

Table 3. Parent stakeholder consultation quotes

Themes	Subthemes	Parent Quotes
1. The necessity of capturing first person perspectives of children and youth	a) Youth with ASD should be heard	<i>“It’s important that we give a voice to the people who need to have a voice, who need to express what it is that they’re living with. It’s one thing for us to perceive it, it’s another thing for them who are living with [ASD].” (Parent 2)</i>
	b) First-person perspectives can inform the experience of future diagnostic journey’s	<i>“To have that information [about child’s perspective], back when we started this journey would have taken so much of the stress away” (Parent 4)</i>
2. Assuming the ability of youth with ASD		<ul style="list-style-type: none"> • <i>“...the message has to get out to all the professionals dealing with these kids. That primary message, that they are capable [of communicating].” (Parent 2)</i> • <i>“...it’s our reflex. We’re over protective already as parents in the vast majority of cases... We are assuming he can’t do it, but he can do it. ‘Til the day he’s 15, I still find that our reflex is to make that mistake.” (Parent 2)</i>
3. Parents’ experiences with communication barriers	a) Oral Communication challenges with youth	<i>“He’s not conversational. So, if I ask him “are you enjoying it?” he’ll say “yes.” But, it’s hard to draw more than that.” (Parent 3)</i>
	b) Cognitive differences as a mutual challenge	<i>“It’s not them communicating with us, it’s more like we have to understand where they’re coming from. Or at least that’s with my son. Because he’s got all that verbal skill, it’s just that he’s coming from a different place and point of view entirely. And I haven’t found a way to get him to switch his point of view. I kinda have to go to his world, rather than him coming into my world.” (Parent 1)</i>

4. Experiences with communication facilitators

Written text: *“We discovered a couple years ago, a teacher discovered it at the school, he’s visual. He was able to have a short communication or conversation via the written word. We started texting each other. So now, we can actually get some things out of him, in terms of what he’s feeling. And that’s wonderful, but on the other hand, it has shown us that clearly there is a lot in there and it just wasn’t coming out, until that particular technique was tried. So just blind luck to be honest, the way it happened.”*
(Parent 2)

Visual art (Drawing): *“Sometimes it’s also with drawings. Like there’s a disconnect, and he’s really motivated. I don’t remember who came up with the drawing, but I might have said, ‘well can you draw what... it looks like?’ And even though he’s not a good drawer, or sometimes I’ll draw as well, that’s also a way to communicate, because he’s very visual. So if you say this is a person, he knows it’s a person. And so for us it’s often drawings, or just digging in with more questions. That type of thing.”* **(Parent 4)**

Dance: *“I was volunteering for a while, and a boy, whenever he’d get all riled up, you’d just dance with him. And as soon as you’d dance with him he’d calm down, but that was that boy...But he was certainly more open to either taking something in or putting something out.”* **(Parent 2)**

AAC: *“I’ve heard of other cases where they have access to a letter board and they can spell, it’s kind of like texting, if they have the alphabet in front of them, they’re able to spell out what they want to say”.* **(Parent 4)**

Creative expression and technology: *“...Even something like those science boards that they do, where they can clip pictures and texts and pull it together either physically or on a computer. I’m thinking for some of our kids that would be awesome, because they can’t draw some of them, some of*

		<p><i>them want some music on there. I've seen my son do amazing things with pictures and music on his iPod.”</i> (Parent 1)</p>
<p>5. Reaching out to experts for input</p>		<p><u>Health Professionals:</u> <i>“My son responds really well to the doctors and the authority people. He loves coming into the hospital, into the offices.”</i> (Parent 1)</p> <p><u>Educators:</u> <i>“He [the youth with autism] would respond really well to one of the teachers, or one of the educators at the school.”</i> (Parent 2)</p> <p><u>Siblings:</u> <i>“There’s kind of like a line of communication that they [the son with autism and his sibling] have that is different. Because with us, it’s basically, what are you going to do with me, what can I get from you. With his sister it’s not, with his sister he’ll try to express something, even if he wants something he knows he’s going to back it up. Why, why do you want it. He has to figure out a way to express that to her. I think siblings can play a big role. A very big role actually.”</i> (Parent 2)</p> <p><u>Other Professionals:</u> <i>“What if you approached people in the arts? In reaching out to people like that. People in journalism, whose art is talking to people, extracting information from them. There are people who do medical journalism, that might act as good facilitators, rather than always looking at the medical and education team. I would even put it out to some dance people because my experience with dance was pretty awesome.”</i> (Parent 1)</p>
<p>6. Tailoring the approach for youth and parent participation</p>	<p>a) Providing appropriate and comprehensible information</p>	<p><i>“I know for my 13-year-old, for him knowing why he’s doing things helps a lot. Like what is the point of these questions. So making sure some of them understand why they are doing this anyway.”</i> (Parent 4)</p>

	b) Finding the “hook”: capture intrinsic interests and motivation	<i>“I think that you have to engage the child. For [the participant’s son] if you wanted to get him engaged, if you were to talk about things that interested him, whether it’s movies that he likes or things like that and then try and draw things out based on that.” (Parent 3)</i>
	c) Give parents options to make decisions	<i>“I think it would be nice, if somebody called they gave you these options [of different methods identified in the scoping review]...Ideally, if it were presented in this way [referring to figure 2], we can do it this way or this way, at your house, here, wherever. That would be great. So that’s what I take from that. It really depends on the person. And the parent would probably be the best to say ok that would work, and this would not work.” (Parent 3)</i>
	d) Emphasize questions not the approach	<i>“In his case, [questions have] to be very fact based. Approaching him with anything emotional, he has no clue what you’re talking about. Very precise and factual.” (Parent 1)</i>
	e) Incentives	<i>“You wouldn’t have an issue getting [the participant’s son] to come here. He likes coming to the hospital, and things like that. As long as he knows he’s going to get something he would participate.” (Parent 4)</i>
	f) Creating a comfortable and safe research space	<i>“[parent and child] are talking about different perspectives, a neurotypical person has a different perspective to life than someone who is on the spectrum... It’s not bad it’s not good. That was a tough sell, because of course he doesn’t want to be on the autistic spectrum” (Parent 1)</i>
	g) Keep it short	<i>“One thing, I think for our kids anyway, you would have to keep it fairly short. An hour or less. You can have a couple of different sessions but keep it short.” (Parent 4)</i>
	h) Select the right setting	<i>“But somebody like [participant’s son], with higher anxiety, he’d be better off at our house for sure. Because you have time to connect more, you can see what he likes. So he’d feel safer inside our house then coming [to the hospital].” (Parent 4)</i>

Table 3. Presents selected parent quotes based on themes and subthemes extracted from the stakeholder consultation.

