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## Development of an Internet Survey to Determine Barriers to Early Diagnosis and Intervention in Autism Spectrum Disorders

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### Abstract

**Background:** Autism Spectrum Disorders (ASD) are complex neurodevelopmental disorders with symptoms presenting in early childhood. Although a reliable diagnosis can be made by age 2, most children with ASD are not diagnosed until age 4. Delayed diagnosis subsequently leads to delayed treatments, thus impacting long-term outcomes for children with ASD. Additionally, alternative therapy use in ASD is common but lacks empirical evidence. Therefore, the purpose of this article is to describe the use of a modified Delphi method to construct an Internet survey for healthcare providers to identify perceived barriers to early diagnosis and intervention, as well as alternative therapy use in children with ASD.

**Methods/Findings:** Survey questions were developed based on an extensive literature review. Preliminary survey questions were presented to an interdisciplinary Community Advisory Board (CAB) of ASD professionals (n=10) to obtain feedback. A modified Delphi method elicited group feedback regarding the survey content. Three independent rounds and analyses were performed during the process. The final survey was constructed online using REDcap (Research Electronic Data Capture) and disseminated to healthcare professionals via the Internet. Limitations include the preliminary nature of this instrument development study and small sample size.

**Conclusion:** The researchers used the Delphi method's structured communication process to collect, group, sort, and rank data in a series of sequential questionnaires distributed to individuals with expertise on the topic. This was an effective method of establishing consensus among providers regarding clinical questions. This work provided insight to the clinical problem of barriers to early diagnosis and intervention in children with ASD, as well as alternative therapy use. Subsequent research should further characterize these barriers in order to reduce or eliminate them, empirically evaluate the most common alternative treatments, and improve long-term outcomes of children with ASD.

**Keywords:** Autism spectrum disorders; Early diagnosis; Barriers; Alternative treatment; Early intervention; Survey; Delphi

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### Introduction

Autism Spectrum Disorders (ASD) are complex neurodevelopmental disorders with no conclusive cause or cure to date [1]. While there is no cure for ASD, several interventions exist that are focused on improving ASD symptoms and thus subsequent-

ly long-term outcomes. Symptoms of ASD fall on a continuum and manifest in early childhood. These include deficits in social communication and interaction across multiple contexts, specifically, deficits in developing and understanding relationships, social-emotional reciprocity, and communicative behaviors [2]. Early diagnosis and treatment in children with ASD is associated

with improved outcomes. Studies have shown that interventions in children with ASD before the age of three have a significantly greater impact than interventions provided after the age of five [3]. Although a reliable diagnosis of ASD can be made by age 2, most children with ASD are not diagnosed until age 4 [2]. This delay in diagnosis and treatment often results in desperate parents seeking their own interventions that often include alternative therapies that lack sufficient empirical validation. Therefore, it is critically important to examine the discrepancy between when a child can be diagnosed with ASD versus when a child actually receives an ASD diagnosis. Additionally, there is great need to identify the types of alternative treatments utilized by parents of children with ASD. Therefore, the purpose of this article is to describe the process of using a modified Delphi method to construct an Internet survey aimed at determining healthcare providers' perceptions of barriers to early diagnosis and intervention, as well as alternative therapy use in children with ASD.

### Modified Delphi method

The Delphi method is a widely used technique that gathers data from respondents within their domain of expertise [4]. This method includes a group communication process aimed at achieving convergence of opinions on a particular topic [4]. In addition, this method consists of three distinctive characteristics: anonymity, controlled feedback, and group response [5]. Anonymity is used to reduce the effects of socially dominant individuals and is achieved by dispersing separate surveys to individuals [5]. Controlled feedback is achieved by undergoing several iterations where participants are given the results of previous iterations and further feedback is elicited [5]. Lastly, group response is the collective summarization of responses and represented in a final product represented to the group.

A modified Delphi method is one that is similar to the traditional Delphi method in terms of intent and procedures (i.e., a series of rounds with selected experts) [6]. However, the main modification is the beginning of the process with a set of carefully preselected items drawn from areas, such as reviews of literature and interviews with selected content experts [6]. Additional modifications, such as the practice of a synchronous modified Delphi method where anonymity is absent, have the advantage of overcoming inherent weaknesses of the Delphi method (e.g., time constraints, low response rates). A modified Delphi method is an important data collection methodology for researchers to utilize when seeking to gather information from those individuals immersed and imbedded in the topic of interest [4].

### Methods

IRB approval was obtained prior to conducting this study and written informed consent was obtained from all participants. Initial survey questions were developed based on an extensive literature review. Preliminary survey questions were presented to the interdisciplinary Community Advisory Board (CAB) in a group process with the preliminary paper format survey to obtain feedback. Meetings were audio-recorded, transcribed, and analyzed by two independent coders. The modified Delphi method was used to elicit feedback from the CAB regarding the content of the survey. Following each iterative round, feedback

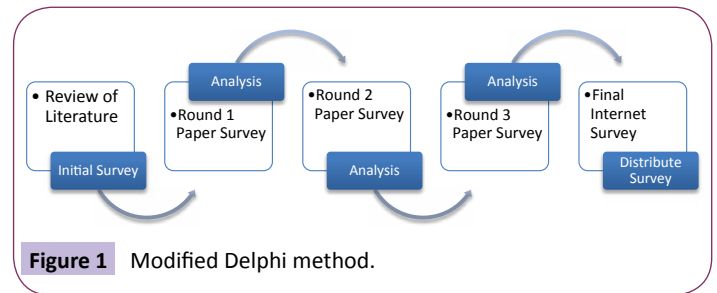


Figure 1 Modified Delphi method.

received from the CAB was used to reconstruct the survey to be presented to the CAB at successive meetings. Three independent rounds of the modified Delphi method were performed with three independent analyses (Figure 1). The final survey (Figure 2) was constructed online using REDcap (Research Electronic Data Capture) and disseminated to healthcare professionals throughout the state of Florida via the Internet.

### Participants

A Community Advisory Board (CAB) consisting of 10 (n=10) ASD professionals was assembled to assist with the development and dissemination of the final Internet survey. CAB members consisted of seven (n=7) females and three (n=3) males.

Nine (n=9) CAB members were Caucasian (90%), while one (n=1) CAB member was African American (10%). The CAB included a board certified pediatrician, neuropsychologist, occupational therapist, behavioral psychologist, certified pediatric nurse practitioner, director of a center for disabilities, professor of early childhood education, community health worker, founder of a community-based clinic, and senior autism researcher. CAB participants were identified through purposive sampling techniques to ensure the CAB represented ASD professionals from various fields.

### Setting

A total of three face-to-face synchronous CAB meetings were conducted at the local community-based outreach center HealthStreet over the course of nine months. HealthStreet is a community-engagement program that aims to decrease health disparities through the partnership of community members with researchers. Additional services provided by HealthStreet include health workshops, screenings, referrals, and research opportunities [7]. Thus, this agency was perfectly suited to the purpose of this study.

### Results

Results of the modified Delphi method included the construction of an Internet survey that was subsequently disseminated to healthcare professionals throughout the state of Florida. The final survey (Figure 2) consisted of a total of 15 questions, which included open-ended and closed-ended questions. These questions addressed provider qualifications, provider role, barriers to early diagnosis in children with ASD, barriers to early intervention in children with ASD, and the use of alternative therapies in children with ASD. The Community Advisory Board (CAB) identified several barriers to early diagnosis and intervention that families of children with ASD encounter. These

1. What is your current role/position?
2. How long have you been in this role/position (Enter in years)? \_\_\_\_\_
3. Estimate the number of individuals with Autism Spectrum Disorder (ASD) that you provide services to each year. \_\_\_\_\_
4. Estimate the number of families who you serve who have more than one member with ASD. \_\_\_\_\_
5. How often have families expressed concern about immunizing/vaccinating their children who have ASD? (Never, Sometimes, Often, Very Often).
6. In your caseload do you have: Only individuals under age 21, Children and adults
7. What type of services do you provide to families of individuals with ASD (Select all that apply) (Counseling/Social Services, Medical/Clinical, Parent Education, Referrals, Advocacy, Therapy, Financial, Legal, Other)
8. Do you think there are barriers to individuals with ASD receiving accurate, timely diagnosis? (Yes, No)
9. Which of the following do you see as a barrier to families getting an early diagnosis of ASD? (Select all that apply) (Socioeconomic Status, Medical Insurance, Geographical Location, Transportation, Parental Education, Parents not Knowing Where to Seek Help, Culture, Time Constraints, Language, Lack of Provider Education, Family Acceptance, Provider Hesitancy, Other, I do not think there are barriers to families getting early diagnosis) (Please describe the barriers to early diagnosis in ASD that were not listed)
10. Do you think there are barriers to individuals with ASD receiving services or treatments? (Yes, No)
11. Which of the following do you see as a barrier to families with children with ASD from getting services or treatment that they need (Socioeconomic Status, Medical Insurance, Geographical Location, Transportation, Educational, Parents not Knowing Where to Seek Help, Culture, Time Constraints, Language, Provider Availability, Technology Availability, Pediatrician Resistance to Services, Other, I do not think there are barriers to families getting services or treatment) (Please describe the barriers to services or treatment for families with children with ASD that were not listed)
12. How far does the average family have to travel in order to get necessary services for their child with ASD? (Please specify approximate number of miles).
13. Are you aware of families using alternative treatments for ASD? If so, which of the following (Select all that apply)? (Gluten-Free and Casein-Free (GFCF) diet, probiotics, omega-3 fish oils, supplements (i.e., melatonin), acupuncture, acupressure, aromatherapy, massage, light therapy, music therapy, play therapy, sensory integration therapy, art therapy, chelation, chiropractic, hyperbaric oxygen therapy, vitamins, and craniosacral therapy).
14. Please describe other alternative treatments used by families with children with ASD that were not listed.
15. Comments....

**Figure 2** Healthcare Provider Survey.

**Table 1** Barriers to Early Diagnosis and Early Intervention in ASD.

Barriers to Early Diagnosis in ASD	Barriers to Early Intervention in ASD
Limited parental education (not knowing where to seek help)	Limited parental education (not knowing where to seek help)
Remote geographical location	Pediatrician resistant to services
Limited provider education	Remote geographical location
Low socioeconomic status	Limited medical insurance
Lack of family acceptance	Low socioeconomic status
Limited medical insurance	Technology availability
Limited transportation	Limited transportation
Language constraints	Language constraints
Cultural differences	Provider availability
Provider hesitancy	Cultural differences
Time constraints	Delay of diagnosis
	Time constraints
■ Represents unique barrier specific to that category	

**Table 2** Alternative Therapy Use in Children with ASD.

Alternative Therapy Use in Children with ASD
Gluten-Free and Casein-Free (GFCF) diet
Supplements (i.e., melatonin)
Hyperbaric oxygen therapy
Sensory integration therapy
Omega-3 fish oils
Chelation
Probiotics
Aromatherapy
Vitamins
Chiropractic
Acupressure
Acupuncture
Massage
Cransiosacral therapy
Play therapy
Music therapy
Art therapy
Light therapy

are presented in **Table 1** and include low socioeconomic status, limited medical insurance, remote geographical location, limited transportation, limited parental education including not knowing where to seek help, culture differences, time constraints, language constraints, limited provider education, lack of family acceptance, and provider hesitancy. Similar barriers were identified to early intervention (**Table 1**) with the addition of a delay in diagnosis,

technology availability, pediatrician resistant to services, and provider availability. Lastly, alternative therapy use in children with ASD (**Table 2**) emerged as a prominent concept. Identified alternative therapies included the gluten-free and casein-free (GFCF) diet, probiotics, omega-3 fish oils, supplements (i.e., melatonin), acupuncture, acupressure, aromatherapy, massage, light therapy, music therapy, play therapy, sensory integration therapy, art therapy, chelation, chiropractic, hyperbaric oxygen therapy, vitamins, and cransiosacral therapy.

## Discussion

The Delphi method uses a structured communication process to collect, group, sort, and rank data in a series of sequential questionnaires distributed to individuals with expertise on the topic [8]. This is an effective means of establishing consensus among providers regarding clinical questions [9]. A modified Delphi method allows for insight to the clinical problem of barriers to early diagnosis and intervention, as well as the increasing use of alternative therapies in children with ASD. Additionally, the use of a modified Delphi method in this study was instrumental in the identification of the target sample for the final Internet survey subsequently distributed throughout the state of Florida.

Findings from this modified Delphi method and survey are an important first step to informing healthcare professionals about alternative treatment use and barriers to early diagnosis and intervention in children with ASD. This knowledge, in turn, can help reduce and eventually eliminate these barriers, inform credible treatment choices, and facilitate future research to improve long-term outcomes of individuals with ASD and their families. Subsequent work should include a larger and more geographically diverse sample of ASD professionals. Future research should also further characterize the barriers that have been noted as well as others that may not have been mentioned in this work in order to reduce or eliminate them. In addition, there is a need to empirically evaluate the most common alternative treatments in order to inform parents and clinicians with the ultimate goal of improving long-term outcomes of children with ASD.

## Funding Agency

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## Conflict of interest

All authors declare there is no conflict of interest.

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