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## Identifying Key Language Research Priorities in Autistic Children According to Parents

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# **IDENTIFYING LANGUAGE RESEARCH PRIORITIES IN AUTISTIC CHILDREN ACCORDING TO PARENTS**

A Thesis

Submitted to the Graduate Faculty of the  
Louisiana State University and  
Agricultural and Mechanical College  
in partial fulfillment of the  
requirements for the degree of  
Master of Arts

in

The Department of Communication Sciences and Disorders

by  
Taylor Grace Hale  
B.A., Louisiana State University, 2021  
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## **Abbreviations**

<b>ADI-R</b>	Autism Diagnostic Interview-Revised
<b>ARC</b>	Autistic Researchers Committee
<b>ASD</b>	Autism Spectrum Disorder
<b>AAC</b>	Augmentative and Alternative Communication
<b>CARS</b>	Childhood Autism Rating Scale
<b>ICCR</b>	Community Collaborator Request
<b>INSAR</b>	The International Society for Autism Research
<b>M-CHAT</b>	Modified Checklist for Autism in Toddlers
<b>MSEL</b>	Mullen Scales of Early Learning
<b>RQ</b>	Research Questions
<b>SPSS</b>	Statistical Software Package
<b>VABS</b>	Vineland Adaptive Behavior Scales

## **Abstract**

The lack of involvement of the autistic community and its stakeholders in autism research has led to a call to action. At present, autism researchers have limited knowledge about stakeholders' priorities for research. The current study aimed to bridge the disconnect between the extant autism research and the recent neurodiversity movement by surveying key stakeholders – parents of autistic children – on their perspectives on autism research that focuses on language. Twenty-six parents of autistic children completed an online survey on their views on autism language research with an option to participate in a follow-up interview. Six parents participated in the interview. Within the survey, 15 language research topics were presented and parents used a slider to rank the importance of each item. Next, each parent selected their top three research priorities. The results indicated that parents highly valued research focusing on how autistic children learn new words, follow directions, learning to read, respond to questions (language comprehension), and on echolalia. Survey responses were then placed in subgroups according to child language ability, age, parent education, and gender. Language sub-grouping revealed that parents who had children with different language abilities ranked language research topics differently. In the parent interviews, all participants explained that their research priorities were individualized to what they thought was important to their autistic child or children. The top barriers parents reported for participating in autism research was time, not being aware of studies, money, and if the research being conductive was invasive. The top incentives for participating in autism research included: whether the study was relevant to their child's specific needs and whether the study was online or at a specific location. A significant portion of the existing autism literature covers these topics, but future work could further examine each of the highly-ranked topics.



## **Chapter 1. Introduction**

Autism spectrum disorder (ASD) is defined as having core features including persistent difficulties in social communication/social interaction and restricted and repetitive patterns of behaviors, activities, or interests. These are present in early childhood, and impact and/or impair an individual's everyday functioning (American Psychiatric Association, 2013). In the medical world, scientists typically align with a medical model viewing all disabilities as a result of a “physiological impairment due to damage or to a disease process” (Llewellyn & Hogan, 2000, p. 158). Within this, disabilities are seen as ‘conditions’, which need appropriate ‘treatment’. In autism research, researchers have a tendency to examine autism through this medical model (Pellicano & Houting, 2021). They see autism as a disorder of brain development and consequently as an undesirable deviation from the norm. This belief system suggests that ASD is a disability primarily rooted within individuals as a consequence of their genetic make-up and psychological being (Pellicano & Houting, 2021). This is where the widespread understanding and knowledge of autism lies in today’s research, but this view of autism fails to acknowledge autistic individuals themselves.

In contrast to the medical model of autism, neurodiversity is a notion that suggests cognitive and emotional characteristics of developmental disorders such as autism spectrum disorder are not purely deficits, but rather fall within a normal variation of the human genotype and phenotype (Masataka, 2017). The human mind can develop in many different ways both structurally and functionally. What we consider “normal development” and “abnormal development” can fall on a spectrum. Neurodiversity aims to include this entire spectrum and rejects the stance that a variation of the “norm” is a flaw or deficit that requires altering (Pellicano & Houting, 2021). Chapman (2020) describes neurodiversity as being both a concept

and movement. It is used to re-examine the previous “pathologized” and “dehumanized” views of disorders such as autism and convert them into something more humane and compassionate. By seeing neurodiversity as a movement, this can alter real relations between people who are neurologically different; it can range from how we empathize with people who are neurologically divergent to how scientists design scientific experiments (Chapman, 2020).

In addition to this, autistic self-advocacy movements have arisen through this neurodiversity shift and autistic individuals are demanding more say in what goes into research. This sprouted the “Nothing about us without us” movement (Charlton, 2000). This neurodiversity movement was created with the realization that there is a lack of “hard facts” or universal truths about autism (Verhoeff, 2015). This self-advocacy movement has shed light on holes in the initial medical model’s view of autism and opens the opportunity to examine autism and conceptualize autism in a different perspective. It gives the autistic community and people with disabilities the opportunity to advocate for what they think is best for them and to have a say in what is happening in their life. Stemming from this, the goal is to view autism in the lens of being a form of variation within a diversity of minds rather than a disability itself (Pellicano & Houting, 2021). It redefines the diagnoses of autism as a neutral difference rather than a negative deficit. With this new conceptualization of autism, researchers can more effectively examine an autistic person as a whole individual instead of one small part. The purpose of this research study is to contribute to this neurodiversity movement. This study aims to survey key stakeholders, specifically parents of autistic children, on their opinions of what should be prioritized in language research focusing on autistic children.

### **Stakeholder research priorities**

The majority of the extant literature has occurred with very little to no involvement of the autistic community (other than autistic individuals serving as the study participants). This has resulted in the absence of autistic individuals having a say in what gets researched, why research is being conducted, or how to conduct research (Pellicano & Houting, 2021). In recent years, there has been a shift towards neurodiversity in autism science and an increase in incorporating autistic perspectives about the scientific process.

With a call to action in this autism neurodiversity movement, it is necessary to include autistic individuals and autism stakeholders in the research process. When researchers give opportunities to receive stakeholder input, it helps researchers prioritize the wants and needs of the population they are serving. This includes the autistic individuals' and autism stakeholders' opinions on topics such as research priorities, input from their personal understanding/experiences, participation on research panels, and ensuring that nothing is being researched without the autistic population. However, it can be difficult for an autistic child to serve as an advocate in autism research. Many younger autistic children or students can have highly restricted communication or social skills that can widely inhibit their ability for self-advocacy (Shore, 2020.). Because of this, it is crucial to include individuals that are able to advocate for children in research priorities. As such, adult advocacy, such as parents of children with autism, is crucial to studies such as this one.

The use of key stakeholders such as parents can give an opportunity for populations that are unable to advocate for themselves to have a level of representation and input on autism research. Autistic children, especially those who are non-speaking, do not possess the ability to optimally advocate for themselves nor are they given the opportunity. Furthermore, the differences between speaking and non-speaking autistic experiences can be contrasting.

Oftentimes in autism research, researchers may ask highly verbal autistic individuals their opinions; however, they fail to include autistic perspectives from autistic individuals who have language impairments or who communicate by using Augmentative and Alternative Communication (AAC). Consequently, research aims and research data from studies can get disproportionately skewed in the autistic perspective. Since these minimally verbal individuals cannot advocate for themselves, researchers should find alternate ways to include their experiences. This is why surveying individuals who are closely involved with them, such as their parents, other family members, or clinicians who work with autistic children, can be helpful.

There have been a limited number of research studies that have polled autistic individuals and autism stakeholders for research priorities. There has been even less polling of stakeholders for autistic children. Like mentioned above, different people in the autistic community will have different needs and research priorities. This is why it is critical to survey a diverse population within the autistic community and to consider their feedback across multiple domains of research.

### **Surveys of research priorities and input**

Roche et al. (2021) completed a systematic review to identify and compare multiple studies that surveyed autistic stakeholders. Their aim was to identify the studies that (a) focused on research priorities of key stakeholders who have a relation to someone with autism; (b) examined autism-focused topics; (c) were published in English peer-reviewed journals; and (d) published after 1994. From their database search, Roche et al. identified 7 studies to compare that fit their criteria. Some of these surveys are outlined in greater detail below, but some were not included in greater detail due to these being too dissimilar to the current topic. A summary of overarching research priority areas found in the study are outlined below in Table 1 from Roche et al.'s study.

Overall, research priorities from all stakeholders focused largely on applied research aimed to improve daily lives of autistic individuals as opposed to basic research science (e.g., the biological causes of autism). Each study has a diverse use of methodologies ranging from focus groups, online surveys, interviews, and scoping reviews. There was also a diverse stakeholder perspective ranging from parents, family members, clinicians, researchers, practitioners, educators, and others.

Table 1.1. Adapted from table 2 in Roche et al. (2021)

<b>Study</b>	<b>Fletcher-Watson et al. (2017)</b>	<b>Frazier et al. (2018)</b>	<b>Gotham et al. (2015) initial survey</b>	<b>Gotham et al. (2017) follow-up survey</b>	<b>Nicholas et al. (2017)</b>	<b>Pellicano et al. (2014b) focus groups</b>	<b>Pellicano et al. (2014b) survey</b>	<b>Shattuck et al. (2018)</b>	<b>Vasa et al. (2018)</b>
	1	2	3	4	5	6	7	8	9
Skill development and training for children through adults, including employment	X			X	X	X	X		
Physical and Mental health and wellbeing		X	X	X	X				X
Knowledge, availability, and accessibility of services across life		X				X	X	X	X
Accuracy of identifying, screening, and understanding of autism.	X		X			X			
Development, cognitive function, thinking, and learning for autistic individuals				X			X		
Transitions and the support for transitions throughout life		X						X	

*Note.* 1. Fletcher-Watson et al. (2017), 2. Frazier et al. (2018), 3. Gotham et al. (2015), 4. Gotham et al. (2017), 5. Nicholas et al. (2017), 6. Pellicano et al. (2014b), 7. Pellicano et al. (2014b), 8. Shattuck et al. (2018), 9. Vasa et al. (2018)

In an informal poll by Cohen (2016), members of The Satellite Community Advisory Council, which is associated with the Interactive Autism Network, were asked their opinions on autism research priorities. This council consisted of volunteers who were primarily parents of children on the autism spectrum, followed by parents or guardians of autistic adults, autistic adults, and professionals involved in the autism field. Fifty-two members responded to this study and were asked to rank 10 topics in autism research from 1 to 10, with 1 being least important and 10 as most important. The results revealed that the most important research priority was employment/work for autistic individuals (average score of 9.02), followed by Social Skills/Interaction (8.73), Education (8.62), Sensory Issues (8.52), Mental Health Conditions (8.48), Transitioning to Independent Living (8.42), Community Services (8.19), Healthcare Access (8.08), Self-Advocacy (7.75), and General Adult Issues (7.67). In this informal poll, it was noted that people rated their research priorities differently depending on their personal connection to the autistic community (i.e., autistic adults had different priorities than parents of autistic children). For example, autistic adults listed work as the highest research priority followed by sensory issues and mental health conditions, while parents of autistic children listed work as the highest research priority, followed by social skills and education. Although this is an informal poll and these answers cannot be generalized to other groups, this poll gave a preliminary view into what stakeholders may generally view as the highest priorities to research.

Frazier et al. (2018) conducted a survey involving autism research priorities across a diverse community of stakeholders. These stakeholders were asked to label themselves either as a person with autism, family member of a person with autism, Researcher, or Clinician/educator. Of the 6,004 respondents, most respondents were female (79.1%) and individuals whose relationship was a family member of a person with autism (73.3%). Fraizer et al.'s online survey

contained seven objective questions to examine a range of research priorities. These questions began as surveyed preferences between basic and applied research and progressed into more specific questions such as genetics, interventions, or funding approaches. Each question was on a Likert scale with three varying formats: 1 (not at all important) to 5 (very important), 1 (no impact) to 5 (very strong impact), 1 (strongly disagree) to 5 (strongly agree). Results showed that overall, respondents more strongly favored applied science over basic research; however, basic science was still in the agreeable/ favorable range. Within the specific research area questions, four were found to be rated as very important: Understanding co-occurring conditions, Adult transition, Lifespan issues, and Health and well-being. The remaining research questions were rated as neutral to important, with the exception of animal models which were rated significantly below neutral. In these research questions, it was also noted that, on average, autistic individuals rated each research question lower than the other stakeholders. In the qualitative research section, individual ratings ranged from very low to very high across all questions. Interestingly, there was a pattern among a small subset of participants that responded differently than the majority of responders. These responders were mostly autistic individuals, and they expressed disapproval of all autism-related research or approval to research focused on co-occurring conditions (e.g., adult transition, lifespan issues, health, and wellbeing) that appeared on the survey. Overall results from this survey indicated large variability in individual perspectives in all aspects of autism research. However, there were clear patterns across participants with different relationships to autistic individuals that proved to be fairly consistent. These patterns all highlight the need and importance of including autistic individuals and their families in autistic research and funding processes.



One study has specifically examined research priorities that focus on young autistic children. Fletcher-Watson et al. (2017) aimed to examine the attitudes of autistic stakeholders and autism stakeholders on early autism research. This study's purpose was to provide a foundation based on evidence for researchers to reference when engaging with this sub-population. The online survey was given to autistic adults, parents of autistic children, and health and education practitioners to examine their views. Prior to the main study, five research groups were conducted to ensure that topic areas for the study were meaningful and relevant. After collecting the data from the focus groups, the researchers met to examine common themes. The top three themes mentioned across all focus groups were: at-risk language, intervention, and transparency between researchers and participants. The term 'at risk' is used to describe the infant groups with traits who would typically be seen as having a higher-than-usual probability of receiving an autism diagnosis (e.g., an infant that has an autistic sibling, or being born preterm). Then, Fletcher-Watson et al. created their research survey; the survey had four main sections: basic personal information, stakeholder category (autistic adult, parent, healthcare practitioner, education practitioner, other), further specific background information depending on stakeholder category, and questions pertaining to their attitudes towards autism research that focuses on early childhood. The early autism research questions on the survey focused on the following: (1) reasons for doing research, (2) involvement in research projects, (3) measurement in research projects, (4) intervention and (5) 'at- risk' language. A total of 2,681 participants completed the online survey, and 2,317 of these responses were deemed adequate for analysis. Fletcher-Watson et al. (2017) reported that each stakeholder group collectively showed an overwhelmingly favorable attitude towards the question "Do you think research into the early signs of autism should be done?" Additionally, the highest ranked categories that all stakeholders

listed as the most important questions scientists should be asking about early autism was (1) genetic basis of autism, and (2) early signs of autism in infants. Stakeholders also ranked the highest goals for early autism research as (1) early identification, (2) better clinical knowledge of early signs, (3) provision of help to develop skills. The overall results from the survey clearly indicate there is a collective support for early autism research.

Recently, Clark and Adams (2020) conducted a study that aimed to survey research priorities of parents of autistic school-aged children. One hundred and thirty-four parents participated in this study. These parents were asked to consider their priorities for their children in three different settings: the child's home, school, and community. Additionally, informal examinations of the collected data were conducted to explore why some priorities were more important to others, and the factors parents identify as the most important research priorities for decision making. Clark and Adams' online questionnaire employed Q-sort technology. Q-sort methodology is a data collection technique that aims to combine qualitative and quantitative methods. In this study, only a "forced sort" Q-sort task was used. The top 15 categories of priorities in home and school and all 13 research priorities were placed onto cards and parents had to sort them from most important (+4) to least important (-4) using a Q-sort grid. This grid had specific slots on each rank from -4 to +4 (e.g., 2 slots for least important, 7 slots for neutral, 2 slots for most important), so parents were forced to sort priorities based on importance. In other words, not all priorities could be ranked as the most important or least important. Results of the online questionnaire showed that the three most important research priorities in the home were: (1) Health and well-being; (2) Parent, sibling, child, and family support, and (3) Self-care, daily living skills and independence. The Q-sort revealed that the category with the highest q-score across all parents was parent, sibling, child, and family impact and stress. The online

questionnaire results for research priorities in school revealed that socialization and social support was ranked the highest by parents, and the highest q-sort ranking was teacher/staff education and support. The highest-ranking priorities for the online survey for the community were increased community awareness of autism, understanding, and acceptance of autism, and the highest q-sort score was recognizing and supporting anxiety (Clark & Adams, 2020). More often than not, parents discussed that the research priorities that were not ranked as high were not less important, but rather these topics have already been researched. Another factor parents discussed was ranking the priorities based on their family's needs at the time of the survey. This is critical to note especially when research is focused on children. Children grow and develop at such a rapid rate, priorities for them may change throughout their lifespan; therefore, researchers who study skills at different points in development, may want to carefully consider or seek out information about desired research priorities for that particular developmental stage.

Table 2 below outlines some questions that the previously discussed surveys have asked to their stakeholder participants. These questions are not all inclusive in the surveys but serve as a general depiction of the themes the surveys wished to examine. Some questions have been modified for clarity.

Table 1.2. Survey example questions from previous studies.

Study	Example Questions Asked in Each Study
Cohen (2016)	<ul style="list-style-type: none"> <li>- “Rate the following topics in autism research that are important to you on a scale of 1 to 10, with 1 being less important and 10 being most important.” (para. 3)</li> </ul>
Frazier et al. (2018)	<ul style="list-style-type: none"> <li>- “What should be the core mission of Autism Speaks Science?</li> <li>- Should funding of basic science be part of the core mission of Autism Speaks?</li> <li>- Should funding of applied science be part of the core mission of Autism Speaks?</li> <li>- Please rate the level of importance of the following research topics to Autism Speaks Science?</li> <li>- What products or improvements would positively impact the lives of individuals and families affected by autism?</li> <li>- How important is it for Autism Speaks to be involved in funding studies that move research findings into clinical practice or communities?</li> <li>- To what degree do you feel it is important to fund the development of young scientists?” (p.3966)</li> </ul>
Fletcher-Watson et al. (2017)	<ul style="list-style-type: none"> <li>- What are the most important questions scientists should be asking about early autism?</li> <li>- What do you think about this kind of research?</li> <li>- One of the foundations of this research is to strive for earlier diagnosis of autism – do you think this is a good goal for research?</li> <li>- What is your opinion on the use of ‘at-risk’ language</li> <li>- What are your attitudes to early autism research in five domains inspired by the focus group data: (1) reasons for doing research, (2) involvement in research projects, (3) measurement in research projects, (4) intervention and (5) ‘at-risk’ language. (p.63-64)</li> </ul>
Clark & Adams (2020)	<ul style="list-style-type: none"> <li>- Child’s age, gender</li> <li>- Number of children diagnosed with autism in family</li> <li>- Parent’s age, gender, highest level of education</li> <li>- “In your opinion, what three areas should research focus on to support your child on the autism spectrum in each of the following settings: home, school, community.” (p.4)</li> </ul>

Given that applied research tends to be highly valued by autism stakeholders, Pituch et al. (2011) designed an internet survey for parents of autistic children to examine treatment priorities in relation to their child's level of ability across different adaptive skills and problem behaviors. Ninety parents participated in this survey. The survey included three sections. Part A included information about the parent's child: (a) gender, (b) age, (c) living conditions, (d) school attended, (e) primary diagnosis, (f) intellectual ability in terms of IQ score, (g) level of speech/communication development, and (h) any additional impairments. Part B focused on the parent themselves: (a) relation to child, (b) age, (c) knowledge of child's disability, (d) knowledge of child's education program, (e) country they are living in, (f) ethnic/cultural background, and (g) level of education. Part C of the survey listed 44 adaptive skills (e.g., toileting, expressing wants and needs, preparing simple meals, etc.) and 10 problem behaviors (e.g., tantrums, self-injury, hyperactivity, etc.) that parents were instructed to rate their child's current ability in. Ratings were made on a 5-point scale ranging from 0 (independent) to 4 (completely dependent). Data collected from these parents were analyzed into a statistical software package (SPSS), and descriptive statistics were utilized to provide an overview of demographic characteristics of the parents and their children. Results determined the top 5 priorities of parents for their children are: making friends, personal safety, pedestrian safety skills, and interacting appropriately with unfamiliar people/strangers. Overall findings show that the top priorities parents rated as most important for their children are skills from the communication and social domains.

### **Language in autistic children**

Within research, it is crucial to research topics that are beneficial to the population being surveyed. One topic that is critical for autistic children is language development. Therefore, it is

not surprising that the findings presented by Fletcher-Watson et al. (2017) and Pituch et al. (2011) identified early language as an important research priority for autism research. Many studies have shown that one of the strongest predictors of positive life outcomes for autistic children is the acquisition of spoken language (Mayo et al., 2012; Toth et.al, 2006). Knowing the importance of early language for an individual's later prognosis, a better understanding of the underlying mechanisms that drive language learning and the child skills that predict language acquisition could shed light on the nature of autism itself and allow for more specific and effective early intervention plans (Toth et al., 2006).

Ellis Weismer and Kover (2015) aimed to examine predictors of early language comprehension and production in young children with ASD, as well as their language growth trajectories across the preschool years. They also aimed to identify factors that discriminate between high and low language outcomes at school entry and to assess individual variation in preverbal language when autistic toddlers were 2.5 years old. The participants in this study consisted of 129 autistic children. At each visit of the longitudinal study, the children were assessed for autism features, language, cognitive skills, and social skills at the following developmental time points: 30.8 months (Visit 1), 44.2 months (Visit 2), 56.9 months (Visit 3), and 66.6 months (Visit 4). Results showed that the children who were included in the full sample exhibited variability in all domains that were tested. Also, the child data revealed clustering, indicating that subgroups of children had differing language skills. Ellis Weismer and Kover reported that cognition, socialization, response to joint attention, maternal education, and autism severity, measured at Visit 1 (30.8 months), were each significant factors that predicted the slope or intercept of a child's language comprehension and/or production at 5.5 years of age. These findings highlight the importance of early language skills in young autistic children; children

with better language comprehension and production abilities at age 2.5 years will be more likely to exhibit higher language growth throughout preschool age compared to children whose early language skills are more limited. This study therefore emphasizes the importance of research studies focusing on language abilities in autistic children.

Further highlighting the importance and value of studying language skills in autistic children Mayo et al. (2012) examined the relationship between age of language acquisition and later functioning in autistic children. In this study, 119 autistic children between the age range of 45 and 72 months were recruited from a previous study who were screened using the Modified Checklist for Autism in Toddlers (M-CHAT). Mayo et al. examined the data from the children who received a diagnosis of ASD at a follow-up study evaluation during the main study. Children were assessed for: the age at which the children produced their first words using caregiver interviews, cognitive development using the Mullen Scales of Early Learning (MSEL; Mullen 1997), adaptive functioning using the Vineland Adaptive Behavior Scales (VABS; Sparrow et al. 1984), and autistic features using the Autism Diagnostic Observation Schedule, the Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994), and the Childhood Autism Rating Scale (CARS; Schopler et al. 1980, 1988). The researchers examined the relationship between the age of first words and later cognitive ability, adaptive behavior, and autism severity. Mayo et al. also compared the children's age of first words to outcome measures of cognition, language, and autism symptoms. The results indicated that children who produced their first words have a better predicted outcome at every age relative to autistic children who were non-speaking. Moreover, an autistic child's ability to verbally produce words by 24 months was a stronger predictor for better outcomes than autistic children who were reported to produce their first words after the age of 24 months. Mayo et al. revealed that, the relationship between early

language skills and later functioning in autistic children indicated that the earlier a child acquires their first word, the higher cognitive ability and adaptive skills they would display when measured in later childhood. The results also indicated that a child who obtains first words by 24 months is a prominent marker of the child's prognosis; children who were able to achieve the milestone of talking by 24 months tended to have a higher cognitive ability and language skills when measured later in childhood compared to children who spoke their first words at a later time, while outcomes did not differ among children showing first words at 12, 18, and 24 months.

Despite many studies that have been conducted such as the ones described above, researchers still have a poor understanding of the mechanisms that drive language learning in autistic children (Arunachalam & Luyster, 2016). If language is a critical subject for autism research, it is crucial to continue this research. In the scope of autism research, it should be a priority to research and understand key mechanisms that contribute to language development. As such, we should seek out additional input from stakeholders from the autistic community on language research priorities. The current study proposes to do just that.

### **Current researcher resources for stakeholder input**

The International Society for Autism Research (INSAR) Autistic Researchers Committee (ARC) is an initiative to connect autism researchers with stakeholders (e.g., autistic people and their family members/caregivers). This initiative was created to assist researchers in designing, conducting, and sharing research studies relevant to the autistic community and autism stakeholders. The INSAR Community Collaborator Request (ICCR) is a resource in this initiative designed to help researchers post classified advertisements to reach out to these autistic stakeholders and autistic individuals to collaborate and consult with as researchers identify



research projects, design research studies, and interpret research findings. Autistic individuals and stakeholders then have the opportunities to provide valuable information, as well as benefit from the research being conducted. INSAR's main goal is to provide an easier route for researchers and stakeholders to create connections to further autism research. This researcher resource was only created in the Spring of 2022.

### **Current study**

Because only two previous studies have examined stakeholder opinions about research topics that have included content about child language research, currently there is a lack of knowledge about stakeholder priorities for autism research. Furthermore, the previous child-focused studies surveyed caregivers' opinions on several child skills that primarily focused on daily living skills but also included questions focusing on language development. Therefore, there still remains a gap in knowledge about caregiver opinions about child language research priorities for autistic children. This gap is important to address in order to develop more highly-valued language studies and eventually, to develop more effective language interventions for autistic children who have limited communication skills. Furthermore, future intervention approaches would be strengthened if they were built from research that incorporates input from the autistic community or stakeholders because the intervention may be more motivating to autistic children or better fit the lives of parents of autistic children.

This study's focus was aimed at bridging this disconnect between current autism research priorities and the recent neurodiversity movement. Specifically, this study aimed to address the following research questions:

1. What developmental language domain(s) is the most important to parents (key stakeholders) for pediatric autistic research?

2. Within different subgroups, are there differences in priorities for language research between each demographic group?

3. What do parents of autistic children believe to be important for autism research?

The proposed thesis study has been approved by the IRB (IRBAM-22-0922).

## **Chapter 2. Methods**

### **Participants**

To be a participant in the current study, participants must have been a parent or legal guardian who was at least 18 years of age and who had at least one autistic child. Parents were recruited through clinic ads, advertisements on social media, and personal connections. The survey had a QR code and link on the advertisement for parents to use to bring them to the survey. Complete survey responses from parents who met all eligibility criteria were collected from 31 individuals. One additional participant completed the first two sections of the survey, so usable data was able to be extracted from this response for the objective section of analysis. Six parents who responded to this survey had autistic children over the age of 18, so their data were not included in the final analysis for results. The total number of participants with children under the age of 18 used in the final analysis were 26 individuals ( $N = 26$ ). Demographic information about these participants can be seen in the Table 2.1.

Table 2.1. Participant demographic information

	<b>Participant Characteristics (<i>N</i> = 26)</b>				
<b>Child's Age</b>	<i>M</i> = 6.50	<i>SD</i> = 3.39	Range: 2 – 16 yrs.		
<b>Child's Gender</b>	Male ( <i>n</i> = 18)	Female ( <i>n</i> = 8)			
<b>Relationship</b>	Mother ( <i>n</i> = 24)	Father ( <i>n</i> = 1)	Grandparent ( <i>n</i> = 1)		
<b>Adult Ethnicity</b>	Non-Hispanic ( <i>n</i> = 25)	Hispanic ( <i>n</i> = 1)			
<b>Adult Race</b>	White ( <i>n</i> = 19)	Black or African American ( <i>n</i> = 3)	American Indian or Alaska Native ( <i>n</i> = 2)	Asian ( <i>n</i> = 1)	Multiple Races ( <i>n</i> = 1)
<b>Highest Level of Education</b>	Graduate/ Professional degree ( <i>n</i> = 13)	Bachelor's degree ( <i>n</i> = 10)	Associate's degree ( <i>n</i> = 1)	Some College ( <i>n</i> = 1)	High School Degree/GED ( <i>n</i> = 1)
<b>Region</b>	Southeast ( <i>n</i> = 14)	Southwest ( <i>n</i> = 4)	West ( <i>n</i> = 3)	Northeast ( <i>n</i> = 3)	Midwest ( <i>n</i> = 2)

*Note.* One of the 26 participants did not complete the third section of the survey; therefore, only 25 participants were analyzed for child language abilities and subjective data about autism research.

## Survey

The online survey was administered through Qualtrics. The first section of survey questions included demographic information such as (1) number of children a parent has with an autism diagnosis, (2) child's age, (3) child's gender, (4) any co-occurring conditions, (4) parent's relation to the child. In the second section, parents were then presented with a ranking task of different language development milestones (e.g., age of child saying first word, responding to yes/no questions, following directions, interacting with other children, length of sentences, etc.). For each language development milestone, parents were asked to rank each on a scale from 0

(not at all important) to 100 (very important). After each milestone was ranked, parents listed their top three most important research priorities as first, second, and third in a separate question box. In the final section, parents were asked to expand on their child's language abilities. These questions consisted of (1) their child's language abilities, (2) child's strongest language ability, (3) child's greatest language difficulty, (4) barriers to participation in research, (5) type of research parents would be willing to participate in, (6) things that would encourage participation in research, and (7) if the parent would be willing to participate in research that does not include treatment or intervention for their child. At the end of the survey, parents had an option to indicate whether they would like to participate in a follow-up zoom video or phone call to further discuss their survey responses.

The current survey was developed following careful examination of the available surveys from the articles that were previously reviewed in this document. Additionally, the child language topics that were included on the survey were selected based on my clinical experiences and research knowledge, with input from my mentor. Once the survey was drafted, I gathered feedback from the Language NeT Lab members, from an autistic speech-language pathologist who is currently working in a pediatric clinic that serves autistic and non-autistic children, and a speech-language pathologist who is also a mother of an autistic child with limited language abilities. Appendix A contains the full survey.

## **Interview**

If a participant noted interest in participating in the Zoom call, a research assistant emailed the individual (using the email address that the participant provided on the survey) to schedule a time to meet. The research assistant also sent a reminder email at least 48 hours in advance of the interview and included the Zoom link and phone number. Six participants who completed the

survey were willing to participate in a zoom interview and scheduled a time to conduct the interview ( $N = 6$ ). These participants were all mothers. The interview consisted of questions asking the parent or legal guardian to expand on: (1) personal barriers to participating in research, (2) which autism research they would be willing to participate in, and (3) reasoning behind selecting their top 3 research priorities. Parents were also asked if there are developmental language milestones that they did not choose as their top research priorities in the survey that are highly important to them or if there are more language milestones they think are important to research that were not included in the survey. The conclusion of the interview consisted of asking parents if they had anything else they would like to state about the language topics or about the survey/interview in general. See Appendix B for the full interview script.

Upon completion of the interview, the research assistant saved the recorded session to a secure LSU lab server as outlined in the consent form. The research assistant ensured no information from the zoom call has been stored on their personal or school computer. Files were kept in secure cabinets to which only the investigators had access and/or saved in secure digital storage space (e.g., lab server). Participants that choose to participate in the zoom call were recorded and the files were saved to an LSU lab server and LSU OneDrive or Box, which are secure data storage platforms. These recordings will be deleted within 24 months of recording; however, the de-identified transcript of the interview will be kept indefinitely. Transcripts were transcribed using the automatic Zoom captioning and will be further reviewed and edited if necessary, using Panopto.

### **Data analysis plan**

Descriptive statistics were gathered from the survey responses to provide an overview of demographic characteristics of the parents who completed the survey (e.g., age, race, ethnicity,

and educational level) and the children and (e.g., age, language abilities, strengths and challenges). These were calculated to characterize the overall survey sample respondents and to note how the autistic children in the current study reflect the general autistic child population. This was used to determine if the data is a representative sample of the autistic child population.

Next, the mean and standard deviation of the parent rankings of each developmental language domain were calculated to describe the parent priorities overall. We also noted the most and least important language skills/domains. Since the survey allows parents to toggle each priority rating on a scale from 0 (not important) to 100 (very important), each mean has a quantity between 0-100. Additionally, the means of this overall data were compared to the top three research priorities the parents were asked to list on the following question of the survey.

After this was completed, survey responses were sorted into subgroups by age of autistic child, parent education, gender and child language abilities. The means from these developmental language milestones will be compared within each subgroup, between subgroups, and to the overall data set. This approach will indicate if a particular subgroup has a distinguished priority that is different from the overall group data or different from the other subgroups. Pearson's correlation analysis was completed to determine associations with child age and language priorities. Spearman's Rank-order correlation analysis was completed to determine associations with child language and parent's language priorities.

## Chapter 3. Results

### **RQ1: What developmental language domain(s) is the most important to parents (key stakeholders) for pediatric autistic language research?**

Overall, participants ranked how autistic children learn new words as the most important language research focus ( $M = 80.38$ ,  $SD = 27.58$ ). Following this ranking, the second most important topic was following directions ( $M = 74.19$ ,  $SD = 31.61$ ), and the third was learning to read ( $M = 73.00$ ,  $SD = 31.05$ ). Across all language research topics, each language research topic had at least one parent score the topic as 0 (not at all important) and at least one parent score the topic as 100 (very important). This contributes to the large standard deviation of each language topic. Each language priority with their mean and standard deviation can be viewed below in Figure 3.1.

#### **Top three research priority ranking**

After parents ranked the language priorities on a scale from 0 - 100, they were then asked to select their top three language research topics. This forced parents to choose only their top three topics that they find to be important. This was especially helpful for the responses that only ranked language topics as all 100's ( $N = 2$ ), or responses that only ranked language priorities with 0 or 100 ( $N = 1$ ). Overall, participants ranked how autistic children learn new words as the first most important priority (27% of all first choices), Child's ability to respond to questions as the second most important priority (24% of all second choices), and following directions as the third most important priority (19% of all third choices). When all responses of the first, second, and third most important ranked topics were collapsed into one list, following directions was the overall most important research topic (selected within the top three priorities by 15.6% of the parents), followed by child's ability to respond to questions (13.0%). The third overall most



important language research topic was a three-way tie between social skill development, echolalia, and how autistic children learn new words (11.7%). This is fairly consistent with the item-level rankings, as these five priorities were in the upper 50% of rankings. The exception to this is learning to read was ranked as third highest on the overall item-level ranking but was not listed as a top research priority when parents were asked to select their top three most important topics.

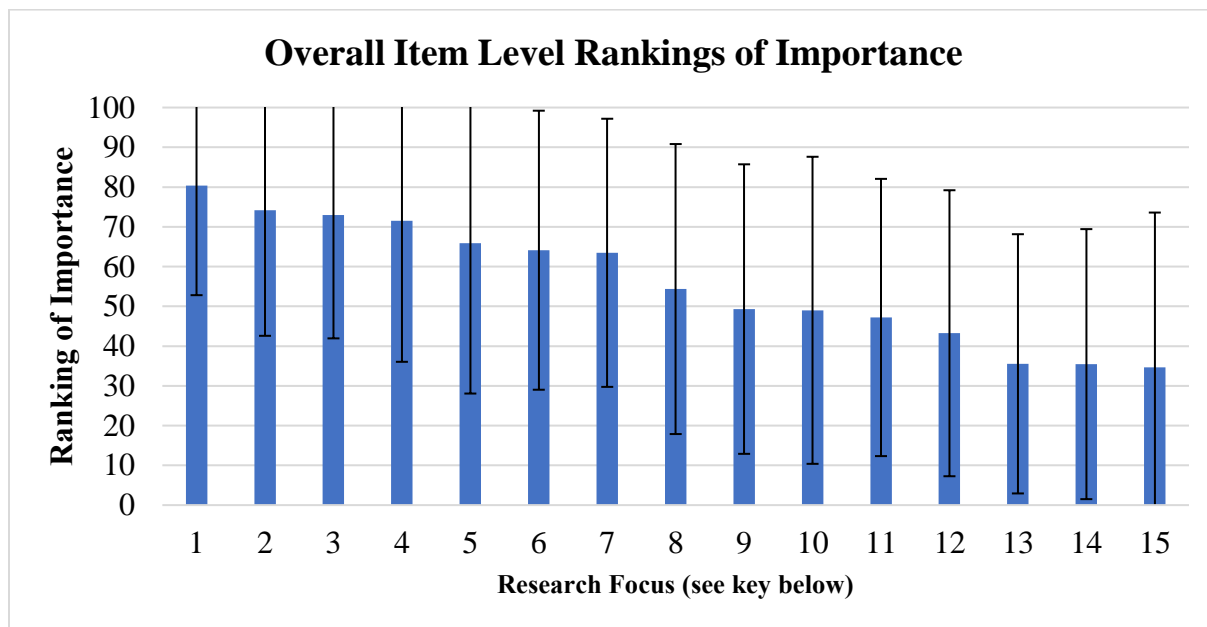


Figure 3.1. Overall language research priority rankings

**Figure key**

	Research Topic		Research Topic		Research Topic
1	Learn new words	6	Grammar	11	Abstract thoughts
2	Following directions	7	Social skills	12	Topic maintenance
3	Learning to read	8	Word usage in context	13	Articulation
4	Echolalia	9	Gestures	14	First words
5	Respond to questions	10	Pretend play	15	Eye contact

### **Research priorities - interviews**

When these six interviews were conducted, all participants explained that their research priorities were individualized to what they thought was important to their autistic child or children. When asked about their reasonings behind their top ranked answers, each parent that was interviewed explained that their top priorities were based on what was most important for their child at this current time in their lives. Three parents explained that it was not that the other language topics were unimportant, but rather what their children need the most at this moment in their lives. One parent further expanded this thought by saying she thinks other research topics may be more important once her children grow older, such as learning to read or staying on topic in conversation.

All parents also expressed that they have no major barriers to most research. One parent mentioned that she would be willing to complete research, but invasive procedures could be challenging. Other thoughts toward research were not that the parents are unwilling, but they have everyday obstacles like work schedules or not being aware of studies that are being conducted that keep them from research. Two parents also mentioned that online surveys are more accessible for them. Four parents also mentioned that they would be more willing to participate in research if it was a topic that they were highly interested in, such as the studies of Marge Blanc's Natural Language Acquisition intervention program, bilingualism with autism, or correlations between reading to autistic and non-autistic children. One interesting topic that two parents expanded on is that they believe that their autistic children have a zone of development; they explained they think that their child must enter this zone before any appropriate learning is understood and therefore obtained. More information about parent opinions on autistic research topics can be found in research question 3.

**RQ2: Within different subgroups, are there differences in priorities for language research between each demographic group?**

**Inter-group comparisons**

Inter-group comparisons between age, education level, language level, and gender were analyzed. Unfortunately, there was too little variability to conduct inter-group comparisons for race, parent gender, ethnicity, and region of the United States. Although our data collected on race closely resembled the 2020 census for America (White 73%, Black or African American 11%, American Indian or Alaska Native 8%, White and African American 4%, Asian 4%), there were some racial subgroups that only included 1 participant. For ethnicity, there were 25 participants that were non-Hispanic, and only one Hispanic participant. With caregiver role, 24 of the 26 participants were mothers. There was only one father and one grandmother participant. For the participant region, there were 14 parents from the Southeast, 4 from the Southwest, 3 from the West, 3 from the Northeast, and 2 from the Midwest.

**Language stage sub-group**

The largest variation when completing inter-group comparisons was with the child's language stage. This can be seen through comparing these sub-groups to each other. For example, every parent that reported their child to be echolalic ranked echolalia as 100 (very important) when ranking language research priorities. Overall, with each group of language abilities, these parents rated different research topics as their first, second, and third most important than compared the other groups. This correlates directly to what was said in the parent interviews with parents ranking language priorities based on what they think is important for their child in the current moment. Complete results can be found in Table 3.1.

Table 3.1. Child's language stage compared to parent's top language rankings

	<b>Non-speaking, Gestures, &amp; AAC (<i>n</i> = 5)</b>	<b>Few Words, One at a Time (<i>n</i> = 3)</b>	<b>Two Words (<i>n</i> = 3)</b>	<b>Echolalia (<i>n</i> = 3)</b>	<b>Simple Sentences (3-4 words) (<i>n</i> = 8)</b>	<b>Complex Sentences (<i>n</i> = 3)</b>
<b>Top Priority</b>	Following directions ( <i>M</i> = 87.60, <i>SD</i> = 16.99 )	Social skill development ( <i>M</i> = 83.33, <i>SD</i> = 28.87)	Child's ability to respond to questions ( <i>M</i> = 100.00, <i>SD</i> = 0.00)	Echolalia ( <i>M</i> = 100.00, <i>SD</i> = 0.00)	How autistic children learn new words ( <i>M</i> = 91.13, <i>SD</i> = 8.23)	Child's ability to respond to questions ( <i>M</i> = 88.00, <i>SD</i> = 9.54)
<b>2nd Highest Priority</b>	How autistic children learn new words ( <i>M</i> = 84.60, <i>SD</i> = 29.17)	Participation in pretend play ( <i>M</i> = 80.00, <i>SD</i> = 34.64)	Using words in correct contexts ( <i>M</i> = 91.67, <i>SD</i> = 14.43)	How autistic children learn new words ( <i>M</i> = 90.00, <i>SD</i> = 17.32)	Learning to read ( <i>M</i> = 85.25, <i>SD</i> = 8.25)	Social skill development ( <i>M</i> = 86.00, <i>SD</i> = 17.78)
<b>3rd Highest Priority</b>	Child's ability to respond to questions ( <i>M</i> = 74.00, <i>SD</i> = 29.08)	Learning to read ( <i>M</i> = 63.33, <i>SD</i> = 55.08)	How autistic children learn new words ( <i>M</i> = 90.00, <i>SD</i> = 17.32)	Development of grammatical language ( <i>M</i> = 80.33, <i>SD</i> = 27.43)	Following directions ( <i>M</i> = 84.13, <i>SD</i> = 11.81)	Understanding abstract thoughts ( <i>M</i> = 80.33, <i>SD</i> = 23.71)

### Age sub-group

Language Priorities based on the child's age were compared in three sub-groups: preschool aged ranging from 2 - 4 years (*n* = 9), elementary aged ranging from 5 - 10 (*n* = 13), and pre-teen/teen aged ranging from 11 - 16 (*n* = 4). Participants were grouped into three categories due to the low number of responses for each chronological age. Overall, patterns from the age subgroup still loosely resemble the overall data shown in Figure 3.1. The largest differences noted from the three age groups are from research priority 7 (social skills) and 10 (pretend play). For the social skills research priority, the pre-teen/teen age group ranked this

priority an average of 40 points lower than the pre-school aged group. For the pretend play research priority, the pre-teen/teen age group also ranked this priority an average of 40 points lower than the preschool aged group. The elementary age subgroup resembled the preschool group closer for these two research priorities. Complete results can be found in Figure 3.2 below.

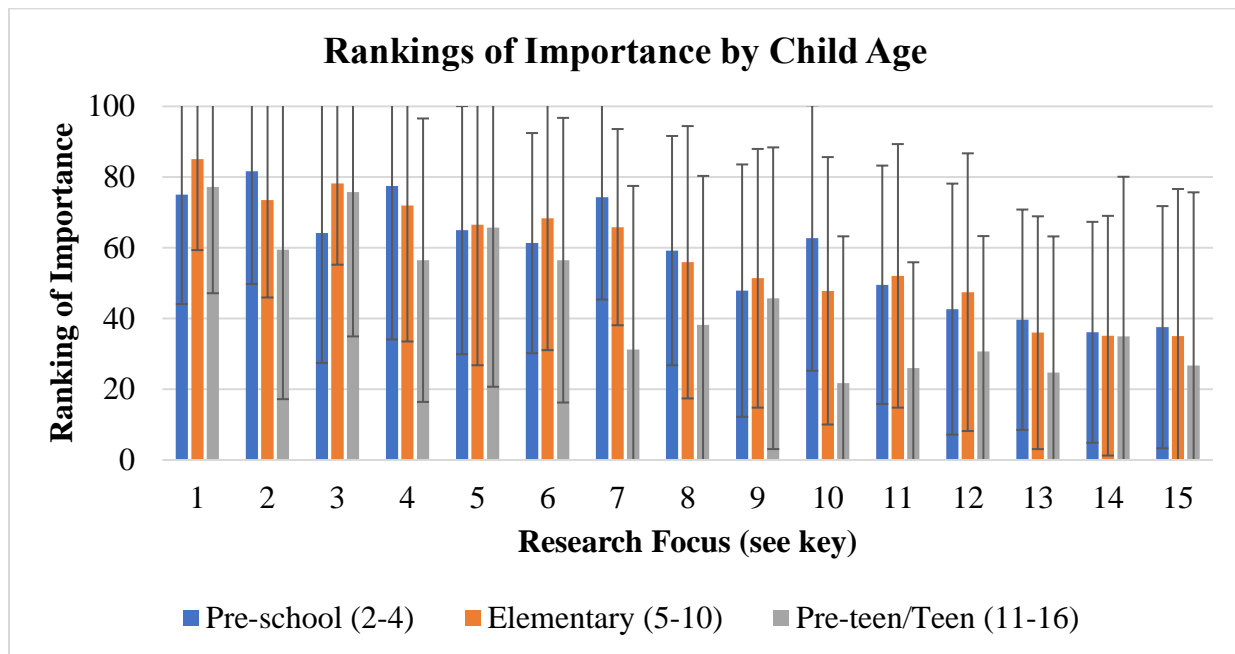


Figure 3.2. Language research priority rankings by age

#### Figure key

	Research Topic		Research Topic		Research Topic
1	Learn new words	6	Grammar	11	Abstract thoughts
2	Following directions	7	Social skills	12	Topic maintenance
3	Learning to read	8	Word usage in context	13	Articulation
4	Echolalia	9	Gestures	14	First words
5	Respond to questions	10	Pretend play	15	Eye contact

#### Pearson's correlations

We also conducted Pearson's correlations to examine the association between child's chronological age and parent's ranking of language research priorities. None of the rankings were significantly correlated with chronological age ( $ps > 0.14$ ).

### **Spearman's rank-order correlations**

To determine if there were any associations between child language ability and parent rankings, we conducted spearman's rank-order correlations. To rank the language abilities for the correlation, a score of 1 was given to non-speaking children, children who primarily use gestures, and children who primarily use AAC devices. A score of 2 was given to children who produce a few words, one at a time. A score of 3 was given to children who combine two words; a score of 4 was given for children who use echolalia. A score of 5 was given for children who speak in simple sentences (3-4 words), and a score of 6 was given for children who produce sentences with complex thoughts and ideas. The only significant correlation in the analyses was that the higher the language abilities of the child, the more likely for a parent to rank abstract thoughts higher in the survey ( $\rho(23) = 0.47, p = 0.017$ ). Another correlation approached significance, indicating that the higher the language ability of the child, the more likely the parent would rank development of grammatical language higher in the survey ( $\rho(23) = 0.36, p = 0.077$ ). All other  $p$ -values were non-significant ( $ps > 0.15$ ).

### **Parent education sub-group**

Parent Education was grouped into three sub-groups: graduate/professional degree ( $n = 13$ ), bachelor's degree ( $n = 10$ ), and other ( $n = 3$ ). The 3 participants listed in the "other" category were one participant with an associate degree, one participant with some college, and one participant with a high school diploma/GED. Given that the "other" category is only from 3 participants, the data should be interpreted with caution. Overall, the participants in the "other" category rated 14/15 research topics considerably higher than the bachelors and graduate degree parents. Overall, the largest difference noted in research priorities between the subgroups was research priority 10 (pretend play), 14 (first words), and 15 (eye contact). These mean scores are

approximately 47, 68, and 56 points, respectively, above the two other education groups.

Between the parents with bachelors and graduate/professional degrees, the largest difference was between research priorities 1 (learn new words), 2 (following directions), 4 (echolalia), and 9 (gestures). All other research priorities between participants with a graduate/professional degree and bachelor's degree had a difference of less than 10 points. Complete results can be found in figure 3.3 below.

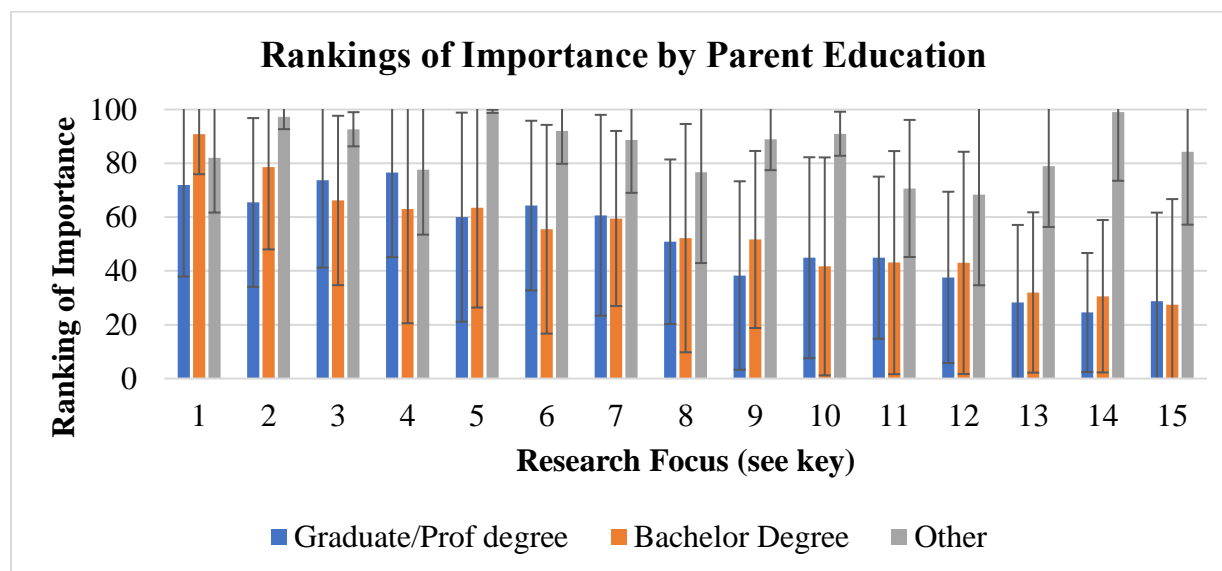


Figure 3.3. Language research priority rankings by parent education level

#### Figure key

	Research Topic		Research Topic		Research Topic
1	Learn new words	6	Grammar	11	Abstract thoughts
2	Following directions	7	Social skills	12	Topic maintenance
3	Learning to read	8	Word usage in context	13	Articulation
4	Echolalia	9	Gestures	14	First words
5	Respond to questions	10	Pretend play	15	Eye contact

#### Child gender sub-group

There were 18 male and 8 female children whose parents completed the survey. Overall, the largest differences between gender and parent research priority is between research topics 4 (echolalia), 6 (grammar), and 10 (pretend play). The differences between research priorities were

approximately 19, 14, and 17 points respectively. Overall, the differences between each research priority from these sub-groups were less than 19 points. This suggests that there was little variation in research priorities between genders. Complete results can be found in Figure 3.4 below.

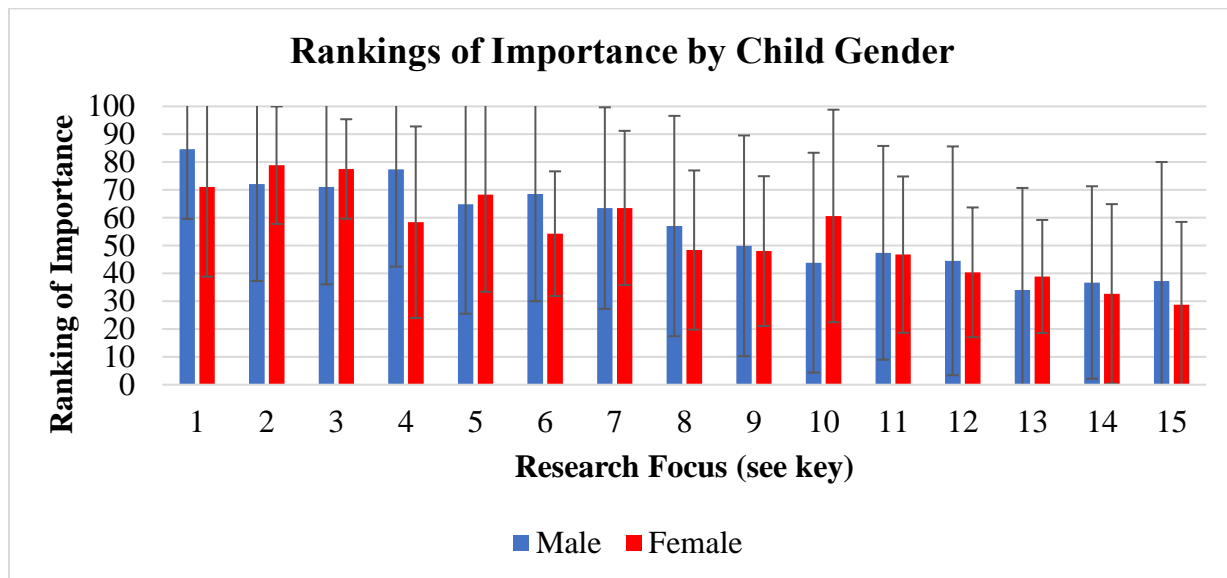


Figure 3.4. Language research priority rankings by child gender

#### Figure key

	Research Topic		Research Topic		Research Topic
1	Learn new words	6	Grammar	11	Abstract thoughts
2	Following directions	7	Social skills	12	Topic maintenance
3	Learning to read	8	Word usage in context	13	Articulation
4	Echolalia	9	Gestures	14	First words
5	Respond to questions	10	Pretend play	15	Eye contact

### RQ3: What do parents of autistic children believe to be important for autism research?

#### Overview

The third portion of the survey was mainly dedicated to determining what research parents may be willing to participate in, what barriers may keep them or their children from research, what incentives may encourage research participation, and if parents would allow their



child to participate in research that did not involve treatment/intervention for research. As noted in the participant demographics in the methods section, one parent did not complete the final section of the survey. This is why the following results are based only on 25 participants.

### **Barriers**

The top barrier parents listed for participating in research was time ( $n = 8$ ; 32%). Following this barrier, the second highest response was that parents have no barriers to participating in research ( $n = 5$ ; 20%). The third highest response was a three-way tie between not being aware of current studies to participate in ( $n = 2$ , 8%), money ( $n = 2$ , 8%), and if the research to the child is invasive ( $n = 2$ , 8%). Parents had an overall positive outlook on research and many barriers were based on extenuating circumstances that were not due to the research itself (e.g., time due to the parent's full-time job).

### **Research participation and incentives for participation**

When parents were prompted with the question of what research they would be willing to participate in, the highest reason to participate is if the research was for a specific topic that the parent was interested in or if it fit their child's specific needs ( $n = 13$ , 52%). The second highest reason for participation was if the study was online or at a specific location ( $n = 12$ , 48%). The third highest reason to participate was for anything ( $n = 6$ , 24%), and if the parents that mentioned they would participate in anything except invasive medical/brain research, the participants for this reason would increase to 9 (36%).

When parents were asked what would encourage or incentivize participation, the top incentive was location ( $n = 17$ , 68%). This was followed by if the study was online ( $n = 15$ , 60%), payment/compensation ( $n = 14$ , 56%), short duration study ( $n = 13$ , 52%), and if treatment/intervention was provided to the child ( $n = 12$ , 48%). A follow-up question was asked

in the survey about if parents would be willing to participate in research that did not involve treatment. A total of 20 parents responded that they would participate (80%).

## **Chapter 4. Discussion**

With the “nothing about us without us” movement on the rise and the shift away from the medical paradigm, it is critical that researchers continue to consider and include autistic stakeholder thoughts and opinions in their research. This is especially true with children; many are not old enough or have the ability to advocate for themselves in research. Asking the caregivers of these autistic children can be one way to give this population a voice.

Very few other studies gave opportunities to parents of autistic children to express their thoughts and opinions and no other published studies to our knowledge researched what these parents believe to be important for specific language topics. Directly surveying key stakeholders of the autistic community, we were able to get a glimpse into what the autistic community thinks is important. This study aimed to expand on the extant literature that targeted surveying key autism stakeholders for research priorities. Previously, only 10 studies aimed to expand autism stakeholder views in research and only 3 of these gathered data from stakeholders involved with autistic children. In previous studies involving children, there were no specific questions regarding opinions about language. The questions asked were more general such as “what do you think is most important for your child in X setting?”, or “What is your opinion on the use of ‘at-risk’ language?” Despite these general questions, parents still responded with saying they think early language is still important. This study expanded this research by providing parents with 15 different research topics in the realm of language specific to communication skills.

After reviewing all subjective and objective data from the parent interviews, priority ranking sliders, and comparing data within subgroups, it is overwhelmingly clear that parents value autism research that focuses on language and parents’ language research priorities are based on their child’s current language level and needs. Parents who prefer certain subjects or

have had more experience with a particular subject had a tendency to rank them as higher or more important (e.g., all parents of children who use echolalia to communicate ranked echolalia as a 100 on importance). Additionally, while reviewing barriers and incentives to participate in research, it is evident that parents are also more willing to participate in topics that they personally think are important.

With the data suggesting that parents rank language research topics based on their child's language ability, it would explain why there is much variety in ranking language priorities overall. This would also explain the large standard deviations when all data was compiled for the overall language priority rankings. The variation in research importance rankings reduced as the data were subdivided according to child language ability. Interestingly, when the data were analyzed by age group, there were also large standard deviations and we found that there were no significant correlations between chronological age and research importance rankings. The different results between age and language abilities indicate that parents rank items based on language ability more so than chronological age. Given that autistic children are so diverse in their developmental trajectories, one child's language ability could be very different compared to other children in the same age range.

Although the overall top ranked priority was how autistic children learn new words, the only language group to have this research topic ranked first was children who speak in simple sentences (3-4 words). Interestingly, this language subgroup was the largest ( $n = 8$ ) compared to the others. Additionally, the parents whose children are non-speaking (non-speaking) or use AAC to communicate and children who use echolalia rated this topic as second most important, and parents of children who use two words to communicate ranked this topic as third.

Throughout all categories and subgroups that were analyzed, this research topic was most consistently ranked in the top three most important research topics.

Other than learning new words, the following research priorities were also highly ranked: following directions (language comprehension skills), learning to read, echolalia, and responding to questions. These topics should also be prioritized in research. Although there is room for growth in expanding the research in these areas, these top ranked topics have not been completely ignored. Many studies have already been conducted to explore some of these topics for autistic children. For example, Haebig et al. (2017) examined statistical word learning in school-aged children with autism spectrum disorder and specific language impairment. Another word learning study by Luyster and Lord (2009) examined 21 typically developing toddlers matched on expressive vocabulary with 21 young children with ASD to see if there were differences in word learning abilities. Additionally, an example from the research literature focusing on language comprehension is Kalandadze et al. (2018); this study examined figurative language comprehension in autistic individuals versus non-autistic individuals through a meta-analysis. This meta-analysis examined 41 studies and 45 independent effect sizes. For learning how to read, a systematic review by Khowaja and Salim (2013) examined strategies and computer-based intervention for reading comprehension for autistic children. This study specifically wanted to examine vocabulary instruction and text comprehension instruction. A study that examined echolalia is one by Luyster et al. (2022). This examined existing approaches for unconventional language in autism such as echolalia and self-repetition (non-generative language), or idiosyncratic phrases, neologisms and pedantic language (generative language). Finally, an example of research that examined autistic children's abilities to respond to questions is Daar, Negrelli, and Dixon (2015). Daar et al. (2015) examined 3 autistic participants aged 10-

12 on their emergence of wh- questions, specifically who, what, and where questions. This is only a short list of examples, but there are also more studies that are published that include research for autistic children in the highly-ranked language research topics. However, it is still important to place emphasis on these research topics because they are still ranked the highest by parents and there can still be more research completed on them.

Compared to the extant literature, the current study yields some similar results in the regards to stakeholder attitudes for their relation to the autistic community in general. For instance, Cohen (2016), people ranked their research priorities based on their personal connection to the autistic community. The participants in the study had different research priorities if they were a parent of an autistic child compared to an adult autistic individual. In Frazier et al. (2018), their study also found that there were clear patterns across participants with different relationships to autistic individuals that proved to be fairly consistent. Clark and Adams (2020) found that more often than not, parents discussed that the research priorities that were not ranked as high were not less important, but rather these topics have already been researched. Another factor parents discussed was ranking the priorities based on their family's needs at the time of the survey. Across the literature, it is abundantly clear that stakeholders have different priorities based on the autism community that they are associated with the most.

Receiving input from stakeholders on language research is especially pertinent because previous studies that involved surveying autistic stakeholders such as Fletcher-Watson et al. (2017) and Pituch et al. (2011) identified early language as an important research priority for autism research. Interestingly, despite parents noting early research as being important in these studies, the language research topic regarding autistic children's first words was ranked as the second lowest priority in this study. Given these results in the other studies, we would have

expected this specific topic to be ranked higher by the parents who participated in the current study. When considering this mismatch, it is important to remember that the current study included language skills that extend beyond the early language acquisition phase are also important to parents. Parents have already identified that language is important to them and this survey was able to give parents a say in what exactly is important because we included more specific language research topics in the survey questions.

Another aim of the current study was to assess research topics that caregivers may find important and to compare that with research they were willing to participate in. One specific query that I wished to examine was what would be the likelihood of the parents and children participating in research studies that do not directly align with the research topics that they specifically stated that they were interested in. In this current survey, 36% of parents mentioned they would be willing to participate in any type of research or any research that was not medically invasive. Furthermore, 80% of parents in this study reported that they would be willing to participate in research if no treatment was given. This contradicts the findings of Fletcher-Watson et al. (2017), where approximately 36% of parents reported that they would only participate in research if treatment was given. This is promising to autism researchers knowing the willingness of these parents.

Additionally, it is also valuable to have insight on what may encourage or incentivize parents to participate in research. For example, given that a large number of parents placing emphasis on location/online studies, suggests that a research study may have more interest from parents if the study is online. This may help shape the way future researchers design their studies; however, this could potentially create small barriers for researchers to overcome. Some large incentives included time/location or payment/compensation. It may be difficult for

researchers to have high validity over an online platform due to some factors such as a lack of control over the environment in which the child is testing. For example, parents could interfere with a study protocol by assisting the child in tasks or repeating things that the experimenter says. High quality data could also be compromised by children having difficulties with attending to experiments that are administered over a computer screen. Furthermore, some experimental paradigms are not possible to use in online tasks and some data cannot be collected online (e.g., EEG data). For compensation, some research studies (much like this study), do not have budgets to pay their participants for participation or may require cumbersome paperwork and personal information like requiring a participant's social security number in order to receive financial reimbursement for participation, which may lead to lower participation.

### **Directions for future research**

Despite some identifying additional important stakeholder priorities for autism research, there are still many topics that autism stakeholders have not provided input on. This study aimed to bridge this disconnect for autism language research by asking parents of autistic children for their input on research topics that were specific to child language and communication. Future studies should consider studies such as the relation of the child's language stage and their ability to learn new words, following directions, or learning how to read. Studies can examine how each child may function differently in these areas based on their language abilities. These specific topics are important to place emphasis on because they were the topics that were ranked highest overall. Furthermore, future work should consider implementing community-based research strategies while engaging in research on the highly-valued topics.

### **Recommendations**



Suggestions for future studies include surveying more stakeholders on their thoughts on autism research. This study only examined a small topic but there are so many other research topics that still need stakeholder input. As for other studies, another study that examines language research priorities could be beneficial, especially if another study can obtain a larger number of participants. In other studies, it could be beneficial to examine stakeholder priorities in inter-subgroup comparison between different regions of the United States or races. Future researchers should also consider what parents believe to be important overall, as well as what each language stage group believes to be important.

When preparing future studies, researchers should consider topics to research such as learning new words, following directions, learning to read, echolalia, or responding to questions. Researchers should consider their reasonings behind research that parents also do not think to be as important such as understanding abstract thoughts, topic maintenance, articulation, autistic children's first words, and eye contact. Even though parents have ranked these topics as lower priorities, there can still be benefits to researching these topics; however, it is important to reflect on if the research being conducted is because the researcher thinks it to be important, if the parents think it to be important, or if past research has evidence to justify the need for further investigation.

### **Limitations**

Although this study added to missing information in the current literature, there are limitations that must be kept in mind. First, the current study included a relatively small number of participants overall, and somewhat limited diversity in racial and ethnic backgrounds and other demographic characteristics. We were unable to compare some subgroups due to this. For instance, had a larger number of individuals participated, it may have been possible to compare

groups by race and location in the United States. Another limitation to this study was our inability to compensate participants for their time in a way that did not require asking for the participants' social security numbers. Participants responded to the survey with no other incentive other than it would benefit autism research. The final limitation to the study was that our respondents were mostly limited to personal connections through personal social media platforms or local autism clinics. We did not have many different platforms to promote our survey, which may have led to a lower participant number as well.

Had a larger population been surveyed, results could have potentially been different, and the means could have possibly been more leveled off. In this survey, because there were few participants, if a parent ranked something as a 0 or 100 it could skew the mean of that language topic a large amount. A larger survey population mean would be able to level out potential outliers more than the 26 participants we had participated in our survey. In our study, there were 2 parents who ranked all 15 research priorities as all 100's, and 1 parent that only ranked items as 0 or 100. Each research topic had at least one parent rank the topic as a 0 and at least one parent rank the topic as 100. The rankings for each research topic were so diverse, so each topic had no outliers. Nonetheless, our surveyors still had similar overarching themes that were still able to be extracted.

## **Conclusions**

Overall, autism language researchers can benefit from these results. Although a larger sample of participants can further improve this study, the current study in its present form can help shape future studies and give a voice to more key stakeholders.

The current study revealed that parents of autistic children value autism research that focuses on child language. Furthermore, research that focuses on how autistic children learn new words,

follow directions, learn to read, respond to questions, and echolalia were consistently ranked as highly-valued overall and should therefore receive more emphasis in future research.

Additionally, we identified some instances of variation in ranking scores according to child language stage, indicating that researchers need to consider the child's language ability when identifying specific research topics to pursue. Given this, additional input from parents who have children within that language phase should be included in the research planning stages.

## Appendix A. Institutional Review Board Approval



**TO:** Eileen Haebig  
LSUAM | Col of HSS | Communication  
Sciences and Disorders | CC00127

**FROM:** Alex Cohen  
Chairman, Institutional Review Board

**DATE:** 15-Nov-2022

**RE:** IRBAM-22-0922

**TITLE:** Research Priorities for Child Language  
Research Focusing on Autism

**New Protocol/Amendment/Continuation:** Amendment

**Brief Amendment Description:** I uploaded a new Qualtrics survey. In this amended survey, we have changed the order of the questions, reformatted some of the questions so that there are more multiple choice options instead of open text boxes (a Qualtrics suggestion for accessibility and ease of use), and we updated our demographic questions.

**Review Type:** Expedited Review

**Risk Factor:** Minimal

**Review Date:** 15-Nov-2022

**Status:** Approved

**Approval Date:** 15-Nov-2022

**Approval Expiration Date:** 06-Oct-2023

**Re-review frequency:** (annual unless otherwise stated)

**Number of subjects approved:** 100

**By:** Alex Cohen, Chairman

**Continuing approval is CONDITIONAL on:**

1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU's Assurance of Compliance with DHHS regulations for the protection of human subjects\*
2. Prior approval of a change in protocol, including revision of the consent documents or an increase in the number of subjects over that approved.
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins); notification

## Appendix B. Survey

# Surveying Research Priorities for Studying Language Development in Autistic Children

### Start of Block: Prescreener

Do you have one or more children who have an autism spectrum diagnosis?

☐ Yes (1)

☐ No (2)

Are you 18-years-old or older?

☐ Yes (1)

☐ No (2)

Complete the Catpcha below to confirm that you are not a robot.

### End of Block: Prescreener

### Start of Block: Consent

**Study Title: Research Priorities for Child Language Research Focusing on Autism**

**The purpose of this research is to understand what parents of autistic children want researchers to focus their efforts on studying when examining child language in autistic children.**

**What does this study involve?**

**This study will consist of one online survey that will last 5-10 minutes. You will be asked questions about your opinions about priorities for research that focuses on language development in autistic children. Also, you will be asked to answer basic questions about your child, like your child's age and language abilities, and basic demographic questions about yourself.**

**You will also be asked if you would like to participate in a follow-up Zoom call to further discuss your opinions about priorities for research focusing on language development in**

**autistic children. If you also choose to participate in the interview, the call will last approximately 15-20 minutes and will be video or audio recorded.**

**Participant Inclusion:** You must be at least 18 years old and have at least one child who has been diagnosed with autism spectrum disorder.

**Participant Exclusion:** You are ineligible to participate in this study if you are under 18 years of age or do not have at least one child who has been diagnosed with autism spectrum disorder.

**Risks:** There are no risks that are beyond minimal risks associated with participating in any research study. There is a risk of an inadvertent release of sensitive information that you may choose to provide about yourself or your child; however, every effort will be made to maintain the confidentiality of your study records. Files will be kept in secure cabinets to which only the investigator has access and/or saved in secure digital storage space (e.g., lab server). Participants who choose to participate in the Zoom call will be video or audio recorded and the files will be saved to an LSU lab server and the LSU OneDrive or LSU Box cloud-based server, which are secure data platforms. These recordings will be deleted within 24 months of the recording; however, the de-identified transcript of the interview will be kept indefinitely.

**Benefits:** There are no direct benefits from participating in this experiment; however, we hope to learn things that will help improve our understanding of what families want researchers to focus on when conducting autism research that focuses on language. We hope that this knowledge will help others in the future.

**Compensation:** There is no compensation associated with the current survey study.

**Performance Site:** Online

**Investigators:** The following investigators are available for questions about this study: Principal Investigator: Dr. Eileen Haebig, PhD E-mail: [ehaebig1@lsu.edu](mailto:ehaebig1@lsu.edu); Graduate students: Taylor Hale, [thale6@lsu.edu](mailto:thale6@lsu.edu); Fatema Mitu, [fmitu1@lsu.edu](mailto:fmitu1@lsu.edu); Caprielle Priola, [cpriol1@lsu.edu](mailto:cpriol1@lsu.edu); Jessica Sykes, [jsykes8@lsu.edu](mailto:jsykes8@lsu.edu); Undergraduate students: Alyssa Schell, and Naomi Tomiyama - (225) 578-3933.

**Right to Refuse:** Your participation in this study is completely voluntary. You may choose not to participate, and you may withdraw from the study at any time without penalty. You may skip over questions or procedures, or you may withdraw by informing the researcher that you no longer wish to participate (no questions will be asked). Your decision to participate, decline, or withdraw participation will have no effect on your status at or relationship with Louisiana State University.

**Privacy:** Every effort will be made to maintain the confidentiality of your study records. Your responses will be assigned a code number that is not linked to your name or other identifying information. All signed electronic consent forms will be stored in a manner that can only be accessed by the researchers. Please be aware that no form of communication is 100% secure. Employers or others may be able to track the information you type into a computer. Results of the study may be published, but no names or identifying information will be included in the publication. Subject identity will remain confidential unless disclosure is required by law. Your responses to questionnaires and computerized tasks will be stored indefinitely. Your permission to use the data in future research studies will not be obtained, since the data will not contain any identifiers. Data from this project may be shared with other researchers or made publicly

available for scientists to use in future work. If data are shared, it will be shared with your encrypted study identification number and not with any of your personal information. By participating in this study, you agree to allow the researchers to use the data for future, as yet unknown research studies.

This study has been approved by the LSU IRB. For questions concerning participant rights, please contact the IRB Chair, Dr. Alex Cohen, 225-578-8692, or [irb@lsu.edu](mailto:irb@lsu.edu)

By continuing this survey, you are giving consent to participate in this study.

Your information collected as a part of this research, with identifiers removed, may be used or distributed for future research.

IRBAM-22-0922

Do you consent to participation in this study?

☐ Yes (1)

☐ No (2)

**End of Block: Consent**

**Start of Block: Default Question Block**

You have agreed to participate in a survey that is gathering information about priorities for autism research that focuses on child language. Please complete the following questions to the best of our knowledge.

Note: Many people from the autism community have indicated that they prefer identity-first language (i.e., autistic child) over person-first language (i.e., child with autism). We know that this is not everyone's preference; however, this is the reason that we have chosen to use identity-first language in the current survey.

This survey has been reviewed by multiple autism stakeholders including: The LSU Language NeT Lab, an autistic speech-language pathologist, and a mother of an autistic child.

Page Break

How many autistic children do you have?

If you have multiple children with an autism diagnosis, please respond to the survey questions for only one of your children.

☐ 1 (4)

☐ 2 (5)

☐ 3 (6)

☐ 4+ (7)

How old is your autistic child?

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What is your child's gender?

☐ Male (4)

☐ Female (5)

☐ Non-binary (6)

☐ Other (7) 

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Does your child have any co-occurring conditions? If so, please list them (e.g., ADHD, apraxia, anxiety).



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What is your relation to your child?

☐ mother (4)

☐ father (5)

☐ grandparent (6)

☐ guardian (7)

☐ other (8) \_\_\_\_\_

What is your ethnicity?

☐ Hispanic, Latino/a, or Spanish origin (1)

☐ Not Hispanic, Latino/a, or Spanish Origin (2)

☐ Prefer Not to Answer (3)

What is your race? (select all that apply)

☐ American Indian or Alaska Native (1)

☐ Asian (2)

☐ Black or African American (3)

☐ Native Hawaiian or Other Pacific Islander (4)

☐ White (5)

☐ Prefer Not to Answer (6)

What is your highest level of education?

- ☐ Some High School (7)
- ☐ High School Degree/GED (1)
- ☐ Some College (2)
- ☐ Associate's Degree (3)
- ☐ Bachelor's Degree (4)
- ☐ Graduate/Professional degree (5)
- ☐ Prefer Not to Answer (6)

What region of the United States do you live in?

- ☐ Northeast (5)
- ☐ Southeast (2)
- ☐ Midwest (1)
- ☐ West (4)
- ☐ Southwest (3)

Page Break

Which of the following do you think is the most important topic to research for autistic children?  
Please rank level of importance using the sliding scale under each item with 0 being not at all important and 100 being very important.

	0	10	20	30	40	50	60	70	80	90	100
1. Autistic children's first words ()											
2. Child's ability to respond to questions ()											
3. Child gestures ()											
4. How autistic children learn new words ()											
5. Making eye contact ()											
6. Correctly producing sounds in words ()											
7. Following directions (language understanding skills) ()											
8. Development of grammatical language ()											
9. Social skill development (e.g., Interacting with other children) ()											
10. Staying on topic in conversations ()											
11. Using words in correct contexts ()											
12. Participation in pretend play ()											
13. Learning to read ()											
14. Understanding abstract thoughts ()											
15. Echolalia (e.g., repeating previously heard words or phrases) ()											

Of the previous list, what is the most important research topic that you think researchers should focus on?

First (most important topic) (4)

▼ Autistic children's first words (1) ... Echolalia (e.g., repeating previously heard words or phrases) (15)

What is the second most important research topic that you think researchers should focus on?

Second most important topic (1)

▼ Autistic children's first words (1) ... Echolalia (e.g., repeating previously heard words or phrases) (15)

What is the third most important research topic that you think researchers should focus on?

Third most important topic (1)

▼ Autistic children's first words (1) ... Echolalia (e.g., repeating previously heard words or phrases) (15)

Page Break

Describe your autistic child's language abilities/ how they communicate with parents or other adults.

- ☐ Nonverbal (4)
- ☐ Produces a few words, one at a time (5)
- ☐ Combines 2 words when communicating (6)
- ☐ Speaks in simple sentences (3-4 words) (7)
- ☐ Produces sentences with complex thoughts/ideas (8)
- ☐ Primarily uses echolalia to communicate (9)
- ☐ Primarily communicates through gestures and/or communication devices (AAC) (10)

What would you say is your autistic child's strongest language ability?

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What would you say is your autistic child's greatest language difficulty?

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What are barriers that may keep you from participating in autism research?

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What autism research would you be willing to participate in?

For example:                      a specific research topic; schedule: one study session vs. multiple study

sessions style: in-person vs. online  
vs. MRI or EEG studies).

behavioral vs. brain studies (e.g., talking tasks

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What are some things that would **encourage** you to participate in research?  
(Select all that apply.)

- ☐ Payment compensation for participating (4)
- ☐ Duration - short studies (5)
- ☐ Duration - multiple visits (6)
- ☐ Online study (7)
- ☐ Treatment/intervention study (8)
- ☐ Location (9) \_\_\_\_\_
- ☐ Other (10) \_\_\_\_\_

Would you be willing to have your autistic child participate in a research study that does not include treatment/intervention?

- ☐ Yes (4)
- ☐ No (5)

Would you be willing to have a 15-minute zoom meeting to expand on any thoughts related to this survey?

- ☐ Yes (1)

☐ No (2)

If yes to the previous question, please provide your email address.

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Are there any final thoughts or comments you would like to share?

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**End of Block: Default Question Block**

## **Appendix C. Zoom Script and Protocol**

1. The research assistant will initiate the Zoom call and record the call to the Zoom cloud.  
During the interview, the research assistant will ask the questions that are listed on the Zoom call interview form while noting the original survey responses.
  - a) Thank you again for agreeing to meet. In this short meeting, I am going to ask you to expand on the things that you noted in the survey.
  - b) First, in your survey response, you noted that a personal barrier to participating in research is XXX. Can you expand on this?
  - c. Can you expand on your answer about which autism research you would be willing to participate in? On the survey, you stated that you would be willing to participate in studies that XXX.
  - d. The top three research priorities that you selected were XXX. Can you explain in further detail why you chose these three priorities?
  - e. Were there any language topics that you did not list in your top three that you think are important? Why?
  - f. Do you have anything that you would like to further explain regarding the language research topics?
  - g. Do you think there are any other language topics that should be researched that were not listed?
  - h. Do you have any other thoughts you would like to share or questions that you would like to ask regarding this survey?
  - i. Thank you for your time.
2. Following the meeting, the research assistant will save the recorded session (recording and the automated transcript) to the secure LSU lab server and the LSU OneDrive folder that is designated for this project, as outlined in the consent form. The research assistant will ensure no information from the zoom call has been stored on their personal computer.
3. A research assistant will listen to the recording and read the automated transcript. Edits will be made when automated transcription errors are identified.
4. A research assistant will listen to the recording and code participant responses and identify response themes for quantitative and qualitative analysis.



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## **Vita**

Taylor Hale was born in Metairie, Louisiana and grew up in Lafayette, Louisiana. After graduating high school, she attended Louisiana State University and received her Bachelor's degree in Communication Sciences and Disorders in May 2021. During her time in undergraduate studies, Taylor participated in research regarding adult fluency techniques alongside her professor, Geoffrey A Coalson. Together, they presented their work titled, "Review of Adult Fluency Techniques Provided in Speech-Language Pathology Textbooks" at Louisiana State University Discover Day in April 2021.

Following her undergraduate degree, Taylor was accepted into the LSU Communication Sciences and Disorders graduate program. She anticipates graduating with her Master of Arts degree in Communication Sciences and Disorders in May 2023. After graduating graduate school, Taylor plans to complete her clinical fellowship and become a licensed speech-language pathologist to help children of all ages and disorders.