

Parent Perspectives on Participating in Intervention Research with Their High-Risk Toddler

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Abstract

Enrolling younger (high-risk; HR) siblings of children with autism spectrum disorder (ASD) in randomized-controlled trials (RCT) is increasingly common; however, little is known about parents' perceptions of these interventions. To date, no studies have examined parents' motivation to enroll in RCTs with their HR toddler or their perspectives about interventions for these children. The current study examines parents' opinions about and motivation to participate in research with their HR toddler. Participants are parents enrolled in an RCT examining the efficacy of a parent-mediated social-communication intervention (Project ImPACT). All parents ($n = 20$) were randomized to either the treatment-as-usual group (i.e., control group) or the Project ImPACT group (i.e., intervention group). Parents responded to interview questions about their motivation to participate in research with their HR toddler, their perceptions of early intervention for children who may not develop ASD, and their opinions about "preventing" ASD. All responses were coded using rapid evaluation and assessment methodology and grounded theory. Results revealed that parents in both groups were motivated by the developmental tracking provided by participating in the study and the possibility of receiving the intervention. Both groups reported mixed feelings regarding the concept of prevention of ASD and described the importance of supporting children with or without a diagnosis of ASD. Results have implications for future HR studies, both for understanding what motivates parents to participate in research and for conceptualizing these projects.

Background

Randomized-controlled trials (RCT) have recently been enrolling younger (high-risk; HR) siblings of children with ASD. HR toddlers are at an increased risk for developing ASD and language and cognitive delays (Grønberg et al., 2013; Messinger et al., 2013; Ozonoff et al., 2011). As such, they may benefit from early intervention to ameliorate or mitigate ASD symptoms as early as possible. Recently, however, the question has been raised about the wisdom of intervening with children who may not go on to develop ASD or other social-communication disorders (Singh, 2017). To date, the question of providing intervention to HR toddlers has been confined to debate amongst researchers, and no published studies have asked parents directly about their opinions of intervention with HR toddlers.

Two recent studies have asked parents about their perceptions of participating in research with their child diagnosed with ASD (Fletcher-Watson et al., 2016; Stahmer et al., 2016). Results from these studies suggest that parents feel positively about community-based early intervention programs. In general, parents also reported a dislike for the use of the term "at-risk" to describe young children who participate in what may be considered "preventative" research (Fletcher-Watson et al., 2016). These studies provide information regarding the general perceptions of parents of children with ASD; however, more information is needed regarding parents' perceptions of participating in a research study with their HR toddler before a diagnostic determination of ASD has been made.

Objectives

To understand parents'

- 1) Motivation to participate in intervention research with their HR toddler
- 2) Opinions about the conceptualization of "preventative intervention" for HR toddlers.

Method

Sample

- Twenty parents of HR toddlers were included in the current study (50% control group). All had provided informed consent. (See **Table 1** for demographics)
- Participants were drawn from two sites (Vanderbilt University and University of Washington) from a study examining the efficacy of a parent-mediated program (Project ImPACT; Ingersoll & Dvortcsak, 2010). Project ImPACT is a naturalistic developmental behavioral intervention (Schreibman et al., 2015)
- Participants who were randomized to the Project ImPACT condition completed 12 weeks of parent-coaching sessions. All sessions took place twice per week in the family's home.
- Participants who were randomized to the control condition did not receive any intervention services as a part of the current study but were free to pursue intervention elsewhere.
- Participants in both the intervention and control condition received lab-based developmental assessments three times over the course of six months prior to the interview.

- After each assessment visit, families were provided with evaluations, feedback, and referrals when needed.

Procedure

- Parents were interviewed over the phone approximately 6 months after they enrolled in the study (i.e., about 3 months following intervention for those receiving intervention). Interviews were conducted by persons not associated with the study procedures.
- Parents were asked what motivated them to enroll in the study, whether they believed in the importance of early intervention, and what they thought about the idea of preventing ASD.
- Calls were audio-recorded and then transcribed by undergraduate research assistants. All transcripts were checked for accuracy by the primary authors
- All transcripts were uploaded to Dedoose® and coded by the primary authors
- Interviews ranged from 15 to 64 minutes.

Analyses

- Immediately after interviews were conducted, the primary authors discussed themes that emerged and added questions to subsequent interviews as necessary. Rapid evaluation and assessment methodology (REAM; McNall & Foster-Fishman, 2007) was conducted until no new themes were identified.
- The themes identified during this process were used during the first phase of grounded theory (Corbin & Strauss, 1990) analysis: open coding. During open coding, codes identified during REAM were consolidated and new codes were identified.
- Reliability between the two primary authors was established on 30% of transcripts (i.e., 6 transcripts) and yielded good internal reliability (i.e., > 80% agreement).
- Consensus coding was used on subsequent transcripts to ensure 100% reliability.
- During the second phase of grounded theory, codes were grouped together into categories and subcategories (see **Table 2**).
- During the final phase of analysis, selective coding was used to integrate the relation between codes.

	Intervention (n = 10)	Control (n = 10)
Primary caregiver sex (% female)	100	80
Caregiver education level (% college or graduate level degree)	80	60
HR toddler sex (% Female)	20	40
HR toddler age at study entry (months) M (SD)	13.9 (2.4)	15.3 (1.6)
HR toddler race		
% Asian	10	0
%White	70	70
%Black or African American	0	10
%Mixed	10	20

Results

Results revealed that parents who were randomized to both the intervention and control group participate in research with their HR toddler for multiple reasons, including a desire to have professionals track their child's development, receive intervention strategies, and contribute to research (see **Table 2** for all categories and subcategories identified).

Parents in both groups reported conflicting feelings regarding the idea of preventing autism. Many parents instead described a desire to support their young child. The vast majority of parents reported feeling positively about early intervention. **Table 3** provides representative parent quotes for each subcategory.

Categories and subcategories	Intervention (n = 10)	Control (n = 10)
Motivation to participate in study		
Tracking child's development	60	80
Possibility of receiving intervention	50	30
Helping the research community	30	70
Early intervention		
Described feeling positively about early intervention	70	90
Prevention		
Yes, would prevent ASD if it was possible	30	10
No, would not prevent ASD if it was possible	0	30
Feel torn between preventing ASD and supporting their child	50	70

Table 3
Representative Parent Quotes for Each Theme

Motivation to participate in study	
Tracking child's development	"I loved the fact that not only was she going to be used to help maybe assess some of this to see how siblings are affected but then she would actually get an assessment at the end... I'm not really concerned...but it is so nice to have... her watched right during this time and to have the assessment at the end." Control Parent "And the other [motivation] was just kind of knowing your trajectory and having those evaluations along the way." Intervention Parent
Possibility of receiving intervention	"I was like 'well if he does get into the like... experimental group oh that would be cool because... any intervention is probably better than no intervention so I was like well that'll be more work or whatever but like it might be beneficial.'" Control Parent "Just for myself to learn more how to, like, foster those early language communications skills...learning how to do that through play and things like that, that was another motivation I think I had at the beginning. Just knowing what to be looking for and how I could help at home, to help her start acquiring language and communicate - communication skills." Intervention Parent
Helping the research community	"We felt like we needed to... do this for the greater good and we deserve and my son deserved it, [HR TODDLER] did, you know he deserved to be treated to have this...resource available in his life as young ...as he can have it." Control Parent "The way that I looked at this study was is anything that I can do to help in the future...to get an earlier diagnosis for families so they can get earlier intervention...I'm willing to do a lot of things involved in research and whatnot." Intervention Parent
Early intervention	
Described feeling positively about early intervention	"Parents that have been through this know that the earlier, the better...It's people who haven't walked a mile in these shoes that, [say] 'Well, why would that matter?'" Control Parent "The earlier you can start it the better because that's more time to learn and figure out ways to deal with it" Intervention Parent
Prevention	
Yes would prevent ASD if it was possible	"But in terms of prevention, yes it should, because it's hard enough for these kids in terms of socializing and other kids picking on them... Yeah, I think it should be prevented." Control Parent "As long as we're not talking about eugenics I definitely think we should be looking for a cure or a way to diminish the disability, which is what early intervention is for children" Intervention Parent
No would not prevent ASD if it was possible	"It's simple. I would not have my kid in any other way than they currently are now." Control Parent "Whatever autism means, if it has something to prevent it or not, I believe that everything in this life is under authority of our Lord, so if my kids are autistic, no one can- or He allowed this, no one can break it." Control Parent
Feel torn between preventing ASD and supporting their child	"Honestly, maybe the word 'prevention' is wrong? ... Maybe people wouldn't get all fired up about it if you didn't use that word, if that word wasn't running around and people either talked about diagnosis and then just help... and then we don't have to call it intervention. but just help for whatever the kid needs." Control Parent "For him, I wouldn't want to take it away - I would take away his anxiety if I could, but...a lot of the other things that make him really unique because of autism - like, I wouldn't want to take those things away... I just want to help, you know, him with those - some of the weaker areas, but... there's a lot of really awesome qualities he has because of autism." Intervention Parent

Conclusions

This study revealed novel information related to parents' decisions to enroll in research with their HR toddler and their perceptions about preventing ASD. Of particular note is that parents from both groups were motivated to participate in research by the developmental tracking offered as a component of the study. These results emphasize that though parents are enrolling in an RCT which includes an intervention condition, many parents may be motivated and satisfied by assessments offered. Overall, results suggest that intervention providers should not necessarily use words such as "prevention research", and instead may present their projects in a more family-friendly manner by describing it as a supportive intervention. Researchers should also be cognizant of the fact that many parents are motivated by the assessment process itself, above and beyond the possibility of being randomized to the intervention condition.