



Prevalence of Autistic Children Who Experience Delays to Behavioral Therapy in Michigan: A Summary of Survey Data Describing Caregiver Needs During this Time

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In response to the growing number of barriers faced by families and caregivers of individuals with autism spectrum disorder (ASD) when pursuing behavioral services (i.e., applied behavior analysis [ABA]) in Michigan, researchers at Eastern Michigan University (EMU) in collaboration with the Autism Alliance of Michigan (AAoM) developed and executed a survey to better understand this phenomenon. Specifically, the purpose of the survey was to 1) assess the prevalence of children with ASD who experience a delay to behavioral services and 2) gain an understanding of the needs of their caregivers during this time.

An initial pilot study was conducted prior to the large-scale dissemination of the survey to determine if the questions were thorough, inclusive, and clear. The primary purpose of this pilot study was to recruit feedback from a handful of select caregivers to inform revisions to the final survey prior to dissemination throughout the state of Michigan. A total of 8 caregivers of children with ASD volunteered to participate in this pilot study. Participants were recruited from ABA clinics in Michigan by clinical directors who are partners with EMU's Behavior Analysis Research Lab. The results of the pilot study indicated that most of the survey questions were either **very clear** or **clear**. Minor edits were made based on caregiver feedback (e.g., adding *Early On Michigan* as a response option to a question about referral sources).

After we updated the survey based on the results of the pilot study, the final survey was opened and disseminated across Michigan in January 2021. Participants were recruited to participate in the study by dissemination of an invitation flyer across several outlets including: (a) the AAoM Monthly Newsletter, (b) AAoM Facebook Page, (c) the Behavior Analysis Research Lab social media pages (i.e., Facebook, Twitter), (d) emailing clinical directors who are partners with EMU's Behavior Analysis Research Lab, and (e) word of mouth (e.g., individuals who re-shared posts on social media). The survey closed in April 2021 (i.e., it was open for 4 months). A total of 78 caregivers consented to participating in the study. Of these 78 caregivers, 48 indicated that they have previously pursued or are currently receiving ABA services for their child with ASD. The following sections will highlight the key findings of the survey for these 48 participants (due to the nature of the survey, not all caregivers were given the opportunity to answer all questions if they were not applicable to them; hence, there is a decreasing number of participants as the survey results progress). Recommendations will be discussed based on the key findings from the data reported below.

Participant Demographic Information

The majority of the caregiver's children were born between **2008** and **2019** (median = 2013, mode = 2015). In other words, the majority of caregivers had children with ASD who were *less than 13 years old at the time of the survey*. About 74% of the children were identified to be **male** (n = 46), with the remaining ~26% being **female** (n = 16).



Most of the children were identified as being White (83.9%), followed by Black or African American (4.8%), Hispanic or Latino (3.2%), mixed ethnicity (3.2%), and Asian/Pacific Islander (1.6%).

The average household income of respondents was variable, with the median household income being **\$50,000 to \$74,999** (range = <\$25,000 to >\$150,000). Lastly, over half of the participants live in a **city setting** (53.2%), followed by living in a **metropolitan area** (24.2%) and **rural town** (22.6%).

The demographic composition of the caregivers who participated in this survey *lack diversity in ethnicity* and thus *represent a limited (and potentially biased) sample*. Specifically, the ethnicities of the participants do not reflect the range of diversity in the state of Michigan and responses may be biased as they represent a traditionally "privileged" (White, middle to upper class) population and may be representative of optimal waitlist conditions. Therefore, the following outcome data and subsequent recommendations should be considered in the context of these limiting variables.



How Caregivers Learned About Behavioral Services

The *majority of caregivers were made aware of ABA services* (*n* = 43 out of 56 caregivers surveyed; 77%). Nearly half reported learning about such services from the Autism Evaluation Center (47.6%), followed by health care professionals (33.3%), Early On Michigan (28.6%), from their own personal research (21.4%), friends (11.9%), and AAoM (4.8%).



Similarly, caregivers most frequently identified Autism Evaluation Centers and/or healthcare professionals as the main sources of referral for services/therapies (e.g., respite care, sensory integration, vitamins, medical treatments, parent workshops, parent training, cognitive behavior therapy, and speech-language therapy). Early On Michigan was the main source that made caregivers aware of social skills training, occupational therapy, and education/school-based services.

Prevalence of Children Waitlisted Prior to Receiving ABA Services

Of the individuals who indicated they plan to or have pursued ABA services for their child (n = 48), 35 out of 48 respondents (73%) indicated their children spent time on at least one waitlist, with 51.4% (18 out of 35 respondents) reporting placement on multiple waitlists at a time.

Amount of Time Spent on a Waitlist for Services

Table 1 (below on p. 4) presents the amount of time children spent on waitlists for behavioral services based on how many waitlists the child was concurrently on. Of note, regardless of the number of waitlists the child was on, the mean time spent on a waitlist for services was 5.66 months (SD = 3.85). Of the individuals who indicated their child has received services after being on at least one waitlist (n = 25), the



average time spent on the waitlist(s) was 4.84 months (SD = 3.37). Interestingly, of individuals who indicated that their child has not started receiving services and are still

awaiting services (n = 7), the average time spent on the waitlist(s) was several months greater than those who have begun receiving services (M = 8.57 months; SD = 4.28).

| Number of Waitlists | n | М | SD | Median | Range |
|------------------------|----|------|------|--------|-------|
| 1 | 15 | 5.33 | 4.05 | 3 | 1–12+ |
| 2 | 8 | 3.38 | 4.5 | 4.5 | 3–12 |
| 3 | 4 | 5.75 | 5.25 | 4.5 | 1–12+ |
| 4 | 3 | 8.00 | 4.58 | 9 | 3–12 |
| 5+ | 2 | 4.50 | 2.12 | 4.5 | 3–6 |

Table 1

Mean, Standard Deviation, Median, and Range of Duration on Waitlists Compared to Number of Waitlists

Note. M and *SD* are used to represent mean and standard deviation, respectively. *M*, *SD*, median, and range present the duration in months.

Table 2 presents the amount of time children spent on waitlists for behavioral services based on the type of setting they lived in. Interestingly, the mean duration of time spent on a waitlist was greater for those who live in a city as compared to those who live in a rural town. No statistically significant differences were found when comparing the duration of time spent on waitlist(s) and (a) number of waitlists (**Table 1**) and (b) type of setting (**Table 2**). This is likely the result of the limited sample of this survey and these variables should be investigated further in the future.

| Setting | n | М | SD | Median | Range |
|-------------------|----|------|------|--------|-------|
| Rural Town | 7 | 4.86 | 3.76 | 3 | 1–12+ |
| City | 15 | 6.33 | 4.17 | 6 | 1–12 |
| Metropolitan Area | 10 | 5.20 | 3.61 | 3 | 1–12 |

Table 2Mean, Standard Deviation, Median, and Range of Duration on Waitlist Compared to Setting

Note. M and *SD* are used to represent mean and standard deviation, respectively. *M*, *SD*, median, and range present the duration in months.

Behavioral Concerns of Child While on a Waitlist

Of the major behavioral domains associated with an ASD diagnosis, caregivers largely reported the occurrence of behavioral concerns as either a *major* or *slight concern* while on a waitlist (range = 85.3–97.1% of caregivers). Specifically, caregivers identified appropriate communication/language (such as requesting what they want, initiating conversations, and answering questions) as their biggest behavioral concern, with 82.4% of caregivers reporting appropriate communication/language as a concern. **Social skills** (such as eye contact, sharing, and conversation with peers/siblings) was identified as the second largest concern, with 67.6% of caregivers indicating it is a major concern. **Daily living skills** (such as toileting, getting dressed, and tooth brushing) was identified as the third largest concern, with 58.8% of caregivers stating that it is a major concern. Finally, **problem behavior** (such as tantrums, hitting, kicking, refusing to do things when asked) was the least major concern for caregivers, with 50% indicating it is a major concern.



Behavioral Concerns

When asked at what severity these behaviors occur, only about 17% of caregivers reported that it occurred at *Low Severity* (the behaviors occurred less than once per week *AND* the behaviors resulted in little to no injury to self or others). Importantly, an approximate **83%** of caregivers indicated the behaviors were either *Severe* or *Medium Severity* (the behaviors occurred daily to weekly, or resulting in injury or a small injury to self or others). These data reflect that caregivers may have significant motivation to get help for their childrens' behavioral concerns.





Needs of Caregivers While They are on a Waitlist

Caregivers identified their *top needs* as 1) strategies for teaching and maintaining child's skills (such as language and social skills; 83.9%), 2) support for teaching and maintaining child's daily living skills (such as toileting, getting dressed, and tooth brushing; 80.6%), and 3) skills for managing child's challenging behavior (71%). Respite care (41.9%), support/services for the caregiver's mental health (48.4%), and support in advocating for child's needs (48.4%) were among the *needs least identified* by caregivers while they are on a waitlist. This may indicate that caregivers are in higher need of learning strategies to help teach skills to and manage behavioral concerns of their children with ASD over receiving resources and aids.



Caregiver Interest in Receiving Supports While on a Waitlist

All of the caregivers surveyed (n = 30) indicated they would be interested in learning more about opportunities to gain skills for addressing the behavioral concerns described above and receiving additional support while on the waitlist. This finding emphasizes the need for these resources while caregivers await behavioral services for their children.

Caregivers indicated that they would prefer for training sessions to be **1-on-1 with an instructor**, where the instructor is able to **model the skill live**, **practice it with them**, and **provide vocal feedback** in the moment. Unfortunately, the majority of caregivers indicated that they were only **somewhat likely to attend**. If they did attend, caregivers said they would prefer sessions to be one hour in duration for two hours a week.



Potential Barriers to Receiving Support

The *most commonly identified barrier* to receiving support reported by the caregivers was having a lack of time to attend (74.1%). Other barriers included distance to services (40.7%), lack of resources or accessibility (e.g., lack of reliable transportation, technology, internet/communication access, or the cost is too high; 25.9%), already committed to too many other therapies/activities (25.9%), and lack of childcare (22.2%). After closer analysis, caregivers that identified a lack of resources as a barrier to receiving support had an average household income of \$25,000-\$75,000. Further, caregivers in rural towns identified distance to services as a barrier more frequently than caregivers who live in city or metropolitan areas.





Summary and Recommendations

We designed and distributed a survey in partnership with the AAoM to measure a well-known, but undocumented barrier to behavioral service provision (i.e., waitlists) and to better understand the needs of caregivers during this time. Of the 78 caregivers who consented to participate in this survey, 48 indicated they pursued (or are currently pursuing) behavioral services for their child diagnosed with ASD. Our summary and recommendations are based on the data generated from these **48 caregivers**.

Overall, results indicated that **nearly three-quarters of caregivers (i.e., 73%) reported having to spend some time on a waitlist** prior to receiving behavioral services for their children. Mean duration of time spent on a waitlist was just over **5 and a half months**, with some caregivers reporting wait times approaching (or exceeding) 12 months. Although more than half of these caregivers (i.e., 51%) indicated that they were on multiple waitlists at a time, this strategy did not appear to significantly affect the duration of time spent on a waitlist. This presents a significant concern given the emphasis on *EARLY* intensive behavioral intervention (Reichow et al., 2018) and the

fact that time spent on a waitlist occurs during a period where it is critical that the child is accessing intensive behavioral intervention.

When caregivers were asked about the primary behavioral concerns they had for their children diagnosed with ASD during this time, **97%** of caregivers indicated **appropriate communication/language** was a concern (with <u>82% indicating it was a *major* concern)</u>, **94%** of caregivers indicated **social skills** was a concern (with <u>68% indicating it was a</u> *major* concern), **91%** of caregivers indicated **daily living skills** (such as toileting, getting dressed, toothbrushing) was a concern (with <u>59% indicating it was a *major* concern</u>), and **85%** of caregivers indicated **problem behavior** (such as tantrums, hitting, kicking, noncompliance) was a concern (with <u>50% indicating it was a *major* concern</u>). Given that demographic information indicated these data represent those who are elementary-aged children, it makes sense that appropriate communication was a concern for nearly all of the caregivers given this is a critical skill for this age range and is very salient when it occurs at a level that does not align with the child's typically developing peers.

Not surprisingly, caregivers indicated their top three needs while on the waitlist were: 1) **Strategies for teaching and maintaining child's skills** (84% of caregivers), 2) **Support for teaching and maintaining child's daily living skills** (81% of caregivers), and 3) **Skills for managing child's challenging behavior** (71% of caregivers). Interestingly, despite problem behavior being nominated as their fourth lowest concern, it was the third highest request for support. This might be because, although caregivers can likely manage most low-magnitude problem behavior on their own, there may be infrequent, but high-magnitude instances of problem behavior that caregivers may need help addressing. In addition, perhaps caregivers can tolerate a certain level of problem behavior; however, it might be that the behavior is not improving so there is motivation to pursue support or gain additional skills to address this behavioral concern. Additionally (although to a lesser extent), caregivers identified needs in **Support in advocating for their child's needs** (48% of caregivers), **Services for the caregiver's mental health** (48% of caregivers), and **Respite care** (42% of caregivers).

100% of caregivers expressed interest in receiving training, support, or services while on the waitlist. Specifically, caregivers indicated a preference for receiving (a) individualized, 1-on-1 training (over training conducted in a group setting), (b) live, in-person models (over pre-recorded video models), (c) immediate performance feedback (as opposed to delayed feedback), and (d) 1-hour sessions, twice a week (over 1 weekly, long session duration). Despite caregivers' preferences for training modality described above, **the majority of them still indicated they were only "somewhat likely" to attend** and noted the lack of time to attend (74% of caregivers), distance to services (41% of caregivers), and lack of child care (22% of caregivers)

wrote-in this potential barrier) as the three major barriers to pursuing these training opportunities.

Taken together, we recommend developing a system that makes a variety of resources available to caregivers who are awaiting access to behavioral service for their child. In particular, caregivers indicated a need for general training to address common behavioral concerns that would teach caregivers how to arrange an environment for their child(ren) that would promote teaching adaptive behaviors (e.g., appropriate communication), maintaining these skills while also managing challenging behavior, and reducing or preventing the emergence of these and other maladaptive behaviors. As noted, these could be pre-packaged general training programs; however, caregivers would benefit from a follow-up coaching component to provide 1-on-1 training to fine tune these skills (e.g., models, role-play, and feedback) and address specific concerns they might have in biweekly 1-hour sessions. Further, providing these services via telehealth could circumvent barriers related to (a) time to attend, (b) distance, and (c) lack of child care. Alternatively, if in-person training is to be offered, we might also consider in-home visits at a time that is convenient to the caregiver and bringing an additional support staff that can provide child care while the primary therapist is meeting with and training the caregiver. Of course, this approach would need to be developed and evaluated prior to launching it on a large scale.

Although the results of the survey generated some interesting and useful data, they must be interpreted in the context of one primary limitation. That is, the size and composition of the sample was limited in its number and diversity, respectively. Therefore, future research would need to conduct the survey again with the hope of recruiting a larger number of respondents. This could be achieved by (a) keeping the survey open for a longer period of time, (b) exploring additional dissemination methods to reach a broader population, (c) incentivizing survey completion to enhance recruitment and survey completion efforts, or (d) some combination of these suggestions.

Finally, the presence of waitlists is a symptom of a much larger issue: The demand for behavioral services greatly exceeds the amount of available behavioral service providers in the state of Michigan. Although the results of this survey are not designed to address this issue, the data collected here can begin to inform our understanding of how much of an issue this is and, if consistently tracked, can determine whether or not access to behavioral services are improving over time.