive outcomes include: (a) the ability to individualize the services and supports offered to individuals with co-existing conditions, (b) the availability of systems with the capacity to provide effective and immediate support to persons in need of emergency assistance and, (c) the presence of effective methods of program planning and support coordination.

Barriers. Factors impeding states' efforts to furnish supports to individuals with co-existing conditions clustered around three major areas. First, service provider capacity, availability and willingness; second, barriers associated with the design and operation of the existing service delivery system, and; third, the lack of funding designated to meet the needs of this group of individuals.

Information Needs. State officials reported that their agency's efforts to

[3] Prouty, R. W., Smith, G. & Lakin, K. C. (Eds.) (2004). Executive Summary. Residential services for persons with developmental disabilities: Status and trends through 2003. Minneapolis: University of Minnesota, Research and Training Center on community Living, Institute on Community Integration.

address the needs of individuals with co-existing conditions were generally effective, but appeared to have little confidence that the particular approach being used produced the outcomes they would like to achieve. Respondents were sensitive to the capabilities and limitations of their own programs, as well as those financed by state mental health and correctional authorities. Throughout the survey, state officials expressed the need for information on "best" or "promising" practices employed by other states to achieve successful treatment and support outcomes. The data strongly suggest the need for research and demonstration projects showcasing: "best-practice" examples of cost-effective support and treatment alternatives, successful training and workforce development strategies, and practical methods for providing emergency intervention, crisis, and clinical support services.

State officials reported that their efforts to support individuals with co-existing conditions would benefit most from information on the following topics (listed in declining order of importance):

- Funding issues, including effective strategies for cost containment, methods of increasing financial flexibility and targeting funds to serve individuals with co-existing conditions – 20 states.
- Best practice examples of effective service delivery models – 15 states.
- Best practice examples of effective treatment and clinical interventions – 13 states.
- Innovative training approaches for service providers and state agencies – 13 states.
- Interagency agreements, and strategies for effective service coordination across state agencies and providers – 10 states.
- The development of effective systems for crisis response, coordination and prevention – 8 states.
- Information on diagnostic and assessment methodologies – 5 states.
- Training for clinical staff – 5 states.

Final Thoughts.

The results of the survey underscore the complexity of the challenges states face when addressing the needs of individuals with co-existing conditions. Fundamentally, the service-related decisions that need to be made to support individuals with co-existing conditions are no different from those made on behalf of other eligible individuals. Determinations must be made with respect to:

- Eligibility and service priority.
- Selection of supports.
- Service planning and coordination.
- Selection of support provider(s).
- Selection of service venue.
- Funding and resource allocation.
- Monitoring and quality assurance.

And, as with all services, policy makers must balance the need to furnish supports that enable a person to "get a life" in the community with the necessity of operating within funding parameters established by the state's Governor and Legislature.

Differences exist, however, in several key areas, any of which has the potential to facilitate or significantly hamper service provision. Individuals with co-existing conditions typically have needs that extend beyond the scope of services offered by state DD agencies. They require more intensive support and supervision, staff with increased levels of skill and experience, professionals with specialized clinical expertise, more active service coordination and follow-up, the presence of consistent back-up and support and, living arrangements that serve fewer people. As a result of these needs, individuals with co-existing conditions frequently are more costly to serve and significantly greater emphasis must be placed on developing effective interagency collaboration and coordination strategies.

A growing number of state developmental disabilities agencies are being restructured as a part of broader efforts to reorganize human services along functional lines. Responsibilities for key program operations such as funding, quality assurance, case management/support coordination, and eligibility determination are being blended among departments formerly responsible for single populations. It is still too early to tell whether these efforts will strengthen or diminish states' capacities to improve the lives of individuals receiving support. An important measure of the success of these initiatives will be the extent to which the community system is able to support individuals with the most intensive needs, particularly those with co-existing conditions, in non-institutional settings.

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