



What Do Families Need to be Engaged?

In March 2017, the Association for Children's Mental Health in Michigan asked families just that question.

Things that make me feel engaged when accessing services and supports are:

- Having a say in my child's treatment
- Feeling like what my family thinks/says/needs is important
- Individualized planning vs. cookie cutter approaches
- Respect and consideration of my family and our needs
- Understanding, not blaming
- A complete list of resources, so that I don't feel like I have to guess what would be best for my family.
- People who listen and understand what I am going through. People who don't judge. People who ask and don't tell me what needs to be done or worked on. People who respect my family and child and make us feel like our opinion matters.
- Ability to access quality care for my child. So lacking and difficult to get mental health needs met for a child. If you need hospitalization you might as well forget it won't happen. Frustrating not being able to get a crisis managed. Feel good when someone finally listens and takes you seriously and you get an appointment, or a test needed.

Things that professionals can do or say to make me feel more welcome or involved in my child's treatment are:

- ASK what we need and what we have tried
- ASK what the barriers to getting what is needed and make an effort to try and reduce those barriers
- Recognize that parenting special needs children is different than parenting a "typical" child, and don't judge me as a parent
- That they will check in with me periodically, let me help make decisions, and allow my child to feel like they are in the driver's seat (as much as possible.)
- Ask "What do you think you need?" and "How can we best support you?"
- Ask how things are going. Ask for ideas or what a parent thinks might be needed or changed.
- Explain why or how medications or treatment is going to help my child
- Asking me how it is going - not just asking my child who says, "Fine."

The Key is Just to Ask Us!

Association for Children's Mental Health

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Things that make me feel less engaged or included are things like:

- When decisions are made without my input
- If I'm feeling judged as a parent
- When scheduling of meetings, etc. isn't flexible to meet the needs of my family
- When the child receiving the services is painted as the only one in the family that matters
- Not being heard.
- People assuming that they know what is going on or what our life is about.
- Not showing up on time for appointments or changing appointment times.
- Saying things like "because policy says"
- Concerns not taken seriously. When a child is deteriorating, and nothing is done. Phone calls during a crisis not returned for over 24-48 hours. Then concerns dismissed.
- When they don't seem to remember any of the details of our case or situation. It makes me think they are not really listening to or hearing me.
- When my family's needs aren't heard and responded to.

My advice or 'Do's and Don'ts' for professionals working with families:

Do:

- Offer hope, offer broad resources, offer guidance
- Recognize that parenting children with special needs is exhausting, and often takes its toll on the family in many ways -- and that those tolls (like lack of sleep, financial stress, etc) can often be important areas to acknowledge and mitigate before treatment can be effective.
- Care about your clients -- not so much that you get to burnout point, but enough that you're engaged and can be someone to be trusted to be an advocate for the child/family
- Be aware of what you say in your reports and how it is said. Often those documents become the determining factor in service provision, etc. down the road. Write factual reports with supporting details, not vague reports or statements out of emotion.
- Include parent input but also engage child. Listen to parent as to how meds working if on them.
- Ask questions
- Do compliment me and my family when we are making progress and do something right.
- Do encourage us to do things on our own and spread our wings
- Do show up hope.
- Do expect setbacks and that life may happen to us like everyone else.
- Do realize we are thankful for your support even though we may not voice it all the time.

What Do Families Need to be Engaged?

Don't:

- Assume things.
- Judge, intimidate, dictate or parent me
- Assume you know the child better than the parents do.
- Assume that you could do things better just because you have a degree or book knowledge...knowing about mental health issues and living with/parenting them are two VERY different things!
- DO NOT be condescending or tell us what our goals should be. respect that we may not move at the pace YOU WANT but that we may take longer to move forward.
- Speak down to families. Let them be an expert of their own feelings.
- Dismiss parent's concerns not taking them seriously. No way to reach anyone after hours for a crisis and when you do you are dismissed as unimportant.
- Do not say I am the expert on my child. If I was I would have fixed things already and that just makes me feel more like a failure. I do know my child the best.

Other comments or suggestions received from families:

Families are experts on their own family.

Parenting a child with special needs isn't a sprint, it's a marathon. Baby steps and backslides are to be expected, and it's important to acknowledge where the child is at and the progress they are making, even if it seems small or so far from the ultimate goal.

In order to meet a family where they are, it might take a few sessions to learn where they have been. Its ok not to solve the problem, as a parent, I want someone to come along side of me and help me see what I might be missing!

RESPECT



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