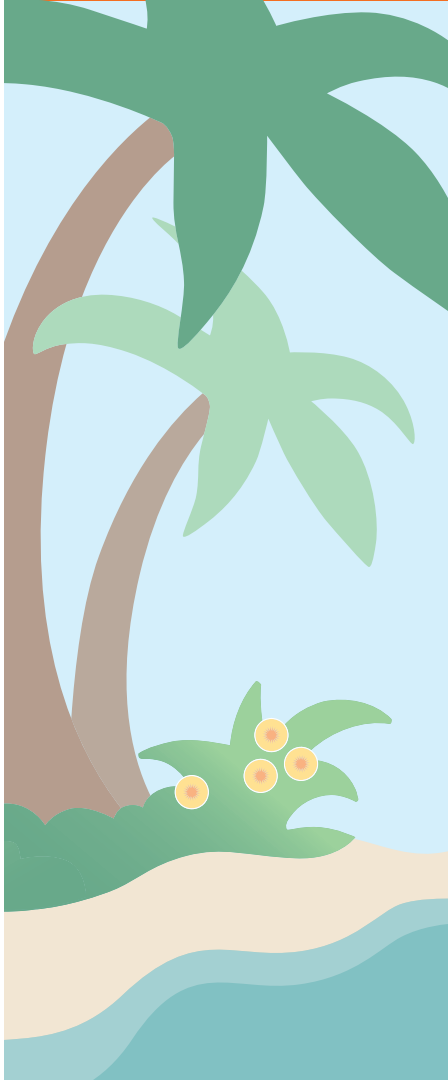


Services for Children with Co-Occurring Mental Health Disorders and Developmental Disabilities and their Families

SUMMARY OF THE SPECIAL FORUM HELD AT THE
2006 GEORGETOWN UNIVERSITY TRAINING INSTITUTES

ORLANDO, FLORIDA • JULY 2006

PREPARED BY: BETH A. STROUL, M.ED.



Introduction

A series of Special Forums were held at the Georgetown University Training Institutes in July 2006 to provide opportunities for dialogue about critical issues in order to contribute to the development of future policy and technical assistance. The Special Forums were designed as interactive discussions about communities and populations with unique service needs, requiring specialized planning and service delivery approaches within systems of care. Specifically, the goals of the Special Forums were to:

- Summarize issues and challenges related to each topic
- Identify effective service delivery strategies for local systems of care
- Develop recommendations for policy and technical assistance that will support communities in implementing these effective service delivery strategies

Each Special Forum began with brief framing presentations summarizing issues and challenges related to the topic and offering examples of effective service delivery strategies. The remainder of the forum consisted of facilitated discussion among forum participants focusing on recommendations for services, financing, policy, advocacy, information development and dissemination, and training and technical assistance. The Special Forums were tape recorded and transcribed, and additional input was collected from participants through worksheets completed at the conclusion of each forum. These materials were used to prepare a paper summarizing the issues and recommendations resulting from each Special Forum.

This paper presents the issues and recommendations from the Special Forum on Services for Children with Co-Occurring Mental Health Disorders and Developmental Disabilities and their Families. Presenters included:

- Diane Jacobstein, Ph.D., *Clinical Psychologist/Senior Policy Associate, National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development, Washington, DC*
- Marc Cherna, M.S.W., *Director, Allegheny County Department of Human Services, Pittsburg, PA*
- Eileen Elias, M.Ed., *Deputy Director, Office on Disability, U.S. Department of Health and Human Services, Washington, DC*

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Issues and Strategies

Barriers to Effective Services

Diane Jacobstein noted that comorbidity of developmental disabilities and emotional disorders is common, though often not identified. These youth frequently are hidden in other populations, and are over-represented in systems including juvenile justice and child welfare and in out-of-home placements. Jacobstein discussed the many barriers to providing appropriate and effective services to youth with both emotional disorders and developmental disabilities. These barriers include problems with access and eligibility, inflexible funding, fragmented service delivery, and service gaps:

- *Access to Appropriate Services and Eligibility*—In most places, screening is inadequate, resulting in lost opportunities for early identification of these disorders and for prevention of unnecessary institutional placements. Often, restrictive eligibility criteria preclude children with these dual diagnoses from receiving needed services. For example, in some places the mental health system will not accept children with mental retardation, and in others the developmental disabilities system will not accept children with mental health issues. Other restrictive eligibility criteria may relate to IQ or age. Continuity of care is a major issue across age transitions—from early childhood to school age or from adolescence to adulthood. In addition, families are not adequately involved in decision making around services for their children. Access to services is further impaired by the exclusion of services for this group by insurance and waiting lists for services; custody relinquishment

sometimes is the last avenue available to a family to access needed care.

- *Inflexible Funding*—Inflexible funding has a profound impact on this population, often resulting in the needs of children and their families going unmet. There are many problems related to insurance coverage for youth with these disorders. For example, in many cases, developmental disorders that are present at birth are not covered under private insurance. In addition, insurance may exclude services designed to maintain level of functioning as opposed to services designed to help someone achieve a higher level of functioning, a type of provision that affects this population. It has been suggested that private insurance companies shift costs to the public system. However, public funding sources for services also may be difficult to access, resulting in long waiting lists for services. In extreme situations, parents are faced with an impossible situation—the only way that they can obtain high-end, costly services for their child is to relinquish the custody to the state or county authority. That may be the only way that they can tap into the funding stream necessary to obtain the services. There is a general lack of knowledge about how to use funds more flexibly to meet the needs of children with co-occurring mental health disorders and developmental disabilities.
- *Fragmented Services*—Services are highly fragmented in most places, because of the separate funding streams for these disorders, as well as the fact that services are tied to a diagnosis rather than to the needs of the child. The focus, then, is on who is going to pay for a

services, and the child's needs get lost in the shuffle. This problem is layered with tremendous disparities in health care and a much higher rate of poverty in the population of people with developmental disabilities. The separate systems for developmental and emotional disorders also contribute significantly to fragmentation. Typically, these two systems interact very little, and if they do, they have different terminology and different cultures to overcome. These two separate systems are difficult for families to navigate. Families might have different care plans in each different system. Data generally are not shared, making coordination difficult. School systems often are not linked with other services, either in the mental health or developmental disabilities systems.

- *Service Gaps*—Across the country, there are fairly consistent gaps in services, such as a lack of services for children with serious behavior problems, respite services, in-home services, after school care, services for adolescents who are not in school, services to support transition to adulthood, and family support. Additionally, alcohol and drug treatment programs generally will not take youth with an intellectual disability or other developmental disability.

There are many effective strategies being developed to serve this population, including, cross-training across systems, interagency planning and braided funding, intensive family supports and wraparound services.

Services in Allegheny County, Pennsylvania

Marc Cherna described the strategies implemented in Allegheny County, Pennsylvania to address these barriers. Allegheny County has an integrated Department of Human Services that is organized into five program offices (Aging; Behavioral Health; Children, Youth and Families; Community Services; and Mental Retardation/ Developmental Disabilities) and three support offices (Administration, Community Relations, and Information Management). The program offices run their respective programs, but the Office of Administration manages all of the fiscal operations and human resources, including controlling all of the funds from the 84 different financing sources that come to the department (an overall budget of approximately \$850 million). The Office of Community Relations handles public information for all of the program offices, and the Office of Information Management handles all the computer systems. This structure helps to break down a lot of the barriers, since the program offices cannot operate independently as separate, “siloed” programs, but rather function as part of the overall integrated agency.

Cherna noted that in 2004-2005, the agency served about 225,000 people cumulatively, about 20% of the county’s population. Of the total population served, over 44,000 were under the age of 21, and of this group 45% were served in multiple systems. In 2006, just over 50% of the children under the age of 21 served by the department were in multiple systems. The county has a data warehouse, developed with foundation money, allowing for all of the data from the various programs to be integrated. Analysis

demonstrates the very high likelihood that if you are served by one of the county’s systems, the likelihood is that the person also will need other services. Accordingly, the agency attempts to provide services holistically to meet all identified needs.

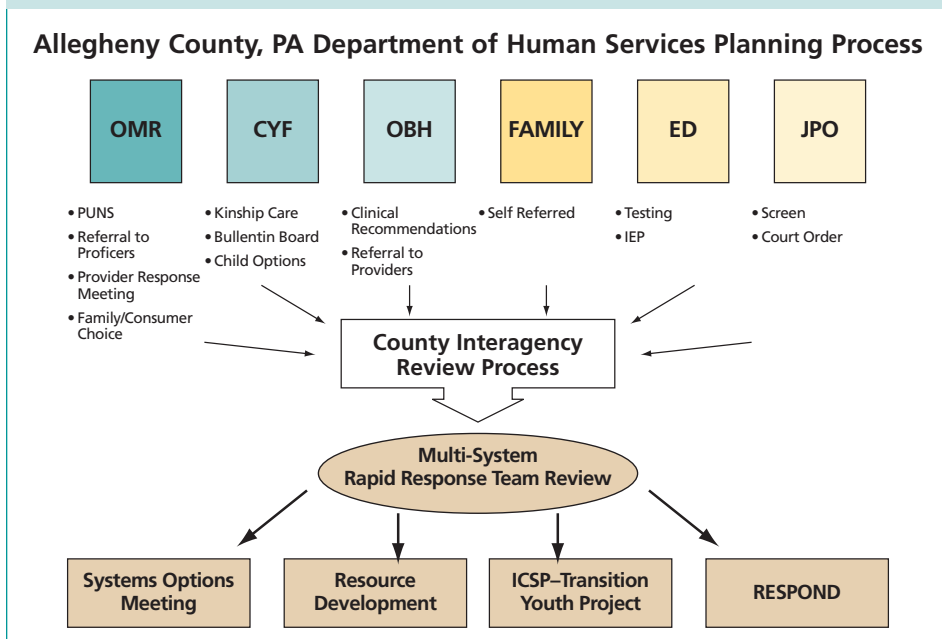
Cherna described some of the collaborative services among the program offices. For example, there is a behavioral health liaison in the Children, Youth, and Family Office (child welfare system) who made 367 referrals for behavioral health services for 306 children last year and who also provides technical assistance. There are addiction counselors in every Children, Youth, and Family office, because the disease of addiction is highly correlated with parents not being able to adequately care for their children. The system is aggressive about conducting assessments and helping parents to enter treatment. There are school-based liaisons to the mental health system who made 670 referrals for services last year. Education specialists located in the Behavioral Health Office deal with educational issues affecting children and youth with behavioral health disorders or mental retardation. There is a mental health juvenile court liaison who works cooperatively with the delinquency system, since there is a correlation between dependency, delinquency, and mental health challenges. Screening (using the Massachusetts Youth Screening Instrument [MAYSI]) is conducted for every child who enters child welfare shelters and juvenile detention. Special screening (Ages & Stages) is conducted for children under the age of five who enter foster care, and referrals are made for early intervention as needed; over 500 screens have been completed.

Collaborative system initiatives have been used to further develop the system. The county has received three federal system of care grants, initially to develop services for 6 to 14 year olds, a second for 14 to 22 year olds, and most recently, a third for the 0 to 6 age group. In addition, the state received a grant to implement family group decision making, which shares some of the system of care philosophy; Allegheny County is one of the pilots. A MacArthur Foundation grant from the Comprehensive Systems Change Initiative is focusing on improving mental health services to delinquents.

Cherna explained that problem solving in the county is done both on an individual basis and systemically. Individually, planning and problem solving is accomplished between families and providers, with families driving the service delivery process. Services are guided by an integrated children’s services plan, which is a single plan of care for children under age 21 that is mandated by the state. System issues are examined through an interagency review process and a higher level multi-system rapid response team. There also is a Children’s Cabinet in the community that includes high-level participants in the community who can make decisions and break barriers, including, for example, superintendents of the schools, heads of the health plans for physical health and behavioral health, major service providers, judges, legislators, and others.

As shown on Figure 1, children can enter the system through each of the different program offices; there is no wrong door. If their service needs cannot be met by the system they enter, they can go to the county interagency process—the County

FIGURE 1



Interagency Review Process. The interagency process brings together providers, consumers, and all the different systems to work together for families. This process is initiated when an individual program office has not been successful in providing the services that are needed, and it is used as a vehicle for discussing problems or for problem solving and conflict resolution to find services for youth. The process reduces fragmentation by bringing everybody together to look at what can be done for children and families, with families at the table. Last year, about 108 children and families were seen through the interagency process, with 82% of them being multi-system involved.

If the County Interagency Process does not solve the problem, the child and family go to the Multi-System Rapid Response Team, which is a standing group of experts comprised of family members, representatives of the various program offices, and of the behavioral health managed

care organization. The team convenes monthly meetings focusing on system issues and also meets on an emergency basis to develop individually tailored, creative solutions in response to children and families with difficult needs. The majority of children referred to the team needed additional supports, were aging out, or needed housing or specialized therapies that we were not readily available. Few children get to this level, only 14 in 2004-2005. All of these youth were in multiple systems; 72% were in at least three systems, 86% were involved with the mental health system, 71% with mental retardation/developmental disabilities, and 71% with the child welfare system. Cherna emphasized that the problem solving process is driven by services, not by the funding. The focus is on what is best for the child, and funding is considered after the fact. Often, the result is shared funding among program offices based on need. The team creates “packages” of tailored support services and resources from

multiple systems to allow the child to return home or to remain in their homes or in a variety of community settings.

One new resource is called RESPOND, which is a skilled residential program serving the dually diagnosed population. The program is located in three sites, with two children per home, and is supported by a mobile treatment team of highly skilled clinicians, nurses, and a psychiatrist. There have been 16 admissions to this program thus far. In the year preceding their admission, the children had a cumulative total of 915 days of inpatient hospitalization. In the year after, there was a cumulative total of only three days of inpatient care. Youth transitioning out of RESPOND have been successfully discharged to less restrictive community settings. With these strategies and processes in place, most children with multiple and complex disabilities can be served in the community, whereas previously out-of-community and out-of-state placements were used frequently.

Federal Efforts

Eileen Elias emphasized the finding that individuals with disability typically do not have just one disability. Generally, this is not understood by elected officials or by individuals who are in administrative positions at the county, state, or federal levels, although families understand this reality. As Deputy Director in the Office on Disability in the Office of the Secretary of Health and Human Services, Ms. Elias works to bring together federal government departments that heretofore have not collaborated. Formerly, she dealt with these issues in the role of a state commissioner. She suggested that the answer to this challenge is

in leadership and in the ability to address the political, fiscal, and specific service delivery challenges together. She emphasized that all three (service, political, and fiscal) must be addressed and balanced, in order for system change to occur.

Elias noted that, at the state and community level, there is the historic “ping-pong game” for youth who have co-occurring disorders and their families. Many state, county, and provider agencies know that if a person is assessed to have both mental health disorders and developmental disabilities, staff want to move them out. “If they are in mental retardation, they want to move them over to mental health. If they’re in mental health, they’d like to move them over to mental retardation. No one, seemingly, will take responsibility for the child’s comprehensive needs. This is the challenge of territoriality.” At the systemic level, there often is reluctance to co-mingle funds across agencies for fear that a judgment will be made that the agency does not need all of its funds. This highlights the political need to explain and demonstrate why it is cost beneficial for systems to blend funds to better serve youth with multiple disabilities. As an administrative official, or as a family member, or as an advocate, or as a provider, the message is, “this makes sense for the child.”

Infrastructure barriers are part of the challenge at the state and community levels, as well as administrative changes or changes in leadership, such as a new governor, that might change direction or impede ongoing process. A solution is to support these interagency, collaborative approaches in statute.

Elias described a federal initiative undertaken by the Office on Disability with the Substance Abuse and Mental Health Services Administration (SAMHSA). The initiative started with a series of meetings bringing together the federal departments to consider the specific needs of children with co-occurring mental health disorders and developmental disabilities and their families. A summit was convened in April 2005, involving leaders from the Departments of Housing, Education, Labor, Justice, Social Security Administration, and others. This work is supported by the Americans with Disabilities Act, the Supreme Court Olmstead decision, and the President’s New Freedom Initiative. The purpose of the summit was to understand the challenges faced by states and communities as they strive to fully integrate children (birth through age 21) who have co-occurring developmental disabilities and emotional and/or substance abuse disorders of varying severity and to develop recommendations.

The summit resulted in an action plan, including the following objectives and action steps:

- **Make services more accessible and child and family centered**
 - Develop strong leadership and infrastructures to convert a silo approach to systems of care across all states.
 - Provide technical assistance to states to develop infrastructures that support the systems of care approach.
 - “No wrong door” approach.
 - Offer/utilize current federal incentive grants, other grants, waivers, or state cooperative agreements to support planning and provision of integrated systems of care.

- **Include family members in all levels of decision making**
 - Families should drive decision making for services.
 - Families should be involved in development of policy.
 - Never should a family be forced to relinquish custody of a child in order to access the services the child needs.
- **Screen at first entry into any system**
 - Provide more early intervention services to identify children with co-occurring disorders.
 - Train providers to recognize symptoms both at intake/referral and for children already receiving services.
 - Provide training and technical assistance to identify/ensure use of evidence based screening tools on areas, such as securing parental consent and service linkages.
- **Individualize and integrate care**
 - Use a single plan of care which incorporates all funding sources.
 - Increase access for families to non-clinical supports (e.g., in-home help, respite care, after school services, family support, advocacy).
 - Address transitions between early childhood/early intervention and school age systems.
 - Address transitions between the child and adult service systems.
 - Assess and identify community-based resources to prevent unnecessary criminalization and/or foster care placement.
 - Educate juvenile justice and child welfare officials on identification of and community-based alternatives.

- **Promote early identification**
 - Increase primary care providers' understanding and awareness of the needs of children with co-occurring disorders.
 - Increase child care providers' and educators' understanding and awareness of the needs of children with co-occurring disorders.
 - Integrate developmental disabilities and mental health services within the schools and the primary healthcare environment.
- **Increase capacity in the field**
 - Recruit child psychiatrists and psychologists and others.
 - Help higher education state systems develop staff cross-training programs.
 - Develop scholarships and loan forgiveness to encourage professional cross-training.
- Promote development of federal, state, and county interdepartmental training programs.
- **Facilitate interagency collaboration and partnership at all levels**
 - Address current categorical funding and “siloed” service delivery system through leadership and attention to administrative infrastructure development.
- **Provide more flexibility for financing services**
 - Bring financing mechanisms and community needs into alignment.
 - Provide Medicaid waivers for services across systems.
 - Provide Technical Assistance to states and communities on using the array of financing approaches.
- **Support technology and research**
 - Launch a public health approach to better understand this population.
 - Support research re. evidence-based practices.
 - Develop clinical practice guidelines and quality monitoring systems tied to cross-system outcomes.
 - Support sharing of federal interdepartmental data systems to enhance integrated clinical decision-making, utilization management, and quality improvement.

Additional information about this continuing effort is available on the website <http://www.hhs.gov/od/programs.html>.

Recommendations

Service Delivery

- *Identify behavioral interventions* that work for youngsters with co-occurring mental health disorders and developmental disabilities.
- *Support parents*—Many parents who are at risk of losing their children with multiple disabilities may also be struggling with developmental disabilities. They may not be labeled or receiving services, but it may be a driving issue. Funds should be made available to work with the parents who have these challenging issues. In Westchester County, a family network approach is being used.
- *Develop appropriate services for youth in transition to adulthood*—In some states, youth age out of child-serving systems at 18; in others the age is 22 or 23. An initiative of the federal Office on Disability in collaboration with the National Governors Association is focusing on the transition age population with six states. The project states are exploring how child and adult service systems can work together to facilitate this transition with appropriate services and supports.
- *Provide assistance with parenting*—Parents need help developing the skills to more effectively handle issues and difficult behaviors in youth with mental health disorders and developmental disabilities.
- *Develop appropriate housing options*—Housing is challenging for individuals with disabilities, especially for youth in transition to adulthood. The Office of Disabilities has done some webcasts on home ownership for persons with disabilities. Information also is available on how to proceed with HUD certificates targeting persons with disabilities and on funding for affordable housing.
- *Implement positive behavior support*—Positive behavior support is a strategy that provides behavioral support for young children that can be used school-wide.

Recommendations

- *Involve vocational rehabilitation agencies* to provide services to youth with co-occurring disorders.
- *Create teams to provide intensive case management* to children with developmental and mental health challenges.
- *Provide respite services* for families of children with co-occurring disorders.
- *Provide “individualized residential treatment”*—Instead of group residential programs, individualized residential treatment can be provided in homes in which a treatment parent is trained to deal with children with specific problems. Treatment parents can be training specifically to work with youth who have developmental and mental health problems.
- *Offer intensive outpatient services*—Intensive outpatient programs can see children several times a week in therapy and provide additional support with therapeutic assistants or community interventionists who can help to support the behavioral plan in the home, school, and community.
- *Develop appropriate services for youth with co-occurring disorders*—Until appropriate services are developed for this population, they will be put into services that are not for children with developmental problems or will end up in costly residential and inpatient programs.
- *Implement crisis intervention teams*—Crisis intervention teams with the ability to go out into the community to work with children and families can help to keep children from entering facilities. In some cases, these teams are organized by facilities (such as state schools, state hospitals, or residential treatment centers).
- *Provide home-based services.*
- *Provide wraparound services.*
- *Improve screening for young children* to identify co-occurring disorders earlier and intervene at younger ages.
- *Provide creative arts therapies*—A challenge in improving access to services for children with emotional disturbances and developmental disabilities is that many of them cannot participate

effectively in the traditional talk therapy for which most mental health therapists are trained. As a result, they are much more likely to be rejected by the mental health system for not really being able to “benefit from the services” offered. Creative arts therapies provide an effective means of working with children who have developmental disabilities. Mental health systems would be less likely to reject children if they had effective strategies for working with children who cannot communicate well verbally.

Financing

- *Use new Medicaid provisions to improve access to appropriate services*—The Deficit Reduction Act allows home and community-based services under the waiver options to be moved to state plan service options. By selecting this option, wait lists for waiver services can be eliminated. Linkages with state Medicaid directors should be established to clarify these new mechanisms, as well as to clarify that waiver services targeted to one population (e.g., developmental disabilities) can be used for dually diagnosed children.
- *Restructure Medicaid rules to support services in the community* rather than creating incentives for residential treatment.
- *Stop allowing insurance companies to drive care.*
- *Review and remove barriers to funding and services* created by federal statutes and regulations.

Policy and Advocacy

- *Address licensure issues in dual diagnosis programs*—In developing residential programs for children with dual diagnoses who need out-of-home placements, differences in philosophy and licensure requirements between the two systems can constitute a barrier. Philosophy clashes can play out with respect to licensure and funding because the developmental disabilities system takes more of a “maintenance-support” type of approach, whereas on the mental health side, there is a greater emphasis on providing active treatment to improve functioning. Bringing a group together to address licensure requirements for children and the federal regulations that guide both of those funding streams

Recommendations

is a helpful approach and may result in licensure standards more appropriate for this population.

- *Work with states to change the age of adulthood to 21 or higher.*
- *Increase collaboration between the family movements in mental health and developmental disabilities to build cross-disability coalitions*—There is a divide between family movements in the developmental disabilities and the mental health worlds. These two movements should collaborate. In southeastern Pennsylvania (Chester County) parents of children with educational issues, developmental disorders, and emotional behavioral disorders have begun a positive and productive dialogue.
- *Support the development of youth movements and organizations that include youth with developmental disabilities and mental health issues*—In Connecticut, a youth organization for youth with developmental disabilities was started, called KASA, Kids As Self Advocates. This group linked with the national KASA, funded by Family Voices. Youth have gone to schools and communities to talk about what has worked for them, what hasn't worked for them, why they experience problems with transitioning, and why they experience systems issues. More youth initiatives should to be funded at local, state, and national levels.

Information Development and Dissemination

- *Increase research to develop the evidence base about approaches for children with co-occurring disorders*—Research is needed to build an evidence base around effective approaches for this population.
- *Develop and disseminate information about effective intervention strategies*—Providers are desperately looking for effective strategies. Information from existing services and programs should be compiled and disseminated to increase knowledge of effective strategies. Technical assistance should be provided on interventions that work. System of care and related conferences can be used to disseminate information and provide training in this area.

Training and Technical Assistance

- *Provide training across the mental health and developmental disabilities systems*—In Westchester County, New York, cross-training is provided around children with developmental and mental health issues. The statewide training academy in Idaho offers a one-day training program on developmental disabilities and mental illness.
- *Develop a curriculum for training on children with co-occurring developmental and mental health disorders.*
- *Train providers to serve dually diagnosed children*—Many providers don't have the skills to work with youth with co-occurring disorders. For example, treatment foster care providers may have the skills and abilities to deal with the mental illness, but are reluctant to serve dually diagnosed youth since they report that they do not know how to handle the developmental disabilities population. Training should be designed to develop these skills for these and other types of providers.
- *Provide training for special education teachers*—Some special education teachers are not sufficiently familiar with developmental disabilities and with effective behavior management strategies. Training is needed in schools for this purpose.
- *Provide technical assistance on federal and state funding streams* that can be used to serve children with co-occurring disorders.
- *Develop and implement a certification program for providers* to gain specific knowledge and skills related to working with this population.
- *Educate and train parents* as to how to provide ongoing support for youth who have transitioned to adulthood.

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