A REPORT OF THE SUMMIT:

State-Community Response to Barriers for Children with Co-occurring Developmental Disabilities and Emotional/Substance Abuse Disorders

Office on Disability
U.S. Department of Health and Human Services

APRIL 27, 2005

TABLE OF CONTENTS

Executive Summary 3

Section I: Purpose of the Summit 7

Section II: Background on the Target Population and Policy Issues 11

Section III: State/County Barriers and Lessons Learned 15

Section IV: State/County Policy Recommendations 25

Section V: Federal Response and Recommendations 29

Section VI: Summit Conclusion 35

Appendix A: Summit Agenda 37

Appendix B: List of Participants 41

Appendix C: Power Point Presentations by Panelists 49

Appendix D: Summary Grid of Issues, Recommendations of Panelists, and Federal Response 145

Appendix E: Supporting State/County Financing Data 159

Appendix F: Biographical Sketches 209

EXECUTIVE SUMMARY

Across America, states and communities are challenged by the needs of children and adolescents with co-occurring developmental disabilities and emotional and/or substance abuse disorders. Because of the complexity of their needs, rarely can one system—the developmental disability system, the mental health system, the educational system, the juvenile justice system or the substance abuse system—provide the comprehensive services and supports these children and their families require. Inadequate screening and early identification mechanisms, differing eligibility criteria, long-term cultural differences between systems, and rigid federal funding streams fuel the situation. In those states and communities that are most successfully serving children with complex disorders, multiple systems are working together in a system of care[1] to provide wraparound services and supports that address the comprehensive needs of the child and family.

To more fully understand the challenges faced by states and communities as they strive to fully integrate children with co-occurring developmental disabilities and emotional and/or substance abuse disorders,[2] the U.S. Department of Health and Human Services Office on Disability in partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA) convened "The Summit: State-Community Response to Barriers for Children with Co-occurring Developmental Disabilities and Emotional/Substance Abuse Disorders" on April 27, 2005. This was the third gathering of federal department leaders to consider the specific needs of this population.

---

[1] A system of care incorporates a broad array of services and supports for a population of children and families that is organized into a coordinated network, integrates care planning and management across multiple levels, is culturally and linguistically competent, and builds meaningful partnerships with families and youth at service delivery, management, and policy levels. Pires, S. (2002). *Building systems of care: A primer.* Washington, DC: Human Services Collaborative.

[2] The term "co-occurring" is often used when an individual's symptoms include more than one diagnosable disorder, especially if the conditions are traditionally treated by professionals in different fields. As it is not unusual for symptom clusters to arise in children, discrete diagnostic categories do not necessarily reflect their circumstances. The term "dual diagnosis" is often when both developmental and emotional disorders are identified, but since this may be confused with the same term as it is used in the substance abuse field, "co-occurring disorders" is used here instead.

Panel presentations by invited parents and state and county representatives highlighted many challenges to providing appropriate services for children and adolescents with co-occurring disorders. For example:

- ***Overall Systems Barriers***
  - Children with co-occurring disorders are often not identified and when they are, their needs are often overlooked.
  - All too often children with co-occurring disorders end up in the child welfare or juvenile justice system because their needs are not understood and addressed.
  - Systems of care represent an effective approach, but adopting this way of operating requires systems change and strong leadership.
  - Systems and their related services are fragmented and in silos.
  - Professionals from multiple systems need to be cross-trained to support cross-system coordination and referral.
  - Professionals from multiple systems need to work in a coordinated and collaborative way to support cross-system service delivery and referral.

- ***Eligibility and Access Barriers***
  - Screening and early detection is essential but difficult.
  - Difficulties with eligibility and access to services remain significant challenges and create barriers to addressing the real needs of children.
  - There is a lack of adequate training for professionals to recognize the possibility of co-occurrence, to make effective differential diagnoses, and to treat and support these children with appropriate evidence-based interventions.
  - Continuity of care is needed when children transition from the early childhood and early intervention systems into school, and when they transition from the child system to the adult system.

- ***Financial Challenges***
  - Investing in the front end—mental health promotion and prevention—is needed to end the ineffective and wasteful practice of only addressing needs at the point of crisis.
  - Financing mechanisms and community needs are not in alignment.
  - Private insurance shifts costs to the government.
  - There is limited use of Medicaid waivers by states to help address the service needs of children with emotional/substance abuse disorders and developmental disabilities.

The panelists offered specific recommendations for what the federal government could do to better meet the needs of children with co-occurring disorders, their families, and the state and local systems that are serving them. These recommendations resulted in five major categories, which include:

- Making services more accessible and child and family centered.
- Increasing capacity in the field.
- Facilitating interagency collaboration and partnership at the local, state and federal level.
- Providing more flexibility for financing services based on needs.
- Supporting technology and research.

Finally, **participating federal departments suggested action steps they could take to address the challenges highlighted and recommendations presented**. For example, the Social Security Administration will investigate further how SSI might be used to relieve some of the constraints imposed by Medicaid in serving children with co-occurring disorders; the Substance Abuse and Mental Health Services Administration will continue to provide training and technical assistance activities to improve screening and early diagnosis; the Administration on Children and Families will use the network of the Administration on Developmental Disabilities grantees to highlight the needs of young people in this target group; and the Health Resources and Services Administration will use the Federal Interagency Coordinating

Council to raise issues related to these children and their needs. The full list of action steps is included in this document in Appendix D and will be revisited as the federal leaders continue to meet and discuss the particular issues of this population.

The appendix to this report includes several documents including the Summit agenda (Appendix A), a list of participants (Appendix B), the PowerPoint presentations used by panelists (Appendix C), a grid that summarizes the issues and recommendations as outlined by the panelists and the federal response (Appendix D) and supporting state/county financing data (Appendix E).

SECTION I

PURPOSE OF THE SUMMIT

On April 27, 2005 the Department of Health and Human Services Office on Disability in partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA) convened "The Summit: State-Community Response to Barriers for Children with Co-occurring Developmental Disabilities and Emotional/Substance Abuse Disorders. " 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 a wide range of developmental disabilities and who also have emotional and/or substance abuse disorders of varying severity. This includes children with autism spectrum disorders and those with both intellectual disability and normal intelligence. In addition, the Department hoped to identify ways in which federal policy and programs can facilitate more child and family-centered, culturally competent services.

Participants included representatives from the relevant federal departments, and representatives from states and local communities who are finding creative and effective ways to address the needs of children with such disorders and their families. Family members were in attendance and offered testimony of the challenges they face in accessing appropriate services for their children. A full participant list is included in the Appendix B.

The Summit was designed with three panels of experts representing families, local programs, and progressive counties and states that are addressing the needs of children with co-occurring developmental disabilities and emotional/substance abuse disorders in a significant way. The panelists and facilitators for each of these sessions are listed in the Summit agenda, which is included in Appendix B.

- The first panel provided an overview of the population and comprehensive and coordinated systems of care.
- The second panel focused primarily on eligibility and access barriers for children and their families.

- The third panel focused on the financial challenges to supporting comprehensive and coordinated systems of care for children with these co-occurring disorders.

Throughout the meeting, time was allotted for federal partners to reflect on the presentations and offer suggestions for what they could do within the confines of their legislative mandates and regulations to support an improved delivery system that would be child and family driven; focus on prevention, early intervention, treatment, and recovery; and that would be flexible and individualized to meet the unique and comprehensive needs of children facing these challenges.

The Summit was organized by Dr. Margaret Giannini, Director of the Office on Disability in the U.S. Department of Health and Human Services; Ms. Eileen Elias, Deputy Director of the Office on Disability; and, with support from the SAMHSA, Drs. Phyllis Magrab and Diane Jacobstein, from the Georgetown University National Technical Assistance Center for Children's Mental Health. Facilitation was provided by Dr. Giannini; Sybil Goldman, Senior Advisor on Children in the Substance Abuse and Mental Health Services Administration; Dr. Magrab; and Dr. Patricia Morrissey, Commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services.

The Summit built upon several earlier decisions, statements, and activities, all of which illustrate a commitment by the federal government to attend to the needs of more than 54 million Americans across the lifespan who are living with disabilities:

- In July 1999, the Supreme Court issued the Olmstead v. L.C. decision that challenges Federal, state, and local governments to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services. The Olmstead decision interpreted Title II of the Americans with Disabilities Act and its implementing regulation, requiring States to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

- On February 1, 2001, President George W. Bush launched the New Freedom Initiative (NFI). The New Freedom Initiative represents a comprehensive government-wide framework for promoting full participation of people with disabilities in all areas of society. The Initiative calls for increasing access to assistive and universally designed technologies, expanding educational and employment opportunities, promoting homeownership, expanding transportation options, and promoting increased access into daily community life.
- President Bush issued on June 18, 2001, Executive Order 13217 calling on federal agencies to "evaluate the policies, programs, statutes and regulations of their respective agencies to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities."
- On April 29, 2002, the New Freedom Commission on Mental Health was formed. The Commission was charged with recommending improvements to enable adults with serious mental illness and children with serious emotional disturbances to live, work, learn, and participate fully in their communities.
- On August 20, 2003, the Georgetown National Technical Assistance Center for Children's Mental Health, sponsored by SAMHSA, held a Roundtable on Children with Co-occurring Developmental Disabilities and Mental Health Needs. This meeting brought together representatives of federal, state, and local governments with parents and advocates to discuss policy related to children in this target group.
- In celebrating the 14th anniversary of the Americans with Disabilities Act in 2004, President Bush recognized "the important progress the ADA has brought about for our citizens and our Nation," but the President also acknowledged that individuals with disabilities continue to face obstacles to full integration.
- In February 2004, Dr. Giannini, in partnership with SAMHSA, convened a meeting to call attention to the unique needs of children with co-occurring developmental disabilities and emotional/substance abuse disorders. This meeting was attended by representatives from the Departments of Education, Health and Human Services, Housing and Urban Development,

> Justice, Labor, Transportation, and the White House Policy Council and from the Department of Health and Human Services—the Centers for Disease Control and Prevention (CDC), Centers for Medicare and Medicaid Services (CMS), Administration for Children and Families (ACF), ADD, and SAMHSA. Four areas of critical concern were addressed: inconsistent access to appropriate systems; limited collaboration within and among federal, state and community systems; eligibility; and financing and coordination of public and private funding. The meeting produced a series of recommendations and action steps. Federal partners met again in April 2004 to continue the discussion. The group consensus was that it would be very important to invite representatives from the states to help clarify how best the federal government might move forward to address these barriers that inhibit innovative practices in states and communities.

The April 27, 2005 Summit summarized in this White Paper, as well as the earlier decisions, statements and activities, demonstrate a commitment to enhancing opportunities for all people with disabilities, and in particular for America’s children who are challenged by co-occurring developmental disabilities and emotional and/or substance abuse disorders.

SECTION II

BACKGROUND ON THE TARGET POPULATION AND POLICY ISSUES

The population of children with multiple diagnoses is increasingly recognized as a challenge to systems at the federal, state and local level. Children with developmental difficulties have an elevated vulnerability to behavioral health issues including depression and anxiety. A literature review published in 2005 by Prout found that 25-48% of children with developmental disabilities also have emotional disorders.[3] Within very specific diagnostic groups, such as Fetal Alcohol Syndrome or Fragile X Syndrome for example, the percentage of children with behavioral and emotional disorders may be far greater.[4] There is growing awareness that many children in the juvenile justice and child welfare systems have significant emotional needs and developmental disabilities as well.

Because of the traditional structure of services, the multiple and specific needs of these children are often not easily identified. For example, the need for mental health services may appear as the obvious issue requiring intervention, but the less clear yet equally important habilitative needs resulting from an intellectual disability or an autistic spectrum disorder may go unnoticed and unaddressed. In part, this is due to the complexity and intensity of the services often required, but it is also due to narrowly focused (or categorical) systems, eligibility, interventions, and funding streams that are not structured to take a holistic approach toward assessing and treating comprehensively. As a result, these children with multiple disorders may not have all of their needs met. Either they are served in one system that is able to address part of their problem, or they are the "unclaimed" children and youth who fall through the cracks and do not get the services that they require. The consequences of this neglect may prove

---

[3] Prout, H.T. (2005). Dual Diagnosis in Children and Adolescents: Issues and Opportunities, *The NADD Bulletin, 8*(1), 3-9.

[4] Dykens, E.M. (2000). Psychopathology in Children with Intellectual Disability. *Child Psychology and Psychiatry, 41*(4), 407-417.

to be pervasive and long-term for the child, the family and our society. Inappropriate hospitalization, out-of-state placements by schools, custody relinquishment to child welfare, and incarceration by juvenile justice can sometimes be avoided when children's needs are identified early and when service decisions are driven by treatment plans that are child and family centered, comprehensive, and culturally appropriate.

Two stories illustrate the challenges faced by children with such multiple needs and their families.

> **MATTHEW**
> *Matthew was diagnosed with autism when he was five. I knew something was different about Matthew when he was very young. He took longer to reach developmental milestones like sitting up, walking and crawling and later, talking. He had sensory issues, was difficult to calm, and would get very upset if someone new came into our home. I raised this with the pediatrician, but the doctor didn't detect anything wrong. At age three, the pediatrician recommended I call early intervention, but Matthew couldn't qualify for services because he was too old. I was told to call the school district. They did tests—psychological, social, speech—and then referred him to a therapeutic preschool. He had six weeks of full day preschool with speech therapy. It was wonderful. And then summer came and they stopped the program.*
>
> *Along the way at about age 4, a woman at church told me about a family support group called Family Ties. I attended this group and was overwhelmed with feelings that I'm not alone. Family Ties provided advocacy for our family at special education meetings. They knew what the school system was obligated to provide. So when the school recommended that my son have a psychiatric evaluation and my husband's insurance would not cover the cost, Family Ties made sure that the school system paid.*
>
> *By age five we finally did get a diagnosis of autism. But in the meantime, many people had said possible ADHD, possible OCD,*

disruptive disorder, mixed receptive-expressive language disorder, developmental coordination disorder. All of these possibilities created anxiety and worry.

The behavior was so bad this year that we had to hospitalize Matthew. We were turned down by some psychiatric hospitals because they said they do not take children with autism.

I wish I would have known about the early intervention program when he was very young. I feel like we missed a lot of help that we could have received if his situation was caught much earlier.

JEREMY

My husband and I adopted an infant 22 years ago. We picked Jeremy up at the hospital when he was 3 days old. His birth mother received no prenatal care and used alcohol and cocaine during her pregnancy. Before our son was a year old, we knew he was struggling with some special needs. However, he was 3 years old before we could get a pediatrician to help us with an assessment. Results of this assessment were somewhat vague, but did indicate social and emotional delays, failure to bond appropriately and inability to regulate emotions.

As he prepared to enter kindergarten several years later, Jeremy went through a battery of cognitive tests revealing that he had borderline mental retardation (IQ 71) co-occurring with his emotional disorders. Special education programs were able to assist somewhat with his educational needs, but teaching staff were ill-equipped to appropriately address his emotional needs that effected all aspects of his school day.

After years of a frustrating journey through multiple inpatient and residential placements, our son finally received a diagnostic assessment that resulted in understanding his disorders and appropriate medications for him. At this point, he was 17 years old. Our son's IQ has stabilized at 86 and he has been diagnosed with Fetal Alcohol Effect, Fetal Cocaine Effect, Bipolar Disorder, a Seizure

Disorder, Attention Deficit Hyperactivity Disorder and a Learning Disorder. He graduated from high school after 12 years in special education and completed a technical program at our community college to become a certified diesel mechanic. He is currently working at Home Depot while making final preparations to become a mechanic in Wyoming's oil fields.

Our biological son had asthma. When he was a toddler, the medical professionals worked with us, they bent over backwards to try to find out what was causing it and how they could treat it. Not once did they blame his dad and I for what was wrong with him. And yet, every time we had to change services providers through the years with Jeremy, one of the first places they started with was what was wrong with us and what had we done to cause this. We were accused of causing his mental health and learning challenges.

The mothers of Matthew and Jeremy shared these stories in the Summit's panel presentations. Their experiences highlight the issues families grapple with on a daily basis across America—inadequate screening, missed early identification, missed and unclear diagnosis, difficulty accessing services, interrupted services, denial of services because of a diagnosis of autism, systems and providers that cannot address the multiple needs of children, assessments and services that are not covered by insurance. Throughout the course of the meeting, panelists and Federal participants reflected on these stories and worked to craft recommendations that would address these issues.

SECTION III

STATE/COUNTY BARRIERS AND LESSONS LEARNED

The Summit was organized into three panels, each of which addressed a specific objective and was grounded by presentations from the field. The main themes from each panel are presented below.

Panel One: COMPREHENSIVE AND COORDINATED SYSTEMS OF CARE

The objective of the first panel was to identify overall barriers and best practices to comprehensive systems of care for children with co-occurring developmental disabilities and emotional and/or substance abuse disorders. Included in this was discussion about coordination among state and community agencies, historic turf issues, and training. What follows are the main themes emerging from the presentations of the panelists and group discussions.

- ***Children with co-occurring developmental and emotional/substance abuse disorders are often not identified and when they are, their needs are often overlooked.*** Families and systems can often address one disability with confidence and appropriate support. But when a second disability emerges or is identified, families are not ready, schools are not equipped, and professional health and human service providers do not typically understand how best to respond.
- ***All too often children with these complex disorders end up in the child welfare or juvenile justice system because their needs are not understood and addressed.*** The child welfare and juvenile justice systems that receive them are most often are unable to address the multiple needs of children with such co-occurring disorders. At times, this reality creates a crisis for those systems that are not equipped to deal with either the emotional/substance abuse issues or the developmental issues or both.

- ***Systems of care represent an effective approach, but adopting this way of operating requires systems change and strong leadership.*** Operating within a system of care requires a level of trust, flexibility, and collaboration that is not always at the philosophical and operational core of public systems. Current service systems typically are not strength-based, individualized, culturally sensitive, nor child and family focused. Several participants suggested that succeeding in a system of care requires great persistence.

- ***Systems and their related services are fragmented and in silos.*** Most programs and services are restricted to one population. In some states, for example, respite services are currently available for children with developmental disabilities, but not for children with emotional and/or substance abuse service needs. Special transportation services are often available to children with developmental disabilities but not for those with emotional needs. Eliminating these silos and coordinating services in a system of care is essential. Participants cautioned that as we move to systems of care that are population-specific, we risk creating system of care silos rather than a universal system of care that will address a very broad population of need. The State of Pennsylvania may be effectively addressing this by mandating that all of the state's counties develop a comprehensive children's plan so that there can be better coordination between children and youth services, mental retardation, and mental health.

  A story from Alabama most clearly illustrates the challenge of complex and fragmented systems:

  The state Department of Mental Health and Mental Retardation is divided into three separate service divisions—mental illness, mental retardation and substance abuse. Each division has an Associate Commissioner that reports directly to a Commissioner who is appointed by the Governor. The Department operates hospitals and developmental centers, but mostly the services are provided through community service providers. Pubic corporations established to contract with the Department and provide planning, studies, and services for a given area are known as 310 Boards. There are eleven "comprehensive" 310 boards and 22 "specialty" boards. In addition there are four regional areas that support mental retardation *community-based services. It is a true challenge for families to know whom to contact to try to access services for their children. Even those working within the systems find it difficult to understand the multiple layers. The rural nature of the state compounds the problem.*

- ***Professionals from multiple systems need to be cross-trained to support cross-system coordination and referral.*** This includes, but is not limited to, professionals from the fields of pediatrics, mental health, developmental disabilities, mental retardation, child welfare, juvenile justice, childcare and education. Through cross-training, information about the special needs of this population can be shared and changes in practice and thinking can be initiated (e.g., developing a common language across systems). This is important, as there are significant cultural differences between systems, especially between the developmental disability and mental health systems. One community in New York has developed broad cross-agency training and peer support for professionals that have addressed these differences in language, culture and knowledge among systems.
- ***Professionals from multiple systems need to work in a coordinated and collaborative way to support cross-system service delivery and referral. In some cases, co-location helps to facilitate this.*** In Ohio, families who have multi-system needs and difficulty accessing services are able to go to a coordinating center where diagnosis and assessment for children and adults can be administered. In Louisiana, each child has its own interagency team that focuses upon the needs of that child and family. In Massachusetts, the system of care pays to have a full-time clinician at one of the Department of Youth Services community residential programs. As part of their "silo breaking" effort, Massachusetts encourages families to meet with a planning review team if they are being served by more than one state agency and do not feel that their needs are being met. Co-location is taking on a more prominent role in Vermont where mental health workers and pediatric practices are co-located not only to provide treatment, but also to conduct screenings for those who may be in need of services. Similarly, in Vermont, some child care providers are welcoming mental health consultants to train the child care workers to identify early mental health needs and to offer services to children and their families as needed. Finally, co-location is practiced within the public schools where

95% of the school districts in Vermont have mental health workers in their public schools. Panelists from all states noted, however, that coordination, co-location, and targeted case management alone is not sufficient. States and communities must be able to provide the services that meet the needs of the child and family, which means having well-trained professionals and adequate funding to support high quality services.

Panel Two: COMPREHENSIVE AND COORDINATED SYSTEMS OF CARE: ELIGIBILITY AND ACCESS BARRIERS

The objective of the second panel was to identify barriers and best practices related to eligibility and access to comprehensive services. Included in this was discussion about prevention, screening at entry to any system, eligibility requirements, coordinating eligibility across systems, IQ cut-off, autism spectrum disorders, custody relinquishment, child welfare, and juvenile justice. What follows are the main themes emerging from the presentations of the panelists and group discussions.

- ***Screening and early detection is essential but difficult.*** All too often, children and families are not asked the questions that would reveal that the child may have both a developmental disability and emotional/substance abuse disorder. Whether the point of entry is primary health, mental health, education, juvenile justice, or child welfare, staff often fail to identify the comprehensive service needs of the child. To some extent, this is because many screening procedures and instruments are too narrow to identify and address the complex nature of children within this target group. Significant work is still needed to identify and/or develop screening tools that have reliability and validity for this population. Parents of very young children sometimes realize there are developmental issues that need attention but they have significant difficulty accessing the early intervention services that can help their child. Missed early detection, misdiagnoses, and resulting missed early intervention have lasting negative impacts. Pediatricians can play a role in asking the right questions and carrying out the screening function, especially in the earliest years. Similarly, childcare providers and educators can also play a significant role in early detection and referral. In all of these environments, it helps to have professionals who are reflective of the culture of the family as they can often be more aware of the needs of the child and family.

- Difficulties with ***eligibility and access to services remain significant challenges and create barriers to addressing the real needs of children and their families.*** Children with co-occurring developmental disabilities and emotional/substance abuse disorders usually need services from multiple agencies, but eligibility is not consistent across agencies and all too often is driven by diagnosis and categorical funding, not need. Agencies use different definitions of what it means to be a child with an emotional disorder or a developmental disability. And for many, the eligibility criteria or definitions are too narrow, so that children are excluded from services. This is often the case for children with autism or intellectual disability and behavioral disorders who may not meet a required IQ threshold but who are quite disabled and need services nevertheless. Children diagnosed with other complex disorders maybe be excluded by the developmental disability and/or mental health eligibility criteria. For those children who are at risk of entering the child welfare and/or juvenile justice systems, the inability to meet eligibility criteria and access needed services translates into a failure of multiple systems to recognize and respond to the root issues that may cause them to be removed from their family and be placed in out-of-home care.

  A story from Ohio illustrates this problem.

  I admitted a young girl to an institution after 73 private providers refused to certify her because she was too difficult and did not want to get involved. The last thing I want to do as a director is to put a child in a state institution. The good news is we kept her there for nine months and returned her back to the community and she has been there ever since.

- ***There is a lack of adequate training for professionals to recognize the possibility of co-occurrence, to make effective differential diagnoses, and to treat and support these children with appropriate evidence-based interventions.*** The lack of adequate training for professionals across multiple systems is a problem in all communities, but especially in rural areas where service providers often have very limited training to work with young children. Medical professionals, educators, social workers, and many others need to recognize the warning signs of co-occurring disorders and know where to refer the child and family for the services they need. As several panelists noted, repeated misdiagnoses results in repeated ineffective treatment. Meeting participants were concerned to hear that some psychiatric hospitals do not admit children who present with autism or intellectual disability because they do not feel prepared to adequately address the clinical needs of these children.

- ***Continuity of care is needed when children transition from the early childhood and early intervention systems into school, and when they transition from the child system to the adult system.*** Because eligibility requirements change from one system to another, all too often the services a child or adolescent has been effectively receiving are either disrupted or terminated during these periods of transition. Further, children with developmental challenges sometimes become very anxious when they enter into a new social environment or experience. In these situations, they tend to exhibit negative behaviors. As such, the attention and care given to supporting continuation and consistency of care is essential. This is especially important with respect to transitioning into post-secondary education, employment and housing. Several participants noted that the adult system is not ready to cope with young adults who have co-occurring emotional and developmental disorders. Pennsylvania is considering an effort to support case management for multi-system children who are aging out of the child system and into the adult system.

Panel Three: COMPREHENSIVE AND COORDINATED SYSTEMS OF CARE: ADDRESSING FINANCIAL CHALLENGES

The objective of the third panel was to identify an array of funding strategies that support comprehensive coordinated systems of care. Included in this was discussion about Medicaid waivers, block grants, funding strategies, and cost benefits. What follows are the main themes emerging from the presentations of the panelists and group discussions. (See Addendum E for information on state/county financial impact and other supporting data).

- ***Investing in the front end—mental health promotion and prevention—is needed to end the ineffective and wasteful practice of addressing needs at the point of crisis.*** Even though it is well-documented that early intervention (including in the case of autism) yields better outcomes for children, funding continues to be used to satisfy urgent needs rather than primary prevention, early intervention, and system reform. Several participants noted that dollars for prevention and early intervention activities are the best way to save high costs down the line, but these are the dollars that are especially hard to come by. As stated by a participant, "Failure to meet the needs of these youth is one of the most costly mistakes that we are making from a public policy perspective."
- ***Financing mechanisms and community needs are not in alignment.*** Funding for services is typically tied to a specific diagnosis or IQ level. And in Medicaid, service definitions are written with the adult in mind, not the child. The reality is that in a system of care multiple flexible sources of funding are needed to pay for services that will yield better outcomes for the children. Collaboration among systems (i.e., care coordination or targeted case management) is not always reimbursed and existing funding mechanisms do not easily allow systems to pay families for participating in planning (i.e., pay for lost wages, child care) or for non-treatment services (e.g., appropriate housing, electricity). This is further complicated if the parent also has treatment needs. Several participants noted that all too often it becomes a pull and tug among systems about who is going to be responsible for paying for a child's need for residential placement or expensive services within the community. It was noted that these historic funding challenges have created a "culture of minimal responsibility."

  A story from Massachusetts illustrates the successes that can be realized when funding is used flexibly to address the needs of families.

  A child was raising havoc at home, in school and in the community. During a systems of care family meeting, the mother was asked what are the most pressing needs for the family. She explained that her most pressing need was help with an electric bill, because if not paid within the next day or two, the electricity would be disconnected. The second need *was for safe housing. The child had to come home after school, go inside and stay there until the mother returned from work, which was late in the evening because she worked two jobs in order to pay the electric bill. The first thing the system of care did with wraparound dollars was to pay the electric bill and to move the child and family to a safer area. Almost instantaneously, with very little mental health service, this child calmed down in school, in the community and at home.*

- ***Private insurance shifts costs to the government.*** All too often families of children who require intensive or prolonged intervention exhaust their private insurance and need to depend on public systems for support. Many private insurance plans do not reimburse for services relating to autism and intellectual and other developmental disabilities. In some of these cases, families are forced to relinquish custody of their children to child welfare in order for their needs to be met through the public system.
- ***There is limited use of Medicaid waivers by states to help address the service needs of children with either emotional disorders or developmental disabilities.*** There are states that have specific waivers for one group or the other. Some states may have two waivers: one home and community based waiver for children with mental health needs and another for children with developmental disabilities. In some states, the same children may be switched from waiver to waiver to deal with the their particular needs. There is a need to reconfigure existing waivers to make it possible to address dual disabilities or to design new waivers for children whose needs bridge existing systems. It was suggested that waivers should be based on clinical and functional criteria rather than diagnostic criteria or even Supplemental Security Income (SSI) criteria. Even when waivers are available, they are typically capped, so that enrollment is limited, which does not support their use for this target group. The federal requirement that waivers be cost neutral also poses difficulties for states.

The barriers and lessons learned outlined above addressed the three specific objectives of the Summit. As discussion evolved, it became clear that there was significant crossover and repetition. For example, a conversation about eligibility and access naturally includes discussion about financing.

Similarly, a conversation about multi-system collaboration includes discussion about turf, training, and financing. This overlap reinforces the importance of holistic reforms and systems change that is being realized in many states and counties across the country. Where comprehensive and coordinated systems of care have been developed, communities are better equipped to address the complex needs of children with these co-occurring disorders and their families. But as many panelists note, developing a system of care is not easy: it requires leadership; common values across systems; a willingness to abandon historic turf issues; an ability to engage in multi-system case planning rather than dispute resolution where systems argue that a child does not “fit” their criteria; flexibility with funding so that service delivery is driven by need, not by diagnosis or the convenience of funding streams; and the guarantee of services, not just a plan for the services that should be provided.

SECTION IV

STATE/COUNTY POLICY RECOMMENDATIONS

The panelists offered specific recommendations for what the federal government could do to better meet the needs of children with co-occurring disorders, their families, and the state and local systems that are serving them. These recommendations cut across the objectives outlined for the Summit and resulted in five major categories of recommendations. The categories include:

- Making services more accessible and child and family centered.
- Increasing capacity in the field.
- Facilitating interagency collaboration and partnership at the local, state and federal level.
- Providing more flexibility for financing services based on needs.
- Supporting technology and research.

Specific recommendations within each category will be outlined below.

MAKING SERVICES MORE ACCESSIBLE AND CHILD AND FAMILY CENTERED

- Involve families in all discussions, service plan development, and treatment so they are able to drive decision making to most appropriately address their needs.
- Increase access for families to non-clinical supports such as in-home help, respite care, after school services, family support and advocacy.
- Provide multiple access points for services and no wrong door. The bottom line is that regardless of where a family enters the system, service providers and agencies should know the pathway to services and assist the family in getting to the appropriate provider. In the ideal situation, there would be one location within the community where assessment and comprehensive wraparound planning can occur.

- Develop an appropriate single plan of care for these children based on need, not diagnosis, and regardless of funding. A multidisciplinary treatment team should oversee this process. Never should a family be forced to relinquish custody of a child in order to access the services the child needs.
- Provide more early intervention services to identify children with these co-occurring disorders early and assure screening on entry into any system.
- Address transitions for these children between the early childhood/early intervention systems and the school age systems.
- Address transitions between the child and adult systems because the very issues that are barriers to appropriate services for children are also barriers embedded in the adult system, and because there is currently a dearth of services for adolescents and young adults with these co-occurring disorders.

INCREASING CAPACITY IN THE FIELD

- Increase understanding and awareness of the unique needs of children with co-occurring developmental disabilities and emotional /substance abuse disorders among primary care providers. Pediatricians are very interested in helping and need the time, training and resources to engage in early detection, assessment and appropriate referrals.
- Increase understanding and awareness of the unique needs of children with these co-occurring disorders among childcare providers and educators. These professionals often see the children daily and have close contact with parents. By being able to recognize the warning signs of co-occurring disorders and asking the right questions, childcare providers and educators can play a significant role in early detection and referral.
- Integrate developmental disability and mental health services within the schools and primary care environment. Doing so will increase implementation of the public health model and help to decrease stigma related to these special needs.
- Recruit child psychiatrists, psychologists, and other professionals and paraprofessionals and train them to work in a system of care environment with this target population. Recruitment strategies should address the need to increase numbers of administrative and direct service providers who reflect the cultures of those being served. Consideration may need to be

given to offering student loan relief to attract more professionals to the field who are prepared to address a wide range of developmental and emotional issues.

- Help higher education develop a multi-disciplinary training program for staff working with this population so that people in education, developmental disabilities, mental health and substance abuse fields learn and work together.

FACILITATING INTERAGENCY COLLABORATION AND PARTNERSHIP AT THE LOCAL, STATE AND FEDERAL LEVEL

- Provide technical assistance to states to develop governance structures that support the system of care approach.
- Offer incentive grants from the federal government in order to motivate groups (e.g., education, mental health, developmental disabilities, substance abuse, primary care, child welfare, juvenile justice) to come together to address the complex needs of this population at the local level. Doing so will empower the community to put together a strategic action plan at the local level. It is important to recognize, however, that this needs to be matched with increased collaboration and coordination across agencies and programs at the federal level (e.g., consistent confidentiality regulations, focus on outcomes and consumer satisfaction, coordinated program improvement plans).
- Insist on interagency collaboration, the system of care model, and inclusion of this population when awarding any grant, waiver, or cooperative agreement.
- Coordinate among government entities at the federal level to model the collaboration and coordination that should be practiced at the state and local levels.

PROVIDING MORE FLEXIBILITY FOR FINANCING SERVICES BASED ON NEEDS

- Provide technical assistance to states and communities so they can analyze expenditures and utilization across systems, use risk-based financing approaches to re-direct expenditures from the “deep-end” to home and community-based services, develop purchasing collaboratives to support a coordinated financing approach, and other such fiscal strategies.

- Identify and remove federal barriers to braiding and blending funds within and between agencies so that funds can be used more flexibly to address the needs of children with co-occurring developmental disabilities and emotional and/or substance abuse disorders.
- Provide Medicaid waivers for services across systems, especially a combined waiver for children with these co-occurring disorders.
- Provide clarification on Medicaid covered services so that mental health and substance abuse officials at the state level better understand the services that are covered by other states.
- Provide more flexible federal funding with a requirement to continue maintenance of effort and retain the entitlement nature of programs such as Medicaid and child welfare.
- Eliminate the cost shift by insurance companies to the government for services and procedures that private insurance will not cover (such as autism services) which are available through the public sector. This cost shift also occurs when people use their lifetime episodes of a service provided through private insurance but still need continued treatment.

SUPPORTING TECHNOLOGY AND RESEARCH

- Launch a public health approach to better understand children with these co-occurring disorders (e.g., tracking incidence, screening, public education, stigma reduction, prevention).
- Provide real time data across systems to support clinical decision-making, utilization management, and quality improvement.
- Develop clinical practice guidelines and quality monitoring systems tied to cross-system outcomes.
- Support research that will foster a healthy growth of evidence-based practices to support children and youth with co-occurring disorders and thus offer hope for recovery. This research should cover both best practices (e.g., pharmacological and behavioral interventions) and the systems change that builds the infrastructure and environment for systems of care to flourish.

SECTION V

FEDERAL RESPONSE AND RECOMMENDATIONS

In the final session of the Summit, Dr. Giannini asked the federal partners to reflect on the meeting's objectives, and the lessons learned and recommendations outlined by the panelists. She invited each federal agency to offer potential actions steps that they might take to help advance the discussion and to address the needs of children and adolescents with co-occurring developmental disabilities and emotional/substance abuse disorders.

Action steps offered by the federal departments and agencies are outlined below. Based on the general discussion, additional recommendations are added (and marked) for consideration by departments that agreed to move this effort forward and to identify specific plans in later discussions.

ALL DEPARTMENTS: actions to consider

- Examine the various federal interagency efforts to develop state/community leadership and foster infrastructure development.
- Assess current and planned training and TA on screening, treatment and service structures
- Assess current state plans as to preventing unnecessary child relinquishment.
- Assess how current and future funding can be used to provide incentive grants, support state and county interagency collaboration and coordination for this population.
- Identify how discretionary and categorical funding can include attention to financing strategies for this population group.

DEPARTMENT OF EDUCATION: actions to consider

- Identify how current and future OSEP grants and IDEA support systems infrastructure and leadership development.
- Assess how the IDEA and other initiatives/programs can help address the screening and eligibility needs of this population.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

The Administration on Children and Families

The Administration on Children and Families will:

- Include the comprehensive service needs of children with co-occurring disorders in the Family Support 360 grants.
- Use the array of ADD networks and their targeted TA and training to develop supporting leadership, highlight the need for comprehensive and integrated care, and address screening, service access and continuity of care for this population.
- Use the ADD networks to train providers in a systems of care approach for this population, including the importance of "no wrong door" service approach.
- Use the training capacity of the ADD networks to assess how more emphasis on providing families with purchasing power can enhance individual/family self-determination
- Use existing programs and initiatives to help address avoidable child welfare placements and develop mechanisms to improve access to needed services for this target population.
- Identify how the IV-E waivers in the Children's Bureau can be used to target this population to prevent unnecessary child welfare placements/parental relinquishment and support coordinated financing.

Centers for Disease Control: action to consider

- Consider coordination of an intergovernmental (e.g., with SAMHSA, ACF, CMS, NIH, SSA, DED, DOL, etc.) research/evaluation action plan, assessment of interdepartmental evidence based practices and public health awareness approaches targeting this population.

Centers for Medicare/Medicaid Services

The Centers for Medicare/Medicaid Services will:

- Explore how the issue of co-occurring disorders can be incorporated into the Medicaid Division's Strategic Action Plan.
- Further investigate the concern that waivers are too categorical and are not offering the flexibility to fully address the complex needs of children with this class of disorders.
- Assess how the current round of System Change Grants and other opportunities can help address some of the challenges for which Medicaid has jurisdiction.

Additional action to consider:

- Assess the impact of private insurance cost-shift to Medicaid and identify mechanisms to help address this problem. Assess how more emphasis on providing families with purchasing power can enhance individual/family self-determination.

Health Resources and Services Administration

The Maternal and Child Health Bureau will:

- Continue to develop the Medical Home Initiative, which is working to help pediatricians engage in early identification of behavioral health needs, and address issues such as time, training, reimbursement, and changes to practice.
- Use the Federal Interagency Coordinating Council and the Medical Home Initiative to help address the comprehensive approach and leadership needed to support this population.
- Assess through the Federal Interagency Coordinating Council and the Medical Home Initiative how families of children with these co-occurring disorders are included in all aspects of planning at the federal, state, community, and provider levels and implement an action plan to enhance such involvement.
- Use MCHB Federal Interagency Coordinating Council and the Medical Home Initiative to address eligibility and screening barriers.

Additional action to consider:

- Assess how more emphasis on providing families with purchasing power can enhance individual/family self-determination.

Office on Disability

The Office on Disability will:

- Coordinate interdepartmental supporting actions.
- Facilitate interdepartmental supporting actions around research and technology.

Substance Abuse and Mental Health Administration

The Substance Abuse and Mental Health Administration will:

- Continue to address this population’s needs as part of the mental health transformation and obtain support from the Senior Federal Workgroup.
- Include attention to this target group in state infrastructure and systems of care grants, and ongoing TA efforts.
- Utilize available training and technical assistance programs to develop infrastructure supports and enhance providers’ skills on screening, treatment, eligibility and service structure for this population.
- Use the Mental Health Transformation Federal National Partnership to help address the eligibility and screening barriers of this population.
- Collaborate with the Centers for Disease Control (CDC) on screening for this population.
- Explore collaboration with the Department of Defense (DOD) to facilitate coordination of services for deployed and redeployed military families.
- Identify how current and planned SAMHSA—federal interagency efforts can increase collaboration and reduce duplications for this population.

Additional actions to consider:

- Assess how more emphasis on providing families with purchasing power can enhance individual/family self-determination.

- Assess current initiatives and federal partnerships related to family involvement may be used to address this specific population and implement an action plan to enhance such involvement.
- Identify how current and planned interdepartmental initiatives can address unnecessary out of home placements.

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT: action to consider

- Identify how current public housing supports for families can help address this population's housing needs.

DEPARTMENT OF JUSTICE: actions to consider

- Identify how current DOJ and interdepartmental funding (e.g., with SAMHSA) can include this population.
- Assess current initiatives and federal partnerships on how families are included and implement an action plan to enhance such involvement.
- Identify how current and planned interdepartmental initiatives are or can address unnecessary out of home placements.

DEPARTMENT OF LABOR

The Office on Disability Employment Services of the Department of Labor will:

- Address the needs of older youth who have fallen through the cracks and who may have co-occurring disorders to learn effective ways to help this group navigate through child welfare, juvenile justice, school and the labor force.
- Identify how DOL's "no wrong door" programs can address this population. DOL:
- Address how ODEP and other DOL offices are addressing the screening, eligibility, employment and transition needs of older youth with these disorders.

FEDERAL TRANSIT AUTHORITY/DEPARTMENT OF TRANSPORTATION

In response to the presidential Executive Order that requires eleven departments to work together to address transportation issues for people with disabilities, the Federal Transit Authority of the Department of Transportation will:

- Include this population in the continuing development of the nationwide human service transportation in continued work with federal departments on transportation one-stop information systems.

SOCIAL SECURITY ADMINISTRATION

The Social Security Administration (SSA) will:

- Investigate further how SSI might be used to relieve some of the constraints imposed by Medicaid in serving children with both developmental and emotional/substance abuse disorders including how this could help prevent unnecessary out of home placements, and address current screening and eligibility barriers.
- Try to help the Office on Management and Budget (OMB) understand that it is economically wise to invest in screening, early detection and early intervention since failure to address needs early will ultimately create greater costs to SSA in the long-term due to income replacement support and health care. SSA would like guidance from other federal offices regarding data on cost benefit and specific recommendations for OMB.
- Place more emphasis on individual/family self-determination by giving families purchasing power so that they may access the services they need and be more self-sufficient.

Additional action to consider:

- Assess use of infrastructure grants addressing youth in transition and other demonstration funding to support this population.

SECTION VI
SUMMIT CONCLUSION

Prior to adjourning the Summit, the following summary of the meeting's accomplishments was made. The objectives of the meeting were met: participants actively discussed the population of children with co-occurring developmental disabilities and emotional/substance abuse disorders, eligibility and access barriers for these children, and challenges associated with financing systems of care. Parents presented rich testimony so that all present could understand the real barriers faced by families in attempting to access appropriate services for children in this target group. States and counties also provided a summary of the barriers they encounter, their lessons learned, and recommendations for what they believe the Federal government should do to better address the needs of these children and their families. And finally, there was a useful dialogue among Federal partners about the next steps each agency will take to address the challenges raised during this Summit. Dr. Giannini will be calling each federal principal to further identify how each entity's identified actions can be met.

The **Appendices** to this report include many useful materials, including descriptions of state and community efforts, financing strategies and cost benefit data.

- Appendix A: Summit Agenda.
- Appendix B: List of Participants.
- Appendix C: Power Point Presentations.
- Appendix D: Summary Grid of Issues, Recommendations of Panelists, and Federal Response.
- Appendix E: Supporting State/County Financial Data
- Appendix F: Biographical Sketches