

**LISTENING AND LEARNING
FROM FAMILIES CARING
FOR A CHILD WITH
CO-OCCURRING DISORDERS**

*"They take care of one thing, but
they're missing everything under it,
around it and behind it."*

- a parent

- Mental Health Disorders
- Substance Abuse Disorders
- Developmental Disabilities

Maryland Coalition of Families
for Children's Mental Health

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Maryland Coalition of Families for Children’s Mental Health

Listening and Learning from Families Caring for a Child with Co-occurring Disorders

*“Multiple agencies take a piece and no one is looking at the big picture.”
- A Mother*

Background

In December 2009, the State of Maryland began an initiative to develop a collective plan for children and youth with co-occurring disorders, focusing on youth with mental health disorders who also have developmental disabilities and/or substance abuse problems, using a systems of care framework. This population has nationally been identified as a high-risk population for out-of-home residential placements.

Co-occurring disorders refer to least two disorders, including any combination of substance abuse, developmental disabilities, or mental health disorders such as:

- ❖ A mental health disorder and alcohol or drug substance use disorder,
- ❖ A mental health disorder and developmental disability that is likely to continue indefinitely,
- ❖ A developmental disability and substance abuse disorder, or
- ❖ A combination of all three types of disorders.

Family Focus Groups and Online Survey

The Maryland Coalition of Families for Children’s Mental Health used focus groups and an online survey to solicit input from families about their needs and experiences caring for a child or adolescent with co-occurring disorders.

In April 2010, the Coalition conducted a series of five focus groups. They were held in Talbot County, Baltimore City, Howard County, Montgomery County and Washington County. Forty families participated in the groups, representing 10 jurisdictions in Maryland. The Coalition also conducted an online survey consisting of 33 questions. The survey was online for two weeks in May 2010 and 40 families, representing 15 jurisdictions, completed the survey. Combining these two methods of outreach to families, the Coalition received input from a total of 80 families caring for a child with co-occurring disorders. Families came from 18 of Maryland’s 24 jurisdictions.

Every effort has been made to use exact quotes from families to convey their experiences in their own words. In this report, italics are used to indicate a direct quote from a family member.

Table 1. Participants in Focus groups and online survey

	Focus groups	Online Survey	Total
# Participants	40	40	80
# Jurisdictions Represented	15	10	18 Unduplicated

Children and Adolescents with Co-occurring Disorders

A comparison between characteristics of the children and adolescents with co-occurring disorders identified through the focus groups and the survey shows many similarities. The majority of children were male and between the ages of 11 – 17 years. Three quarters of the families reported that their child had a mental health disorder and developmental disability, most notably on the autism spectrum. Only 27% of the focus group participants and 16% of the families responding to the survey had a child with a mental health disorder and substance abuse disorder. Survey responses indicated that seven percent of the children had a combination of mental health, substance abuse and a developmental disability. (See Table 2.)

Table 2. Characteristics of Children and Adolescents

	Male	Female	10 yrs and under	11-17 yrs	18-21 yrs	Mental Health and Developmental Disability	Mental Health and Substance Abuse	Mental Health, Substance Abuse and Developmental Disability
Focus Group	72 %	28%	22%	54%	24%	73%	27%	0%
Online Survey	68%	32%	33%	61%	6%	76%	16%	7%

The focus groups and online survey both confirmed that children with co-occurring disorders are a complex population with lengthy histories, intensive needs, numerous hospitalizations and countless medications.

- All of the children had two or more mental health diagnoses with some children having a long list of diagnoses. (See Table 3.)

Identification is difficult. When you look at each symptom you could put him in anywhere.

One label doesn't really describe him. I don't really care about the label.

- The majority of children were taking medication for their mental health disorders (85% survey responses and 60% focus groups).

He's taken 'umpte million' meds

Meds made him like a 'floppy dog.'

- About half of the children had experienced multiple hospitalizations (46% survey responses and 50% focus groups). The number of hospitalizations ranged from 1-15 times.
- Nearly all of the children were in special education (92% survey responses and 67% focus group). School was difficult for these children. Survey responses indicated that 60% attended a non-public school, sometimes paid by the family, and 33% had been on home and hospital teaching because they could not attend school.

He had anxiety about going to school and becomes violent.

He was just released from the psychiatric hospital and the night before having to go back to school, he rode his bike back to the hospital to admit himself.

He dropped out of school, but walked out the door every morning like he was going to school.

- Families also reported that children had accompanying health issues such as asthma, obesity, eating disorders, or self-injurious behaviors. Many children had significant weight gain from medications.

They called him a ‘fat pig.’

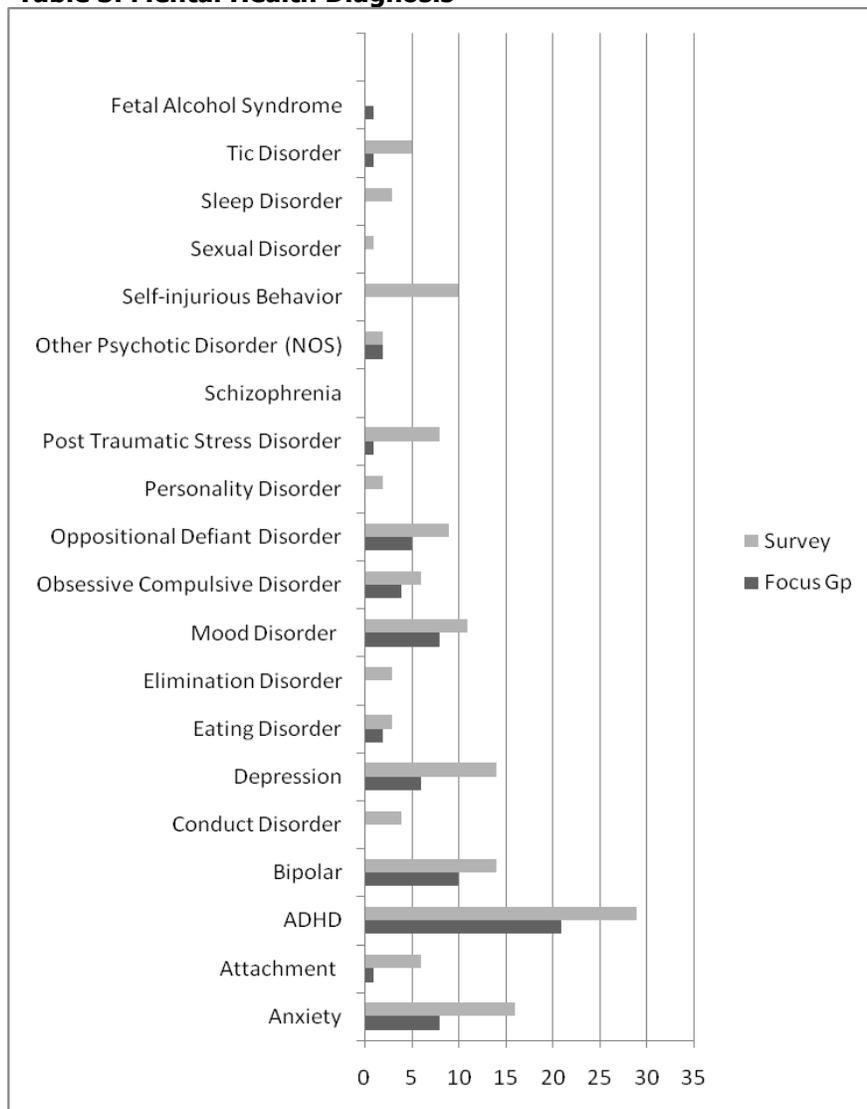
- Socially, children had few friends in school or where they lived and were often a target for bullying. Children often retaliated with aggression.

Younger kids in the neighborhood were picking on him. I had to put up no trespassing signs. He takes a stick and says he’s monitoring his zone.

Because he’s being bullied, they segregate him and it seems like they are punishing him.

He’s self medicating – smoking pot provides a social entrée.

Table 3. Mental Health Diagnosis



It’s hard to get a diagnosis – it’s all in a big ball.

Families' Needs

Each focus group had families caring for a child with mental health, substance abuse, or developmental disabilities. Interestingly, there were more similarities than differences among different populations. They shared frustrations with the system and fears for their children. Their common experiences crossed socioeconomic, racial and geographic boundaries.

All families were **desperate** for help! Each family member reported taking their child to countless therapy appointments with little improvement to show for it. They were drained from being on call 24/7 without relief.

I am the buffer for everyone.

We can't do anything as a family that's not dealing with his disability.

Other kids are going to soccer; our kids are going to therapy.

Families reported that caring for a child with co-occurring disorders affected all members of the family, relationships with spouses, other children, and extended family. Family members felt isolated and cut off from friends and family.

It's been chaos, resentment from younger brother, anxiety and fear of harm, alienation by friends and family.

(My daughter is) breaking apart and becoming withdrawn because I have to focus on my son.

I am isolated from everyone. My house is a mess. I cannot communicate with anyone and he misses his family. My family doesn't understand and they think I'm spoiling him.

She scares her younger siblings with her anger and violence. She requires 90% of our parenting efforts and the other children resent that. She has done extensive damage to our home.

Caregivers shared that unrelenting stress from caring for their child with co-occurring disorders took a toll on their own health. Families reported getting little sleep because they had to be vigilant 24/7. Many caregivers had medical conditions such as high blood pressure, depression, diabetes, and heart conditions they attributed to stress.

I'm tired of walking through life on eggshells. Everyday is a challenge.

I don't want to live in my own home.

Many children were aggressive and often became violent. Homes became unlivable for other family members. Many families expressed a foreboding feeling that their child would hurt someone. Repeated requests for help might result in short hospitalization, but nothing with long-term results.

There's no help unless they hurt others or themselves.

Then they want to send them to detention or the Carter Center. I've been pleading for help.

My son weighs 240 pounds and they give me instructions to block and ignore him.

My son is violent and at age 16 we really can do nothing with him except call the police or give up custody. We love our son and would like to keep him in the home but we have no services to address the violence we deal with. There are services for battered women, but not battered families. I can't even find an anger management class for him.

It is difficult to estimate the financial cost of caring for these children. Families reported losing income as a result of being fired because of repeated emergencies with their child. Some families quit their full-time job and took part-time jobs in order to accommodate all of their child's appointments. In addition to lost wages, families often incurred expenses from property destruction or making restitution for stolen money or items. Families with private insurance often incurred huge costs for treatment, medication, and sometimes, special schools for their children.

It has damaged every aspect of our lives: financial ruin, husband/wife relationship, negative effect on my daughter and extreme damage to property.

I have had to quit working and my younger son has experienced multiple episodes of anxiety/stress that has impacted his ability to be at school.

He stole \$10,000 from us.

He's broken all of the doors and doorframes in the house. I started taking pictures of my house to show the therapist because no one would believe me.

I'm on the verge of losing my home because of him.

Private insurance pays for almost nothing!

We have emptied our bank accounts in search of help.

Children with Mental Health and Substance Abuse Disorders

Families caring for a child with mental health and substance abuse disorders felt their hands were tied unless their child voluntarily agreed to treatment or they reported their child to Juvenile Services. The philosophy of self-directed care is a barrier in getting treatment for children with mental health and substance abuse. Families felt Drug Courts and Mental Health Courts were effective in getting children into treatment and holding them accountable.

I had to charge my son in order to get him in drug court. It helped him get into placement.

When my daughter didn't get treatment for her substance abuse, she drove into a wall and got into the criminal justice system. She didn't need criminalization; she needed treatment.

If kids have the right to decline drug treatment, when they get in trouble, then don't call us.

Children with Mental Health and Developmental Disabilities

Most mental health providers, clinicians and hospital psychiatric units are not equipped to effectively work with children who have co-occurring mental health and developmental disabilities. Because of cognitive or language disabilities, children may have severe acting out behavior that puts them at risk of over-medication, out-of-home placement, and a series of providers and placements. Specialty programs for children with co-occurring mental health and developmental disabilities should be available with joint funding from Developmental Disability and Mental Health Administrations.

*Because of his PDD there isn't a hospital that would take him.
I exhausted all community services.*

Recommendations from Family Members

1. Integration of Systems and Access to Services

Families felt that silos of care are detrimental to effectively serving children with complex needs. Systems need to coordinate eligibility and applications for services.

Do you want the substance abuse door first or the mental health door first?

There are criteria for everything and you have to fit in.

No program that meets his needs. Can access through DDA and mental health, but they don't come together to address the grey area. He doesn't fit in either system clearly.

*Cracks in the system are huge. Cracks are bigger than the system.
It's easy to fall through and tough to land on your feet.*

More integration of services is needed in Maryland with supports under one umbrella so that a person with co-occurring disorders can have coordinated support and won't be rejected in both camps.

2. Specialized Services and a Team Approach

Specialized services to serve the unique needs of children with co-occurring disorders should be jointly funded and co-located. The complexity of the children's needs requires a team approach including education, mental health, developmental disabilities, and substance abuse.

Finding supports that will meet his needs and not changing his needs to fit into the programs & supports available.

We need a congruent approach that includes mental health, education, developmental disabilities and substance abuse.

They (agencies) desire to pound a square peg into a round hole.

There's no integration of mental health and substance abuse. So many kids are using (drugs), but there's no recognition of the need to integrate services.

*Need more wraparound. It's conceptually on target and designed to have good outcomes.
There's no competing agenda.*

3. Skilled clinicians and providers

Families felt that clinicians and providers were knowledgeable in their respective fields, but were not equipped to work with children and adolescents with co-occurring disorders. Families felt a team approach was most effective and recommended crossing training or possibly developing certificate programs on co-occurring disorders offered through universities.

I think that people are using too much book knowledge and not enough reality.

We look to them (professionals) for information but they don't have it either.

4. Respite Services

Families expressed complete exhaustion, isolation and at times hopelessness about the future. Families pleaded for relief! Respite care was the service most frequently identified in focus groups and responses to the online survey to help families continue to care for their child at home. Respite services should be available to all families caring for a child with co-occurring disorders and eligibility should be consistent across agencies.

Definitely respite!!!!

Please create a safe environment for my child to be separate from me. When people come into the home and the family has to be there, you've chained my hand and foot.

Trying to find someplace for him to go so I can have some peace.

5. Support Services

Family Navigators that provided one-to-one support to families, family organizations, support groups, and parent education programs were all noted as services that helped families reduce isolation and share resources. After school programs, summer camps and mentoring were also cited as programs families found essential to being able to keep their child at home.

What helps? Navigators to answer 800 bazillion questions.

The only break I get is when he's at the after school program.

6. Crisis Intervention Services

One thing is predictable – children with co-occurring disorders will have crisis. Crisis services should be readily available in every jurisdiction to avoid unnecessary emergency room visits or police calls.

It's a great concept that there's a safety net – nonsense!

Mobile crisis doesn't come for hours. By then it's too late.

Everyone sends you to the Emergency room – it's the key to getting a bed but there is no place for children/adolescents with co-occurring disorders.

When you call the police and tell them you need an evaluation, they're (kids) taken down, handcuffed and taken in the police car.

System is dysfunctional. You don't get help until something tragic happens.

7. Education

Training is needed specifically to increase knowledge about the nature of mental health, substance abuse and developmental disabilities so administrators, teachers and staff fully understand the scope of the behavior they are observing and are able to utilize best practices to optimize student success. Training should be designed as a process, not a one-time event, to create a culture shift toward supports to students rather than implementing disciplinary action first.

Our kids get in trouble, but the teachers are often the trigger because they don't understand.

8. Private Insurance

Families with private insurance feel penalized because the array of services available to children is limited to inpatient or outpatient care. Families are faced with trying to get their child on medical assistance in order to access comprehensive services. Families felt that eligibility for services should be based on the severity of need, like waiver programs.

I am at the end of what I feel like I can personally do for my son. I have called all programs and because my son has private insurance and hasn't been arrested...yet there are no options for him. So, now I am looking at having him arrested or voluntary relinquishment just to get him more services.

Appreciation

The Coalition is grateful to families who participated in the groups and completed the survey. They openly shared very personal and painful stories along with their fears and dreams for their children. It is hoped their voices will result in policy changes and expansion of integrated services for children with co-occurring disorders and their families.

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Dissemination

The Coalition hopes that this information will be disseminated widely to maximize its use. When copying or quoting from this report please credit:

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The report is also available on the Coalition website: www.mdcoalition.org.

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