Creating Responsive Systems for Children With Co-Occurring Developmental and Emotional Disorders

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A categorical and fragmented service structure often prevents children with co-occurring developmental and emotional or substance abuse disorders from receiving appropriate care. This article describes a federal interdepartmental initiative that is attempting to awaken awareness of the needs of these children, and to institute appropriate programmatic and policy responses. Available data related to this population is discussed. Recommendations for policy reform address improvements in accessibility and responsiveness to family needs, capacity within local communities, and interagency collaboration at the local, state and federal levels. Steps to provide more flexible financing and to support technology and research are also described.

Keywords: children, co-occurring disorders, developmental disability, emotional disorder, intellectual disability, mental health policy, mental retardation, psychiatric disorder

The typically fragmented and categorical structure of children’s services often prevents those with co-occurring developmental and emotional or substance abuse disorders from receiving appropriate care. All too often, federal, state and local systems are ill prepared to address the complex needs of these children. Results from the recent National Survey of Children with Special Health Care Needs suggest that the mental health needs of children with special health care problems, including developmental disabilities, are commonly unmet. Indeed, services in the community for individuals with both developmental and emotional disorders are often described as fragmented, inaccessible, insular and inadequate.

This is an issue of great importance, not only for child-serving systems, but also for adult agencies, as unmet needs during childhood compound and often develop into more serious problems during adulthood. Severe mental health problems complicating intellectual disability, as one example, are often persistent and have been characterized as “a common and costly public health problem.”

The human cost of neglected care can be staggering for the child and the family. Parents of children with pervasive disabilities describe being turned away from one after another of an array of public agencies because their children had the “wrong” diagnosis or intellectual abilities that were either too low or too high to qualify for services. Others describe long and painful searches for appropriate assessments or treatment. Tragically, many parents with extremely ill or violent children have been forced to choose between watching their children languish without needed care or relinquishing custody and control to public child welfare authorities. Children with issues that do not neatly fit one agency’s expertise or funding may be “ping-ponged,” tossed back and forth between historically territorial systems reluctant to bear the costs of their treatment. As a group, children with both developmental and emotional or substance abuse disorders whose needs are not met are believed to be at increased risk for out of home placements through institutionalization, incarceration or child welfare, as well as interrupted education and homelessness. The impact of this societal failure can be life-long and devastating for the children and their families.

Parents and professionals across the country are calling for practical reforms at the federal, state and local levels so that public systems can better respond to children with co-occurring disorders. The summary of barriers and
recommendations that follows was drawn from public testimony of federal officials, state administrators, parents and directors of effective programs at the federal Summit: State-Community Response to Barriers for Children with Co-occurring Developmental Disabilities and Emotional/Substance Abuse Disorders convened by the Department of Health and Human Services Office on Disability in April 2005. The following is also reflective of testimony from parents, providers and state officials in several other public forums. These included a Special Forum on Services for Children with Co-Occurring Mental Health Disorders and Developmental Disabilities and Their Families held at the July 2006 Georgetown University Training Institutes, a Focus Group for Parents of Children with Both Developmental and Emotional Disorders at the July 2004 Georgetown University Training Institutes, the August 2003 Georgetown University Roundtable on Children with Both Developmental Disabilities and Mental Health Needs, and from discussions during conference and teleconference presentations on the topic.

**Scope of the Problem**

Reliable population-based estimates are not yet available for the incidence of co-occurring developmental and emotional disorders in children. Estimates of prevalence vary greatly, in part because of mixed etiological groups and differing measures of psychopathology in many of the studies. It is not unusual to find emotional disorders among children with known developmental problems, and to find developmental disorders among children referred for emotional or behavioral concerns.

Emotional maladies are common among children with developmental disorders for many reasons, including biological factors, limited coping skills, social rejection and isolation. Children with disabilities are far more likely to suffer maltreatment than children without disabilities. Those with intellectual disability, specifically, are at increased risk for psychopathology of many different kinds, including mood disorders, disruptive behavior disorders and anxiety. Suicidal behavior is considered both an under-recognized and significant problem in children who have both intellectual and psychiatric disorders.

Prout reviewed sixteen studies that reported between 25% and 48% of children with intellectual disabilities have emotional disorders as well. Dykens cites studies that give estimates from 10-70%. In some of the genetic intellectual disability syndromes, co-morbid emotional disorders may occur in as many as 96% of the children. In addition, these children may also have biological vulnerabilities to complicating problems such as seizures, which are inversely correlated with IQ, or sensory impairments. Perhaps 30% of individuals with intellectual disability may have associated autism spectrum disorders.

According to the U.S. Surgeon General, about 21% of children in the general population have emotional disorders, and roughly 11% would be classified as severe. There is thought to be a high incidence of developmental disorders among children with emotional and behavioral problems, but data is not readily available. Few studies have examined the prevalence of developmental disorders among children referred for mental health treatment. For the subset who have severe emotional disorders, however, there is some data. In one study of 146 consecutive children and adolescents admitted to psychiatric day treatment, 20% met criteria for pervasive developmental disorders. Another recent study examined assessment data on 8,481 children and adolescents with severe emotional or behavioral problems who enrolled in the SAMHSA-funded System of Care sites. Co-occurring developmental disorders were identified in 10.9%. Of those with developmental disorders, 31.5% were diagnosed with intellectual disability, 3.7% with autism, and 35.5% with significant learning disability. More than half of those with developmental disorders (51.5%) had more than two diagnoses. The implications of these data are unclear for the larger population of children referred for mental health treatment, especially since programs vary in their acceptance of children with developmental problems.

Many children with co-occurring disorders may be hidden on child welfare roles or “tracked” into the juvenile justice rather than the mental health system. This is especially true for children from poor, African-American or Latino families. In one recent large study, 47.9% of children (ages 2 to 14) in child welfare were found to have emotional and substance abuse disorders. At least one-third of the more than half-million children in child welfare may have disabilities. Thirty-two percent, by a conservative estimate, of
children in juvenile justice are believed to have disabling developmental conditions and 45% meet the criteria for emotional disturbance. Some studies place the incidence of diagnosable mental health problems among incarcerated youth as high as 50 to 75%. The number of children in these systems who require attention for both emotional and developmental issues is unknown.

A FEDERAL INITIATIVE AS A CATALYST

An interdepartmental initiative at the federal level has served as a catalyst for efforts to identify policy barriers and possible solutions to this burgeoning problem. The initiative’s focus is children from birth to adulthood who have a broad range of developmental disorders such as intellectual disability, cerebral palsy and autism and also a broad range of emotional or behavioral difficulties.

Several intergovernmental meetings and a federal summit were convened by the Director and Deputy Director of the Office on Disability in U.S. Department of Health and Human Services (DHHS), Margaret Giannini, M.D. and Eileen Elias, M.Ed. The Center for Mental Health Services at the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Social Security Administration are co-sponsors of the initiative. Participants included the Departments of Education, Housing and Urban Development, Justice, Labor and Transportation, as well as DHHS agencies, that included the Administration for Children Youth and Families, Administration on Developmental Disabilities, Centers for Disease Control, Centers for Medicare/Medicaid Services and Health Resources and Services Administration. The April 2005 Summit: State-Community Response to Barriers for Children with Co-occurring Developmental Disabilities and Emotional/Substance Abuse Disorders elicited recommendations from parents, as well as state and community leaders who have successfully addressed the needs of very young children through adolescents with co-occurring disorders. Ongoing efforts are focused on state infrastructure reform and early identification and intervention.

CURRENT BARRIERS

The barriers below, which were identified in the federal Summit, include problems with access and eligibility, fragmented service delivery, inflexible financing and lack of data sharing.

Children’s co-occurring disorders are often overlooked or misdiagnosed, which leads to inadequate or inappropriate care. Lack of adequate screening and comprehensive interdisciplinary assessment in schools and other settings is a major reason for failure to understand a child’s complex needs. Another common reason for under-identification is diagnostic overshadowing, the mistaken attribution of symptoms to an obvious diagnosis. In this way, “acting up” in school may be attributed to anxiety and hyperactivity when the child may, in fact, have an unrecognized autism spectrum disorder requiring a much different approach.

Since services are largely organized around categorical funding streams, eligibility is often quite restrictive. This leads to tremendous frustration for parents as well as inadequate and fragmented care. For example, children may be turned away from a local mental health agency explicitly because they have low IQ scores or autism. They may be rejected from a developmental disability program because of alarming behavioral symptoms or alcohol abuse. Some but not all of the developmental disabilities defined under federal law may be recognized. If a diagnosis does not fit a school system’s categorical coding, children may be denied specialized intervention (such as for autism). When placed in programs for serious emotional disturbance, in particular, they may lose access to reading specialists or other special education supports that should be provided to address their comprehensive needs.

Fragmented service delivery seems to be the norm in most places, which means care is often inadequate and difficult for families to access and maintain. Weary parents complain of having a separate case manager and an unrelated care plan in each system. Mental health and developmental disability agencies generally do not relate with each other or the schools at the local level. There are traditional differences in culture, philosophy and even language that need to be bridged among the mental health, school and developmental disability “worlds.”

Continuity of care is particularly important for children and adolescents who have complicated needs, but such continuity can be very difficult to achieve. Many programs are organized by age, so
that families must transition from early intervention systems into school programs at three, then from preschool to school-aged services, then later from the adolescent system to the adult system. Eligibility requirements are not aligned in these systems, leading to disruptions in care. If adolescents drop out of school, it can be hard to obtain developmental services until they are able to access the adult system on their twenty-second birthday.

This fragmentation also contributes to gaps in essential community services. Parents from many parts of the country decry the dearth of programs for children with severe behavior disorders and adolescents who are not in school. Alcohol and drug treatment programs willing to work with youth who have developmental problems are hard to find. Critical family programs such as respite care, crisis behavioral supports, home-based behavior intervention and after school care are also lacking, as are appropriate supports for family caregivers.

Few professionals have the training necessary to recognize co-occurring disorders and to treat these children appropriately with evidence-based practices. Part of the difficulty is that specialized skills are needed. Many psychiatric conditions present differently in individuals with intellectual and other developmental disorders than in the general population. Specialized training for primary care providers, special educators, regular classroom teachers and paraprofessionals such as respite workers is also needed.

Financing mechanisms and community needs are not in alignment. It is difficult to get reimbursement for needed collaboration among systems, such as for care coordination. If families are to participate in treatment planning, programs need to cover lost wages, transportation or child care, but rarely do programs have flexible funding for such expenses. This is also true for non-traditional services like assistance with housing. Treatment for parents can be hard to access. The focus on who will pay for expensive care often becomes central, rather than the needs of the child. This leads to a “culture of minimal responsibility.”

Private insurance companies shift costs to the government through restrictive eligibility and reimbursement practices. Insurance companies restrict care for congenital conditions, effectively excluding expensive treatments for autism or other developmental problems. Many conditions now understood to be neurological in origin continue to be reimbursed under a lower mental health rubric. Families of children who require intensive or prolonged intervention can easily exhaust their private insurance so that they must turn to public systems for support. It is in this situation that some families have been told they must give up custody of their children as a requirement to access care.

States have made only limited use of Medicaid waivers for children with co-occurring disorders. Some states have specific waivers for home and community services for children with severe emotional disturbance or for individuals with developmental disabilities. Children with multiple needs are sometimes deemed ineligible or switched back and forth between waivers. Funding is typically capped, so waiting lists are very long, which does not support their use for this target group. The federal requirement that waivers be cost neutral also poses difficulties for states.

Another barrier is that most of the agencies involved maintain data but do not share it. This makes coordination very difficult. In addition, it is very inefficient, as children are tested and retested for eligibility for various programs such as special education and Social Security Income.

**System of Care Networks**

Many forward-thinking communities and states have organized their agencies into coordinated networks that integrate care planning and management in a way that makes services more responsive for children with complex needs. Effective approaches rely on the principles, values and philosophy of the Systems of Care funded through SAMHSA. Programs experienced with this target group have developed ongoing cross-training and cross-system planning, standing community teams, intensive case management, wraparound services, reflective peer supervision, and strong family supports. Further, effective approaches focus first on the needs of the child, and then on financing the needed services. Descriptions of effective strategies and cost-benefit data are available online. In addition, detailed guidelines are available for creating and financing collaborative, individualized, family-driven, youth-guided and culturally competent networks, including specific approaches for very young children.
RECOMMENDATIONS

Participants at the April 2005 Summit\textsuperscript{29} offered many recommendations for improving practice, policy and financing so that children with co-occurring disorders could receive more appropriate support and services to reach their fullest potential. These are summarized below.

Make Services More Accessible and Responsive

1. Families should be involved in all clinical decisions as well as all discussions at the policy level.
2. Non-clinical supports such as respite care, home-based services and after school programming should be greatly increased.
3. Provide easier access to services, so that there is “no wrong door” and the services are fully networked. Co-location of services can be helpful.
4. Each child should have a single service plan developed by a multidisciplinary team that integrates all required services based on needs rather than diagnosis.
5. Funding should not guide treatment decisions.
6. The practice of forcing parents to relinquish custody of a child to access public services should be prohibited.
7. Develop coordinated screening at entry to all systems.
8. Address transitions between the early childhood and school age systems and the transition to adult services.

Increase Capacity in the Field

1. Integrate developmental disability and mental health services within the schools and primary care environment.
2. Systematically address the gaps that exist in community services.
3. Increase understanding and awareness of this population among primary care providers.
4. Increase skill level among childcare providers, special educators, classroom teachers and the paraprofessionals who work with them.
5. 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. Consider scholarships and student loan relief to attract more professionals to the field.
6. Promote multi-disciplinary cross-training programs for staff working with this population.
7. Engage parents as teachers and curriculum designers in all of these efforts.

Facilitate Interagency Collaboration at the Local, State and Federal Level

1. The System of Care approach provides a framework for community-based collaboration that is both culturally competent and family-driven. It has proven effective for complex multi-system children including those with co-occurring developmental and emotional disorders.
2. Technical assistance to states will be needed to develop the necessary infrastructure changes to support true collaboration.
3. The federal government should insist on interagency collaboration, the system of care model, and inclusion of this population when awarding any grant, waiver, or cooperative agreement.
4. Federal incentive grants would motivate states and communities to build necessary collaborations and design a strategic plan across service sectors.
5. Increased collaboration and coordination across agencies and programs at the federal level is also needed to address federal barriers by bringing regulations, eligibility, and financing into alignment with the needs of this target group. Doing this will help to facilitate better collaboration and coordination at the state and local levels.

Provide More Flexibility for Financing Services Based on Children’s Needs

1. 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, and develop strategies to support a coordinated financing approach.
2. Remove federal barriers to coordinated funding among programs and agencies.
3. Provide Medicaid waivers for services across systems, especially a combined waiver for children with co-occurring disorders.
4. Reconfigure existing waivers to make it possible to address dual disabilities.

5. Waivers should be based on clinical and functional criteria rather than diagnostic criteria or Supplemental Security Income (SSI) criteria.

6. Clarify Medicaid regulations for state administrators and provide technical assistance on how to best serve this population.

7. It is important that a continued level of effort is maintained when flexible funding options are provided and that the entitlement nature of programs such as Medicaid and child welfare is retained as well.

8. Eliminate the cost shift to government by insurance companies.

**Support Technology and Research**

1. Launch a public health approach to better understand children with these co-occurring disorders (e.g., tracking incidence, screening, public education, stigma reduction, prevention).

2. Provide real time data across systems to support clinical decision-making, utilization management, and quality improvement.

3. Develop clinical practice guidelines and quality monitoring systems tied to cross-system outcomes.

4. Support research that will foster a healthy growth of evidence-based practices to support children and youth with co-occurring disorders. 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.

**Discussion**

Children and adolescents with complex needs reveal the fissures in our traditional service structure. This is certainly true for those who have developmental disabilities of various kinds along with emotional or substance abuse problems. They can be found in special education programs and regular classes across the country as well as early childhood settings, institutions, foster homes and jails. This is a concern, then, about children with rather common needs who do not happen to match our narrowly defined categories and programs.

Many assume that these issues are important for the child-serving systems only. In reality, an appropriate response to children's needs is critical for the adult system, too. Failures in caring for our children ultimately rest on the doorsteps of adult agencies, family caregivers, income replacement programs for those who could have been employable and our society as a whole. No economic value can be placed on the emotional scars created by our policies and practices that fail to provide equal opportunities for children with co-occurring disorders so that they may receive the services and supports they need to reach their fullest potential.

This is certainly not solely about bridges between developmental disability and mental health provider agencies, although they are important. Well conceived and effective systems of care encompass a broad array of services including education and, above all, parents. Success depends on the willingness of enlightened and courageous leaders to take risks in challenging the historic territoriality among systems, which is fueled by reductions in funding and growing demands on shrinking resources. The importance of family advocacy in this context cannot be overstated. Nor can the value of pushing for legislative changes that will last beyond the tenures of elected leaders. The moral imperative of caring for the most vulnerable among us is clear. The greatest costs will follow from doing nothing.

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REFERENCES


22. Pires Sheila A. Building Systems of Care: A Primer, National Technical Assistance Center for Children’ Mental Health, Georgetown University, 2002.


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