Introduction and Methods

The Autism Spectrum Disorders Project conducted three focus groups with parents of children with Autism Spectrum Disorders in the state of Delaware between February 17 and March 7, 2012. Focus groups were held in three different locations: Georgetown, Middletown and Newark. Eight individuals participated in the Georgetown focus group, four in Middletown and 12 in Newark. In total, 24 individuals participated across all three focus groups.

Focus Group Protocol

The focus group interviews utilized a semi-structured interview protocol (Appendix A). Questions addressed the following themes:

1) The process of obtaining a diagnosis.
2) Negative and positive experiences with the healthcare system (doctors, hospitals, pharmacies, therapists, etc.).
3) Negative and positive experiences with the educational system.
4) Negative and positive experiences with vocational rehabilitation and employment.
5) Thoughts on the interaction of all of the service systems in Delaware, including how they could work together better to provide comprehensive, high quality services.

Each focus group was facilitated by two individuals: one professional staff member at the Center for Disabilities Studies and one professional staff member from Autism Delaware. Prior to participating in the focus group interviews, the participants signed an informed consent document. Participants were instructed that their participation was voluntary and that they did not have to answer any questions they did not want to and that they could chose not to participate or withdraw at any time. Participants were also informed that the focus groups would be audio recorded as a way of ensuring accurate information for analysis was obtained. Participants were given a $50 Visa gift card for participating in the focus group.

Data Analysis

Focus group interviews were transcribed verbatim. Transcripts were uploaded into the NVivo Qualitative Research Software Program. Transcripts were read and codes were assigned to passages of text. Primary themes were developed in accordance with the interview questions. Secondary themes were developed under each primary theme in order to capture dominant categories of conversation. The themes reported here reflect the issues that were most often raised by focus group participants.

Themes

1. Obtaining a Diagnosis

Focus groups were asked to talk about when they first noticed something was different with their child and to discuss the process of obtaining a diagnosis for their child. Participants noted a range of ages at which they first noticed something was wrong with their child, from six months up to pre-school age.
Not all parents responded to this question, but among those who did, the process of obtaining a diagnosis for the children was varied, with five participants noting that their child’s primary diagnosis came from a psychologist at the school. Five participants noted having their child diagnosed by a doctor at a local hospital or health care center and five participants noted having their child diagnosed by a local service agency for children with developmental delays. Three of these participants reported also having a doctor diagnosis their child. One participant informally diagnosed their child and then went to a doctor at a local hospital for an official diagnosis (Table 1).

Table 1

<table>
<thead>
<tr>
<th>How Diagnosed</th>
<th>Number</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Psychologist at school</td>
<td>5</td>
<td>21</td>
</tr>
<tr>
<td>Doctor</td>
<td>5</td>
<td>21</td>
</tr>
<tr>
<td>Local service agency for children with developmental delays</td>
<td>5</td>
<td>21</td>
</tr>
<tr>
<td>Parent diagnosed then confirmed by doctor</td>
<td>1</td>
<td>4</td>
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N=24

2. Education System

Positive aspects of the education system

Table 2

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<thead>
<tr>
<th>Education System-Psos</th>
<th>Number</th>
<th>Percent</th>
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<tbody>
<tr>
<td>“Luck” involved in finding good teachers</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>School responsive to parent demands</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Open communication with school</td>
<td>2</td>
<td>8</td>
</tr>
</tbody>
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N=24

When asked to discuss the more positive aspects of the education system, three themes emerged: 1) “Luck” involved in finding good teachers; 2) Schools are responsive to parent demands; and 3) Open communication with the school (see Table 2).

First, three parents reported feeling “lucky” to have found teachers or schools that responded appropriately to their child’s needs:

And we’ve been very fortunate to have excellent teachers there who truly, truly care about those children, and go above and beyond what anyone has ever expected of them. And just, you know, embrace our children as if they were their own. (A3, Middletown)

I think, everything you need luck. Even teachers. We need good luck to have the good teacher. I understand that, you know... I’m happy with [school]. But because I’m not really pushy, I just
respect what the teachers think. They’re already trying their best to help my son. I take it. And... (A4, Newark)

Well, I’m glad there’s a... You know, I’m glad there is an existing organization that helps kids with autism have some kind of...school experience. I’m grateful to the people who have dedicated their lives to that. You know, and teach, and I’m sure it must be very difficult for them, on many levels, to do that. (A2, Middletown).

Second, when talking about what worked well with the education system, parents noted that the schools and school personnel respond when parents are assertive and push for their child’s needs. Three parents expressed the necessity for parents to be consistently demanding in order to make sure their child is getting an appropriate level of care and support at school:

I found out that once you get to be known, and if you know your...and they get to know you, and they know whenever you say something you mean it, and you are going to follow through, if they do not answer your e-mail, the do not answer your phone call, they will see your face. There will be a meeting. They found out, in my two years with the...school districts, they better jump or say how high when I say to do it. (A1, Georgetown).

Yeah. Well, that’s the thing. If you’re a go getter type of parent, and you’re pushy like I am, then they know that you want input, and they get it. You know, they don’t guide you through the process or tell you how to do it if not pushy about it. (A2, Newark).

I like the fact that I can communicate with his teachers at any time. Not just his teacher, the team. He has a team of providers that service him in the school. There’s an open communication, and you have to stay in the school’s face. I mean, I don’t mean going up yelling, screaming, you know, acting crazy. But be seen. Use some of the terminology that they’re familiar with. Give them some of the codes as part of these policies and procedures that they have in place so that you’re just not looked at as a foolish parent. (A3, Middletown).

Finally, two parents noted that communication between them and the teachers or school personnel was open, making the process of collaborating with personnel and addressing the child’s needs much easier. One of these parents noted that a particularly helpful teacher wrote updates and progress reports for them. The other parent noted that school personnel consistently asked the parents what they would like in their child’s IEP.

Problems

Table 3

<table>
<thead>
<tr>
<th>Education System-Problems</th>
<th>Number</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Lack of training among school personnel</td>
<td>9</td>
<td>38</td>
</tr>
<tr>
<td>Problems with administrative processes regarding IEP</td>
<td>8</td>
<td>33</td>
</tr>
<tr>
<td>Lack of continuity or consistency in implementation of IEP.</td>
<td>5</td>
<td>21</td>
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N=24
Participants were asked to discuss their positive and negative experiences within the education system. Many participants noted more than one problem. Three topics related to problems encountered within the education system were brought up and discussed by participants (Table 3).

**Lack of teachers/school personnel trained to deal with children.**

First, five parents noted a challenge related to teachers or school personnel not being trained to deal with children with autism spectrum disorders. Two of these parents noted that the teachers or personnel weren’t properly creating or implementing an IEP for their child. One parent from Georgetown explained how their child’s IEP was not thorough or implemented properly due to the lack of training of the school personnel:

> But they, like I said, as soon as that, they gave me a diagnosis, they gave me an IEP. Or course, I didn’t know what an IEP was. I’m like, “Okay. Okay.” But as reading, I found out things that they weren’t putting in the IEP which, you know, they’re supposed to be trained on this. Which they’re not. I’ve had to go through so many times, they wanted to... They want to write him up for behavior, when they know he has this. Or, he’s now in middle school. I just recently had to call an IEP meeting, because they wanted to write him up because they said he wasn’t paying attention in school, and in class... And I’m just finding that a lot of these teachers, even special ed teachers that we have are not being trained in autism. They have no idea. They... I mean, they want to... The teacher that he had...from third grade to fifth grade, she was a new teacher, but she was willing to work with me. It wasn’t her that I was having problems with. I was having problems with the people. (A1, Georgetown).

Another parent from Newark explained that their child’s teacher had not read the IEP for their child and was, therefore, not implementing it:

> When I went to the [school] intake [advocate] came with us. And even though [advocate] came with us, and she said a lot of things, like, “He works best with TLC. He reads already, and we give him instructions, read him instructions. And that’s a better way to, you know, give him instructions, than just verbally.” Do you think that they ever looked at that? When I confronted the teacher... This was July. When I confronted the teacher like in February...I said, you know, “He reads...” She never, ever, apparently, read the IEP. So again I go up in February, in one of those visits...ask to go and observe and stuff. And I said, “Oh, you know, come here, and let’s read this book.” And so he starts reading a book. “He reads?” And I’m thinking...And come at the teachers, “So how about the, blah, blah, blah, blah?” And she looked at me with a blank stare. And she’d never heard of what I was talking about. And I mean, I’m thinking...read the IEP. (A6, Newark).

Three other parents expressed concerns about teachers not being trained to deal with children with autism. These parents noted that they felt the school personnel were not dealing with their child in a way that was appropriate, instead applying a “one size fits all” approach to dealing with children with autism spectrum disorders. One parent explained that their child, one of two autistic children in the school, was placed in a class reserved for children with behavioral issues, despite the fact that the child did not have behavioral issues: “The special ed teachers, since she’s one of two autistic kids, they’re not
really honed in on autism. They’re honed in on the academics...all they’re doing is academics.” Another parent explained how their child was being disciplined or punished inappropriately:

As of yet, we have not had any offers from school to do anything different. I am meeting with them tomorrow morning, however. Because it’s been very much a concern of mine in that [child] does not get along with, cannot relate to kids his age in school. In group settings when they have to do projects, nobody wants to be with him. He is made to do a project by himself. And therefore, if it’s, like, a group of four or five, he can never get the group grade because he can’t do that much by himself. So that’s kind of an internal let down he’s going to deal with. He has been written up and gotten lunch detention several times this year because of kids making fun of him. And from what I can see, as far as I can see, it’s basically because they can’t related to him...But in the meantime it’s not... It’s not behavior issues, but he’s getting written up and being isolated from the other kids like he is a behavior problem. (A3, Georgetown)

This same parent from Georgetown talked about how their child was getting into trouble for shouting at other kids during class, which they later discovered was due to being placed in front of the rest of the class:

And as I sat where he did, and the teachers explained to me that [child] would shout out at the kids in the class, and I realized that as they were doing the smart board, he felt they were all looking at him because he was sitting here. And then once we switched it, then that actually dissipated. (A3, Georgetown)

**Problems with administrative processes.**

Second, eight participants noted problems with administrative processes within the education system related to planning services for children with autism spectrum disorders, citing confusion over the process or inconsistent implementation of an IEP. Four of these participants noted that the process of establishing IEP goals for children was problematic due to lack of flexibility in the planning or implementation of an IEP, especially regarding taking into account individual differences among the children. For example, two parents explained:

I find that the IEP is, it’s one of those square things that you...they taught [child] a lot in school, but, when you sit there as leader of this team and trying to guide things so that it works best, and [child] gets the support that he needs to get through his day, they say, “Oh, well that’s not where we put that. That’s not how we put that. That’s just, you know...he needs the questions read to him. That he needs a different room to take this test. He needs scribe, he needs, you know, this or that.” Well, that’s doesn’t fit the IEP. It seems too political. Too many rules, “This is how it has to be.” [Child has to fit it. It is not fitting [child]. (A4, Newark)

A1: And I don’t know if you’re at a...but I know that [school] has just the basic goals that they pull from. They say, “Okay, this goal is appropriate. Let’s put that in there.” But, you know, sometimes you get to the point where you say, “Okay. I’m writing the goals. You guys clean it up and put the measurable stuff in there, whatever you want to do but, this is what he needs. And then, you know, as a team we can discuss it, whatever.” But that should be totally welcome at an IEP meeting. And it’s not. You’re right.
A4: It's like you said. That they go through it, and they get into whatever guidelines they have to, have everyone sign it. And they're so focused on, "You have to initial here. And did you get your..." (Newark)

Similarly, another parent reported feeling pressured to sign off on an IEP that was developed for their child, despite disagreeing with some aspects of it. This parent reported that they were afraid of what might happen to the care their child received if they didn't sign off on it:

But I send it back even though I know I don’t agree with...You know, I think I’m afraid if I start ruffling their feathers...that they won’t help, or take care of [child]. And in order for me to think that he’s going to get this care, sometimes I agree with people when I know I don’t...(A3, Newark)

Two other participants noted that the processes for developing IEP’s were unclear or inefficient. For example, one parent shared their experience with attending an IEP meeting that did not require them to be there:

And it drives me insane that they don’t know what they’re doing before they set up the meetings to do the program. And they waste... They literally called me in because a new thing happened and they had to change some things. And it took them five minutes to re-read the whole different thing that changed, and it took us 35 minutes later for them to figure out what they were doing with the copies of things to give to everybody. And I went, “Wow, you couldn’t have just, you know, called me...” (A2, Georgetown)

Another parent explained that the vice principal of the school was unaware of the process of administering services for children with autism spectrum disorders:

So we’re at the award thing, and I spoke to the vice principal, and she said, “Well, why don’t we... You know, when are we going to meet? We’re meeting Thursday. What are we going to...” I said, “Well what you all, first of all, have to diagnose him.” “Oh, we have to give him psychological tests?” And that just kind of threw me. That she didn’t know that they also needed to diagnose him as well to find out what the school district and the school system can do to help him. (A3, Georgetown)

**Lack of continuity or consistency.**

Third, five parents noted the lack of continuity or consistency children often encountered in the educational system. For example, one parent explained that they had to remind their child’s school of the IEP established for their child at the start of each new school year.

And it’s just kind of go through the IEP, I have to call them, almost every year I have to go in and call them, and I have to go through the same thing. “Okay you guys, this is what he has. You know, you have to take in consideration this. Give him social skills. Social skills thing...” I said, you know, “Let’s try this.” I bought the books. Gave them the books. And they started... implementing the IEP, writing it down, they’re not doing it half the time. Even though you write it up and it’s there for them to do, they’re not doing it. I’m finding out that they’re not doing it. And I’m going, “Wait a minute. It’s in his IEP. Why aren’t you doing it?” So it’s like, every year I
Every year I have to go to them. It gets tiresome, but you just have to... I always am thinking about him. I don’t really care if they get mad at me or anything like that. At this point I’m saying, “Excuse me. This is my son.” (A1, Georgetown)

Another parent reported having trouble establishing consistency between home, school and therapists:

And I keep trying to get the behaviors at home to be the same that we have at school. And work with the therapist, and we all work together, and have the same consistency in his behavior issues that we have as well...Well, in this classroom, the teachers are working really hard. They... Every IEP meeting I go to they have the details of what they’ve broken down, and how they’ve discovered certain behaviors. But when mom wants them to take recess away because [child] has an issue with homework, and he won’t do his homework, they say they can’t do that. That’s my biggest issue. Is that when we try to be consistent between the therapists at home and school, that’s where the difficulty comes in. Because the [school] is not willing to be compliant with the therapy. They’re willing to work with the therapist, but they’re not willing to take [child’s] recess away because mom says, you know, he’s not going to do his homework at home. And it’s a requirement for school...Junior high is coming, and so is high school, you’re expected to get your homework done. And he needs to be trained. They won’t do it. And they tell me no. Then they have these programs where, he’s pretty much figured out that he can either run the place, or...So he’s being more defiant. And I try to make them be a little more strict on him. Well, that’s not part of their program. And they won’t do that. So we have behavioral issues that come home. And then mom has to be stricter. And then tell the teacher what I’ve done. And she says, “Well, I can’t do that at school...”That’s just not good. (A6, Georgetown)

Three other parents noted that not being able to keep the same teachers is a problem because their child has to re-establish a new relationship with a new teacher each year. One of these parents noted that though they found skilled teachers in a summer program, those teachers often move on and do not work with the children doing the school year. Another parent expressed similar frustrations:

He hasn’t had continuity of being in one elementary school for grades one to three, or whatever...Part of it is probably because we’re out of the district...And I guess they have to coordinate the busses with other kids. So depending on who’s his age, and where they’re going. I think that that has more of an issue about the school. Yeah. Because I think he’s been to every elementary school. (A1, Middletown)

An exchange between two parents in Newark indicated that they both felt frustrated with the lack of consistency and continuity for their children in the schools:

A1: That they change the teacher every year. And they took three or four months to understand my son had never had the... It’s time to write a new IEP, and then...

A2: You, as the parent, are the one that has to...teachers every single year to the same thing, over and over again...And if things are going well, then they want to take the service away. If things are going well...so every year you fight tooth and nail to keep things the way they are. (Newark)
3. **Health Care System**

**Positive aspects of health care system**

Table 4

*Distribution of Responses Across Coded Categories for Positive Aspects of Health Care System*

<table>
<thead>
<tr>
<th>Health Care System- Positive Aspects</th>
<th>Number</th>
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<tbody>
<tr>
<td>Supportive/cooperative doctors</td>
<td>6</td>
<td>25</td>
</tr>
<tr>
<td>Positive experiences with medical centers, organizations or programs</td>
<td>4</td>
<td>17</td>
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N=24

When asked to discuss the more positive aspects of the health care system, two themes emerged. Parents largely noted singular cases of finding a helpful doctors or having positive experiences with medical centers or autism focused organizations and programs (see Table 4 for the distribution of responses within coded categories).

First, six parents mentioned finding doctors that were supportive and/or cooperative. For example, one parent explained that because she has medical knowledge and was able to discuss things with her doctor using that knowledge, the doctor was willing to work with her when she wanted to transition her child off of medication:

> And because I did know my information, and when I presented it to the doctor, I did have a doctor that did listen to me, and worked with me to do a step down from all the meds that [child] had been on...But at least I had a doctor that as I did the things, and I said, “Can we slowly work these meds down?” that he did do that with me. But I had to know my knowledge first, and I had to walk in and present it, and then go through the process. But at least I did have someone that listened. (A3, Georgetown)

Other parents also indicated that their doctor was cooperative in helping them get the services they needed for their child:

> I think because it’s so hard to find a doctor or a professional who really focuses, or really has expertise in autism ...That they need to understand our needs, and when making a referral, don’t give us hard time. Because we know better than him. And my son’s doctor is good at whatever I need. I told him, “I’ll make an appointment with something, something.” Specialist referral is given the next day. (A7, Newark)

> Because if it wasn’t for his pediatrician, I don’t think he would get half the things that I ask for. Because if...that he has to write a prescription for it, he would do it, even down to Ibuprofen when I don’t have the money to buy...Ibuprofen for a fever for [child], I said, “Oh, write a prescription, I need, I don’t have the money for it.” And he does everything I ask him to do without a second thing, so our pediatrician...I don’t know what he’s going to do, I don’t know what I’m going to do when he turns 18. But he’s the best right now. (A9, Newark)

And that’s what I’d like to say. That I’ve come across some great therapists across the board. And teachers, and doctors who when pushed, and when pressed, and when I asked the right...
questions...“Here’s what you do.” You know. Or, “Okay, we’re going to put this diagnosis down. We’re going to put this code down for insurance, because they’re not going to take that one.” Or, you know, “Look, this is what you need to go and tell them.” Then they tell me verbatim. Or they say, “Look, I can give your kid services, but you have to ask for a special, dah, dah, dah, dah.” So God bless those people who are really in it for the benefit of the kid. And not just as a job. (A5, Newark)

Other parents noted finding dentists that were adept at dealing with children with disabilities:

But dentists I’ve had to change, keep switching to the right one, because the hygienist scares...keep searching. And here I’ve got one, and she’s so good at making him open his mouth, taking x-rays without...I was like, but I cannot recommend because maybe she’s good with my son, but not to everyone. And they are not even a special...for special needs at all. It’s just, they take adults and children. (A6, Newark)

Dental care? Yeah. But right now I have one that’s...and he’s been going to her for maybe two years now. But I think that’s the only one I have, that even accepts our insurance. Or that could even deal with children that have disabilities. (N1, Newark)

Second, four parents also noted that some of the medical centers, organizations or programs specializing in treating children with autism had been particularly helpful in helping them get diagnosed or get treatment for their children. For example, when discussing the positive aspects of the health care system, two parents from Georgetown specifically mentioned one organization as being helpful to them. One of these parents credited that organization with officially diagnosing their child: “I’ll never forget when [organization] had done their watch on her for her first...months, and they sat down at a table like this, and they were all so scared to tell me that they thought my child might possibly have autism.”

Another parent from Georgetown explained how their therapist immediately referred them to a local hospital that has autism specialists: “So...we didn’t get the run around. You know, we were given to them, and I called up there, and they immediately set an appointment, and that was that.” Another parent from Middletown also reported having a positive experience with the same hospital, saying “I feel like we’ve had a good experience there.” One parent from Georgetown reported positively on another treatment program, saying, “They’re working with the documentation to prove that some of this, when you start these different therapies at a really young age... they’re doing a great job.”

In addition to positive experiences with organizations or medical centers that specialize in treating children with autism, two parents from Newark mentioned a summer program that they felt was particularly beneficial to their children, saying the program was “wonderful” and “one of the best programs.”
When asked to discuss the kinds of problems they have encountered within the health care system, four themes emerged. Parents noted problems with the quality of care their child has received within the health care system, a lack of specialists with proper expertise in autism, problems with scheduling appointments and problems with health insurance (Table 5). Many parents reported multiple problems.

First, parents’ comments regarding the quality of care their child received from medical professionals covered a range of issues. Fifteen parents reported experiencing problems with the quality of care they received from medical professionals. Among these parents, five reported feeling as though their child’s doctor was dismissing their child’s symptoms or ignoring their concerns regarding their child’s development. For example, one parent from Newark explained “my doctor thought I was, really acted like I was totally off base” after explaining their concerns about their child. Another parent from Newark explained their pediatrician’s response: “From the beginning our pediatrician kept saying that ‘Oh, your child is a little different, but they’ll be fine.’” When describing her/his experience with a therapist at [organization], a parent from Newark explained their disappointment: “[Therapist] kind of saying, ‘okay, all kids have very good memories.’”

Two others parents explained they felt their doctors were both dismissive and lacking in proper expertise to diagnose their child:

He had seen her from day one and it was always.... “She’ll get out of, or she’ll grow out of that.” You know, “Some speech will come later with other kids. No big deal.” These other... She’s not a behavior problem at all. But there’s a lot of social stuff that he just didn’t... He didn’t have the time to hear me out. Or didn’t, it didn’t connect. (A1, Georgetown)

The experience that I just mentioned with the pediatrician was very frustrating. Here’s a medical professional saying, you know, “I don’t think this is autism.” And two months later he has a full blown diagnosis...[child] has very low verbal skills. You know, lots of repetitive behaviors. And almost, well, close to nil on the social kind of side of having that, you know, any of those social abilities. So to have a pediatrician basically, you know, brush us off. And have that kind of feeling, like, if I hadn’t been so insistent, would we, would Connor have been four before we got a diagnosis instead of two? So I feel like, you know, conventional medicine really let us down there. From there on out, honestly, Connor has been to a pediatrician like, once in the past three or four years. Because we feel like it’s almost entirely useless. (A2, Middletown).
Second, aside from the two parents who indicated their doctors were both dismissive and lacking in expertise, nine parents indicated that the health care system does not have enough providers with expertise to diagnose autism. Due to this shortage of experts in autism, many parents have had trouble obtaining a timely diagnosis. One parent in Middletown explained that, though they liked their child’s pediatrician, they didn’t feel she necessarily had a thorough understanding of autism. Other parents also described their struggles with doctors or therapists who were not properly trained enough to recognize the symptoms of autism or know how to diagnose:

Pediatricians...they know their discipline, but they may not know anything about autism. So to see their discipline do the autism...it’s really important...autism training...in whatever discipline they’re in, they’re really hard to find. Especially down state. (A2, Georgetown)

Yeah. Because I even mentioned to ...to try to get him evaluated...can’t get that done. Nobody wants to do that. And...because what if he has the wrong diagnosis. You know. Even his school has said, you know, he needs to direct that. (A8, Georgetown)

I think my frustration with the healthcare system with the inability to agree. Some will say, ‘Oh yeah, there’s a problem.’ Some will say, ‘Oh, no, no, he’s fine.’ ‘Oh, it’s PDD.’ ‘No, it’s anxiety.’ ‘No it’s this.’ ‘No it’s that.’ Would you please just figure it out? And I was very resistant at the beginning, because I, there isn’t anything wrong. I didn’t see anything wrong. But after all of his pre-school failures, and at that time it was, ‘There’s something wrong with your parenting. Because your child can’t behave in class.’ (A7, Newark).

Our frustration was the fact that he went from four years old where he was diagnosed ADHD and put on medication, and really just watched during the school day in terms of how his behavior was changing. Like he... They wouldn’t allow him in class, not being on the medicine, because he couldn’t sit still and so forth, to going to outside therapists. And never having brought to our attention, through seeing outside therapists from age four to age 14, the suggestion that this could be it. You know, that this could be the problem. I mean, they met with him, they have all of our concerns. You know, where a lot of the concerns that you, that the characteristics of Aspergers. And, then, you know, as soon as I brought it to this therapists’ attention, ‘Could it be Aspergers?’ She goes, ‘Oh, my God, I think you might be right.’ And it was just ten years later, like, three therapists he’s been through, and nobody even suggested it. Never even suggested. They...just took for granted, ‘okay, well he’s got ADHD,’ because that’s what he was diagnosed with. (A4, Georgetown)

You know, that’s the biggest thing. And it set him back. Also the fact that it took up until age of five to get him diagnosed. Nobody wanted to have to diagnose...And the fact that after he was at [organization], someone I knew from the [organization]...told me that there was a suspicion of autism, but I was never told. And it took five years for him to even been diagnosed. And that’s the biggest issue with us. (A5, Georgetown).

I guess I kind of have blanket theme for all of the medical professionals that I’ve come in contact with...If I only had the information the medical professionals, including all the therapists that I’ve come in contact with, and including, you know, people or organizations that I dealt with. If I only had that information about my son, we would be nowhere right now... Thank God for the
Thank God for books. Otherwise I would not know nearly as much as I need to know. (A8, Newark)

Third, eight participants also noted problems in scheduling doctor’s appointments for their children. These parents specifically identified experiencing scheduling problems with hospitals or doctors specializing in autism spectrum disorders. Many parents spoke of having to wait months before their child could be seen by a specialist. For example, one parent from Newark reported waiting four months to see one of the specialists in the area. Other parents reported similar experiences:

I think the biggest thing is, AI is, you know, the premier. The place to take the kids. But it was hard to get timely appointments to see them. It seemed like I’d make an appointment, and it was three or four months down the road, and that kind of thing. That was hard. (A1, Middletown)

[Organization]. She recommends, she’s like, “Look, you can choose whatever provider you want. But I will let you know there’s a spot in the [organization] right now. Or you can wait up to six months, probably, for [organization].” So that was a huge thing in our decision making as to where to get services. (Newark)

Another parent spoke of having to wait for 10 months before a major treatment center in the area could see their child:

Well, the first thing was to go for an appointment with a developmental pediatrician. That was... My husband kept saying, by the time we get this appointment, this kid will be, you know, in school already. And, like, if there was some hope for him, it would be finished right then, and it would be gone...Then speech therapy took, like, six months to get. (A1, Newark)

Other parents reported feeling as though they had to wait a long time for an appointment because the treatment center or specialist was dismissing their requests for appointments or didn’t have room:

When we finally did get to his evaluation to be sent to [organization], it took another three years. We kept losing the paperwork, and we couldn’t get a hold of them. And they didn’t have any space for him (Georgetown).

Month after month I called, they either just put me off, or they just said they lost it. I don’t know what happened. Because nobody...two years I did that. I was on the phone every couple of months. You know, after a while you just quit calling, and you give up hope...And I didn’t know where to go or what office to... (A3, Georgetown)

One parent from Newark explained how the long waiting time at a local treatment center prompted them to seek treatment somewhere else:

We were on the wait list for [organization] with the developmental pediatrician and, you know, ten months after you get diagnosis, there’s a huge period of time...It’s so funny, because they called me like, “Oh, you know, your son’s appointment is, you know in two weeks, blah, blah, blah.” And I laughed in the phone. I remember laughing and be like, “What are you... We’re so past that.” Like, are you kidding? If I waited for that, I would have... (Newark).
Fourth, three parents also noted problems with their health insurance. These parents noted a variety of problems pertaining to health insurance, including having trouble finding doctors that will accept their insurance, finding insurance that covers developmental delays and problems with the process of applying for Medicaid. The following comments demonstrate these issues:

One of my struggles I’ve had is because of [child] having come so far, and now that we are with an older child who needs a therapist to help him with a lot of the other different issues, I can’t find one down here. If I do, it’s not a PTO, it will not accept my insurance. Or we have to struggle with the insurance company to attempt to get them to see if they will override the in or out of network. It’s, I, it’s….It’s very frustrating. It’s very frustrating (A2, Georgetown)

Well, I’m finding in Delaware they don’t do anything for autism anyway. ..At least my insurance doesn’t. And my insurance doesn’t do any…they don’t do anything for developmental delays. So when we get something, we need to put it under the, you know, neurological, blah, blah, blah, blah, blah, disorder. And, you know…blah, blah, blah. Because otherwise it doesn’t get… So that’s why we rely on the…and professionals who are in the, you know, who know which codes will get covered by certain insurances. (A1, Newark)

But the navigation process is ridiculous. You know, they send you a 40 page packet, and you go through the packet and write…it’s all the same questions for every single thing you apply for. You know. And then they have a psychologist or somebody call you and, you know, three months later, and go over the same kind of stuff with you, or do a screening with you. Or…sent me the thing, and I gave them, you know, on my own observations, and the behaviorist sent it back. Of course when I didn’t get it back a month later, “Oh, no, I never got it.” And then I got a message later, “Oh, I found it in our mailroom.” It had been there for a month and a half in the mailroom. So you know, that whole process for medicaid took about four months. (A11, Newark)

4. Vocational Rehabilitation and Employment

Table 6

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<thead>
<tr>
<th>Vocational Rehabilitation and employment</th>
<th>Number</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Fears- preparation for being an independent adult</td>
<td>6</td>
<td>25</td>
</tr>
<tr>
<td>Hopes for child</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Hopes for school emphasis in vocational training</td>
<td>3</td>
<td>13</td>
</tr>
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</table>

As the children of most of the parents attending the focus groups were not yet old enough to have gone through vocational services in the school, the focus group facilitators asked parents to talk about their hopes for their children in terms of what they would have access to in school and what they would be able to accomplish in life. Three themes emerged, including parents’ fears regarding their child’s preparation for adult life, their hopes for their child’s future and their hopes for what schools will provide regarding vocational training (Table 6).
First, six parents mentioned being concerned about their child’s level of preparation for adult life. These parents focused on managing money, being prepared for employment and being prepared to be an independent adult. For example, one parent from Georgetown explained that her/his child is very adaptable to working with other people and developing skills, but also expressed concern about their child’s understanding of money management:

I don't think [child’s] going to have a problem at all. You know. In today’s society, self work, you know, working with an individual or two people even. You know. He’s that adaptable. That’s his, that’s where he’s comfortable. You know. He doesn’t have the concept of money yet. But, and I’m not making excuses for him, or anything like that. He’s going to get it. You know, he’s made some real progress just through therapy. You know. And...and I constantly, constantly think, he’ll get the money, I pray, soon. But, you know, he has no problem buying a...card for 40 bucks. You know. He went out and worked, and pulled a stump out of some neighbor’s yard. It took a week, for one purchase. You know. For one little thing (A4, Georgetown).

In addition to money management, two other parents expressed concern about their child’s level of preparedness for adult life, including employment and other social relationships. Two parents from Georgetown explain their concerns for their children:

How do we deal with money? And I know we don’t talk about this, but the social side of marriage. And relationships like that. I mean, that’s... I’m four years away from her at least being done with her normal school stuff. So, very much a concern. (A1, Georgetown)

But I just, I can picture him, if it was him going out into the world today, because of the social issues, he’d be unemployable. I really do feel that he’d be unemployable. I don’t see him being able to work with other people in a setting... I, you know, he has these aspirations of going to college and becoming an engineer. And he’s got the academics, he’s got the brain for it, absolutely. You know. And even, perhaps, to work on his own somewhere, some how. You know. But as a parent, just, you know, the whole idea when you brought up money, he socially has no concept of, at 14, how to save a dollar. If he has it, we have to spend it somewhere. I mean, and by 14 I remember having a savings account, being able to... He has no concept of what, of money paying for bills. None of that. None of that social stuff that most kids are aware of. (A2, Georgetown)

Second, when discussing their hopes for their child’s future, four parents made comments over such topics as: finding a job they are interested in, being able to live an independent life and achieving what they are capable of. The following quotes demonstrate parents’ thoughts on these topics:

But I guess my hope for him is that, at least they can find something that he’s interested in. He loves doing computer things. You know, he’s great on the computer. That he can find something that he likes doing that he can at least do for four to five hours a day. That he could get some, you know, work experience, that type of thing. But I think that he’ll never be... I don’t know if he will ever be able to be completely independent on the job. I think he’ll always probably need some kind of supervising. And I’m hoping that will be, a place that there are people that will be able to do that. I just don’t want him being, at, you know, at home with no, you know, meaningful kind of work to do (A1, Middletown).
...I want [child] to have opportunities to, you know, continue to grow after the school period has ended. And I think some kind of employment area would be great for him in that, very similar, I don’t, at this point it doesn’t look like he would be able to ever be, like employed at a regular setting, unsupervised. But I would want him to have some kind of program. The flip side of that is for, you know, for my relationship with my wife, and with my other child, and potential grandchildren that come, and other things that, you know... I think the best chance for us to really love [child] for the rest of his life is to have opportunities to not be with him, just as much as it is to have opportunities to be with him. So to look down the road and think, when school ends, you know, to have the responsibility of [child’s] care 24 hours a day seven days a week is very disconcerting. You know, it’s very ominous. And, you know, I think that my hope then is, just as [respondent] said, there’s a program there where he can be, still have some kind of involvement for both those reasons. For his sake, and for our sake, and then it goes back to his sake. You know, so...(A2, Middletown).

My dream for my son is that he can be as independent as possible. Number one. My hope for him is that he will be able to have a job. Take care of himself, whether it’s in a group setting or something semi private, or what have you. And I know the older that our children get, the less resources are available to them, unfortunately. Especially in the school system. But my goal for him, my hope for him is that he develops enough that he can be independent, and he doesn’t have to... I won’t even say live with me forever. But where he can have his own individuality, that he can kind of come and go as he pleases. You know, within reason. As any adult would. But, that he doesn’t have to depend on me for everything. That’s my hope for him. (A3, Middletown).

But you know what I mean. I’m really trying to push him, because he seems to be smarter than people can sometimes assess. That he should try to do the most he can with his life. You know. If at the end he wants to do something else with his life, and he’s happy with it, I’ll be happy with it too. But he’s still a child, and I’m going to push him as much as I can. And, you know, it’s like they don’t expect anything from him because, you know, he’s autistic. I mean, and I’m like, “Excuse me, but haven’t you noticed that he’s actually fairly smart?” You know. The last thing they told me in school is, “He’s so hard to assess. You know, because he can’t really express himself very well speaking. You know, the other kids who at least can test them verbally, because they cannot write. And he cannot read...long essays. So he’s so hard to assess.” And it’s very frustrating for me. Because I’m looking to the future. And I want my child, you know, to study, and to do well. Right now he has a 93 in math, an 87 in language arts, 74 in social studies, which, you know, oh well. You know, he cannot be that dumb. They’re not really making special concessions. So he cannot be that bad. So why are you going to tell me, “Oh, what do you really want to do with your kid? What do you really want out of this?” I want him to go to college. So I don’t know how you, you know... Am I doing something wrong? Am I being too pushy? Am I expecting too much from my kid? I mean, it’s my kid. I feel he has the potential. (A1, Newark)

Third, three parents specifically mentioned what they hoped the schools would provide in terms of vocational training. These parents focused on the importance of starting vocational training earlier in order to more fully develop a child’s skills over a longer period of time and introduce the children to various service options earlier. Starting earlier would also allow the schools to customize the training to the child’s interests and needs. These ideas are demonstrated by the following comments:
I mean, just really quickly... Really quickly, I mean, the schools ought to be providing vocation training for kids starting, I believe at age 14...not when they’re 18. Way before they’re 18, they should be figuring out who, which adult service provider do I want to pick. You know...So you need to find out who are the providers in my area and go see them all, learn about them so you can pick one. It’s your choice when your child is an adult. No one decides for you who can help your child with employment services. DDDS or another agency...and then they can help pay for child within the services. They...but they will help pay for the job coach that will help ensure a child can stay on the job. It absolutely should be. There should be employment goals on the IEP once they turn 14, I believe (A1, Georgetown).

So I would think that as a child gets older, the school has to shift some, you know, what are the goals now? And if one of those goals is some kind of meaningful employment opportunity. Wouldn’t it be great if there’s conversation happening between whatever that opportunity is, and the school, early on in the game, so that when a kid turns 16 or 17, there’s already this sort of... Just like you have an IEP for the school experience, there’s an IEP that...Does that make sense? (A2, Middletown)

Well, I think that by the time they are... I don’t know. They go grade levels based on their age. So even though my son is in second grade, he may have a kindergarten mentality rate. You know. But I think by the time they are maybe sixth or seventh grade, maybe eighth grade at the most, to start feeding those ideas to them. Some of that being independent. They do these outings now where they go into the community as far as the market and restaurants, and dollar stores, and those kinds of things. Which is good. But at some point when they are in their teens, to kind of start feeding them this independence. You know, allowing them to do some things on their own, or helping them to develop the skills. Because it just doesn’t come natural to them. So to help them develop the skills to be able to do some things independently. And then continue to build on that each year through the school system. And while they’re still in school, to help them with employment. You know. Or take them to a place where, this is assisted living, or independent living, whatever it’s called in Delaware. Where you can live in a group setting, and you’ll have your own room. You know, and show them that. You know, so they can visualize and say, “Well, maybe I could.” Unfortunately, we don’t know what our children are thinking. They can’t tell us, you know, what they’re thinking. But if we keep feeding them the information, hopefully some of it will sink in. (A3, Middletown)

5. Service Systems

Table 7

Distribution of Responses Across Coded Categories for the Interaction of Service Systems

<table>
<thead>
<tr>
<th>Interaction of Service Systems</th>
<th>Number</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Lack of centralized information regarding services</td>
<td>9</td>
<td>29</td>
</tr>
<tr>
<td>Lack of open communication among state agencies</td>
<td>5</td>
<td>21</td>
</tr>
<tr>
<td>Stress on parents</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Lack of engagement by doctors</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Service systems are not keeping up with autism research</td>
<td>2</td>
<td>8</td>
</tr>
</tbody>
</table>

N=24
Respondents were also asked to talk about how all of the service systems (medical system, educational system, vocational rehabilitation and employment) operated together. This portion of the focus group asked participants to identify how the service systems could work together better and what an ideal service system would look like. Responses focused largely on the difficulties parents have faced in dealing with service systems. Parents’ comments fell into five categories: a lack of centralized information regarding services, a lack of open communication among state agencies, stress on parents, lack of engagement by doctors and a concern that the service systems are not keeping up with recent research (Table 7).

**Lack of centralized information regarding services.**

First, parents indicated that they felt as though it was difficult to find the information they needed to get their child the proper services. Parents attributed this difficulty to two separate problems: a lack of a centralized information regarding services and a lack of open communication among state agencies and. Nine parents expressed a desire for more guidance, saying that it would be easier if there was a guidebook or a set of directions for parents to help them navigate the system of autism providers and procedures regarding diagnosis and treatment. For example, one parent from Georgetown noted that the state had resources for other conditions, but not autism, saying: “The state has it for other things. For everything else. For almost everything else, they do.” Another parent from Middletown explained their experience of having to rely on word of mouth from other parents regarding which providers to see or what steps to take. Other parents also expressed the desire for more guidance:

I think…even for new parents, there’s nothing out there that’s in a guidebook, or anything. I mean, I work for the state. And they don’t have…and the state doesn’t have anything that is out there. And I think that’s what they need. I mean, I know all you guys do it, I do too, we just all got in and went on the internet and tried to find out everything we knew. (A2, Georgetown)

If there was one guidebook that tells you, these are the groups that we want to talk to….I would rather...these are the people that you speak with. Some kind of directory of help. (A3, Georgetown)

Okay...The autism protocol. This is what you do at six months. You know, if we start finding it that early, which we should. You know. And I know there’s a lot of work on that end. But, this is what you do at six months. This is what you do at two years. That’s what I would wish for. (A2, Middletown)

Well I still think, I mean, you as the parent, has to be the primary advocate. Just that there’s more, I don’t know, like, central knowledge that people know, “Oh, your child was just diagnosed with autism. Here’s a list of, you know, pediatricians in Delaware that you can go to. These all have, you know, they all have more research in them, more extensive knowledge of the condition.” And the other healthcare professionals. You probably need to see a gastroenterologist, a neurologist, that kind of thing. Delaware’s really lucky that it has a school system. I mean that, you know, the only public one I think...in the country, right? (A1, Middletown)
Or even, let us kind of know which, if pediatrician, you know, really specialize in autism. You know, who those are? And people don’t really want to... You know, you hear more word of mouth other than, “Oh, this, these three pediatricians really... You know, they specialize in it. And they take kids with autism.” Just like with cancer. Yeah. (A1, Middletown)

Similar to wanting more guidance, two other parents also expressed the desire for a local center that is dedicated to the treatment of autism. For example, one parent from Middletown wanted an “Autism Center.” Another parent from Middletown expressed a similar sentiment:

Or even, like a medical center or something that’s, that maybe not strictly with autism, but the people that work there, there’s, you know, there’s occupational therapy, there’s a place where you can go that... (Overlapping chatter)... You know, with a dentist, or you know, pediatricians that are more in-tune with children with autism. So you can get more answers. Rather than have it so scattered. (A1, Middletown)

**Lack of open communication among state agencies.**

Second, five parents indicated that many state agencies do not openly communicate with one another, causing confusion among providers regarding where children should be referred. One parent from Georgetown suggested that there should be an advocate for autism resources at the state level to make sure that the state agencies work together. Other parents also express the desire for open communication and teamwork among the professionals that deal with children with autism:

Just for the providers to work, for all of the providers to be on one playing field when it comes to autism, and other spectrum disorders. And be informed. Make it almost like, you have to. Because if you’re going to be a provider in the State of Delaware, you should be on this list. Because that’s the biggest thing, like he was saying, his pediatrician didn’t know anything. And there’s a lot of providers out there, that when I get services for my son, tell them, and they go, “Oh, really?” And they write it down. They don’t know. And then the ones that are already existing, don’t know how to communicate with each other. Because unless they have a signed paper here, or the rules of their program actually say so, that you can talk to this person, they’ll tell you about this, then they’ll... Everybody has to work together. It’s not consistent or cohesive. They just don’t do it. And it’s a struggle. I mean, there should not be a system like it is right now where it’s so hard for parents to find out things. And then the lack of education on autism. My son’s biggest issue was pottyng. There isn’t one single person in this state that could tell me how to get my son to stop going in his pants. Well, through parents and...And then therapy got into place because there was actually somebody who had experience with another child, and... You know. Finally. But it took nine years. Nine years of a lot of mess. And nobody else knew. You know. It’s lack of education. (A1, Georgetown)

I think I’d like to see, like...schools got more training, that has to have people, like every single person can’t then... At least a certain number in every school building should have autism training. And also, some kind of...so the agencies can work together. And...no, your...should handle that. No, DDDS should really handle that. So all of those...come together for all kinds of reasons. Especially really...getting better and stronger, our kids with autism. And...nobody can help them because everybody’s going like this. It is really frustrating. So, I would like to see
some kind of system that can pull all of those people together onto one system where they can all share resources and planning together. To make that better. Then the education...training experts. (A6, Georgetown)

One gripe that I really have is, the state agencies don’t know what the other state agencies are offering. So for example, I had a very lively conversation with my [organization] coordinator...When we left the system, or shortly after we left the system, and the things that were going on, I said, “Why didn’t you tell me about this?” And her answer was, “I didn’t know.” And it was, I mean, stuff she should have known. How to register for DDDS. How to apply for medicaid. You know, stuff that they should know, I think. And they do do a little bit on transition care. Like, even with [school], like, I had to find out from other parents how to go through that process. And it was mentioned briefly somewhere with her along the line. But, I mean, these are, all these resources are out there, and the people... Everybody should do a better job in communicating with each other. These are created all through Delaware, or [organization], or whatever, to try to help people connect the dots. But even they, like... Just, everybody needs to talk to each other a little bit more. I want to corner all of the groups representing... “Here’s what we’re offering, and here’s how you apply for it. Here’s what we’re offering...” And that’s just what needs to happen. (A1, Newark)

And even...like, you know, I take my child to private therapy three times a week. And I have asked the speech therapist that he sees privately, which he sees, you know, he has three sessions of private speech therapy, to get in touch with the school and vice versa. The school has no desire to hear what these other people have to say. You know. It’s just, we’re doing what we’re doing. Like, they know what they’re doing. You know, be... I mean, wouldn’t it work a little better if they communicate with each other? (A2, Newark)

**Stress on parents.**

Third, parents also talk about the constant battle to make sure that their children are getting the proper services or adequate services. The parents discussing this refer to the exhaustion, stress and strain they often face in dealing with personnel in the service systems. For example, two parents from Newark talked about feeling as though they have to be overly assertive in getting what they need for their child:

Parents are the center. And there shouldn’t be so much turnover with personnel. I think that in [child’s] case, he’s very... He guides me with many of the things that I struggle with. And I’d like to see an awful lot of the threats and legal actions go away. Why does that have to happen? Because you feel like you’re getting pushed around until you say, “It’s written in there.” Or, “I’m bringing a parent advocate with me.” You know. That has to happen before you’re listened to. (A1, Newark)

That’s like the number one thing that I tell therapists. I’m like, “Now would you be satisfied with this level of service if this was your child? Would you think that they would learn from one half hour a week of doing this activity? Of course not. You know. So you either need to communicate with me better so that I can do it at home, or offer him more services at school, or talk, communicate better with the classroom teachers so they can do it in the class...” You know, it’s like... get on the ball here, and stop making me, like, maybe get on the ball and... I’ve said as a parent, I have spent more time and money on, you know, nice dessert trays and
apologizing for my pushiness, and saying, you know, “I know I’m pushy, I know, I’m sorry. I don’t mean to be rude but. You know. This is my kid. This is my one and only kid. I only have one shot at these early years. We’re going to do this as best we can. You know, either you’re with me or not. Let’s do it…” Teachers laugh at me all the time. I say, “I’m sorry I’m such a pain in the ass.” Like, I know, I know I am being. And if somebody, you know, came to me, and pushed me as much as I push you, I’m like, “I know. I’m sorry. You’re so terrific, and you’re so busy as it is. But could you please, you know, do this. Thank you.” (A5, Newark)

Other parents noted that they have experienced a great deal of stress due to spending extra time doing research on the internet, dealing with IEP meetings or documents or otherwise trying to navigate the administrative aspects of the service systems. These frustrations are expressed in the following three parents’ comments:

Parents are so exhausted all the time as it is. We don’t get paid to stay up late all night, every night, researching and searching the internet, and reading over IEP’s, and trying to...that we don’t know, and, we don’t get paid to... Well, so I feel like people who, it’s your job, you chose it as your career to be with these kids and help them. So you need to step up and be a professional, and do your work, and not be lazy, and... You know, these are people... These are people. You know. These are lives that you are affecting. And the way that you deal with them, and the way that you deal with parents is going to have long lasting effects throughout their lives. You know. And who’s going to be left to clean up the mess? The parents. So it’s like, you know, it’s really frustrating (A5, Newark).

After all the things that I’ve done with my son, my blood pressure went up. I never, ever, ever had high blood pressure. You know. I mean, all kinds of things. I almost had a heart attack in the school where I work. When I was talking about what happened in the last IEP meeting, and, you know, this was, like, three years ago. Or three years ago...I mean, it’s like outrageous. We don’t need any more stress. We’re already, thank you very much. (A4, Newark)

So why do they make...so much harder. You...so much harder, you make us spend all our money, you make us do all this stuff, when really, if you know what the kid needs, you should just offer that in the first place, instead of trying to have us fight for more speech therapy. More attention. You know. (A5, Newark)

**Lack of engagement by doctors.**

Fourth, three parents’ comments indicated that many doctors don’t necessary want to deal with a child with autism. For example, two parents from Middletown felt as though many pediatricians are not properly informed about autism to make a proper diagnosis or fully engagement in their child’s treatment:

My thoughts on that would be because the autism spectrum is so broad, that there...diagnosis that fall under the umbrella of autism that a lot of providers just don’t know how to properly diagnose. To say that they specialize specifically in autism. And I think that, like you said, unfortunately, we have to be advocates for our children because a lot of times, providers really don’t even take into consideration what the parents think. You know, it’s kind of a, “Oh, you know, most children are slow these days.” So they’re not talking at it. And those kinds of things.
So you really have to be persistent and keep at it, so that you can get the services that your child is entitled to. (A3, Middletown)

It just seems like the conversation isn’t happening. That’s one of the most... I don’t know. It just, like, why is our pediatrician so uninformed? If they’re really... It’s really like one in 112 kids that have autism, like, seriously? If one in 112 kids had cancer... It seems like there’s a lot of noise about autism. Which, I’m grateful, yeah, let’s walk a 5K, let’s raise some money, let’s find a cure. I’m glad for that. But it just seems like, how is it not translating into, at least the pediatrician being informed? And not looking at a family and going, “Yeah, I don’t think that’s autism.” And then two months later it is. I mean, you know, or you don’t take... I hear this all the time, usually from parents with kids with autism. “We just don’t take our kid to the pediatrician anymore.” And that’s how we feel. It’s just irrelevant. There’s nothing to gain from it. The pediatrician doesn’t say, “Okay, your kid is in stage four autism. So do these five things, and he’s coming in for this treatment later this month, right, and talk to the specialist.” There’s none of that. So, I mean, I guess that... There’s a lot of wishful thinking in what I’m saying. Because I know that...(A2, Middletown).

This same parent went on to say that many providers do not want to engage in treatment for a child with autism:

And a lot of those providers really just don’t know where to refer you. And the schooling that they have is more of an education piece versus physical medicine piece. That’s where the specialty comes in with autism, on the education level. Not so much the medical level. And I think that’s where they’re missing the boat, and I think that also a lot of fingers, if you will, could be pointed at the medical profession for this explosion of autism. So a lot of them don’t want to touch it. I had to change my son’s provider, primary care physician, because his doctor was just so hands off. And I told him, I said, “I’m going to have to change you, because when I come to you, I expect you to help me. Not to answer every single question, but to have some knowledge base of what my child is going through, so that you can treat him properly. Or at least refer me to someone who can.” But a lot of them are very hands off of this disorder that our children go through... (A3, Middletown)

Another parent from Middletown expressed similar experiences, saying that they felt as though her/his son’s pediatrician did not want to engage in treatment their child:

[Child’s] pediatrician was my daughter’s pediatrician. And we were very happy with her. Because, you know, she was very involved in the process...Very on top of the milestones. Very, you know, informed. But it’s exactly what you said. With my son, there is this weariness, like this glazed look that comes. And this unwillingness or inability to engage...(A1, Middletown)

Service systems are not keeping up with autism research.

Finally, two other parents explained that they felt as though the service systems weren’t able to keep up with the field of autism research and that many of the techniques and services are not up to date or diverse enough to accommodate the range of needs for children on the autism spectrum. For example, one parent from Newark commented on how slow the service systems are to adapt to evolving knowledge:
Another huge...is, you know, the face of autism is changing. The diagnosis is changing. The, you know, systems and education around autism are changing with every knowledge, every study that gets done. And these organizations are very slow to change with it. And very slow to promote some things that are working for lots of autistic kids. And, you know, and just, they just get complacent. Doing what they’ve been doing for the past two years, and it’s not working anymore. (A2, Newark)

Another parent expressed concern that the service systems were not equipped to deal with the highly functioning autistic children, who often do not need the services that are available:

In all of these agencies, you have the educational system, the healthcare system, whatever. They need to catch up with the whole...population of the highly functioning autistic crowd... And those types of people who, you know, either get denied services, or never need them, or who are playing nicely in the corner by themselves, so there are no behavior issues, so they’re doing great in school. So it’s like, these kids that aren’t getting reached...then they hit middle school, high school, and wait, they can’t function right in society, and they can’t work with a group and do their class work. And nobody knows what to do with them, really, and they’re just kind of getting left in the lurch. (A5, Newark)

Summary

Three focus groups, containing a total of 24 individuals were conducted in Delaware in the Spring of 2012. The content of the focus groups centered on the experiences of parents with children with autism spectrum disorders. Parents were asked about their experiences with obtaining a diagnosis for their child and their experiences within the health care system, the education system and vocational rehabilitation and employment services. Parents were last asked to discuss how all of the above mentioned systems interacted and whether or not they felt they worked together well. Overall, parents’ comments highlighted problems they have encountered within these systems as well as positive aspects they identified within these systems.

First, parents’ comments regarding getting a diagnosis for their child indicate varied experiences. Comments indicate that diagnoses came from four general sources: 1) a psychologist at school; 2) parent diagnosis followed by confirmation from a doctor; 3) a doctor; and 4) a local service agency for children with developmental delays.

Second, parents were also asked to talk about the positive aspects of the education system. The positive aspects of the education system noted by parents fell into three categories: 1) open communication with the school; 2) the perceived “luck” involved in finding good teachers; and 3) schools responsiveness to parent demands.

Parents were also asked to discuss the problems they have encountered within the educational system. Problems reported by parents fell into three general categories: 1) problems with administrative processes regarding the IEP; 2) a lack of continuity or consistency in the implementation of the IEP; and 3) problems perceived to be due to a lack of training among school personnel.
Third, when asked to talk about the positive aspects of the health care system, parents’ comments fell into two categories: 1) finding supportive or cooperative doctors; and 2) positive experiences with particular medical centers, organizations or programs.

Parents also discussed the problems they have encountered in within the health care system. Problems reported by parents fell into four categories: 1) quality of care; 2) lack of provider expertise in autism; 3) scheduling appointments; and 4) health insurance.

Fourth, parents were asked to discuss vocational rehabilitation and employment services offered in the schools. Because most of the parents participating in the focus groups had young children who were not yet participating in these services, they were asked to talk about their hopes for the kinds of services that will be offered their child and their hopes for their child’s future. Responses fell into three categories: 1) fears regarding their child’s preparation for being an independent adult; 2) hopes for their child’s future; and 3) hopes for what the schools will offer in terms of vocational training.

Finally, parents were asked to talk about how all of the service systems operated together, focusing on what they think an ideal service system would look like. Parents’ responses largely focused on the problems they have encountered. Parent responses fell into five categories: 1) lack of engagement by doctors is a problem; 2) the service systems are not keeping up with autism research; 3) parents are under a great deal of stress due to failures in the service systems; 4) there is a lack of communication among state agencies; and 5) there is no centralization of information regarding services available to children with autism.
Part I. Welcome

Hello. My name is Annalisa Ekbladh and I am the listening session leader tonight. Here with me tonight is Heidi Mizell.

Thank you for being willing to participate in this listening session so that we can gain more information about your experiences with the services to families and individuals with Autism Spectrum Disorders here in Delaware. Please make yourselves comfortable and get something to eat and then I tell you a little about the listening session and its purposes.

I want to emphasize that we will not identify you in any way either verbally or in any report that is written based upon this meeting tonight. I also want to make sure that you know that you can refuse to answer questions, can leave the group at anytime, and can ask that your answers or comments not be used in a report and that you will not be penalized in any way for making these requests. I also want to make sure that you know that the meeting will be tape recorded and that your comments will be written down on paper as a way of recording the ideas that you communicate. The tape recorder will be turned on after we introduced ourselves. Finally, I want you to know that there are no known risks to you and that you will receive a $50 Visa gift card for participating in the meeting.

In this meeting, we are going to focus on your experiences and thoughts about the services to children and adults with Autism Spectrum Disorders and what could be improved in these services.

This meeting is one of three meetings in which we will ask these same set of questions. Each meeting will take approximately 1½ hours.
This meeting is being held on behalf of the Center for Disabilities Studies at the University of Delaware. The meeting is facilitated by me, Annalisa Ekbladh, from the Center for Disabilities Studies at the University of Delaware and by Heidi Mizell from Autism Delaware.

Does anyone have any questions before we begin?

**Part II. Introductions**

To help us become acquainted with one another, please let’s introduce ourselves by first names. I will start with myself. My name is Annalisa and I will lead this group meeting tonight. What is your name? (Wait until everyone introduced themselves).

I think the one thing that draws us all together is that we are all interested in making the system better for families and individuals with autism.

**Part III. Guidelines and Norms**

We’re going to get into our main purpose for being here in a little while but first I’d like to discuss some guidelines for the focus group meeting.

First, we need to make sure that this is a safe environment for each of you to share your thoughts and knowledge about the topics we will discuss. So we need to ensure that each person’s opinion is respected. At the same time, we need to feel comfortable offering different points of view. The purpose of this focus group meeting is to ensure that we get all of your thoughts, recommendations and suggestions about the discussed topics, so please, respect others’ perspectives and feel free to offer different opinions about the topics.

Second, please allow others to talk. You may have strong opinions about some of the topics that we bring up. Please share your thoughts, recommendations and suggestions but also know that we need to hear from all those in the group who would like to comment on the topics. There may be times when I will ask you to wrap up your thoughts in order to allow time for everyone to speak.
In order to hear from everyone, I may specifically ask if you have any comments regarding a question. If you would like to comment, please do so. If you don’t want to, please feel comfortable telling me that your opinion has been stated by others or that you don’t want to comment at this point. You never need to talk about a topic or issue if you do not want to.

Again, the purpose of this meeting is to ensure that we get all of your thoughts, recommendations and suggestions about the discussed topics. These focus groups are part of a larger project that will bring together parents and individuals with autism with agencies and service providers across the state to improve the system of services. I would like for you to think of this meeting as a piece of a quilt. The other parts of the quilt are the survey that you all participated in and a series of meetings that will bring together all of the pieces to help create a better system for individuals with autism. So, again, thank you for being willing to participate in this process.

Part IV. Questions

We have a number of questions to ask and would like to start with some more general ones.

Experiences with healthcare, education and employment service systems:

1. Please share with me the process of getting a diagnosis for your child.
   a. When did you first notice that something was different with your child?
   b. What was different about your child?
   c. How did you about getting a diagnosis?
   d. Who gave you the diagnosis?
   e. Who is involved in care and services for your child?

2. Thinking about the healthcare system (doctors, hospitals, pharmacies, therapists, etc.):
   a. What was/is really difficult?
   b. What frustrated/frustrates you?
   c. What worked /works really well?
   d. What did/do you really like?

3. Thinking about the educational system (child care, school):
   a. What was/is really difficult?
   b. What frustrated/frustrates you?
   c. What worked /works really well?
   d. What did/do you really like?
4. Thinking about vocational rehabilitation and employment (employment preparation, employment services, internships, volunteer work, etc.):
   a. What was/is really difficult?
   b. What frustrated/frustrates you?
   c. What worked /works really well?
   d. What did/do you really like?

5. Creating the ideal healthcare, education and employment service systems in Delaware:

   Now thinking about all of these different systems:
   a. How could they work (better) together to provide comprehensive and high quality services?
   b. What would the ideal (dream) comprehensive service system look like for you as a parent of a child who has ASD?
   c. Who should all be involved in this system?
      i. Probe for involvement of parents
      ii. Probe for involvement of children/youth/adults with ASD?
   d. Who would take the lead in this system?

   Final thoughts/comments:

6. We are at the end of our focus group/listening session. What else would you like to share with me that I haven’t ask you?

Part V. Conclusion

Thank you for taking the time to discuss these issues with us. This is an important part of our process and we greatly appreciate you sharing your thoughts with us.

Just as a reminder, none of what you have said will be identified by your name or by other information that could identify you. If you have any second thoughts about what you have said, please feel free to call or email us and we will remove any comments that you have made from the report of this meeting.

Thank you again for your willingness to participate!