

## Children's Services in the Real World

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*A real world scenario: Picture a handsome red-headed thirteen-year-old boy Trevor has a variety of neurological problems including intellectual deficits. He begins to attack his little brother quite ferociously around the time that he learns to set large fires. The police are called in along with the fire department. His single mother cannot leave him with a sitter or relatives because of these dangerous behaviors and also because he runs away. On a couple of occasions, he has also torn up the drywall in his bedroom. The public school has succeeded in teaching him to read on a basic level, but does not feel it has the resources necessary to work with his outbursts. The mental health agency will not accept him because he has intellectual deficits. The state developmental disabilities agency says they can't help until he turns twenty-two.*

Real world services for children with both developmental disabilities and mental health needs are bewildering and fragmented. Services are generally segregated by age and by diagnosis, and often multiple agencies maybe involved with the family, including the schools, child welfare, juvenile justice, primary care and mental health. In some states, the developmental disability agency provides care for adults only and in other states care may be limited, which in the absence of community alternatives may encourage the use of residential schools.

Many of the same discriminatory practices that affect adults are found in the pediatric population as well, including managed care plans that provide woefully inadequate care for persons with specialized needs. If able, parents are often forced to attempt to use private insurance, but the benefits may be disheartening and time-limited. Public mental health agencies may not accept children with severe developmental problems. In some states care for children with the most severe medical, behavioral and emotional needs may be provided through public funds only if parents relinquish custody. This puts parents in an impossible situation if community based services are not available. Additionally, this is counter-productive for collaboration with families and violates the basic System of Care principles of child-centered and family-focused service.

How many children are involved? No one knows for sure. Many children with co-occurring developmental disabilities and severe emotional disorders are thought to be hidden in the child welfare and juvenile justice populations. Under-identification is believed to be significant for some of the same reasons as for adults, including diagnostic overshadowing. There is often a real concern, as well, about identifying a child with a mental health diagnosis in addition to developmental disability. We do know that about 2000 of all children have serious emotional disorders and that children with developmental disabilities are more vulnerable to such difficulties than are their typically developing peers.

Mental health agencies at the state and local level are starting to realize just how many of children with developmental disabilities have a cooccurring serious emotional disorder. This is very important from a policy standpoint, because the high cost of care for children with the most severe needs is affecting the state and county budgets. These "million dollar kids" have convinced administrators that community based services and better interagency collaboration is needed. Unfortunately, some of these children are on a fast-track for the juvenile justice system and their serious emotional disorder and co-occurring developmental disability is never fully investigated.

There is a desperate need for providers who are cross-trained and have current knowledge about co-occurring childhood disorders. This deficiency is layered on an existing fundamental crisis in the children's mental health workforce across the nation. This reflects not only the current dearth of child psychiatrists and other clinicians in many areas of the country, but also the dearth of direct support professionals trained to care for children who need competent home-based or community-based care. The need for culturally and linguistically competent caregivers is particularly acute.

Organization of services is impressively baroque. Segregation by diagnosis can play out in appalling ways. For example, children with autism may be exhibited from some treatment programs. Children who

have no clear DSM IV TR diagnosis may also be excluded even if they meet the legal definition of developmental disability and are exhibiting symptoms that are dangerous to themselves or others. The mental health and developmental disabilities worlds may never meet, and the schools, which often bear the main responsibility for these complicated children, may have little contact with either system. It will not surprise those who work with adults who have developmental disabilities that substance abuse treatment for youths with dual diagnoses is notoriously hard to find. Parents of children with disabling neurological conditions that commonly involve mental health concerns, such as Nonverbal Learning Disorder and Asperger's Disorder, commonly find it very difficult to find appropriate educational programs or effective mental health care. Sadly, children in many programs for severe emotional disturbance may not receive the full array of special education supports mandated by federal and state law.

Segregation by age is the norm in most places. Parents of very young children with developmental difficulties usually approach an Early Intervention Office for help. Unfortunately, specialists who work in early intervention may have limited knowledge and experience in early childhood mental health and may have less expertise in working with families of young children with dual disorders. When the child ages out of early intervention or "Part C" services (commonly at 36 months) the family must seek care through an office in the public school system that has different personnel, requirements, eligibility and regulations. In many places the parents must seek yet another office, again with different rules and requirements, when the child approaches five. Age becomes a significant barrier again for adolescents who are out of school with no transition or vocational services to receive them.

Of course, much of this situation boils down to dollars and cents. In the absence of "blended" or "braided" funding streams and truly comprehensive and collaborative systems of care, agencies quite naturally get caught up in disputes around "whose baby is this?" or who will pay. When the child has a developmental disability and a possible mental health diagnosis, parents may be caught in the middle, since it is difficult to have a funding source step up to the bat. There is often an over-shift to either diagnosis rather than an effort to collaborate. These decisions, early in a child's life, may cast the treatment for the rest of life, even as an adult. This is especially true if a child is sent to a distant residential school that ages out at twenty-one and parents are, for practical purposes, excluded from their child's care.

This does not have to be the way things work. Around the country, there are now examples of state and county agencies that have pulled together all of the parties that could be needed to identify and fill gaps in care. Creative braided funding strategies have been designed, such as shared care coordination across agencies. Some of the federally funded System of Care sites designed for children with serious emotional disturbance have created an array of family-driven community services. One in Westchester County NY, for example, has included respite care, standing interagency planning teams at the community level, summer camps, parent retreats, groups for siblings, and programs for fire-setters and sexually aggressive teens. They have created intensive cross-training courses and school classes for children with dual diagnoses who cannot be served in either SED or DD classroom. Other strategies in use around the country include comprehensive training in early childhood mental health, home-based crisis services, positive behavioral supports, and written interagency agreements to coordinate funding, access, and eligibility. Support for family members who provide unpaid "24/7" care remains a critical need.

One bit of good news is that there is strong and growing interest at state and federal levels in improving service delivery to children with co-occurring disorders. Some states have developed dual diagnosis point persons within their Children's Bureaus. A recent Roundtable, funded by the federal Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (SAMHSA) and hosted by the Georgetown National Technical Assistance Center for Children's Mental Health, was well attended by state and federal officials as well as parents and representatives of advocacy groups, including NADD. Plans are underway to bring together a federal interagency group to look further into the structure of services and implications for the federal agencies.

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