

**DETERMINING THE PREVALENCE OF CHILDREN WITH AUTISM
WHO EXPERIENCE DELAYS TO BEHAVIORAL THERAPY IN MICHIGAN
AND UNDERSTANDING THE NEEDS OF THEIR FAMILY DURING THIS TIME:
PRELIMINARY SURVEY RESULTS AND FEEDBACK**

By

Jaimie Barr

A Senior Thesis Submitted to the

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Honors College

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Determining the Prevalence of Children with Autism who Experience Delays to Behavioral Therapy in Michigan and Understanding the Needs of their Family during this Time:

Preliminary Survey Results and Feedback

The Centers for Disease Control and Prevention recently estimated that autism spectrum disorder (ASD) now affects 1 in 59 of the nation's children (Baio et al., 2019). This translates to approximately 40,000 children in Michigan. Autism is a disorder which emerges early in life and features a combination of communication and social impairments and repetitive, restrictive behaviors (APA, 2017). Early intensive behavioral intervention is an empirically-supported treatment approach based on the principles of applied behavior analysis (ABA) that has the potential to reduce core and associated features of ASD, and possibly even result in children catching up with their typically developing peers (Reichow, 2012). Receiving ABA services as early as possible is a key factor in predicting positive treatment outcomes as it helps to increase the child's learning rate, thus improving their overall developmental trajectory, and narrowing the gap between children with ASD and their peers (Eldevik et al., 2011; Klintwall et al, 2013). A focus on early intervention may also decrease the risk of undesirable problem behavior emerging, such as self-injurious behavior and severe aggression, by teaching appropriate communicative and other adaptive behaviors in their place (Klintwall et al., 2013).

Unfortunately, there are many barriers that families must hurdle while they pursue a diagnosis and seek ABA services for their child that impedes this process and delays the child from receiving the services they need. That is, when a child presents with early signs of autism, the caregiver must pursue a formal evaluation to determine if their child meets diagnostic criteria for ASD; however, navigating this process can be challenging (e.g., knowing which assessment approach to pursue, limited number of approved autism evaluation centers, logistics of

scheduling an appointment and traveling to an approved center) and often results in a delay to receiving a formal diagnosis. Further, once a diagnosis is made, identifying an ABA service provider and enrolling one's child may be challenging given the relatively low number of ABA providers in the state (116 ABA centers; Autism Alliance of Michigan, n.d.) and limited space at these centers due to the overwhelming demand for ABA services in the state (i.e., only 1,300 behavioral technicians to serve 40,000 individuals with ASD; BACB, 2018). According to a study done by Vohra et al. (2013), caregivers of children with ASD are more likely to report difficulty with access to services compared to other caregivers with children that have other developmental disorders, mental health conditions, or both. Specifically, issues due to eligibility, availability of services, difficulty obtaining information about services, and delays in appointments were indicated as barriers to access in this study (Vohra et al., 2013). This is concerning, especially considering that the demand for Board Certified Behavior Analysts (BCBAs), the professionals who develop ABA interventions, has more than doubled in recent years (BACB, 2019).

As the demand for ABA services continue to outpace the current availability of behavioral technicians and BCBAs in the state of Michigan, families pursuing ABA services are almost guaranteed to experience another delay to receiving the services they need: Waitlists. That is, even when an ABA service provider is identified and determined to be a good fit for the child's therapeutic goals, there is a high likelihood that the family will need to wait even further before they can be enrolled in the center to receive services given the service provider is likely already at capacity. As mentioned, the time a child spends waiting to receive treatment may be detrimental to their development and their health. Further, the lack of available ABA services, increasing gaps in skills and language as compared to their peers, or the appearance of problem

behavior may drive caregivers to seek alternative methods of treatment. Complementary and alternative medical treatments have been used by 28% to 95% of children with ASD, despite there being little proof to support the effectiveness of these alternative treatments (Höfer, 2017). Not only are these alternative treatments often ineffective, but they also consume valuable resources (e.g., caregivers money and time), and can be harmful in some cases (James et al., 2015).

In addition to being detrimental to the child's wellbeing, an extensive waitlist period can also have a negative effect on caregivers as well. Researchers have found that attaining support and services for their child is one of the top concerns for caregivers of children with ASD (Tehee, 2008). Thus, questions surrounding waitlists, such as “How long will my child be without services?”, may further subject caregivers to this stressor. Given that these are crucial periods of rapid development for their children and stressful times for caregivers, available services and supports are a vital resource to establish positive developmental trajectories and family wellbeing. Additionally, families of children with autism have also been found to report an employment, financial, or time related burden in comparison to families with children who have other developmental disorders, mental health conditions, or both (Vohra et al., 2013). These burdens may be exacerbated by waitlists by delaying important skill acquisition and further keeping the caregiver from their employment.

Although a straightforward solution to this problem would be to increase the number of behavioral technicians and BCBA's in Michigan to expand ABA service provision throughout the state, this will likely take years to achieve. Another approach may be to offer training or support to families while they are on the waitlist to provide caregivers the skills they need to manage their child's behavior and maintain their skills and improve long-term outcomes. However,

despite the increase in demand for ABA service delivery and the common occurrence of families being waitlisted, there is no actual data available to indicate how often (and for how long) families experience a waitlist prior to receiving ABA services. Further, it is presumptuous to assume that one can provide effective interventions without first understanding the caregiver's needs, the child's needs, and the barriers to treatment that a family may face during this time.

Therefore, a survey assessing the needs of caregivers and their family during this waitlist period needs to be developed and deployed. However, prior to disseminating the survey widely throughout the state of Michigan, there needs to be a pilot to determine that the survey questions developed are thorough, inclusive, and clear. Thus, the primary purpose of this survey was to recruit feedback from those who completed the survey to determine whether the survey content was presented clearly and was inclusive. We used the feedback to make any necessary edits to the survey regarding clarity, organization, and thoroughness of the survey questions. Feedback was used to determine if any questions or response options created confusion, were missing, needed to be added, or needed to be reorganized. We utilized these data to improve the overall quality of the survey.

Additionally, the results of this pilot phase will provide us with some preliminary data that might predict outcomes related to (1) the amount of time a family typically spends on a waitlist for services, (2) the needs of caregivers while they are on a waitlist, (3) caregiver's interest in receiving support while on a waitlist, and (4) the caregivers preference for such supports. These results provide a preliminary summary of family needs and preference for services and supports while awaiting treatment. This information is vital to understanding the state of ABA services in Michigan so that limitations to the current system can be addressed and support systems and training curriculum can be developed and offered to address this need.

Method

Participants

Eight residents of Michigan volunteered to participate in this study by completing the survey in its entirety. Participants were eligible to complete the survey if they were the primary caregivers of children (2-8 years old) with a diagnosis of ASD. To aid in the identification of eligible participants, we contacted several ABA clinics in Michigan and asked for their clinical coordinator to reach out to families who they knew were either currently on or had previously experienced a waitlist and ask them to complete the survey.

Materials

Participants who volunteered to enroll in this study and who agreed to the consent were asked to complete an online survey designed to understand the state of ABA service delivery in Michigan. A group of scientist practitioners developed the survey and used their clinical experience working within this population to design questions that would produce data needed to (a) determine the prevalence of families who spend time on a waitlist prior to receiving ABA services, (b) assess families motivation for support, and (c) identify specific needs during this challenging time. Several other professionals individually reviewed the questions, all of which (a) had experience conducting survey research, (b) had experience working with caregivers who had a child diagnosed with ASD, (c) were the primary caregiver for a child with special needs, or (d) some combination of these characteristics to ensure the content validity of the questions. The feedback from these professionals improved the clarity, format, and organization of the questions.

Within the survey, multiple opportunities were provided for participants to provide feedback on the content. Questions regarding content occurred after seven different groups of

questions across the length of the survey, approximately every 16 questions. The first group of questions asked about demographics and the second group of questions asked about the type of services and supports the caregivers were aware of and who made them aware of them. The third group of questions asked caregivers about their experiences on waitlists. The fourth group of questions asked about the caregivers' needs while on a waitlist, child's behaviors, preferences for services, and the types of services that the caregiver pursued while on a waitlist. The fifth group of questions asked about other preferences for services and their previous experience with services and supports. The sixth group of questions asked about caregiver needs and challenges that might prevent them from utilizing supports and services. Lastly, the seventh group of questions asked for further information about their preferences for services and supports. Specifically, at the end of each of these question groups, questions were posed that requested feedback on the following: (a) clarity of questions, (b) whether additional questions should be added, (c) whether additional questions should be deleted, and (d) whether they had any additional feedback. These sections consisted of a 5-point Likert scale (very unclear to very clear), yes/no, and short answer questions. At the end of the survey the participants were presented with several social validity questions using a 3-point Likert scale (unsatisfied to satisfied) that asked how they felt about the survey's (a) length, (b) content, (c) thoroughness, and (d) overall experience. All questions requesting feedback were optional and the participant could submit the survey without answering these questions.

In general, the survey presented the participant with a series of questions related to (a) participant eligibility, (b) participant demographics, (c) whether or not their child was placed on a waitlist prior to receiving ABA services, (d) the approximate duration of time spent on this waitlist, (e) the participant's primary concerns while their child was awaiting services, (f) the

participant's needs at the time their child was awaiting services, and (f) the potential barriers that might interfere with accessing services while their child was awaiting services and (g) content clarity and thoroughness (see *Survey* in Appendix A).

The entire survey consisted of 114 closed-ended and 46 open-ended questions. Of the 114 closed-ended questions there were 22 yes/no questions, 29 multiple choice questions in which only one answer can be selected, 20 multiple choice questions in which more than one answer can be selected, 5 multiple choice questions displayed in a dropdown format, and 38 questions presented in a matrix format. Of the 46 open-ended questions, 33 were short-answer questions (e.g., please specify) and 13 were longer open-ended questions in which there was space for a paragraph to be written.

At a minimum, the survey took less than 1 min to complete (i.e., if they did not meet initial eligibility) or approximately 15-20 min if they were eligible and answered all relevant questions within the survey. The survey was built in and disseminated through REDCap, which is a HIPAA compliant and secure web platform for managing online databases and surveys.

Procedures

The online survey was disseminated to caregivers throughout the state of Michigan by several ABA clinics after IRB approval (see *IRB* in Appendix B). The researchers involved in this study contacted several ABA service providers in the state of Michigan to determine if they might be willing to assist in recruiting caregivers to participate in this preliminary survey. Five ABA clinics agreed to send out information regarding the survey by emailing families that fit our eligibility criteria. We limited the number of clinics involved in this preliminary survey to prevent the risk of widely spreading the initial survey link before our finalized survey was completed. Feedback data collected from this preliminary survey informed us of issues regarding

clarity, organization, and questions or response options that needed to be added or deleted. Because this survey can be characterized as a broad-based autism community needs assessment, we did not run any sophisticated statistical packages and thus did not require a larger number of respondents to ensure statistical power. We used descriptive statistics to analyze the survey results. After the survey window closed, we used participant feedback about clarity, the need to add or delete certain questions, the need to add or delete any response options, and additional comments or thoughts to inform edits to the final survey. Additionally, the data were analyzed across a number of relevant variables (described below in detail).

Survey

We conducted an in-depth questionnaire on families from across the state of Michigan to pilot the initial survey questions. The purpose of conducting the pilot survey was to recruit immediate feedback on the clarity, organization, and thoroughness of our questions. That is, if we recognized that any survey questions or response options (a) created confusion, (b) were not organized in an optimal manner, or (c) were missing, we used this information to update and improve the overall quality of the survey. In addition, the information gathered in this survey provided preliminary results on waitlist duration and caregiver needs.

Dissemination of Survey

Approximately five clinics participated in disseminating the survey. Clinicians that we reached out to were asked if they would send information about our survey and the survey link to caregivers associated with their clinic that had either been on a waitlist or were currently on their waitlist. Clinicians that did not respond to the initial email received a follow up email approximately one week later. Clinicians who agreed were given the survey link, a flyer

advertising the study (see *Recruitment Flyer* in Appendix C), and an optional email script to include in messages to potential participants.

Completion of the Survey

Participants interested in volunteering to enroll in the study completed the online process of consent (see *Consent Form* Appendix D). The process of consent consisted of reviewing descriptions of (a) the purpose of the study, (b) eligibility, (c) the study procedures, (d) types of data collected, (e) risks of participating in the study, (f) benefits of participating in the study, (g) confidentiality (h) procedures for storing study information, (i) compensation, (j) contact information, and (k) the voluntary participation statement. Following participant consent, respondents completed an authentication process by entering their email address to receive a pin that they needed to enter in order to access the survey. The respondent's IP address was masked from the researchers.

Measurement and Data Analysis

Participant responses to survey questions were stored on the REDCap Cloud database and researchers could only access the database by entering their username and a password. When the survey was completed or when the participant closed the survey window, all participant responses were aggregated in REDCap and summarized as the following outcome measures: (a) proportional summary of respondents thoughts on content clarity, (b) proportional summary of whether participants thought that any questions needed to be added or deleted and subsequent qualitative analysis of suggestions, (c) qualitative analysis of respondents comments and thoughts regarding survey questions, (d) mean, median, mode, and range of respondent duration spent on waitlist, and (e) proportional summary of respondent's child concerns, needs while on waitlist, and potential barriers interfering with receiving services. We calculated the average

duration of time spent on a waitlist by using the upper value of each range. This ensured that the duration of time spent on a waitlist was not underestimated. We used R and RStudio to analyze the survey responses (R Core Team, 2020; RStudio Team, 2021). The psych package within RStudio generated a descriptive summary of the data including mean, standard deviation, median, range, minimum, and maximum for relevant questions. In general, variables that are potentially related to waitlist durations (e.g., various demographic variables, level of child concern, reported barriers) were analyzed to determine if there are any interesting and significant differences between demographic groups.

Results

Demographics

Eight participants responded to our pilot survey. As the survey was distributed by partnered clinics through an internet link, we do not know how many caregivers were invited to participate and thus we cannot determine the response rate. All participants met the inclusion criteria which required that they were residents of the state of Michigan and had a child or adolescent that had been diagnosed with ASD. All of the respondents were biological parents of their child and identified themselves as white/caucasian. 100% of respondents reported that English was the primary language spoken at home. The range of reported household income varied from *less than \$25,000* to *\$150,000 or more*. Of the families surveyed, one family (12.5% of respondents) reported a household income less than \$25,000, Three families (37.5% of respondents) reported a household income of \$100,000 to \$149,000, and four families (50% of respondents) reported an income of \$150,000 or more. Household size varied from three to 6 or more, with four members as the mode. Three families (37.5% of respondents) reported a

household size of three and one family (12.5% of respondents) reported a household size of 6 or more.

In addition to caregiver demographics, we also collected data on their children with ASD. Of our participants, Six caregivers (75% of respondents) cared for a male child with ASD and two caregivers (25% of respondents) cared for a female child with ASD. 100% of the children that our participants cared for were white/caucasian. In response to the question “ What setting best describes where your child with ASD lives?”, Five caregivers (62.5% of respondents) answered a city, two caregivers (25% of respondents) answered a rural town, and one caregiver (12.5% of respondents) answered a metropolitan area. Michigan counties that participants reported their child primarily resided in included Washtenaw (three respondents), Wayne (two respondents), Monroe (one respondent), Kalamazoo (one respondent), and Shiawassee (one respondent). Caregivers were asked whether their child had any additional diagnoses other than ASD. Three caregivers (37.5% of respondents) reported additional diagnoses (including: 16p11 duplication, ADHD, Generalized Anxiety Disorder, and speech delay). Further, participants were asked about their insurance provider for their child: Three caregivers had Blue Cross Blue Shield of Michigan Mutual Insurance Company (37.8% of respondents), two caregivers had Blue Care Network of Michigan (25% of respondents), one caregiver had Aetna Better Health of Michigan (12.5% of respondents), one caregiver had UnitedHealthcare Community Plan (12.5% of respondent), and one caregiver had Anthem Blue Cross Blue Shield (12.5% of respondents).

Survey Feedback

After the first section of questions addressing participant demographics, all eight caregivers (100% of respondents) answered that the questions in that section were *very clear*. This information is summarized in Table 2. Seven caregivers (87.5% of respondents) thought

that *no* other questions needed to be added or deleted. One participant (12.5% of responses) said *yes*, indicating that they thought that questions needed to be added and deleted. When asked what question(s) needed to be added the participant responded that we should add “Any complications during pregnancy?” and “Were there any medications taken during pregnancy or while breastfeeding?” Additionally, the participant responded “I’m not clear on why income matters” when asked what questions should be deleted. There were no additional thoughts or comments about the questions in the section. Responses to questions regarding adding or deleting questions or response options are shown in Figure 1.

In the second section we asked questions about the type of services and supports that caregivers were aware of and who made them aware of these supports and services. Information regarding feedback responses to this section are in Table 1 and Table 2. In this section requesting feedback, six caregivers (75% of respondents) said that the section was *very clear*, one caregiver (12.5% of respondents) said it was *clear*, and one caregiver (12.5% of respondents) was *indifferent*. One respondent (12.5% of respondents) answered that the survey could be made clearer with the following comment: “The Center that our son was diagnosed at made us aware of social skills training and parent training. However, they had no availability, and did not offer help to find those forms of therapy.” One participant answered that Early Start should be added when asked what questions should be added. One participant answered that question(s) should be deleted, however, they did not indicate which ones. One caregiver (12.5% of caregivers) had additional thoughts or comments about the questions in the section and suggested that we add Early Start as an option for how they were made aware of services and supports. Additionally, one caregiver (12.5% of respondents) suggested adding a school option for information.

The next group of questions was pertaining to caregivers experiences while on a waitlist. After this third group of questions, five caregivers (62.5% of respondents) answered that the section was *very clear* and three (37.5% of respondents) answered that the previous section was *clear*. There were no suggestions from any respondents about adding or deleting any questions in this section or on how to make the questions clearer. However, two participants (25% of respondents) had additional thoughts or comments. These comments included; “Our son was on 3 waitlists for ABA. An opening for one occurred after 3 months, but was shut down because of COVID before he could begin. It eventually took 6 more months before he was able to begin services with another center.” and “The only reason we got in so quick (4-6 months) was because of covid19. Otherwise we were looking at about a year in most places. That's after waiting a year for a diagnosis. It shouldn't take 2 years to receive help for our children.” These responses relating to clarity, adding/deleting survey content, and additional thoughts are shown in Figures 1 and 2.

Next, we asked about the caregivers' needs while on a waitlist, child's behaviors, preference for services, and what services they pursued while on a waitlist. As shown in Table 1, five caregivers (62.5% of respondents) said that the questions in the previous section were *very clear* and three caregivers (37.5% of respondents) said that the questions in the section were *clear*. Of the participants, all answered that no questions needed to be added or deleted and no additional comments or thoughts were supplied. This information can be seen in Table 2.

In the fifth section we collected data on caregiver preferences for services and supports as well as their previous experiences with services and supports. The fifth section was rated as *very clear* by five of the caregivers (62.5% of respondents) and as *clear* for three of the caregivers

(37.5% of respondents). As shown in Table 2, all of the respondents answered that no questions should be added. One caregiver (12.5% of respondents) answered that question(s) should be deleted from this section, however, they did not elaborate on which questions. No caregivers reported any additional comments or thoughts about this section.

Additionally, we asked questions about caregiver needs and challenges that may prevent them from seeking out or utilizing potential services or supports. As noted in Table 1, in this sixth group of feedback questions five caregivers (62.5% of respondents) said that the questions in the section were *very clear* and three caregivers (37.5% of respondents) said that the questions in the section were *clear*. None of the participants reported that any questions needed to be added or deleted (see Table 2). Likewise, no additional comments or thoughts were provided.

Finally, after answering the seventh group of questions addressing more caregiver preference for supports and services, five caregivers (62.5% of respondents) said that the questions in the section were *very clear* and three caregivers (37.5% of respondents) said that the questions in the section were *clear*. None of the participants thought that any questions needed to be added or deleted. When asked if they had additional thoughts or comments one participant answered that “ With Covid, I think this would have to be done virtually right now”, regarding possible services and support for caregivers. Information regarding this and feedback from previous sections is shown in Tables 1 and 2.

Overall, the eight participants (87.5% of respondents) reported being *satisfied* after going through all of the survey questions and one participant (12.5% of respondents) reported being *very satisfied*, as shown in Table 3. Of the participants, eight (87.5% of respondents) were *satisfied* or *very satisfied* with the survey’s thoroughness and one participant was *neutral*.

Likewise, eight of the participants (87.5% of respondents) answered that they had been *satisfied* with the survey content and one remained *neutral*. In regards to the survey length, five participants (62.5% of respondents) reported being *satisfied* and three participants (37.5% of respondents) remained *neutral*.

Waitlist

All eight participants (100% of respondents) answered that they had at one point been on a waitlist. We asked participants that had been on a waitlist how much time they had spent on the waitlist that they received services from. The average amount of time spent on a waitlist was 10.8 months with a standard deviation of 3.19 months. One caregiver (12.5% of respondents) responded that they waited for less than one month, one caregiver (12.5% of respondents) waited 4-6 months, one caregiver (12.5% of respondents) waited 7-9 months, and three caregivers (37.5% of respondents) waited more than 12 months. These data are illustrated in Figure 1. Of the eight participants, two families (25% of respondents) answered that they were still on a waitlist and had been waiting 4-6 months and 7-9 months. In addition, we asked participants if they were ever on multiple waitlists at once. Six participants (75% of respondents) reported that they had been on multiple waitlists with a range of two to five or more waitlists. The number of waitlists a child was reported being on at a given time are illustrated in Figure 1. A mode of two waitlists at a time was reported. When asked what year they started pursuing ABA services, three caregiver (37.5% of respondents) said 2020, two caregivers (25% of respondents) said 2019, one caregiver (12.5% of respondents) said 2017, one caregiver (12.5% of respondents) said 2012, and one caregiver (12.5% of respondents) preferred not to answer. We also asked the two participants that did not report receiving services why they had not received services since being

placed on a waitlist. One caregiver (50% of question respondents) reported a lack of resources/price of services and both reported that they were still waiting for services.

Awareness of Services

We asked caregivers of children with autism what services they were made aware of at the time of diagnosis and who made them aware of these services. Of the eight participants, seven participants (87.5% of respondents) were made aware of speech language therapy at the time of diagnosis. Of the caregivers that were made aware of this therapy, a healthcare provider made six caregivers (75% of question respondents) aware of speech language therapy and three caregivers (42.9% of question respondents) found out through their own research.

We also asked caregivers if they were made aware of occupational therapy. Five caregivers (62.5% of respondents) had been made aware of occupational therapy and three caregivers (37.5% of respondents) had not made aware of occupational therapy. Of these five that were made aware of occupational therapy, four participants (80% of question respondents) were made aware by a healthcare professional, two participants (40% of question respondents) by their own researcher, and one participant (20% of question respondents) by a friend.

All eight participants (100% of respondents) were made aware of ABA services at the time of diagnosis. Six caregivers (75% of respondents) reported being made aware of ABA by a healthcare professional, five caregivers (62.5% of question respondents) reported being made aware of ABA services through their own research, and one caregiver (12.5% of question respondents) were made aware of ABA by a friend. Participants could indicate multiple answers if they had learned about the service through multiple methods.

Regarding educational/school-based therapies, seven participants (87.5% of respondents) had been made aware of such services and one participant (12.5% of respondents) had not been

made aware of them. Of the participants that had been made aware of educational/school-based therapies, four participants (57.1% of question respondents) indicated that a healthcare professional made them aware, three participants (42.9% of question respondents) indicated that they learned about these therapies through their own research, and one participant (14.3% of question respondents) indicated learning about these therapies through a friend.

Three participants (37.5% of respondents) were made aware of cognitive behavior therapy, four participants (50% of respondents) were not made aware, and one participant (12.5% of respondents) did not know if they were made aware at the time of diagnosis. Of the three participants that were made aware of cognitive behavior therapy, two caregivers (66.7% of question respondents) reported learning about it through their own research and one participant (33.3% of question respondents) reported learning about it through a healthcare professional.

Social skills training was made aware of to three participants (37.5% of respondents) and was not made aware of to five participants (62.5% of respondents). All three participants reported that they were made aware of social skills training through a healthcare professional (100% of question respondents).

Two participants (25% of respondents) reported being made aware of patient training services and six participants (75% of respondents) reported not being made aware of these services. Of the participants that were made aware of these services, two participants (100% of question respondents) were made aware of it through a healthcare provider and one participant (50% of question respondents) were made aware of it through a friend.

All eight (100% of respondents) answered that they had not been made aware of parent workshops. Of the eight participants, two participants (25% of respondents) were made aware of medical treatment. The two caregivers that reported being made aware of medical treatments

both answered that it was through a healthcare provider (100% of question respondents). One participant (12.5% of respondents) answered that they had been made aware of diet/nutritional therapies. This participant reported that they had been made aware of this through a healthcare professional. Additionally, all participants (100% of respondents) answered that they had not been made aware of vitamins. Two participants (25% of respondents) reported being made aware of sensory integration therapy. One participant reported that they had been made aware of this therapy by a healthcare provider and the other reported that they had been made aware of this therapy by their own research. Lastly, no participants (100% of respondents) had been made aware of respite care at the time of their child's diagnosis. When asked if they had been made aware of any other services, six participants answered that they had not been made aware of any other services and two participants did not answer.

Caregiver Needs

In order to determine the needs of caregivers while on a waitlist we collected information about their child's behavior. Major concerns across different developmental areas reported are shown in Figure 2. All eight caregivers indicated that problem behavior was a concern, with 87.5% of respondents reporting that problem behavior was a *major concern*. Likewise, appropriate communication was a concern for most participants with this being a *major concern* for six caregivers (75% of respondents), a *slight concern* for one caregiver (12.5% of respondents), and *not a concern* for one caregiver (12.5% of respondents). Social skills deficits were a reported concern for seven participants, with social skills deficits being a *major concern* for three caregivers (37.5% of respondents). It was also a *slight concern* for four caregivers (50% of respondents) and one participant did not answer this question. Daily living skills were a concern for six of our participants, with four caregivers (50% of respondents) reporting daily

living skills as a *major concern*. Daily living skills were not a concern for two of the caregivers (25% of respondents).

We also asked caregivers about the severity of their child's behaviors while on a waitlist. Of these responses, five caregivers (62.5% of respondents) reported *severe behaviors* (the behaviors occurred daily OR the behaviors resulted in injury to self or others) and three caregivers (37.5% of respondents) reported *medium behaviors* (the behaviors occurred more than once per week AND the behaviors resulted in little to no injury to self or others).

Based on the length of time that families were waiting for services we asked caregivers to report whether their child's behaviors/skills got worse, stayed the same, or improved while on the waitlist. The participant that reported waiting one month or less reported that behaviors/skills stayed the same. The two participants that waited for services for 4-6 months reported that their child's skills/behaviors improved. Of the two participants that reported waiting for services for 7-9 months, one child's skills/behaviors stayed the same and one's skills/behaviors got worse. Lastly, all three participants that reported waiting for services for more than 12 months saw their child's skills/behaviors get worse. As shown in Figure 3, caregivers who were on a waitlist for a period of time greater than 6 months reported worsening behaviors unlike those who waited for services under six months.

Based on their needs, caregivers were asked to indicate their greatest needs while on a waitlist for services (see Figure 4). All of the participants (100% of respondents) indicated that they needed skills for managing their child's challenging behavior. Six caregivers (75% of respondents) indicated that they needed strategies for teaching and maintaining their child's skills. Four caregivers (50% of respondents) needed support for teaching and maintaining daily

living skills and five caregivers (62.5% of respondents) needed assistance in addressing other routine behavior such as mealtime. One caregiver (12.5% of respondents) indicated that they needed support in advocating for their child's needs. Additionally, three caregivers (37.5% of respondents) indicated that they needed support and services for their own mental health and one caregiver (12.5% of respondents) indicated that they needed respite care.

Caregiver Interest and Preferences for Supports

Preferences for supports varied across the participants; however, all eight participants indicated that they were interested in supports. Caregivers indicated their preferred type of instruction and were able to choose multiple types as preferred. The most preferred methods were Individual/1-on-1 setting, observing live- in-person modeling, and observing pre-recorded video models. Each of these options had five caregivers (62.5% of respondents) indicating that it was a preferred method. Of the eight respondents, six caregivers (75% of respondents) indicated that they would prefer to receive written feedback and six caregivers (75% of respondents) also preferred to receive feedback in the moment. In regards to the most preferred time for support or services, six caregivers (75% of respondents) preferred afternoons. The weekdays were also more preferred than weekends for support and training; six caregivers (75% of respondents) indicated that they preferred weekdays and two caregivers (25% of respondents) preferred weekends.

Given the participants' responsibilities, two caregivers (25% of respondents) responded that they were very likely to attend support services, five caregivers (62.5% of respondents) would be somewhat likely to attend, and one caregiver (12.5% of respondents) were somewhat unlikely to attend. Of our participants, five caregivers (62.5% of respondents) preferred that the

sessions last 1 hr. The amount of time participants were willing to dedicate each week varied between participants; four caregivers (50% of respondents) preferred 1 hour, three caregivers (37.5% of respondents) preferred 2 hours, and one caregiver (12.5% of respondents) preferred less than an hour per week.

We also collected information on possible barriers to attending training and support services. None of the caregivers in our sample reported a lack of resource accessibility (e.g. transportation, technology, etc.) but five caregivers (62% of respondents) reported they had too many other therapies/activities, two caregivers (25% of respondents) reported distance to services, six caregivers (75% of respondents) reported lack of time, and one caregiver (12.5% of respondent) reported that they were already receiving services at school. Reported barriers to services and supports are shown in Figure 5. Further, no caregivers indicated that the requirement/commitment/work amount was too much, that they didn't believe it would be helpful, that they were not sure it would be helpful, or that they were uncomfortable having people in their house.

Discussion

Survey Feedback

Since the majority of participants answered that the survey questions were either very clear or clear, the wording of the survey questions remained the same. One participant suggested that we add questions regarding complications and medications during pregnancy after finishing the first group of questions. We did not make changes to the survey to address these comments by adding questions regarding pregnancy because the purpose of this survey is to determine caregivers' needs and experiences while on a waitlist, not to collect data about their experiences

while pregnant with their child. In addition, a participant questioned why income was a relevant variable and indicated that they thought the question should be discarded. We decided to keep the question asking about income to allow us to analyze any differences between those with higher incomes and those with lower incomes in regard to barriers to services, waitlist duration, and other variables in a larger sample size.

However, in the second section we did add the option of “Early On Michigan” as a source of information about services and reports based on feedback. The feedback requesting Early On as an option was made by two participants suggesting that it may be a valuable source of information that many caregivers utilize. We did not add the school option for information due to educational/school-based services being a service that we collected data on already. “Autism Evaluation Center” was added as an option since our question specifically asked about awareness of these services and supports at the time of diagnosis and they are potentially a source of information for many caregivers after their child receives an autism diagnosis that was not included in the current survey.

No further changes were made to sections in response to the feedback and comments that we received. The comments in section three about changes to waitlists due to the COVID-19 pandemic were not addressed because there is an additional open text box at the end of the survey to address additional waitlist comments and thoughts where this information can be entered. In addition, if the caregiver is still waiting for services they have the opportunity to express why in a short answer text box within that section. Lastly, we received no negative feedback regarding the survey in our concluding questions. Most of the participants were highly satisfied with their overall experience while taking the survey. Likewise, the majority of

respondents reported being satisfied with the survey content, length, and thoroughness. Given these data, we did not make any further edits to the survey.

Waitlists

All of the participants in this study had been on a waitlist or were currently on a waitlist. This was due to our survey dispersal methods, which asked ABA clinical directors to contact potential participants from their client base that had been on a waitlist or from their waitlist. Of the caregivers that had received services at the time of this survey, the average waitlist duration was 10.8 months. Additionally, many of the participants reported being on multiple waitlists at once. These data indicate that long waits of over 6 months for access to behavioral services are common in the state of Michigan, regardless of whether the child is on more than one waitlist.

Furthermore, there was a discrepancy in behavior change among those whose child waited on a waitlist of less than six months or for more than six months (see Figure 3). Those that were on a waitlist for less than six months reported no change in their child's behavior or improvement of their child's behavior. However, the majority of those that were on a waitlist for longer than 6 months reported worsening behaviors. This suggests that six months of being on a waitlist may be the length of time that behaviors take to significantly escalate in the absence of behavioral interventions. This reported worsening of child's behavior may also be due to caregiver perspective and a reaction to the long wait for services. More research is needed to determine if waiting longer than 6 months significantly negatively affects behavior. In general, these findings are very concerning and indicate the need to decrease the number of families spending time on a waitlist. For those that must spend time on a waitlist, we must either (a) decrease the duration, (b) provide services and supports during this time, or (c) some combination of a and b.

Awareness of Services

Caregivers were commonly aware of speech-language pathology, ABA, occupational therapy, and educational or school based therapies. The awareness of a majority of these therapies were made through medical professionals or through the participants own research. Not making caregivers aware of these services as early as possible may prevent the child from receiving these services in a timely manner. Thus, it is important that medical professionals, such as those at autism evaluation centers, provide caregivers with information on evidence-based treatments and therapies to encourage caregivers to utilize these services and introduce them to the child as early as possible for the most effectiveness. Although all caregivers were aware of ABA therapy for their child, only two caregivers were made aware of parent training services and no caregivers were made aware of parent training workshops. Additionally, no caregivers were made aware of options for respite care services. Therefore, communication of these supports to caregivers is extremely lacking. However, this may be due to a lack of knowledge about the benefits of caregiver support or due to a lack of these resources and services. Finally, survey responses indicated that most caregivers were not made aware of alternative interventions that are not evidence-based (e.g., nutritional therapies, vitamins, or sensory integration therapy). This is a positive sign as many of these practices have no effect or have negative effects, such as being unnecessarily restrictive.

Caregiver Needs and Preferences

Caregivers reported being concerned about several areas of their child's development, with many indicating major concerns across more than one area. These data indicate that there are strong needs for supports or services offered to caregivers while they are awaiting ABA therapy. Over half of the participants stated that their child exhibited severe problem behavior,

defined as engaging in behavior daily that resulted in injury to self or others, while being on a waitlist. This is very concerning since if caregivers do not get the support that they need, these behaviors may continue to persist or escalate, thus possibly endangering the child and those around them if they do not get the proper training and support during this time. Furthermore, high rates of problem behavior can complicate ABA therapy and delay progress once therapy has begun. Another risk of not addressing problem behavior in a timely manner is that an ABA therapy clinic or setting that is appropriate at the start of seeking treatment may not be equipped to treat new or escalated behaviors that develop while on a waitlist. This would require that the child go to a clinic that specializes in the assessment and treatment of severe problem behaviors, possibly resulting in more time on a waitlist and further escalation of behaviors.

All families that participated in this survey indicated a need for skills addressing their child's problem behaviors, including families who did not experience severe problem behaviors. This was followed by a desire to learn strategies for teaching and maintaining their child's skills. These needs indicate a strong demand for caregiver training supports addressing these skills that are accessible to these families.

Preferences for Supports and Services

All caregivers were interested in additional supports and services. Based on their preferences for these services, we propose either 1-on-1 live in person modeling or pre-recorded video models to reach caregivers. Pre-recorded videos may be a practical method for disseminating a caregiver skills training curriculum effectively and efficiently. Additionally, live in-person modeling and training may be an option for those with more complex or greater needs, such as those with children that have more severe behaviors. Caregivers also reported a preference for written feedback and feedback in the moment. Feedback in the moment is possible

with one-on-one in person modeling whereas written feedback may be utilized after the fact if caregivers record their interactions with their child and allow clinicians to review and comment at a later time. This asynchronous format allows for more flexibility and thus may reach a wider group of caregivers. In addition, most caregivers preferred to receive services for one hour on weekday afternoons. A caregiver skills training program may be most accessible to caregivers at this time according to these preliminary results. Several caregivers indicate that a commitment to other services are a barrier to receiving potential caregiver training. A solution to this may be to educate caregivers on the benefits of learning these skills in order to increase the priority level of learning the skills offered in a caregiver training curriculum.

Limitations

Limitations to this study include the small sample size and lack of diversity. Although the ratio of male to female children in this study was consistent with the reported 3:1 boys to girls ratio in the nation, our participant population was limited to only white/caucasian families and their biological children. In addition, the majority of participants lived in cities and made \$100,000 or more a year.

Future Directions

To address the limitations of this study we will disseminate the edited survey throughout the state of Michigan with the goal of recruiting a more diverse sample of respondents (e.g., rural and lower income families). The data collected from these surveys will provide insight on the state of waitlists and determine what curriculum and format will benefit the most caregivers in need. One method of providing support and services to families may be to instruct the caregivers of children with ASD on a mixture of evidence-based behavior analytic skills and therapies over telehealth sessions. Parent training curricula have been used to effectively educate and train

parents and caregivers on a variety of different ABA concepts such as reinforcement, and have even been used to teach caregivers therapy techniques such as Functional Communication Training and others (Lindgren et al., 2016). In many cases, these training sessions take place in-person over the span of several weeks.

However, this format has many potential drawbacks. In-person training requires transportation to the curriculum site which may limit the availability to those in need that live in rural areas or do not have reliable transportation. Going to a training session also requires the caregiver to secure child care during the meeting which may inhibit their availability to attend. Current parent training curriculums are a promising tool to provide much needed support to caregivers with children with autism that are on a clinic waitlist. However, this tool may not be available to caregivers and may not be set up to provide instruction while caregivers are waiting on a waitlist. Clinic waitlists may vary in the time spent on them and thus require either a shorter or longer period of instruction and be flexible to adjust to the caregivers needs.

Telehealth practices offer a solution to some of these common barriers. Telehealth is the use of technology to distribute therapy and health related services. This method of curriculum dissemination allows for communication and instruction over long distances and can be used to greatly reduce the time spent away from home. Telehealth has been shown to be an effective and cost-efficient way of delivering parent training (Lindgren et al., 2016; Wacker et al, 2013). Telehealth is a viable way of distributing a curriculum to parents and caregivers with children on a waitlist in a flexible manner.

Conclusion

More data is needed to determine the accessibility of ABA services in the state of michigan. However, this preliminary study indicates that waitlists are a common occurrence for

families seeking behavioral services. Families on waitlist often have concerns about their child's problem behavior. This delay to service may result in worsening behaviors which have the potential to be harmful to the child and to those around them, as well as presenting a possible barrier to therapeutic success.

Caregivers in this study indicated a general interest in receiving training to address their child's problem behaviors and teaching skills for developing and maintaining behaviors. Preferred modes of training suggested either 1-on-1 live model or remote asynchronous video model training type. Telehealth services may be a viable option to reach caregivers and accommodate their needs and barriers. Further data from disseminating an edited version of the survey discussed here will provide a better understanding of waitlist experiences and caregiver needs while awaiting services.

References

- American Psychological Association. (2017, January 2). *Diagnosing and managing autism spectrum disorder (ASD)*. <https://www.apa.org/topics/autism-spectrum-disorder>
- Autism Alliance of Michigan. (n.d.). *Navigator*. Retrieved October 11, 2020 from <http://navigator.autismallianceofmichigan.org>
- Baio, J., Wiggins, L., Christensen D. L., Maenner M. J., Daniels, J., Warren Z., Kurzius-Spencer, M., Zahorodny, W., Rosenberg, C. R., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp M., Lee, L., Harrington, R., Lopez, M. Fitzgerald, R. T., Hewitt, A., ... Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children. *MMWR Surveillance summaries*, 67(6), 1-23.
- Behavior Analyst Certification Board (2018). *BACB certificant data*. Retrieved October 11, 2020, from <https://www.bacb.com/BACB-certificant-data>.
- Behavior Analyst Certification Board. (2019). *US employment demand for behavior analysts: 2010-2018*. https://www.bacb.com/wp-content/uploads/2020/05/US-Employment-Demand-for-Behavior-Analysts_2019.pdf
- Behavior Analyst Certification Board. (2020). *About behavior analysis*. Retrieved from <https://www.bacb.com/about-behavior-analysis/>
- Eldevik, S., Hastings, R. P., Jahr, E., & Hughes, J. C. (2011). Outcomes of behavioral intervention for children with autism in mainstream pre-school settings. *Journal of Autism and Developmental Disorders*, 42(2), 210-220. <https://doi.org/10.1007/s10803-011-1234-9>

- Höfer, J., Hoffmann, F., & Bachmann, C. (2017). Use of complementary and alternative medicine in children and adolescents with autism spectrum disorder: A systematic review. *Autism, 21*(4), 387–402. <https://doi.org/10.1177/1362361316646559>
- James, S., Stevenson, S. W., Silove, N., & Williams, K. (2015). Chelation for autism spectrum disorder (ASD). *The Cochrane database of systematic reviews, 5*(5), CD010766. Advance online publication. <https://doi.org/10.1002/14651858.CD010766.pub2>
- Klintwall, L., Eldevik, S., & Eikeseth, S. (2013). Narrowing the gap: Effects of intervention on developmental trajectories in autism. *Autism, 19*(1), 53-63. <https://doi.org/10.1177/1362361313510067>
- Lindgren, S., Wacker, D., Suess, A., Schieltz, K., Pelzel, K., Kopelman, T., Lee, J., Romani, P., & Waldron, D. (2016). Telehealth and autism: Treating challenging behavior at lower cost. *Pediatrics, 137 Suppl 2*(Suppl 2), S167–S175. <http://doi.org/10.1542/peds.2015-2851O>
- R Core Team (2020). R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL <https://www.R-project.org/>.
- Reichow B., Barton E.E., Boyd B.A., & Hume K (2012). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews, 10*. <https://doi.org/10.1002/14651858.CD009260.pub2>
- RStudio Team (2021). RStudio: Integrated Development Environment for R. RStudio, PBC, Boston, MA URL <http://www.rstudio.com/>.
- Tehee, E., Honan, R., & Hevey, D. (2008). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities, 22*(1). <https://doi.org/10.1111/j.1468-3148.2008.00437.x>

- Vohra, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism: the international journal of research and practice*, *18*(7), 815–826. <https://doi.org/10.1177/1362361313512902>
- Wacker, D. P., Lee, J. F., Padilla Dalmau, Y. C., Kopelman, T. G., Lindgren, S. D., Kuhle, J., Pelzel, K. E., Dyson, S., Schieltz, K. M., & Waldron, D. B. (2013). Conducting functional communication training via telehealth to reduce the problem behavior of young children with autism. *Journal of Developmental and Physical Disabilities*, *25*(1), 35–48. <https://doi.org/10.1007/s10882-012-9314-0>

Tables

Table 1

Clarity of Questions in Each Section

How clear were the above questions in this section?	Percentage of responses (n = 8)		
	Very Unclear & Unclear	Indifferent	Very Clear & Clear
Section 1: Demographics	0%	0%	100%
Section 2: Types of services aware of	0%	13%	88%
Section 3: Experiences on Waitlist(s)	0%	0%	100%
Section 4: Needs, Child behavior, Service preferences, Services used while on waitlist	0%	0%	100%
Section 5: Preferences for services, Experiences with services	0%	0%	100%
Section 6: Caregiver needs, Barriers to services	0%	0%	100%
Section 7: Preferences for services	0%	0%	100%

Table 1 presents the participant's feedback on the clarity of the questions in each section.

Table 2

Survey Feedback by Section			
Section	Question*	Percentage Answering "Yes"	Written Feedback
1	Q1	13%	"Any complications during pregnancy? Where any medications taken during pregnancy or while breast feeding?"
	Q2	13%	"I'm not clear on why income matters."
	Q3	0%	"No"
2	Q1	13%	"Add Early on as an option. They were the most helpful."
	Q2	13%	
	Q3	25%	"school option for information" "Maybe add "Early On" as an option."
3	Q1	0%	
	Q2	13%	
	Q3	25%	"Our son was on 3 waitlists for ABA. An opening for 1 occurred after 3 months, but was shut down because of COVID before he could begin. It eventually took 6 more months before he was able to begin services with another center." "No" "The only reason we got in so quick (4-6 months) was because of covid19. Otherwise we were looking at about a year in most places. That's after waiting a year for a diagnosis. It shouldn't take 2 years to receive help for our children"
4	Q1	0%	
	Q2	0%	
	Q3	0%	"No"
5	Q1	0%	
	Q2	13%	
	Q3	0%	"No"
6	Q1	0%	
	Q2	0%	
	Q3	0%	"No"
7	Q1	0%	
	Q2	0%	
	Q3	13%	"With Covid, I think this would have to be done virtually right now." "No"

*Questions:

Q1: Do you think any question(s) should be added to this section?

Q2: Do you think any questions should be deleted in this section?

Q3: Do you have any additional thoughts or comments about the questions in this section?

Table 2 shows the feedback that we received across the different sections regarding questions that should be added or deleted as well as any additional thoughts or comments that the participant had.

Table 3

End of Survey Feedback				
Question in Section	Unsatisfied	neutral	satisfied	Very satisfied
Survey Length		38%	63%	
Survey Content		13%	88%	
Survey Word Choice		13%	75%	13%
Survey Thoroughness		13%	75%	13%
Overall Experience			88%	13%

Table 3 summarizes the feedback that we received at the end of the survey. We asked participants to rate the overall survey on a likert scale ranging from satisfied to unsatisfied. The majority of responses were satisfied or very satisfied with aspects of the survey and no participant reported being unsatisfied.

Figures

Figure 1

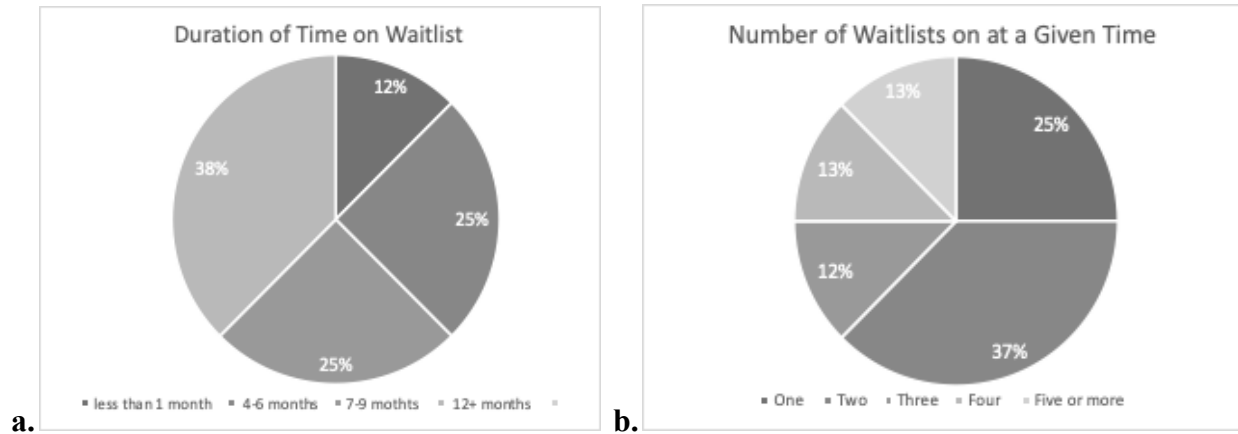


Figure 1. Figure 1.a illustrates the duration of time that caregivers reported being on a waitlist and figure 1.b demonstrates the number of waitlists that caregivers reported participating in.

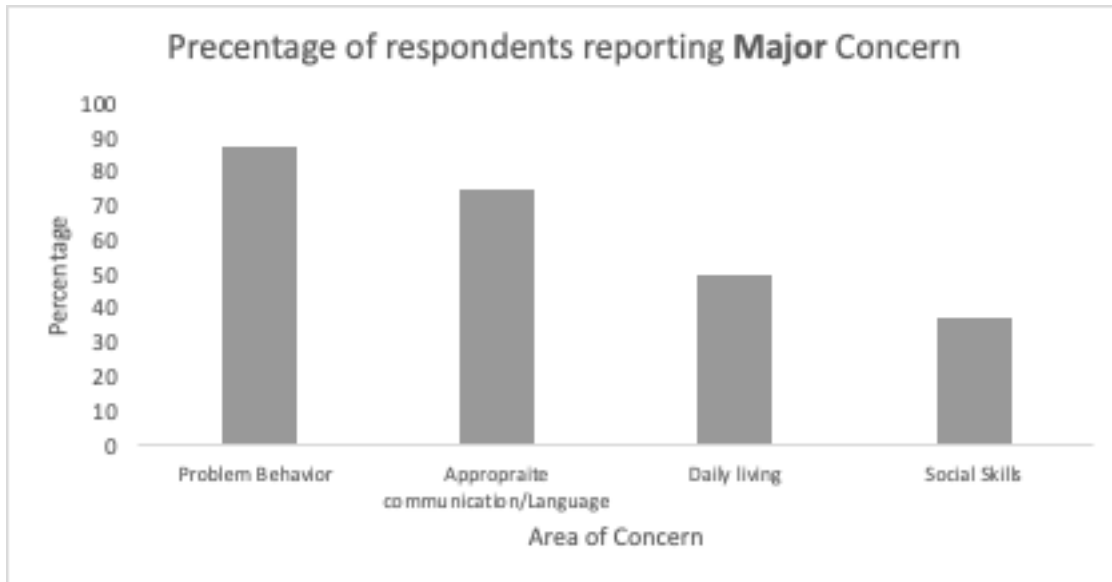
Figure 2

Figure 2 shows the major concerns reported by caregivers from the most commonly reported concern to the least commonly reported concern.

Figure 3

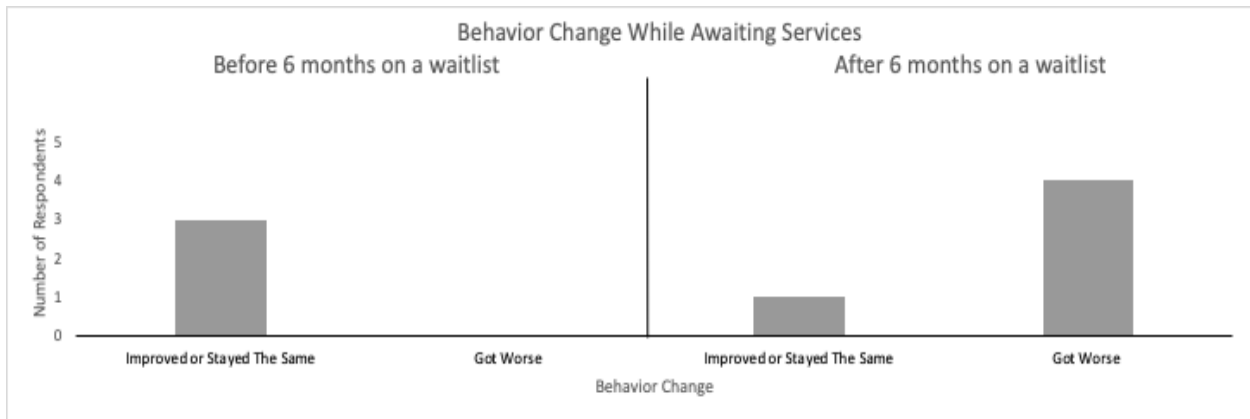


Figure 3 illustrates the change in children’s behaviors while on a waitlist to receive ABA services.

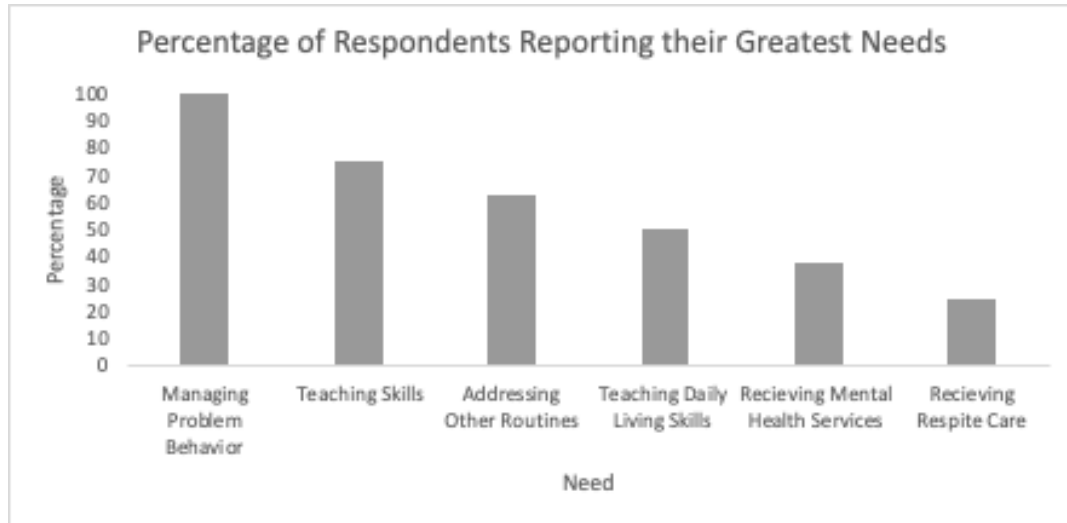
Figure 4

Figure 4 lists the percentage of respondents that reported a great need for one of the services listed in order from most common greatest need to least common greatest need.

Figure 5

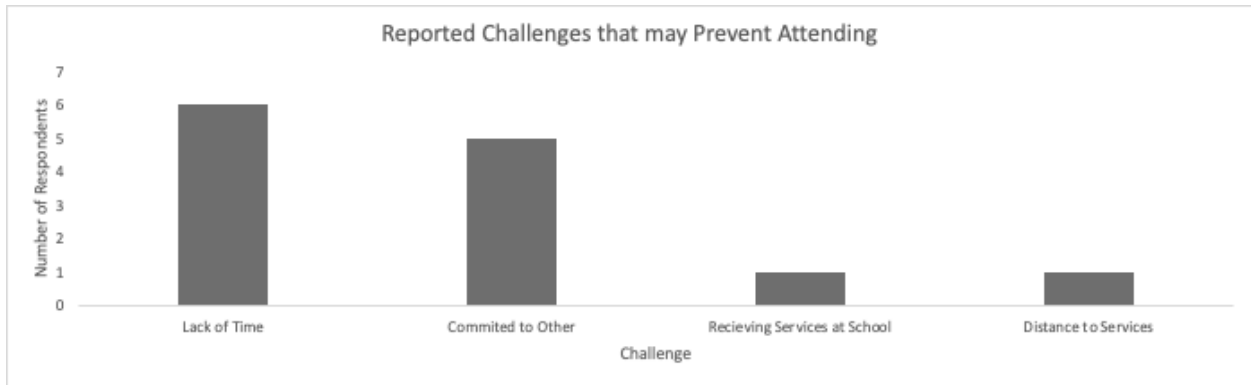


Figure 5 shows the reported barriers that may prevent attending supports and services.

Pilot Survey

Record ID

Record ID

Diagnosis and Services

Do you currently reside in Michigan?

- Yes
 No

Do you care for a child or adolescent who has been diagnosed with autism spectrum disorder (ASD)?

- Yes
 No

What is your relation to the child with ASD?

- Biological Parent
 Adoptive Parent
 Relative
 Other (please specify)

Please specify your relation to your child with ASD:

What year was your child with ASD born?

- Prior to 1994 1995
 1996 1997 1998
 1999 2000 2001
 2002 2003 2004
 2005 2006 2007
 2008 2009 2010
 2011 2012 2013
 2014 2015 2016
 2017 2018 2019
 2020 Prefer not to answer

What is your child with ASD's sex?

- Male
 Female
 Intersex
 Other (please specify)
 Prefer not to answer

Please specify your child with ASD's sex:

What is your child with ASD's ethnicity?

- Asian/Pacific Islander
 Black or African American
 Hispanic or Latino
 Native American or American Indian
 White/Caucasian
 Other (please specify)
 Prefer not to answer

Please specify your child with ASD's ethnicity:

Does your child have any additional diagnoses other than ASD?

- Yes
 No

Please specify your child with ASD's additional diagnoses:

What language is primarily spoken in the child with ASD's home?

- English
- Spanish
- Arabic
- German
- Chinese
- Other (please specify)

Please specify the language spoken in the home:

What setting best describes where your child with ASD lives?

- Rural town
- City
- Metropolitan area

What county does your child with ASD primarily reside?

- Alcona
- Alger
- Allegan
- Alpena
- Antrim
- Arenac
- Baraga
- Barry
- Bay
- Benzie
- Berrien
- Branch
- Calhoun
- Cass
- Charlevoix
- Cheboygan
- Chippewa
- Clinton
- Crawford
- Delta
- Dickinson
- Eaton
- Emmet
- Genesee
- Gladwin
- Gogebic
- Grand Traverse
- Gratiot
- Hillsdale
- Houghton
- Huron
- Ingham
- Ionia/Iosco
- Iron
- Isabella
- Jackson
- Kalamazoo
- Kalaska
- Kent
- Keweenaw
- Lake
- Lapeer
- Leelanau
- Lenawee
- Livingston
- Luce
- Mackinac
- Macomb
- Manistee
- Marquette
- Mason
- Mecosta
- Menominee
- Midland
- Missaukee
- Monroe
- Montcalm
- Montmorency
- Muskegon
- Newaygo
- Oakland
- Oceana
- Ogemaw
- Ontonagon
- Osceola
- Oscoda
- Otsego
- Ottawa
- Presque Isle

- Roscommon
- Saginaw
- St. Clair
- St. Joseph
- Sanilac
- Schoolcraft
- Shiawassee
- Tuscola
- Van Buren
- Washtenaw
- Wayne
- Wexford

What insurance provider currently covers your child with ASD?

- Aetna Better Health of Michigan
- Alliance Health and Life Insurance Company
- Blue Care Network of Michigan
- Blue Cross Blue Shield of Michigan Mutual Insurance Company
- Blue Cross Complete of Michigan
- HAP Empowered
- Health Alliance Plan of Michigan
- Health Care Service Corporation
- Healthy Michigan Plan
- Humana Insurance Company
- Humana Medical Plan of Michigan
- McLaren Health Plan
- Meridian Health Plan of Michigan
- MiChild
- Molina Healthcare of Michigan
- Oscar Insurance Company
- Physicians Health Plan
- Priority Health Insurance Company
- Total Health Care USA
- TRICARE Michigan
- UnitedHealthcare Community Plan
- Upper Peninsula Health Plan
- Other (please specify)

Please specify the insurance provider:

What is YOUR ethnicity?

- Asian/Pacific Islander
- Black or African American
- Hispanic or Latino
- Native American or American Indian
- White/Caucasian
- Other (please specify)
- Prefer not to answer

Please specify your ethnicity:

What was YOUR total household income before taxes during the past 12 months?

- Less than \$25,000
- \$25,000 to \$34,999
- \$35,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 or more
- Prefer not to answer

Including yourself, how many people live in your household?

2
 3
 4
 5
 6 or more

What year was your child diagnosed with ASD?

Prior to 1994 1995
 1996 1997 1998
 1999 2000 2001
 2002 2003 2004
 2005 2006 2007
 2008 2009 2010
 2011 2012 2013
 2014 2015 2016
 2017 2018 2019
 2020 Prefer not to answer

How clear were the above questions in this section?

Very clear
 Clear
 Indifferent
 Unclear
 Very Unclear

Please specify how we can make the questions clearer:

Do you think any question(s) should be added to this section?

Yes
 No

Please specify what question(s) you think should be added

Do you think any question(s) should be deleted in this section?

Yes
 No

Please specify what question(s) you think should be deleted

Do you have any additional thoughts or comments about the questions in this section?

Percent Completed: 12.5

.

At the time of diagnosis, please indicate the services you were made aware of [and by whom]:

	Made aware of	Not made aware of	Do not know
Speech-language therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Applied behavior analysis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Educational/school-based therapies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive behavior therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social skills training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parent training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parent workshops	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medication treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diet/Nutritional therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamins	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory integration therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Who made you aware of speech-language therapy?
(Please check all that apply)

- Don't remember
 Healthcare professional
 Family
 Friend
 Autism Alliance of Michigan
 Own research (e.g., internet, books)

Who made you aware of occupational therapy? (Please check all that apply)

- Don't remember
 Healthcare professional
 Family
 Friend
 Autism Alliance of Michigan
 Own research (e.g., internet, books)

Who made you aware of applied behavior analysis?
(Please check all that apply)

- Don't remember
 Healthcare professional
 Family
 Friend
 Autism Alliance of Michigan
 Own research (e.g., internet, books)

Who made you aware of educational/school-based therapies? (Please check all that apply)

- Don't remember
 Healthcare professional
 Family
 Friend
 Autism Alliance of Michigan
 Own research (e.g., internet, books)

Who made you aware of cognitive behavior therapy?
(Please check all that apply)

- Don't remember
 Healthcare professional
 Family
 Friend
 Autism Alliance of Michigan
 Own research (e.g., internet, books)

Who made you aware of social skills training? (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

Who made you aware of parent training? (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

Who made you aware of parent workshops? (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

Who made you aware of medical treatment? (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

Who made you aware of diet/nutritional therapy? (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

Who made you aware of vitamins? (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

Who made you aware of sensory integration? (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

Who made you aware of respite care (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

Please specify the other service you were made aware of

Who made you aware of the other service you identified (Please check all that apply)

- Don't remember
- Healthcare professional
- Family
- Friend
- Autism Alliance of Michigan
- Own research (e.g., internet, books)

How clear were the above questions in this section?

- Very clear
- Clear
- Indifferent
- Unclear
- Very Unclear

Please specify how we can make the questions clearer:

Do you think any question(s) should be added to this section?

- Yes
- No

Please specify what question(s) you think should be added

Do you think any question(s) should be deleted in this section?

- Yes
- No

Please specify what question(s) you think should be deleted

Do you have any additional thoughts or comments about the questions in this section?

Percent Completed: 25

Applied Behavior Analysis and Waitlists

Do you plan to pursue, have previously pursued, or are currently receiving applied behavior analysis (ABA) therapeutic services?

- Yes
- No

What year did you start pursuing ABA services?

- Prior to 1994 1995
 1996 1997 1998
 1999 2000 2001
 2002 2003 2004
 2005 2006 2007
 2008 2009 2010
 2011 2012 2013
 2014 2015 2016
 2017 2018 2019
 2020 Prefer not to answer

Is your child with ASD currently on, or were they ever placed on, a waitlist to receive applied behavior analysis (ABA) services in Michigan?

- Yes
 No

Was your child with ASD ever on more than 1 waitlist for ABA services at a time?

- Yes
 No

How many waitlists for ABA services was the child with ASD on at a given time?

- 1
 2
 3
 4
 5 or more

For the waitlist(s) your child with ASD was on, did they eventually receive ABA services from a provider?

- Yes
 No

How long was your child with ASD on the waitlist for the ABA provider your child with ASD is receiving or received services from?

- Less than 1 month
 1-3 months
 4-6 months
 7-9 months
 10-12 months
 More than 12 months
 Still on waitlist

Since your child with ASD was on a waitlist for ABA services, why didn't they receive ABA services? (Please check all that apply)

- Still waiting
 Chose other therapy over ABA
 Lack of resources/price of services
 Time commitment was too great
 Receiving services from school
 Other

Please specify

How long has your child with ASD been on the waitlist to receive ABA services?

- Less than 1 month
 1-3 months
 4-6 months
 7-9 months
 10-12 months
 More than 12 months

Overall, do you feel like your child with ASD's behavior/skills _____ while you were awaiting services for less than one month?

- Improved
 Stayed the same
 Got worse

Overall, do you feel like your child with ASD's behavior/skills _____ while you were awaiting services for 1-3 months?

- Improved
 Stayed the same
 Got worse

Overall, do you feel like your child with ASD's behavior/skills _____ while you were awaiting services for 4-6 months?

- Improved
- Stayed the same
- Got worse

Overall, do you feel like your child with ASD's behavior/skills _____ while you were awaiting services for 7-9 months?

- Improved
- Stayed the same
- Got worse

Overall, do you feel like your child with ASD's behavior/skills _____ while you were awaiting services for 10-12 months?

- Improved
- Stayed the same
- Got worse

Overall, do you feel like your child with ASD's behavior/skills _____ while you were awaiting services for more than 12 months?

- Improved
- Stayed the same
- Got worse

How clear were the above questions in this section?

- Very clear
- Clear
- Indifferent
- Unclear
- Very Unclear

Please specify how we can make the questions clearer:

Do you think any question(s) should be added to this section?

- Yes
- No

Please specify what question(s) you think should be added

Do you think any question(s) should be deleted in this section?

- Yes
- No

Please specify what question(s) you think should be deleted

Do you have any additional thoughts or comments about the questions in this section?

Percent Completed: 37.5

.

While on the waitlist, please indicate your level of concern with:

	Not a concern	Slight concern	Major concern
Problem behavior (such as tantrums, hitting, kicking, refusing to do things when asked)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appropriate communication/language (such as requesting what they want, initiating conversations, answering questions)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social skills (such as eye contact, sharing, conversation with peers/siblings)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Daily living skills (such as toileting, getting dressed, tooth brushing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please specify the severity of your child with ASD's problem behavior on the waitlist

- Low (the behaviors occurred less than once per week AND the behaviors resulted in little to no injury of self or others)
- Medium (the behaviors occurred more than once per week AND the behaviors resulted in little to no injury to self or others)
- Severe (the behaviors occurred daily OR the behaviors resulted in injury to self or others)

Please describe how your child with ASD's problem behavior interfered with your family's day-to-day activities

While on waitlists, when did you identify you would prefer services to be conducted? (Please check all that apply)

- Morning
- Afternoon
- Evening
- Weekdays
- Weekends

While your child with ASD was on the waitlist for ABA services, what types of other services or therapies did you pursue? (Please check all that apply)

- Speech-language therapy
- Occupational therapy
- Educational/school-based therapies
- Cognitive behavior therapy
- Social skills training
- Parent training
- Parent workshops
- Medication treatment
- Diet/Nutritional therapy
- Vitamins
- Sensory integration therapy
- Respite care
- Other

Please specify the other services or therapies you pursued

How clear were the above questions in this section?

- Very clear
 Clear
 Indifferent
 Unclear
 Very Unclear

Please specify how we can make the questions clearer:

Do you think any question(s) should be added to this section?

- Yes
 No

Please specify what question(s) you think should be added

Do you think any question(s) should be deleted in this section?

- Yes
 No

Please specify what question(s) you think should be deleted

Do you have any additional thoughts or comments about the questions in this section?

Percent Completed: 50

While on a waitlist for ABA services, have YOU participated in any training, workshops, or support groups designed to teach you:

	Yes	No
About your child's autism?	<input type="radio"/>	<input type="radio"/>
Strategies for managing your child with ASD's challenging behavior?	<input type="radio"/>	<input type="radio"/>
Methods for teaching your child with ASD new skills?	<input type="radio"/>	<input type="radio"/>

Briefly describe your training, workshop, or support group experience:

Did you find this training, workshop, or support group to be helpful?

- Yes
 No

Please describe why you found this helpful:

Please describe why you did not find this helpful:

How clear were the above questions in this section?

- Very clear
 Clear
 Indifferent
 Unclear
 Very Unclear

Please specify how we can make the questions clearer:

Do you think any question(s) should be added to this section?

- Yes
 No

Please specify what question(s) you think should be added

Do you think any question(s) should be deleted in this section?

- Yes
 No

Please specify what question(s) you think should be deleted

Do you have any additional thoughts or comments about the questions in this section?

Percent Completed: 62.5

Potential Training or Support Opportunities

While awaiting services, what have been (or were) your greatest needs as the caregiver to a child with autism? (Please check all that apply)

- Skills for managing child's challenging behavior
 Strategies for teaching and maintaining child's skills (such as language, social skills)
 Support for teaching and maintaining child's daily living skills (such as toileting, getting dressed, tooth brushing)
 Assistance in addressing other routine behavior (such as mealtime, sleep)
 Support in advocating for child's needs
 Supports/services for your mental health
 Respite care
 Other

Please describe your other needs:

If you were offered opportunities to learn these skills and receive support while you were on the waitlist, would you be interested in learning more about these opportunities?

- Yes
 No

What challenges might prevent you from attending these training and support opportunities? (Please check all that apply)

- Lack of resources or accessibility (e.g., lack of reliable transportation, technology, internet/communication access, or the cost is too high)
 Distance to services
 Lack of time to attend
 Already committed to too many other therapies/activities
 Already receiving services at school
 I don't believe participation in training would align with the way things are being done at/during other therapies my child is receiving
 Requires too much work/commitment to attend
 I do not feel comfortable having people in my home (if training was at home)
 I'm not sure it would be helpful
 Other

Please specify the other reason(s) that might prevent your from attending:

How clear were the above questions in this section?

- Very clear
 Clear
 Indifferent
 Unclear
 Very Unclear

Please specify how we can make the questions clearer:

Do you think any question(s) should be added to this section?

- Yes
 No

Please specify what question(s) you think should be added

Do you think any question(s) should be deleted in this section?

- Yes
 No

Please specify what question(s) you think should be deleted

Do you have any additional thoughts or comments about the questions in this section?

Percent Completed: 75

If a training were offered and you were interested in attending, please select your preferences for the training experience from the available options below:

	Prefer	Indifferent	Do not prefer
Individual/1-on-1 setting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Group setting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lectured-based instruction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self-directed computer modules	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Observing live, in-person modeling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Observing pre-recorded video models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practice with another person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practice with yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Receive vocal feedback	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Receive written feedback	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Receive feedback in the moment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Receive feedback at the end of session	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Given all your responsibilities, how likely is it that you could attend?

- Not at all likely
 Somewhat unlikely
 Somewhat likely
 Very likely

Given the feasibility for you and your family, if something like this were offered, how long should each session last?

- Less than an hour
 1 hour
 2 hours
 3 hours
 More than 3 hours

Given the feasibility for you and your family, how many hours would you be willing to dedicate each week for this?

- Less than an hour
 1 hour
 2 hours
 3 hours
 More than 3 hours

How clear were the above questions in this section?

- Very clear
 Clear
 Indifferent
 Unclear
 Very Unclear

Please specify how we can make the questions clearer:

Do you think any question(s) should be added to this section?

- Yes
 No

Please specify what question(s) you think should be added

Do you think any question(s) should be deleted in this section?

- Yes
 No

Please specify what question(s) you think should be deleted

Do you have any additional thoughts or comments about the questions in this section?

Percent Completed: 87.5

Other Thoughts

Do you have any other thoughts on waitlist, challenges, concerns, available services and supports, barriers to services or supports, or preferred method of receiving services?

How did you hear about this survey? (Please check all that apply)

- Autism Alliance of Michigan MiNavigator Newsletter
 Autism Alliance of Michigan Website/Homepage
 Social Media
 Other (please specify)

Please specify how you heard about the survey:

Please rank how satisfied you are with the following:

	Very Unsatisfied	Unsatisfied	Neutral	Satisfied	Very Unsatisfied
Survey length	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Survey content	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Word choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thoroughness of survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your overall experience taking this survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Percent Completed: 100

IRB #: UHSRC-FY20-21-69

Title: Determining the Prevalence of Children with Autism who Experience Delays to Behavioral Therapy in Michigan and Understanding the Needs of their Family during this Time Creation Date: 10-9-2020 End Date:

Status: **Approved**

Principal Investigator: Adam Briggs

Review Board: University Human Subjects Review Committee Sponsor:

Study History

Submission Type Initial Review Type Limited Decision **Exempt - Limited IRB**

Key Study Contacts

Member Angela Staples Role Investigator Contact astaples@emich.edu

Member Adam Briggs Role Principal Investigator Contact abrigg11@emich.edu

Member Jaimie Barr Role Primary Contact Contact jbarr13@emich.edu

Member Jaimie Barr Role Investigator Contact jbarr13@emich.edu

Initial Submission

General Information

Complete this form for a new human subjects project submission. For multi-site studies, contact the Office of Research Compliance at research_compliance@emich.edu or 734-4873090 prior to completing this application.

Each question must be specifically answered or your application will be returned without review. Do not copy and paste language from other documents into the application.

All items with red stars are required and must be completed in order to submit. Save changes frequently.

Questions? Contact human.subjects@emich.edu or 734-487-3090.

Is your study any of the following:

-
- Exclusively a program evaluation (data collected for program improvement purposes)?
- Journalistic activity?
 - Oral history without the purpose of extracting and generalizing themes from the oral
 - histories?
 - Biography?
 - Literary criticism?
 - Historical scholarship?

Note: Mark Yes if your data will only be used for the purposes above.

Yes

No

Affiliation:

Check one

Faculty/Staff

Graduate Student

Undergraduate Student

Principal Investigator

Name: Adam Briggs

Organization: Psychology

Address: Psychology 341, Ypsilanti, MI 481970000

Phone: 7344871155

Email: abrigg11@emich.edu

Briefly describe your qualifications to conduct the study.

Students: Please include a brief statement about how your adviser will mentor you on this project.

I am a Board Certified Behavior Analyst (BCBA) and have been working with children diagnosed with autism spectrum disorder and their families for over 10 years. During this time I've worked in a number of clinical settings conducting center-based and in-home therapy and understand the importance of conducting high-quality behavioral intervention. I am also painfully familiar with the reality that families face having to wait for services and know that during this time parent concerns increase as child skills decrease or become problematic. In addition, I have experience successfully developing, conducting, and completing research projects throughout this same time span. Please see my attached CV for an exhaustive list of my research, clinical, teaching, and training experiences.

Human Subject Training

Attach your human subject training completion report (copy of grade page for Canvas course, completion certificate for CITI). Online human subject training must have been completed in the past THREE YEARS in order to be valid. [CITI Completion Certificate \(Briggs\).pdf](#)

Attach a CV or resume here. If you are conducting in-person research during the COVID-19 pandemic, attach your approval email from the Dean's Office and your In-Person Human Subject Research Application responses here.

[CV_AMBriggs \(October, 2020\).pdf](#)

Primary Contact

Select someone who can be contacted about the study in the absence of the principal investigator. If you do not have a primary contact, please list yourself.

Name: Jaimie Barr

Organization: Eastern Michigan University

Address: , Ypsilanti, MI 481972212

Phone: (810)282-8188

Email: jbarr13@emich.edu

Research Personnel

Add all other investigators who will either have contact (in-person or virtual) contact with human subjects or who will have access to identifiable data.

Name: Jaimie Barr

Organization: Eastern Michigan University

Address: , Ypsilanti, MI 481972212

Phone: (810)282-8188

Email: jbarr13@emich.edu

Name: Angela Staples

Organization: Psychology

Address: Psychology 341, Ypsilanti, MI 481970000

Phone: 7344871155

Email: astaples@emich.edu

If your research personnel are not affiliated with Eastern Michigan University, list their names, titles, and affiliations below.

Andrea Peterson, Doctoral Fellow, EMU Clinical Psychology Program

Brittany Loder, Masters Student, EMU Clinical Behavioral Masters Program

Attach human subject training completion reports for each member of the study staff.

[CITI Completion Certification \(Peterson\).pdf](#)

[CITI Completion Certificate \(Barr\).pdf](#)

[Grades for Brittany Loder_ Human Subject Research Training.pdf](#)

[Staples_citiCompletionReport_Certificate.pdf](#)

Does this study involve research sites or locations other than EMU?

Note: This does not apply for survey studies in which surveys are completed on the subjects' personal computers.

Yes

No

Conflict of Interest

Do you or any study staff members have a potential conflict of interest for this project?

Yes

No

Is this project funded?

Choose No if you have department or internal funds to conduct your study (including a Faculty Research Fellowship or a Summer Research Award).

Yes

Funding is pending

No

Study Abstract and Summary

Abstract

Provide a brief abstract of your study procedures in non-technical terms. Limit this abstract to no more than 300 words.

The Centers for Disease Control and Prevention recently estimated that autism spectrum disorder (ASD) now affects 1 in 59 of the nation's children (Baio et al., 2019), which translates to approximately 40,000 children in Michigan. Early intensive behavioral treatment is an evidence-based treatment that may reduce core and associated features of ASD (Reichow et al., 2012). Notably, a key factor in predicting

positive treatment outcomes for these individuals is receiving these behavioral services as early as possible. Unfortunately, due to a number of variables (including a growing demand for behavioral services for children diagnosed with ASD), families commonly experience delays to receiving services for their child. Despite the increase in demand for behavioral services and the common occurrence of families experiencing a delay to services, there is no actual data available to indicate how often (and for how long) families experience a delay to receiving behavioral services for their child. Therefore, the purpose of this study is to survey caregivers of children diagnosed with ASD who have experienced a waitlist to (a) determine the prevalence of families that spend time on a waitlist prior to receiving ABA services, (b) determine the amount of time a family typically spends on a waitlist for services, (c) assess the needs of caregivers while they are on a waitlist, (d) assess caregivers interest in receiving support while on a waitlist, and (e) assess the caregivers preference for such supports. Results will reveal vital information for understanding the state of behavioral service provision in Michigan so that limitations to the current system can be addressed and support systems and training curriculum can be developed and offered to address these needs.

Purpose

In one or two sentences, what is the purpose of your study?

The purpose of this study is to (1) determine the prevalence of families that spend time on a waitlist prior to receiving ABA services, (2) determine the amount of time a family typically spends on a waitlist for services, (3) assess the needs of caregivers while they are on a waitlist, (4) assess caregivers interest in receiving support while on a waitlist, and (5) assess the caregivers preference for such supports. This information is vital to understanding the state of ABA services in Michigan so that limitations to the current system can be addressed and support systems and training curriculum can be developed and offered to address this need.

Study Procedures

Describe step-by-step, very clearly, all of the research procedures that will occur during your project. Please include the following information:

1. Describe your subject population(s).
2. What procedures will be conducted on the subjects? If you have two or more groups of subjects, please describe in detail the procedures for each group.
3. Specify any experimental procedures.
4. How long will participation last? If the study will take place over multiple days or there are multiple procedures, please specify the amount of time per day or procedure.

If you think it helps with clarity, please upload a chart or timeline under Study Measures below.

Participants

Participants will be approximately 500 residents of Michigan who voluntarily choose to complete the survey in its entirety. Participants will be eligible to complete the survey if they are the primary caregiver of a child (2-10 years old) with a diagnosis of ASD. To aid in the identification of eligible participants, we have entered into a partnership with the Autism Alliance of Michigan (AAoM) who have agreed to use their platform to help recruit participants to complete the survey.

Procedures

Prior to disseminating the online survey to caregivers throughout the state of Michigan, it will be piloted with approximately 10 families. Information gained from this pilot phase will be used to improve the survey prior to mass distribution. Once the survey is ready, it will be disseminated to potential participants through several e-communication formats (e.g., e-mail, social media). The survey will remain open until either 500 participants complete the survey or 2 months has elapsed, whichever comes first. Because this survey can be characterized as a broad-based autism community needs assessment, we do not plan to run any sophisticated statistical packages and thus do not require a larger number of respondents to ensure statistical power. After the survey window closes, the data will be analyzed across a number of relevant variables to understand the state of ABA service delivery in Michigan, including prevalence estimates of families who spend time on a waitlist prior to receiving ABA services. At a minimum, the survey may take less than 1 min to complete (e.g., they do not meet initial eligibility) or approximately 1520 min if they are eligible and answer all relevant questions within the survey. The survey will be built in and disseminated through REDCap, which is a HIPAA compliant and secure web platform for managing online databases and surveys.

Pilot Survey. We will conduct a pilot-version of the survey with approximately 10 families from across the state of Michigan to test the initial survey questions. The purpose of conducting the pilot survey is to recruit immediate feedback on the clarity, organization, and thoroughness of our questions. That is, if we

recognize that any survey questions or response options create confusion, are not organized in an optimal manner, or are missing, we can use this information to update and improve the overall quality of the survey. In order to recruit caregivers to participate in this pilot phase, we plan to reach out to several ABA service providers across the state to see if they will hand select a caregiver or two that is on (or was currently on) a waitlist for ABA services that would likely be willing to complete the survey. The pilot version of the survey will recruit respondent feedback on the clarity, organization, and thoroughness of the survey questions several times throughout the survey. Feedback will be used to improve the survey questions prior to it being widely disseminated.

Dissemination of Survey. An invitation to enroll in the study that includes a link to the survey will be shared across various online platforms to recruit eligible participants. Specifically, the study invitation and survey link will be shared (a) on the homepage of the Autism Alliance of Michigan (AAoM) website, (b) via email in the AAoM MiNavigator Newsletter, and (c) across various social media outlets (e.g., Facebook, Twitter, Next Door) and online boards (e.g., Craigslist).

Completion of the Survey. Participants that are interested in volunteering to enroll in the study must complete the online process of consent. The process of consent will consist of reviewing descriptions of (a) the purpose of the study, (b) eligibility, (c) the study procedures, (d) types of data collected, (e) risks of participating in the study, (f) benefits of participating in the study, (g) confidentiality (h) procedures for storing study information, (i) compensation, (j) contact information, and (k) the voluntary participation statement. Following participant consent, respondents will complete an authentication process by entering their email address initial of their first and last name and the last four digits of their primary phone number in order to access the survey. The respondent's IP address will be masked from the researchers.

Study Measures

Provide a brief description of each measure/assessment/survey you plan to use.

Survey

Participants who volunteer to enroll in this study and agree to the consent will be asked to complete an online survey designed to understand the state of ABA service delivery in Michigan. The survey questions were developed by a group of scientist practitioners who relied on their clinical experience working within this population to design questions that would produce response data needed to (a) determine the prevalence of families who spend time on a waitlist prior to receiving ABA services, (b) assess families motivation for support, and (c) identify families specific needs during this challenging time. These questions were reviewed independently by several other professionals who (a) had experience

conducting survey research, (b) had experience working with caregivers who had a child diagnosed with ASD, (c) were the primary caregiver for a child with special needs, or (d) some combination of these characteristics to ensure the content validity of the questions. Feedback from these professionals was used to improve the clarity, format, and organization of the questions.

In general, the survey will present the participant with a series of questions related to (a) participant eligibility, (b) participant demographics, (c) whether or not their child was placed on a waitlist prior to receiving ABA services, (d) the approximate duration of time spent on this waitlist, (e) the participant's primary concerns while their child was awaiting services, (f) the participant's needs at the time their child was awaiting services, and (g) the potential barriers that might interfere with accessing services while their child was awaiting services.

The entire survey consists of 87 closed-ended and 18 open-ended questions. Of the 87 closed-ended questions there are 9 yes/no questions, 20 multiple choice questions in which only one answer can be selected, 20 multiple choice questions in which more than one answer can be selected, 5 multiple choice questions displayed in a dropdown format, and 33 questions presented in a matrix format. Of the 18 open-ended questions, 11 are short-answer questions (e.g., please specify) and 7 are longer open-ended questions in which there is a space for a paragraph to be written.

Measurement and Data Analysis

Participant responses to survey questions will be stored on the REDCap Cloud database and researchers will only have access to the database by entering their username and a password. When the survey window is closed, all participant responses will be aggregated and summarized to determine the following outcome measures: (a) proportion of respondents who indicated they were on waitlist, (b) mean, median, mode, and range of respondent duration spent on waitlist, and (c) proportional summary of respondent's child concerns, needs while on waitlist, and potential barriers interfering with receiving services. In addition, we have recruited Dr. Angela Staples (Associate Professor of Psychology at EMU) to serve as our statistician. Dr. Staples will assist with the data analysis portion of the study. In general, variables that are potentially related to waitlist durations (e.g., various demographic variables, level of child concern, reported barriers) will be analyzed to determine if there are any interesting and significant differences between demographic groups.

Attach all measures, assessments, and surveys.

For students conducting surveys and interviews: You must attach a completed [Survey Development Checklist](#).

[survey_development_checklist \(Barr and Briggs\) copy.pdf](#)

[PilotSurvey_PilotABACaregiverW.pdf](#)

[CaregiverABAWaitlistStudy_Care.pdf](#)

Does your study use [drugs](#) or [biological products](#)?

Yes

No

Does your study use [medical devices](#)?

Yes

No

Exemption

[Exempt studies](#) are not subject to the [Common Rule](#) (45 CFR 46), federal regulations regarding the protection of human subjects in research.

They are, however, subject to [Eastern Michigan University policies and procedures](#). As such, the UHSRC requires that Exempt research be submitted for review.

According to UHSRC policy, investigators may not make their own Exempt determination. Exempt determinations may only be made by the UHSRC or their designees.

All of your research activities must fall into at least one of the following categories.

Check all that apply.

If your research activities do not fall exactly into the categories below, click "None of the above" and complete the sections appearing in the left menu.

1. Research conducted in established or commonly accepted educational settings, involving normal educational practices that are not likely to adversely affect students' opportunity to learn or the assessment of educators who provide instruction.

This includes research on regular and especial education instructional strategies and research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

2. Research that only includes interactions involving educational tests, survey procedures, interview procedures, or observations of public behavior if at least one of the following criteria is met:

a. The information obtained is recorded by the investigator in such a manner that the subjects cannot

readily be identified, either directly or through study IDs that are linked to identifiers;

✓ b. Any disclosure of the subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or

c. The information obtained is recorded by the investigator such that subjects can be identified, and

the UHSRC has reviewed the privacy and confidentiality provisions in the study.

Note: This category is only applicable to adults age 18+. Educational tests, survey procedures, interview procedures, or observation of public behavior involving minors cannot be Exempt except for educational tests and observation of public behavior if the investigator's presence will not in any way affect the behavior of the research subjects in conditions a and b above only.

Condition c above can never be Exempt if the research involves minors.

3. Research involving benign behavioral interventions using adult subjects provided that the subject provides consent/permission to participate beforehand and at least one of the following criteria is met:

a. All information collected about the subject (research data) is anonymous (not directly or indirectly identifiable).

b. Any disclosure of the subjects' data would not reasonably place subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or

c. The information obtained is recorded by the investigator such that subjects can be identified, and the UHSRC has reviewed the privacy and confidentiality provisions in the study.

Note: Benign behavioral interventions are brief in duration, harmless, painless, not physically invasive, not likely to have an adverse lasting impact on the subjects, and the investigator has no reason to think the subjects will find the interventions embarrassing or offensive. Research involving deception cannot be Exempt unless the subject authorizes the deception beforehand during the consent/permission process.

4. Secondary research for which consent is not required.

This category can include identifiable private information or identifiable biospecimens provided that

at least one of the following criteria is met:

a. The information or biospecimens are publicly available;

- b. The information is recorded by the investigator so that subjects cannot be directly or indirectly identified (i.e., the investigator's data set is anonymous), the investigator does not contact the subjects, and the investigator will not re-identify subjects;
 - c. The research is subject to HIPAA regulation and conducted under a HIPAA-covered entity; or
 - d. The research is conducted by, or on behalf of, a Federal department or agency using government-generated or government-collected information obtained for non research activities.
5. Research and demonstration projects which are conducted by or subject to the approval of Federal department or agency heads, and which are designed to study, evaluate, or otherwise examine:
- a. Public benefit or service programs;
 - b. Procedures for obtaining benefits or services under those programs;
 - c. Possible changes in or alternatives to those programs or procedures; or
 - d. Possible changes in methods or levels of payment for benefits or services under those programs.

Note: All projects under this Exempt category must be published on public list maintained by the Federal department or agency before any human subject research begins.

6. Taste and food quality evaluation and consumer acceptance studies, if:
- a. Wholesome foods without additives are consumed; or
 - b. A food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration or approved by the Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

7. Storage or maintenance of identifiable private information or identifiable biospecimens
for secondary research for which broad consent is required.

The UHSRC must conduct a limited review of the broad consent form, the privacy and confidentiality protections, and any additional protections for vulnerable subjects. **Note: This category applies only to creating and maintaining a repository of identifiable data, not to the analysis or other uses of such data. At this time, the UHSRC does not support the use of broad consent for administrative reasons. Contact the Office of Research Compliance at research_compliance@emich.edu with any questions.**

8. Secondary research for which broad consent is required. This category involves the research use of data stored and/or maintained using broad consent.

The UHSRC must conduct a limited review to make sure that the purpose of the research is within the scope in the broad consent, of the privacy and confidentiality provisions for the data.

In addition, the study plan should not include returning individual results to subjects. **Note: This category applies only to analysis of data from a repository of identifiable data, not to the creation or maintenance of such a repository. At this time, the UHSRC does not support the use of broad consent for administrative reasons. Contact the Office of Research Compliance at research_compliance@emich.edu with any questions.**

None of the above.

Exempt Documents

Attach the following documents in MS Word:

1. Consent form
2. Recruitment scripts, email texts, social media texts, letters, fliers, etc.
3. Study measures: surveys, interview questions, educational tests, focus group questions, etc. (if not attached in Study Abstract and Summary section)

[Briggs LOS - EMU Survey \[AAoM\] 10-9-20.docx](#)

[Email script for pilot.docx](#)

[Phone script for pilot.docx](#)

[Social media text.docx](#)

[Caregiver Survey Flyer \(10.27.20\).pdf survey_consent](#)

[\(Briggs, 11.5.20\).docx](#)

Describe the consent process

Explain how, when, where, and by whom consent will be obtained. For studies involving minors, include a description of how, when, where, and by whom assent will be obtained.

The consent form will be presented at the start of the online survey. Participants will acknowledge their understanding and consent to participate by pressing "continue." They will indicate that they are at least 18 years old, currently reside in the state of Michigan, and are the primary caregiver for a child diagnosed with autism who is between 2-10 years old.

Will subjects be compensated for participation?

Note: Compensation does not include refreshments provided during participation.

Yes

No

Privacy and Confidentiality

Please see the EMU Board of Regents Policy 6.4.4: [Research Data Retention](#)

Explain how you plan to protect subject privacy.

Privacy refers to the individual person and not the data. .

Participants will complete the survey in their own home or private space, thus protecting their privacy.

Data collected will be:

Check only one.

Anonymous

- Subjects cannot be identified directly, indirectly through a study ID code and key, or through combination of elements in the data set (e.g., job title and employer).

Coded

Data file does not contain subjects' identifiable information, but there is a separate key that links study ID codes with subjects' identifiable information.

Identifiable

Data file contains direct identifiers, such as name, phone number, social security number, EID number, or elements that, when combined, allow for identification (e.g., job title and employer).

Audio and video recordings are considered identifiable.

How do you plan to keep data confidential?

Include special precautions for identifiable or coded data, and address how data in multiple media (e.g., paper data, electronic data, audio recordings, etc.) will be stored.

In order to minimize the risk of a breach of confidentiality for participating caregivers and their children, procedures are in place to minimize these risks. First, all responses will be kept confidential within the limits of REDCap privacy policy (see <https://www.redcapcloud.com/privacy-policy/> for further information).

Second, all electronic data will be password protected. Third, researchers working with the data will complete confidentiality trainings prior to accessing and handling any survey data. Fourth, participant responses will be released to the principal investigator and approved research personnel, who will download all the responses from REDCap Cloud to a password protected computer. Fifth, ~~the REDCap survey will be deactivated once the survey window is closed and participant email addresses will be deleted after they are used to identify (and remove) multiple responses from same address.~~ Sixth, survey questions do not ask for any personal or identifying information, so there is no other way to link the respondent with their responses.

How will research results be disseminated?

Include plans for protection of privacy/confidentiality in publications, presentations, and other methods of dissemination.

Results will be disseminated in aggregate through scientific publications and presentations. Participants will not be identifiable in these reports. Participants will not be informed of study results unless requested.

Attachments

PI CV

[CV_AMBriggs \(October, 2020\).pdf](#)

PI CITI certificate

[CITI Completion Certificate \(Briggs\).pdf](#)

Research Staff CITI certificates

[CITI Completion Certification \(Peterson\).pdf](#)

[CITI Completion Certificate \(Barr\).pdf](#)

[Grades for Brittany Loder_ Human Subject Research Training.pdf](#)

[Staples_citiCompletionReport_Certificate.pdf](#)

Exempt forms: consent/assent, recruitment, study questions if applicable

[Briggs LOS - EMU Survey \[AAoM\] 10-9-20.docx](#)

[Email script for pilot.docx](#)

[Phone script for pilot.docx](#)

[Social media text.docx](#)

[Caregiver Survey Flyer \(10.27.20\).pdf survey_consent](#)

[\(Briggs, 11.5.20\).docx](#)

Informed Consent form

[survey_consent \(Briggs, 10.15.20\).docx](#)

Study Measures

[survey_development_checklist \(Barr and Briggs\) copy.pdf](#)

[PilotSurvey_PilotABACaregiverW.pdf](#)

[CaregiverABAWaitlistStudy_Care.pdf](#)



Autism Services in Michigan Survey



**Are you a caregiver
of a child with ASD?**



**Do you live in
Michigan?**

**If so, then we would like to invite you to complete an
approximately 15-30 minute survey!**

The Autism Alliance of Michigan and Eastern Michigan University researchers wonder: how long children with ASD are on behavioral therapy waitlists and the needs of caregivers while on the waitlist

Complete the survey:

<https://j.mp/36KEGan>



Approved by Eastern Michigan University Human Subjects
Review Committee, Project ID: UHSRC-FY20-21-69



Consent Form

Project Title: Determining the Prevalence of Children with Autism Who Experience Delays to Behavioral Therapy in Michigan and Understanding the Needs of Their Family During This Time.

Principal Investigator: Adam M. Briggs, Ph.D., BCBA-D, LBA-MI, Assistant Professor of Psychology

Purpose: The primary purpose of this research study is to determine how often (and for how long) caregivers of children diagnosed with autism have to spend on a waitlist prior to receiving behavioral services (e.g., ABA, EIBI, DTT). The secondary purpose is to assess the needs of caregivers who currently are (or have been) on a waitlist.

Eligibility: You are eligible to take part in this study if you are over the age of 18, currently reside in the state of Michigan, and are the primary caregiver for a child diagnosed with autism who is between 2-10 years old.

Study Procedures: Participation in this study involves completing an online survey. It should take between 15-30 minutes to complete the survey.

Types of Data Collected: We will ask questions about whether or not your child spent time on a waitlist prior to receiving behavioral services and what were some of your and your child's needs during this time. We will also ask for information about what city you currently reside, your ethnic origin, and your annual income to determine if these factors are related to the probability of experiencing a waitlist or for how long one might be on a waitlist prior to receiving behavioral services.

Risks: The primary risk to participation is that you may feel uncomfortable answering some of the questions. You do not have to answer any questions that make you uncomfortable or that you do not want to answer. The questionnaire does not request any identifying information. Since no identifiable information is collected, there is little to no risk of privacy or confidentiality issues in the dissemination of the results.

Benefits: You will not directly benefit from participating in this research. Benefits to society include understanding of the prevalence of families who experience a

waitlist prior to receiving behavioral services for individuals diagnosed with autism, including the determination of average durations families spend on waitlists and identification of the needs of the families during this time. By better understanding these circumstances, our findings will contribute to the development of services that can be offered during these times that will directly address caregiver and child needs during this challenging time.

Confidentiality: In order to minimize the risk of a breach of confidentiality for participating caregivers and children, procedures are in place to minimize these risks. All responses will be kept confidential within the limits of REDCap privacy policy (see <https://www.redcapcloud.com/privacy-policy/> for further information).

All electronic data will be password protected. Researchers working with the data will complete confidentiality training prior to accessing and handling any survey data. Participant responses will be released to the principal investigator, who will download all the responses from REDCap Cloud to a password protected computer. The REDCap survey will be deactivated once the survey window is closed.

Information from this study will be reported and published in aggregate form. Data will be retained for 5 years or until final publication (whichever is later). Should you choose to participate, we encourage you to complete the consent form and survey in a private location on a secure computer network.

Completing the survey is completely voluntary and you can choose not to fill out any information. You may cancel your consent at any time without negative consequences. If you choose to withdraw from the study, you can opt to withdraw all of your already completed data.

Compensation: There is no compensation for completing this study.

Contact Information: If you have any questions concerning your participation in this study nor or in the future, you can contact the principal investigator, Dr. Adam Briggs, via email (abrigg11@emich.edu).

For questions about your rights as a research subject, you can contact the Eastern Michigan University Office of Research Compliance at human.subjects@emich.edu or by phone at (734) 487-3090.

Voluntary participation: Participation in this research study is your choice. You may refuse to participate at all or choose to stop your participation at any point in the research without fear of penalty or negative consequence. If you do not wish to take part in this study, just close this window. If you leave the study, the information you provided will be kept confidential. You can withdraw your consent by emailing the Principal Investigator listed above. You may request, in writing, that your

information be destroyed; however, we cannot destroy any information that has already been published.

Statement of Consent: I have read and understand this form. I click “continue” below to indicate my consent to participate in this research study.