

Coffee and Conversation: Parenting Children with Mental Health Challenges

Saturday August 12, 2017, 10 am-11:30 am; Augsburg Library, Mpls.

Hosted by the Hennepin County Parent Leader Catalyst Group

Themes:

- Being a parent of a child with mental health difficulties is very isolating and can take a toll on the whole family. Parents in this group consider themselves part of an “underworld” where they have to live in different worlds to support their children and families because there is still not understanding or welcoming of people with mental health needs in most places.
 - They often struggle not only with the system but feel judged and misunderstood but their natural support systems (their friends and family).
- For active members of the group, being together with other parents that “get it” has been helpful not only socially but in learning the system and how to be better advocates for themselves and their children. It was noted that research is continuing to validate the value of parent support and parent education as critical to helping children and families.
- Across the board it is still very difficult to get access to resources and system knowledge. Every parent has to learn from scratch. The “community” professionals (teachers, pediatricians, faith leaders, etc.) are not connecting people to resources (they often don’t have any). They don’t seem to understand the system or know how to connect parents to other helpful services and professionals. Even parents who are part of the “system” (teachers, social workers, therapist, human service workers, doctors, etc.) are overwhelmed by how complicated it is to get help for their child and family. Parents who were part of the “solutions” (such as sitting on special education committees) had experiences where they still didn’t hear about critical resources that would make a difference for their children in a personal way (via the school) but often found out about things through their committee work.
- Though more experienced parents were accepting that learning the system happened through these informal networks, parents newer to these systems felt very dissatisfied with the need to learn everything through trial and error or informal networks. It seemed to them it wouldn’t be that complicated to organize this information and get it out to people. Some parents were aware of resources that were being developed or that were available in some places (certain school districts).
- There were some resources in the schools (school based MH clinics and social workers/psychologists) but they are maxed out so it’s often difficult to get their help or support in a timely way.
- County case managers turn over quickly. They are often young and have no children of their own (“no skin in the game”). They come into family homes to work with the child but begin to correct the parent. This is not welcome and to some families is a strong sign of disrespect. (African- American families being mentioned). If the therapist is there to work with the child, the parent expects them to focus on the child.
- Parents experience difficulties getting information or services from schools that is clear or helpful even when a child has an IEP. There is a belief that schools are unmotivated to support a child in getting a diagnosis because they will have to pay for special education

costs. On the other side of this experience is the prohibition on teachers and unqualified school personnel talking about “diagnosis” was also somewhat protective of youth of color since they are often targeted for labels rather than supported.

- Parents are willing to learn but they also want professionals to learn from them and start from a place of respect. Asking about the family history or stressors can feel invasive and blaming if not done well. Parents often feel like they have failed their children even though they are doing everything they can for them (having to consider medication for young children was mentioned as difficult, even though outcomes were often good). Parents are often exhausted. They may lack skills they need but the needs of the child or children can also be very significant and they may just need practical support. Parents in this group relied on each other to test the advice of professionals that didn’t make sense to them.
- A problematic area was transition from youth to emerging adult. The abrupt cut off from parental support and the expectation that young people simply be informed about services (such as on campus counseling) did not work. In addition, for some cultures and with many youth, the idea of seeing a counselor was not appealing. An idea put forth was looking at “coaching” rather than “counseling” and also considering what proactive/global ways there were of helping youth connect to wellness resources without having to identify as needing help. As with other areas there were some places where this was being done better in the state (for example having college reps attend IEPs in last years of high school, etc.) but it wasn’t global.
- Parents and children of color stated that they experience all of the difficulties every parent and family does but at a multiplied rate. They felt professionals needed training specifically to help children and families of color as these families are impacted in multiple ways and face equity issues and biases. They are less trusted and respected in the systems meant to support them. They have higher risk for difficult outcomes such as over or under diagnosis or being offered too much or too little medication or children being dismissed from programs rather than supported and accommodated. The experience of these parents is that they had to fight much harder to get what white parents got more easily or even without asking.