

Families Envision Integrated Services for their Children with Significant Mental Health Needs and for Themselves

Background: In 2005 parents and guardians for children enrolled in Oregon Health Plan-funded mental health services were surveyed regarding their satisfaction with the services they received.¹ 59% of responding families said that their children required service coordination between the public mental health system and *two to six additional public service systems* (including: education, developmental disabilities, child welfare, substance abuse treatment and state and/or county juvenile justice). Another 22% reported the need for coordination with one additional public service system.

On January 27, 2006, family representatives gathered to talk about the challenges of navigating the multiple systems that serve children with mental health disorders. These are the dominant themes of the families' experiences:

What families want for their children

- Families' goals for their children are simple. They want them to be *at home, in school and out of trouble*.
- They want them to be safe.
- They want them to get along with people at home and in the community.
- They want them to succeed in school and have a chance to succeed as adults.

What families want from service systems

- Families want systems to work together: **no wrong door and/or a single point of access** to get help; systems then collaborate to form **one team** and **one plan** for the child and family.
- Families don't want to be sent from system to system to find services that meet their needs. They don't want to unnecessarily encounter the police or the juvenile court system (child welfare or juvenile justice) merely to gain access to services.
- A "care coordinator" to take the burden of coordinating across systems off of the parents.
- Multi-disciplinary teams that meet when it works for the family (including evenings or weekends). Team members have the authority to commit resources from their agencies/systems.
- Teams that utilize natural supports as well as resources from the private, non-profit and public sectors.
- Services that are individualized, rather than pre-determined by the slots available in the system providing them.

What families want from professionals:

- Identify and address children's needs early, when problems first become apparent.
- A little information goes a long way: Families want access to the same training other caregivers, such as foster parents, get. Parenting books and classes don't address the special needs of their children.

¹"2005 Youth Services Survey for Families," conducted by OMPRO for the Office of Mental Health and Addictions Services.

- Support to care for their own children, rather than turning their children over to be cared for by strangers. Specific types of supports requested by families included:
 - Time to rest and recuperate: A couple of days of respite can prevent an expensive hospital stay.
 - A break: Someone to watch their child so that going to the store to buy milk isn't a traumatic experience.
 - In-home behavior support to help keep the family together.
 - Listen to what families have learned that works for their children.
 - Support in the home during the most challenging times of the day (examples given: getting children ready for school in the morning or getting them to bed at night).
 - Wraparound services to divert children from hospital (example given: Catholic Community Services of Western Washington's Family Assessment and Stabilization Team)

Challenges

Lack of Coordination and Integration of Systems and Services

- Conflicts between systems are often driven by funding, and families suffer due to these conflicts.
- Several parents cited examples of recommendations they received from one system being disputed or contradicted by other systems (one example: a hospital recommends day treatment for a child upon discharge, but the school system does not agree).
- Parents added that disputes between systems delayed service provision, leading the children's symptoms to worsen, and these children ended up needing more expensive and more invasive services (e.g., children who were denied in-home or day treatment services ended up in hospitals or residential treatment centers).
- Some professionals refuse to participate in team meetings or collaborate with other systems who are serving the same child and family (examples given: parole and probation staff; school district staff).
- Each system offers services, but their standard services may not fit the family's needs. When one system doesn't have the services that fit the family's needs, they are referred to another system, where the same cycle repeats itself.

Eligibility Barriers

- Many families make too much money to be eligible for public services (e.g., Medicaid or SCHIP), but they don't have the resources to pay for intensive mental health services themselves.
- Children have to get worse, or families have to become poorer to become eligible for services.
- A child has to have severe symptoms or behaviors to qualify for some services, but when the services work, they are cut off because the child no longer qualifies.
- Some disabilities don't fall neatly into categorical eligibility and service systems (e.g., Autism Spectrum Disorders, Fetal Alcohol Spectrum Disorders). Systems disagree about who is responsible to provide services.

Stigma

- Many parents talked about the stigma they face. Many have been blamed or treated as though they caused their child's mental illness by professionals and by their communities.
- Families who have not been able to obtain adequate or effective services for their children have been accused by child welfare or law enforcement officials of mistreating their children.
- Both children and families experience less understanding and compassion from professionals and the community as youth with mental health disorders reach adolescence.

Legal System

- Parents seeking support and assistance have been encouraged to call the police or have their children arrested in order to access services or merely to keep their families safe.
- Several parents reported that contact with law enforcement has been traumatic for their families, whether they or someone else had called for help.
- Given that law enforcement personnel are often first responders to a crisis situation, they have relatively little understanding of mental health issues. Crisis responders need to be included in an integrated service system.
- Several parents had to sign custody of their children over to the state to get help (including Medicaid coverage and/or residential placement). Several more had contemplated giving up custody or had been encouraged to do so.

Method for collecting this information

On January 27, 2006, family representatives gathered in Salem, Oregon to talk about the challenges of navigating the multiple systems that serve children with mental health disorders. Family members attended from the following Oregon Counties: Benton, Clackamas, Hood River, Jackson, Lane, Marion, Multnomah and Polk. A special thanks to these family members for sharing their experience and insight: Laura Rodello, Margaret Puckette, Kris Anderson, Debra DePew, Jammie Farish, Marilyn Postlewaite, Jean Vanlue, Maria Martinez, Ron Sipress, Chris Hince, Michelle Westfall, Carly DeVos, Stephanie Boyer, Theresa Rice, Cody Rhea, Shelley Joyce, Brandy Steiner and Angela Kimball.

Dr. Nancy Koroloff, Director of the Regional Research Institute at Portland State University, facilitated the discussion. Seventeen parents and one youth participated. These parents have cared for their biological, foster and adoptive children who have experienced significant mental, emotional and/or behavioral disorders. Some of their children have also had developmental and learning disabilities.

The discussion focused on the challenges families face in navigating multiple public systems, including mental health, education, child welfare, juvenile justice, developmental disabilities, and others, to access appropriate services for their children and for their families. Participants were encouraged to talk about what they wanted to from helping systems and how services would look if the multiple systems were to collaborate and coordinate effectively.

The audience included Erinn Kelley-Siel from Governor Kulongoski's office; Dr. Bruce Goldberg, Director of the Department of Human Services; Phil Lemman, Deputy Administrator of the Oregon Youth Authority; Robert Nikkel, Administrator of the Office of Mental Health and Addictions Services; Donna Keddy, the manager of Residential Treatment Services for Children, Adults and Families (DHS); Mike Maley, a manager from Seniors and People with Disabilities (DHS) and Jay Gense, a manager from the special education division of the Oregon Department of Education. Other family members, family advocates and state employees attended as well.

The results were summarized by Nancy Koroloff, Portland State University, and Mark McKechnie, Juvenile Rights Project.