

Summary of Autism Parent Focus Group
7/15/09

FACILITATOR: Tell us about your feelings as you went through the process of getting a diagnosis.....what the process was like for you as individuals and families... and what could be improved.

Parent 5: Part of the frustration for us was not really knowing what daughter had, and so ADHD severe was one diagnosis, PDDNOS, I guess is that a lump all kind of a catch all because we don't know for sure what you have.... It took us, to get a true doctor's diagnosis with her, probably, she was six.... I actually heard it from other people before I heard it from a doctor.

Parent 9: I think the biggest frustration at the very beginning was that it just seemed like we didn't know what to do and it didn't seem like we were getting a diagnosis.... everyone was just quick to assume he's just got ADD disorder.

Parent 5:...one time we went in and she was just herself, which was all over the place and throwing a fit and doing her things, and he looked at me like what is this, and it's like why do you think I'm here... I mean he heard me a little bit because she didn't talk and she didn't respond to answers or questions or anything so he appeased me a little bit but then when she did misbehave or act like herself, he was just completely amazed that oh, she really does this.

Parent 2: I don't think doctors, honestly, they really don't know with kids that have Autism, they're in their own little world. So I think it's a matter of really not knowing what's going on.

Parent6: ...for the doctor, I was so grateful that he believed me because I was getting family members, and neighbors, and teachers who didn't believe me, so that was a big thing as a doctor to say yes, I believe what you're saying. I think him guiding us to the right places and just the compassion that he had was the most helpful.

Parent 10: I think we went through three pediatricians... he would like start talking and I couldn't understand a word he was saying, and I kept telling my pediatrician he doesn't talk, he'll grow into it, he'll grow into it. Finally, was he two when he got his speech evaluation? , I guess, so it was just one doctor after another when we originally thought it was just a speech.

FACILITATOR: So were there frustrations that could have been avoided if doctors would have known how to do something differently or would have approached things differently?

Parent 1: I think so because at first she was diagnosed with MD, they told me she would never walk and we had to go through that and it was like a long weekend and I couldn't get any answers until Tuesday, we were told on a Friday that that's what she probably had..... **FACILITATOR:** Muscular Dystrophy? *Parent 1:* Right, and then it came back saying no she doesn't have that, so they took that one away, and then they didn't know for sure what it was...

Parent 4: I noticed when I bring my boys in there, he is very focused on them and he watches what they're doing. .

Parent 8: ...it's a huge thing to me for the doctor to be comfortable with the child and for the child to be comfortable with the doctor. He also if there are there recommendations that he would like some more testing, he talks to you about what it is and what he needs and will follow-up with getting you the doctor appointment for what you may need to have done. He doesn't just leave it to you to find your own, he's found them for you.

Parent 6:... the one thing I appreciated from Dr. T was that he gave me time to realize, and didn't force it on me... it was a huge relief to know that I wasn't a bad parent

Parent 3: I think they diagnosed, and we had a conference and they talked about our options.

Parent 8: ...he just watched what he did, and I think that would be, for most doctors, is to cue in on what they're doing....

FACILITATOR: So while the doctors were trying to figure this out, one of the things they could have done is they could have communicated better, this is why it has taken us a while, this is why we are struggling?

Parent 1: I think definitely, and it seemed like the appointments were hard to get, like you had to wait forever to wait to get an appointment with a certain specialist too. That's what was hard too, the waiting and then you know what I wish I would have done...I wish I would have wrote everything down as I went along. I'm starting to do that now, but she's 16.

Parent 4: I've never not gone in there and he's never (*not*) asked how are you doing, how are you dealing with this, every single time.

Parent 5:....he tries to involve everybody... do you guys have date night because it's important to get out and do this.

Parent 6: He's even asked me about my husband.

Parent 10: Well they want to make you happy, get her happy and get her out of my office, that's kind of how I always felt with my son because he had so many issues... (Current Dr)...Fridays are for special needs kids only. It's like he sets away a whole separate day for them so you know he just...you just don't feel rushed, you feel like when your child is put on medication that he put thought into it...

Gender differences Dad's perspective

FACILITATOR: Do you have any kind of support around that ...any doctors come check in with you, support you, talk to you about your experience?

Parent 2: Not a whole lot, no.

FACILITATOR: Do you guys think that maybe sometimes the doctors spend a little more time, on kind of how it affects the moms?

Parent 2: Yeah I think so

Impact on Siblings

FACILITATOR: Can you tell me a little bit... about siblings, what's been the impact on your other children...?

Parent 8: For us it's been like the kids are always, how come it's OK for *son* to do it and not for us to do it, well it's not really OK for *son* to do it but there is no way you can contain him not to do it...he loves to go to the store because he wants to see what he can sneak in for you to buy him, and it's like ah...you'll get the bill and it's like how come

it's so much and you start looking at the stuff and you're going I didn't get that... and the other kids are going how come you bought it, well I didn't really buy this for him

Parent 5: What's fair for *son* isn't fair for anybody else. .

FACILITATOR: So the other kids see that he is pushing all these limits and yet they're bound by these different set of rules and then that creates some friction... So it changes some of the activities that the family participates in?

Parent 4: ...it gets tough for parents because you want to do things and have fun with your family but you can't always do that because it is too much for them and it is frustrating for parents but it's frustrating for him.

Parent 8: Then the other kids feel slighted because they want to go

Parent 8: I still have to try...you still go to Lagoon and press those limits...because it's not fair to the other kids.

FACILITATOR: I want more specific information about how the doctors gave you information about the diagnosis... what do you wish maybe had been done differently at that moment in time.

Parent 4: We got ours from a neurologist and he told us that over the phone... I wish they would have talked to me more about it but I kind of did it on my own, I went and got books,... but it's helpful to talk to other parents and have the resources and say oh you're going through the same thing,

Parent 6: If I were the doctor and I were in with some parents, I think a packet of some kind, some information, maybe a book or two. When the doctor told us, we didn't really have anywhere to go, it would be nice to know what to do now, so to have the doctor say these are your options, you can do this, at school they've got these programs, just something a little more concrete...

Parent 2: I think information, where to get some help on what Autism is and programs and support groups or whatever.

Parent 5: Information or if doctors know like there are certain things, like you said, music, because some relate to music, some of them relate to water, some of them relate to pets.

FACILITATOR: So if they told you that upfront, say a lot of kids with this diagnosis do well with music, you could say OK...

Parent 8: I think part of that too is talking with parents. What kind of insurance do you have, do you have mental health coverage... as soon as you say Autism to a health insurance company, nope, not covered

Parent 5: If you put it in anxiety, they cover it differently.

Parent 1: Yes, I think if a doctor would say listen there is a parent support group, they also have children with disabilities, you know they understand, because they've been there, been through ...

FACILITATOR: What's the most helpful way for parents to receive information – books, reading materials, website.

Parent 2: Internet

Parent 8: Internet works if you have internet at home

Parent 1: It depends on the person

FACILITATOR: So certainly not just verbal information. You really want to leave there with some kind of written packet

Parent 8: Even regionalized to your area, like this is Salt Lake County, this is what Tooele County has, so if you want to drive to Ogden, this is what Ogden has but at least regionalized stuff

Parent 1: Jodie (PP for medical practice) has been a tremendous resource in our lives to tell us where to go and different websites to look at.

Parent 8: it would be nice to here is a list of the people that have said that it's OK for us to give their numbers out that you can call, that would even be helpful... somebody who has had a kid for years in the system that can come in and say hey, you need to talk to this person and this person and this person...

Parent 6:... when your child is first diagnosed, you have so many things rushing through your head it's hard to remember everything that's been told so just to have an outline or something to give the parents to take home with them to refer to I think would be very beneficial.

FACILITATOR: So they could give you a little bit more refined resource list than just here is everything under Autism in the phonebook

FACILITATOR: What's the number one resource that has been beneficial to you and then what's the number one resource you wish you had access to?

Parent 10: I guess our best resource would be the doctor, he knew where to go to different...not so much resources as far as like playgroups or stuff like that but referring us to the genetic department or the sleep doctor or stuff like that, a doctor that was knowledgeable that's probably been our best resource.

Parent 1: the Utah Parent Center is really good as far as they do have I think books you can check out and DVDs that will help you with different things..., but the biggest resource has been Jodie(PP for medical practice)

Parent 4: I would say the focus (meaning support) group.

Parent 8: the social worker that our son has been involved with...She's just been really a wealth of knowledge...

FACILITATOR: What's the one resource that you wish you had access to?

Parent 10: Something socially for him because he has no friends in the neighborhood... So that's my biggest thing, I wish I knew where to go to get him friends

Parent 5:...because daughter has four different meds, and then finding the doctor actually to deal with kids for medications has been hard... so finding doctors to care for these kids, medicine doctors, I have found that to be difficult because there's just not a lot out there or you get some that just aren't very good.... The lack of resources is frustrating or when you get resources there just aren't enough or there is way too much or they cost a fortune

Parent4: I would say school and recreation.

Parent 9: ...maybe find for him a social network of any sort, maybe some resources for me and for her to actually talk to other people not just on the internet

Parent 8: I wish that insurance companies would pick up more and pay on those resources to help because they fit in better with society when they get that intervention

FACILITATOR: That's a great segue to the last area that I really want to talk about and that's the financial impact. We've kind of talked about how do you get connected to the services.

Parent 8: If you mention that word Autism, the insurance company says not covered

Parent 4: ...My son had his own ABA therapist in St. Louis before we got here and it was wonderful. He had so many minutes a month of speech therapy, he had like 360 minutes a month, he was getting 30 minutes a month out here

Parent 10: My experience with that in Arizona, there was a program called Division for People with Disabilities... He had the speech, the OT, the music therapist came into our house, once a week for an hour, He did horseback riding for free... we move here and I go OK we need to get on your service and they go there is like a six year waiting list...

Co- pays and I don't know but even at the co-pays a couple times a week forget it

FACILITATOR: This is good to hear experiences from other states because a lot of people that will hear or see this are on that state planning commission

Parent 5: I quit working when she was four, for three years, and we did speech and it was \$90 a week for speech and it wasn't covered.

Parent 6: ...we got him on SSI because we didn't feel like we could afford to put him in everything that he needed but the social skills class came out of our pocket, and that was about \$150 a week.

FACILITATOR: So, there is things that are out there, we know they work, but we just can't get them to the point where we can afford them.

Parent 5: Insurance coverage. I think because then the doctors too, their hands aren't tied, I think if the doctors if things were more accessible, insurances were more helpful in covering all this stuff, you could do a lot more but when the doctors know some of the parents finances and how do you say try this and try this and try this because it's all going to cost too much and then that's so discouraging, as a parent, to call all these places too and to find out how much everything costs just to try to help your kid and it's just another slap in the face.