A Systematic Strategy to Improve Services to Individuals With Coexisting Developmental Disabilities and Mental Illness: National Trends and the "Connecticut Blueprint"

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One method to evaluate community based systems of care based on service effectiveness standards for individuals with mental retardation and behavioral health needs is described. Thirty-five evaluations were conducted throughout the U.S. to identify obstacles to effective service delivery and determine remedies to improve the system as a whole. Common trends were found in almost all aspects of service delivery reviewed. The service evaluation process used in the state of Connecticut and the new initiatives now taking place there exemplify one state's attempt to evaluate services, overcome common obstacles and seek positive, long-term remedies to meet the challenge of providing effective services for this population. The authors recommend that state and local municipalities consider implementation of a systematic evaluation process to better identify gaps in the system and plan future services.

Keywords: bipolar, community services, developmental disability, forensic, intellectual disability, mental retardation, psychiatric, psychotic disorders, systems

Numerous national reports have been published to examine the problems associated with poor mental health (MH) service delivery for people with mental retardation (MR) and other developmental disabilities (DD) over the last 25 years, and articles and books written that describe model programs.[1,5] Recommendations include close examination on the state and local levels to evaluate the current public and private sector and promote positive outcomes, with a strong emphasis on cross-systems collaboration on all levels of service provision.[7] However, in many locations the problems persist. Few have responded to the need for federal and statewide policies to ensure that effective services are provided, and in some cases, this has resulted in class action lawsuits on behalf of people with MR and behavioral health needs (see Dorfman article in this issue). This article describes one method to evaluate community based services that can be used by state and local governments to assess their service delivery system. The process used in the state of Connecticut and the new initiatives now taking place there will also be described as an example of an attempt to overcome obstacles and seek positive, long-term remedies to meet the challenge of providing effective services for people with MR and behavioral health needs.

In 1999, the US Department of Health and Human Services Report[17] to the Surgeon General of the United States on Mental Health described the system of MH care as "multifaceted and complex," made up of public and private providers, multiple agencies and disciplines. (p. 8) The report attributed the configuration of the system to advances in MH practices, reform movements, financial incentives and variable payment streams. However, the report also acknowledged that the "hybrid" system does not always "function in a coordinated manner," creating problems especially for people with complex needs and limited means. The evidence indicates that the inability of MH providers to coordinate their efforts with other providers and agencies has most likely adversely affected services to individuals with MR and other DD.

In February 2002, in a report of the Surgeon General's Conference on Health Disparities and Mental Retardation,[18] Dr. David Satcher described MH care services to people with MR as a "pressing unmet health need and disparity" in the current system. The "national blueprint" prescribed in Satcher's report includes action steps to evaluate

service systems and services on local, state, and national levels.

Advocates have long supported both structural and strategic remedies to create positive long-term changes in the system and a number of model programs were developed in response.[5] The anecdotal evidence is that in many locales, rigid boundaries often found in both private and government operated agencies continue to compromise the ability of individual service users, who may require multiple services to receive effective care. Furthermore, there is a general lack of public policies that promote collaboration and information sharing between service systems. For example, we know that a comprehensive clinical evaluation requires time and active collaboration between caregivers and professionals,[13,14] yet the reimbursement practices of both private and public insurance carriers rarely allow for this to occur.

Model programs were designed in some locations to fill in the gaps that result from the systems issues just described, with positive outcomes. For example, a recent study in Massachusetts[1] found a significant decrease in the use of emergency services over a four-year period when services were provided based upon a comprehensive coordinated approach. However, more often than not, model programs are not typical of the programs available in a state's service system. Furthermore, many of the program models developed over the years, including the one in the study above, eventually experience dramatic cuts in resources or may be dismantled entirely because there is no policy in place to support their continuance. In order for national trends to improve, federal, state and local policies must support and promote a better approach to care. Such an approach begins with a comprehensive evaluation of the state of the current service delivery system.

In 1988, Gettings[7] outlined his own blueprint of the steps needed to make permanent and effective changes in the service system to better serve individuals with DD and MH needs. Gettings articulated that states and local governments should foster interagency collaboration and cooperation at the administrative and public policy levels. Formal affiliation agreements between administrators operating separate MH and MR (state and local) agencies should be developed so that information and resource sharing occur on behalf of individuals with DD and mental illness. In addition, he determined that state and local policies and resources should be dedicated to ensure that professionals collaborate across disciplines and participate in joint forums for service and treatment planning.

Gettings also suggested the establishment of an agreed upon common diagnostic language and protocols for the care and treatment of individuals with DD and behavioral health care needs. A major goal of this effort is to avoid having individuals go from one system to the next with neither system having the resources or responsibility to meet the individuals' needs.

To deal with the structural obstacles to effective service delivery, the development of local committees made up of stakeholders in the existing community system to assess the current state of service delivery and determine the need for resources and shifts in the service structure was recommended. Obstacles to effective service delivery would be identified through these forums, and collaborative efforts across service systems should take place to remove the obstacles. Finally, Gettings recommended that we evaluate the efficacy of existing and newly formulated methods of MH and support service delivery to people with DD and behavioral health care needs.

SERVICE EVALUATIONS

As was suggested by Gettings,[7] in order to identify obstacles to effective service delivery, it is important to evaluate the existing service system. Furthermore, the system should be evaluated from an individual service user's perspective, in the context of an evaluation of the service system as a whole.

In the evaluations described in this article, the review process was guided by two questions: "What are the obstacles in the service system that may compromise or undermine the ability to effectively meet the service needs of individuals with coexisting mental illness and developmental disabilities in the community?" and "How can the system as a whole provide remedies to these obstacles?"

This article presents findings from 35 evaluations conducted in 2001 and 2002. The method used to evaluate services included: individual case conferences, interviews with service users, family members and stakeholders, and the use of a Service Evaluation instrument based on the 3 A's for effective service use: access, appropriateness and accountability.[2] The goal of service evaluations was to focus on individuals known to "fall between the cracks" of two or more

service sectors. Evaluations were conducted on both the east and west coasts of the U.S., in six states. All of the individuals reviewed for the assessment process were considered to be more challenging and complex than the "typical" service recipient including many people with MR who may also use MH services.

In addition to their MH needs and behavioral difficulties, the individuals reviewed were all considered to be either difficult to place in the community, difficult to maintain in the community, or both, placing them at "high risk" for crisis service use, hospitalization and institutionalization. Multiple regions were represented that included urban, suburban and rural demographics and systems of care. Many of the individuals reviewed had active family involvement, although none of the individuals lived with their families at the time of the reviews.

Case conferences were held to discuss the service experiences and service needs of each individual referred. Meetings included the participation of the individual service user and their family whenever possible. In some cases, individuals chose to meet with the evaluator privately. The information gathered from case conferences focused primarily on the history of each individual's service experiences, diagnoses, treatment plans, and unmet service needs.

In addition, case conference participants were either interviewed or asked to evaluate the state of the service system using The Community Support Services Summary and Assessment forms provided to them.[4] The forms contained a list of services ordinarily used by individuals with DD and MH needs (residential, day, outpatient MH, inpatient MH, case management, crisis services, consultation and training). Since none of the respondents lived with their families, family support services were not considered in this analysis. However, it should be noted that family support services are essential in an effective services system.[3]

Participants were asked to identify which services existed in their local system. In addition, each service identified was evaluated by participants based on service effectiveness measures of access, appropriateness and accountability.[2]

For each of the services listed, respondents were asked to answer the following questions on the form provided:

- *Is this service accessible?* Measures include: timeliness, service options, availability, and geographic proximity.
- *Is this service appropriate?* Measures include: service meets the needs of the individual, providers have the expertise and training to provide service, and service allows for individual self-determination whenever possible.
- *Is this service accountable?* Measures include: cross-systems collaboration, affiliation and linkage agreements, changing services with the changing needs of the individual, service satisfaction, cost effectiveness, and ongoing service evaluations to measure goals attainment and outcomes.

SERVICE EFFECTIVENESS TRENDS

There were a number of trends found in the 35 individual evaluations conducted throughout the U.S. However, although trends clearly existed, it is important to note that differences were found among different types of locations. For example, urban areas tended to present as more rigid than rural settings with agencies and service system boundaries sometimes prohibiting the use of one type of service or another. As a result, they were reportedly less likely to provide flexible services based on the needs of the individuals than their rural counterparts. Rural settings were also more likely to have at least informal service linkages across systems, however urban settings were more likely to have more choices with regard to service options. Regions also differed due to the expertise and interest of leaders and policy makers. Therefore, although the findings indicate that both national and statewide policies are needed to promote effective change, they also indicate that a broadbrush approach that does not account for individual differences among local systems may prove to be ineffective.

1. **Staff Training and Development.** As is indicated in Table 1, many participants questioned the level of expertise and training of professionals currently providing care and treatment to the people they served. This is not a surprising outcome. In spite of advances in

TABLE 1. SERVICE EFFECTIVENESS TRENDS			
SERVICE	**ACCESS**	**APPROPRIATE**	**ACCOUNTABILITY**
Staff training and development	Lack of experienced and trained MH clinicians and direct support personnel	Shortage of training opportunities No common language across service systems	No credentialing available to determine the level of provider expertise No specific training requirements for people who serve individuals with DD and mental illness
Crisis prevention and intervention planning	Difficult to access crisis teams for support (refused) to plan or assist	Residential providers felt they were often left "holding the bag" in difficult circumstances	Limited cross-systems planning; roles and responsibilities across systems were often unclear
Crisis intervention/ respite beds and community based psychiatric inpatient services	MH providers often refused to serve people with MR Took too long to access; long waits in emergency rooms for evaluations	Not always appropriate for people with MR Often told to contact the police for assistance	No alternatives for people with MR who could not benefit from generic MH services
Outpatient MH services	Increased access to generic community MH services in most cases over the last few years Few specialized services	Often very little contact with psychiatrist or nurse practitioner; many individuals had ambiguous diagnoses and treatment plans	MH providers not compensated for the time it takes to properly treat individuals with DD in the community More resources found in state operated community based or institutional settings
Day/vocational services	Many providers state they are unable to serve people with complex behaviors	Many received residential "wrap around services"; clients complained of boredom	Lack of effort to improve vocational and day services for people with DD and mental illness
Residential services	Most "challenging" individuals were often living in congregate (institutional) settings	A great deal of resources dedicated to high staffing patterns to "manage" difficult behaviors safely	Some people reviewed were managed with high staffing costs over a number of years, without active attempts to change treatment or services
Case management	Most individuals reviewed had active case managers	Case managers expressed the need for more training	Caseloads too large to assist people with complex needs effectively

diagnostic procedures, there remains a tendency to overlook the presence of a mental illness in persons with MR. Many observers attribute this failure to inadequate training.[9,10,12,15] The study of MR is not part of the curriculum in 75 percent of the clinical psychology programs in the country.[11] In addition, few psychiatric residency programs offer specialty training in MR.[16]

Direct support staff require ongoing training in order to be effective.[8] All participants expressed a need for more training for their staff to better understand the MH aspects of DD and manage difficulties when they occur. There was also an expressed need to provide cross-systems training to include both MH and developmental disability specialists to better understand each system's mission and the services it offers. There was extensive discussion about how to determine that a person is "discharge ready" and what that means to the individuals representing different service systems.

Many of the teams that participated in the assessment process reported that they benefitted from this opportunity to meet with an outside consultant. In most cases, on-going consultation that focused on the MH aspects of DD was rarely provided. Participants suggested that on-going consultation from an expert in the field to assist with high-risk individuals would be very helpful.

2. **Cross-Systems Crisis Prevention and Intervention Services.** A number of residential providers reportedly had internal crisis intervention systems. However, many depend on the MH system as part of their community service safety net. Access to crisis services was often considered to be difficult. Respondents reported refusal of services, a lack of responsiveness on the part of crisis team providers, or long waits in emergency rooms. Many reported that they used the police department as an alternative, to address crises as do other sectors such as social services. Although behavioral plans were often found in individual records to assist providers in times of difficulties, there were few if any cross-systems crisis plans. In addition, crisis and diversion beds designed for the MH population was rarely accessible to individuals with DD, or respondents reported that services provided there were ineffective when accessed. Crisis intervention/respite beds are used effectively in many parts of the U.S. to assist individuals with DD and MH needs who require short term out-of-home services, but who may not need or benefit

from psychiatric inpatient services.[1,6,19] However, in only a few cases were alternative respite crisis beds available to meet the needs of the individuals reviewed at the time of the assessment.

3. & 4. **Community Mental Health Services (inpatient, outpatient, crisis intervention).** Although many individuals with DD who use MH services can benefit from generic community MH services, the individuals who participated in this assessment for the most part had not been able to benefit from available generic MH services.

Many of the individuals reviewed had complex medical profiles, including, but not limited to seizure disorders. In addition their records indicated that MH work-ups were not definitive, and lacked a clear diagnosis and treatment formulation. Many participants were on a number of medications including anti-psychotics with no diagnosis to explain the treatment. In addition, many participants complained that individuals were "stuck" in hospitals because they had no place to go. Participants also reported a lack of available inpatient and outpatient providers, and crisis intervention specialists with the expertise needed to effectively treat their clients.

5. **Day and Vocational Services.** According to participants, more day program and vocational services are needed to better serve individuals with DD and MH needs. Participants reported that residential providers are often asked to provide wrap-around day services when day program providers are not available, with mixed results. Although the use of wrap-around day services may be effective when appropriate resources and training are available, this was often not the case.

6. **Residential Services.** All of the participants expressed the need for many additional resources and supports. However, it should be noted that, in some cases, a great deal of money was being expended to provide residential services. A majority of funding was reportedly dedicated to high staffing patterns, usually a one-to-one, and sometimes a two-to-one, staff-to-client ratio. The most expensive services were provided in publicly operated institutional settings, which were not designed to provide residential services to individuals living there with both DD and MH service needs.

7. **Case Management.** It appeared that case managers were relied upon to provide service linkage and advocacy services. Some case

managers expressed frustration with gaps in the service system, while others claimed that caseload size prohibited sufficient devotion of time to respond to crises, forge service linkages and follow-up on referrals. All expressed an interest in more training and resources that would assist them to do a more effective job.

SUMMARY OF FINDINGS

For the "high risk" individuals reviewed, it appears that the service system was ineffective and that available resources were primarily dedicated to crisis management. This approach can often inflate costs with little return, including failed placements in spite of the best efforts of staff in the DD and MH service sectors. In spite of the extraordinary amount of resources dedicated to residential services for many of the individuals reviewed, it is unclear that the residential services they received afforded extensive benefit to them. Shortages in expertise, training, day services, appropriate community MH and crisis services, and a lack for the most part, of cross-systems collaboration to provide these services, may have lead to residential services that can be very costly and largely ineffective. The findings indicated that individuals considered to be at "high risk" would certainly benefit from a closer look at the local service system, as a whole, with proposed remedies extending beyond crisis management. Their "high risk" status is likely to be more of a reflection of the problems in the system than might be assumed by clinicians and policymakers alike.

The state of Connecticut initiated an evaluation of their service system and has embarked on a journey to improve services and service outcomes. The beginning stages of the Connecticut "blueprint" for change follows.

THE CONNECTICUT "BLUEPRINT"

The Department of Mental Retardation and the Department of Mental Health and Addiction Services in Connecticut initiated collaborative planning at the state level in 1999. The two departments had worked together in the past through regional efforts and during the early 1990's to transition people with DD and mental illness, who lived at state psychiatric facilities which were closing, into more integrated community alternatives.

The initial prompt for a renewed partnership was concern about people with MR who were placed in psychiatric facilities and who were unable to return home after being stabilized psychiatrically. During the first six months of this collaboration, efforts were made to return people who resided in funded residential settings. Joint planning resulted in a Memorandum of Understanding between the Department of Mental Retardation and Department of Mental Health and Addiction Services that assures access to inpatient services for people who have been dually diagnosed. The Memorandum of Understanding identifies each department's areas of responsibility to implement timely, well-planned transitions as people return to their communities and funding responsibilities for inpatient services.

Both departments cooperatively planned an orientation session for key managers of the Department of Mental Retardation and Department of Mental Health and Addiction Services central and regional offices and administrators of Local Mental Health Authorities. Each department presented overviews of services and eligibility requirements and reviewed the components of the Memorandum of Understanding. Local MR and MH planning teams developed and continue to meet to discuss crisis intervention and individual discharge planning. A number of staff training opportunities have been made available to both agencies as a result of these local collaborations. Over the past two years staff of both departments have been trained on the MR and MH service delivery systems, eligibility and referral processes, behavioral assessment, psychiatric evaluation, behavioral versus mental disorders and case studies of effective psychotherapy and behavioral interventions.

At the state level, bimonthly meetings occur to track psychiatric hospitalizations at both Department of Mental Health and Addiction Services (DMHAS in Table 3) and the University of Connecticut Health Center facilities. The Department of Mental Health and Addiction Services and the Department of Mental Retardation administrators also review and advise

TABLE 2. PSYCHIATRIC ADMISSIONS SUMMARY			
	TOTAL NUMBER ADMITTED	TOTAL REMAINING HOSPITALIZED	TOTAL REMAINING PAST STABILIZATION
FY01	117	43	14
FY02	266	34	9

TABLE 3. PSYCHIATRIC DISCHARGE BY FACILITY AND AVERAGE LENGTH OF STAY				
	NUMBER DISCHARGED		AVERAGE LENGTH OF STAY (DAYS)	
	FY01	FY02	FY01	FY02
Private Hospital	42	186	19	13
DMHAS	32	22	N/A*	108.5**
UCONN	17	26	16	19
* Data not available **This includes long-term admissions through the Psychiatric Security Review Board				

on policy matters. The Department of Mental Retardation developed a monthly report to capture information about all MH inpatient admissions for private or public hospital facilities. Data is reported and analyzed about the residence at the time of admission, private and public facility utilization, and the average length of stay.

The data indicates that there has been a significant increase in access to community based inpatient services, a decrease in state hospital admissions, and fewer patients remaining past stabilization. Summary Tables 2 and 3 above compare FY01 and FY02.

Interagency (cross-systems) case conferences have been arranged for individuals who are dually diagnosed and whose severity of disability makes it difficult to maintain them successfully in the community with supports only from the MR system. Through the case conference process a range of services is provided: psychopharmacologic evaluation, medication review and stabilization, community based MH crisis intervention, follow up inpatient hospitalization, and staff training.

These strategies have resulted in shorter inpatient stays for individuals admitted from the Department of Mental Retardation residential service system and more stable community transitions. However, a major challenge remains. The Department of Mental Retardation cannot plan timely discharges for individuals who were admitted to the psychiatric facility from their family homes. For the past two years the Department of Mental Retardation has had very limited funding to develop new residential supports for people living with their families. Currently that would be the primary funding source for the individuals who have been admitted to psychiatric hospitals from their families' homes.

The Memorandum of Understanding acknowledged this difficulty and addressed it by requiring that the Department of Mental Retardation place the names of these individuals on the Residential Waiting List as an emergency. However, there has been a significant decline in funding for the Waiting List and no new money targeted for this group in the coming year. If the person's family can no longer care for him at home, he may remain hospitalized past the time it is clinically warranted. This has caused

regression for some people and results in unnecessary hospitalization expenditures.

The Department of Mental Retardation designed a step down program, the Woodbridge Project, in the greater Hartford area, to begin to address this issue. Based to some extent on other respite program models found in the U.S.,[5] a residence was established in September 2002 to serve six individuals ready to be discharged from a psychiatric facility who cannot immediately return to their homes. The Woodbridge site is designed to provide short-term (30-60 days) residential support, assessment, cross-systems crisis and community transition planning.

Woodbridge is targeted for clients of the Department of Mental Retardation who reside with their families. On occasion, it may be available for individuals from the community residential system. Woodbridge will be operated directly by the Department of Mental Retardation as a statewide program. Each region has access to one bed and maintains case management and discharge planning responsibilities. Ideally, psychiatric services will be available from the community to which the person will return. The University of Connecticut will be available when necessary to provide outpatient psychiatric follow up.

A steering committee of the Department of Mental Retardation and Department of Mental Health and Addiction Services personnel representing all regions planned the project. Consultation from an expert who designed similar programs in other states has been consistently available. Staff members who have been hired and trained to serve people with DD and mental illness have been provided. Monthly inservice trainings will continue as part of the program.

Evaluation will occur during the first year to ascertain the level of success in transitioning people within 60 days to a permanent community setting. The program will involve families immediately, with the goal of designing supports that will allow the person to return home. When that is not possible, appropriate residential settings will be sought through vacancies in supported living or group home opportunities.

Phase 2 of the Woodbridge Project is to expand from serving six to 12 people. At that time, the Department of Mental Retardation could then provide some planned respite opportunities for previous participants who remain with their families. Additionally, the project will be utilized to divert psychiatric admissions through placement of individuals at risk of hospitalization.

SUMMARY

Improvements in publicly funded services to individuals with DD and mental illness begins with evaluating the effectiveness of the current service system, gaining an understanding of model services, and the inclusion of all stakeholders throughout the planning process. But, permanent and lasting change requires a commitment in the highest levels of government in order to improve service outcomes.

The Connecticut "Blueprint" describes one state's effort to overcome structural obstacles to effective services through a cross-systems public policy initiative. Consistent with many of the findings in Connecticut, service evaluations conducted throughout the U.S. indicate that cross-systems collaboration, professional expertise, training and community based crisis prevention and intervention services are often needed to improve the community based system. However, these are limited by the fact that some state and some federal Medicaid and Medicare policies do not acknowledge the level of MH care many "high risk" individuals need.

In some locations, additional resources are needed. However, the evaluation findings suggest that in many cases reallocation of resources rather than the emphasis on more resources may be indicated. It appears that there is a great deal of waste associated with managing rather than treating people, due to ineffective cross-system service integration. A policy that brings down structural barriers and fosters proactive care may be the most cost-effective remedy to this problem.

Model programs do exist and policy planners can learn a great deal from them. However, they are usually not embedded in systems throughout a state, and they often lack established provider and advocate constituencies. As a result, intensive or model services remain vulnerable to future funding cuts and limited time-spend operations. Furthermore, federal and state funding policies should require both training and collaboration between MH and MR service systems, as well as attention to the medical and MH service needs of people with DD and behavioral health issues. Without established public policies, model programs will continue to serve as islands of excellence in a sea of difficulties.

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