

Factors Influencing How Parents Report  
Autism Symptoms on the ADI-R

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## **Abstract**

**Background:** The Autism Diagnostic Interview - Revised (ADI-R) is one of the most common caregiver reports for diagnosing autism. It has been hypothesized that when in time caregivers report symptoms about their child affects how the behaviors are reported. The aim of this research is to determine whether the order that caregivers report behaviors on the ADI-R impacts the severity of the symptoms described.

**Methods:** In this study the order of questions on the ADI-R were altered and three different groups of caregiver were randomly administered one of three versions of the ADI-R. The first version asked 32 caregivers to report all current symptoms in their child followed by prior history of behaviors. The second version asked 30 caregivers to report all prior behaviors in their child followed by current symptoms. The third version asked 75 caregivers to report current and prior history of behaviors simultaneously in typical ADI-R format. Analyses compared current and prior behavior totals between the two groups that received altered ADI-R setups and additional analyses included the caregivers who completed the Typical ADI-R.

**Results:** Caregivers who reported current behavior questions first described more severe current and prior history of behaviors in their child compared to caregivers who first described prior history of behaviors. There were no differences in current behaviors among all three groups; however, caregivers that were first asked prior history questions received lower prior behavior totals than the caregivers who reported current behaviors first and those who received the Typical ADI-R.

**Conclusions:** This research suggests that caregivers rely on reporting of current behaviors in their child to provide the framework and serve as an anchor for caregiver report. Therefore both prior behavior and current symptoms are necessary for ADI-R diagnosis and a best estimate of diagnosis by a clinician.

## **Review of Literature**

Autism Spectrum Disorder (ASD) is defined as a neurodevelopmental disorder with deficits in social interaction, communication, and ritualistic or repetitive behaviors (American Psychiatric Association, 2000). ASD undoubtedly has a strong genetic base (Rodier, 2000), but is diagnosed by behavioral assessments. A common range of symptoms includes lack of sharing with others, drifts in direct eye gaze and delays in language and direct communication (Pelphrey, 2002). Autism has become an increasing health concern, due in part to a rise in prevalence. According to a report in 2008, 1 in 88 children are diagnosed with autism (Baio, 2008), a stark increase from a report in 2005 that showed 4 in 10,000 children diagnosed. The reasons for the boost are debated; it is unknown whether autism prevalence itself has increased or if the rise in numbers is merely a result of new diagnostic criteria, the array of methodologies used to diagnose and their inconsistencies and inaccuracies in regard to testing (Matson and Kozlowski, 2011). Regardless of the shift in prevalence, the boy to girl ratio of 4 to 1 remains unaltered (Frombonne, 2005).

The uncertainty in regard to prevalence mirrors the uncertainty of the causes of ASD. While there is no cure, treatments vary on a patient to patient basis. Treatments range from dietary restrictions to independent and group therapies and applied behavioral analysis (ABA) which involves an initial assessment of an autistic patient which is then used to formulate an individualized curriculum focused on learning independent skills (Green, 1996). However, it is undisputed that early intervention is the best possible

scenario for receiving the right treatments (Rogers and Vismara, 2008). Recent research involving extensive literature searches on the study of the effectiveness of Early Intensive Behavioral Intervention showed that autistic children in those programs generally did better on IQ measures and adaptive behavior tests than those who had received and were following alternative treatments (Peters-Scheffer et al, 2011).

Since early intervention is a pivotal step for treatment and learning opportunities for children with autism, there are many diagnostic tools and screening procedures that were developed to evaluate and potentially diagnose children with autism as early as 18 months of age (Lord et. Al, 2000). There are vast differences in autism severity and manifestation of symptoms, making it difficult to use a singular method or test to diagnose the disorder. Therefore often multiple tests are necessary for accurate evaluations (Huerta and Lord, 2012).

Clinicians diagnose autism using direct observation of the patient and parent report symptoms. Two diagnostic tools that employ direct observation are the Childhood Autism Rating Scale (CARS) (Schopler et. al, 1988) and the Autism Diagnostic Observation Schedule (ADOS) (Lord et. Al 1989). The CARS is a 15 item rating scale designed to aid early diagnosis of toddlers and distinguish diagnosis between autism and other developmental disorders (Schopler, 1980) The ADOS is a standardized diagnostic tool that assesses patients during structured interactive play with the clinician. The test is broken down into four modules that cover a range sensory interests and social interactions. There are specific activities and materials that clinicians present to elicit a response from the patient and the clinician uses these responses to make a diagnosis. (Lord 2000). Direct observation has proven to be necessary in accurate diagnosis of

autism, but parental report is also essential to the diagnosis process (Kim and Lord, 2012).

One of the most commonly used parental reports is the Autism Diagnostic Interview - Revised (ADI-R) (Rutter et. Al, 2003). The ADI-R is a 93 item questionnaire that is broken up into five domains covering reciprocal social interaction, verbal and nonverbal communication, and repetitive and stereotyped behaviors (Lord, Couteur and Rutter, 1994). A unique feature of the ADI-R is the range of time in the child's life that the questions cover. The test is formatted in a way that asks caregivers to report about their child's current and prior history of symptoms so that the examiner has information about the child covering a wide span of time. (Hus et al. 2012). These answers are then divided into current behaviors and prior history of symptoms.

Trained clinicians administer the ADI-R in order for the questions to be standardized and the test is lengthy, as it can take up to 2.5 hours to administer. The data obtained can be used as an important piece for a diagnosis (Lord et al. 2012). Yet despite standardization of questions and coding, the test still heavily relies on parent's perspective, and their perceptions can be faulty. An example of this came about in Mildenbergers study of autistic toddlers in 2001. It was found that clinicians observed more severe symptoms in patients compared to parents who perceived their children's behaviors to be less severe (Mildenberger et. Al, 2001).

Disagreement between clinicians and caregiver report suggests that despite standardization of questions and coding, caregiver perceptions are subjective. An interesting perspective from Tversky and Kahneman's research in 1981 proposed that the

framing of survey questions could influence responses (Tversky and Kahneman, 1981). In other words, the order questions are asked and question layout has an affect on the outcome of participant response (Payne 1951). Items asked at the beginning of a survey are often thought about as the test continues. This keeps participants from viewing questions and answers independently (Koriat et al. 1980). The possibility of caregiver reports changing due to framing of how questions are asked on the ADI-R is the focus of the current study of the ADI-R. Previous research focused on the diagnostic validity of ADI-R algorithms and question format (Kim and Lord, 2012), this research will specifically focus on the order of when in time of the child's life caregivers are being asked to report symptoms, and whether the order the parents are given the questions could result in under or over-reporting of ASD behaviors.

### **Research Questions**

Due to the length of time to administer the ADI-R, many clinicians and researchers have sought a way to shorten the interview. One way to make the interview shorter is to only ask about one set of symptoms in time. However as evident by research of Tversky, Payne and Koriat framing influences survey responses. The aim of the current study is to determine whether the order that caregivers report behaviors on the ADI-R impacts the severity of the symptoms described.

The Hypothesis reflected the following questions:

- 1) Do parents inflate symptoms in the past if they discuss current behaviors first?
- 2) Do caregivers inflate symptoms currently if they discuss prior history of behaviors first?
- 3) Do parents anchor their description of past symptoms on current behaviors?

### **Hypothesis:**

H1) Asking caregivers to first report current behaviors will increase the severity of behaviors described in the past

H2) Asking caregivers to first report behaviors in the past without the context of current behavior will decrease the severity of how they describe prior behavior

H0) Altering the format of questions will not change how behaviors are reported on the ADI-R

### **Methods**

#### **Participants**

163 caregivers whose children were 6 years of age and older were recruited from University of Michigan Autism Center. All caregivers completed the Autism Diagnostic Interview – Revised (ADI-R) (Rutter et. al 2003). 33 caregivers were asked about current behaviors in their child on the ADI-R and then were asked about prior behaviors (*Current – Prior*). 38 caregivers were asked about prior history of behavior in their child on the ADI-R followed by current behavior questions (*Prior – Current*). A third group of 92

caregivers were administered the ADI-R according to the typical format which asks both current and prior history of behavior questions simultaneously (*Typical*).

Data from 6 caregivers was excluded as there was more than 50% of the data that was unknown during the ADI-R or if the verbal IQ (VIQ) or non-verbal IQ (NVIQ) of the child was unknown. Furthermore, in order to ensure that all samples were matched on IQ, 6 individuals with the highest VIQ and NVIQ were excluded from the *Prior – Current* sample, and 13 individuals with the highest Verbal IQs were excluded from the *Typical* group. The final sample included 32 caregivers in the *Current – Prior* group (mean age 12.74 years, SD = 8.23, 9 Females), 30 caregivers in the *Prior-Current* group (mean age 12.58 years, SD = 6.11, 10 Females) and 75 caregivers in the *Typical* group (mean age 11.74 years, SD = 6.10, 21 Females). Participants in the *Current-Prior* group had a mean VIQ of 81.4(SD=36.4) and an NVIQ mean of 81.2 (SD=34.4). *Prior-Current* group had VIQ mean of (87.5) (SD=28.1) and NVIQ mean of (87.7) (SD=25.0) and *Typical* group had VIQ mean of (90.5) (SD=30.5) and NVIQ mean of (89.2) (SD=27.5).

Group	<i>Current-Prior</i>	<i>Prior-Current</i>	<i>Typical</i>
VIQ: Mean (SD)	81.4 (36.4)	87.5 (28.1)	90.5 (30.5)
NVIQ: Mean (SD)	81.2 (34.4)	87.72 (25.0)	89.2 (27.5)

## **Procedures**

### **Location**

The data for this research was collected at University of Michigan Autism Center from 2003 to 2005. Trained clinicians administered all ADI-R tests.

### **Format**

Three versions of the ADI-R were used and were administered randomly to caregivers who came to the clinic in order to receive Autism diagnoses for their child or to participate in research. To address the potential that caregivers alter their description of ASD symptoms on the ADI-R, the order of questions regarding current versus prior history questions were altered.

In the *Current – Prior* sample, caregivers were asked to first report current symptoms in their child on the 93 ADI-R items and then were asked to report prior history symptoms. In the *Prior – Current* sample, caregivers were asked to report the prior symptoms in their child on all 93 items and then were asked to report current behaviors. In the *Typical* sample, caregivers were asked all 93 ADI-R items and were asked to report current and prior history of symptoms together.

## **ADI-R Scoring and Algorithms**

The ADI-R has two algorithms that are used to determine the amount of autism symptoms in a child and is comprised of a subset of items on the ADI-R. There is a current algorithm based on current symptoms and a diagnostic algorithm that relies on prior history of symptoms. According to ADI-R scoring conventions, clinicians give score symptoms on a scale of 0-3 with the higher score for more severe cases and 8 or 9 for unknown or not applicable. When scores are translated to the algorithms, 3's are recoded as 2's and 8's and 9's recoded as 0's.

### **Current Algorithm**

The current algorithm items ( 23 questions that ask about current symptoms) are totaled in each domain. The four main domains are Qualitative Abnormalities in Reciprocal Social Interaction, Qualitative Abnormalities in Verbal Communication, Qualitative Abnormalities in Non-Verbal Communication, and Restricted, Repetitive, and Stereotyped patterns of behavior. In order to make scores comparable across participants, the scores from Verbal Communication were excluded as not all participants had totals for this domain. Totals were made from the three domains and higher totals corresponded to more severe autism behaviors.

### **Diagnostic Algorithm**

The diagnostic algorithm items (30 questions that ask about most abnormal symptoms) are also totaled in each of the four domains. As with the current Diagnostic Algorithm, totals did not include the Verbal Domain scores in order to make scores comparable across the greatest number of participants. These totals are also used to obtain domain cutoff scores. If the total is very high it reaches the cutoff and the patient exceeds the threshold for autism in that domain. Based on domain cutoff scores a patient may reach autism criteria in some domains but not others.

## **Diagnosis**

Participants were not assessed solely based on ADI-R diagnostic cutoffs. Each child was also observed during an Autism Diagnostic Observation Scale (ADOS). Clinicians reviewed scores from the ADI-R, ADOS as well as other measurements including cognitive testing scores (IQ) in order form a “Best estimate,” or a diagnosis based on clinical judgment (Lord et al. 2012)

## **Data Analysis**

The three-caregiver samples (*Current – Prior*, *Prior – Current*, *Typical*) were the independent variables. In order to make sure IQ was matched across all three sample groups, a multivariate ANOVA was performed with VIQ as the dependent variable and group (*Current-Prior*, *Prior-Current* and *Typical*) as the independent factors. This same test was then done with replacing all NVIQs as the dependent variable.

There was no significant difference between verbal iq between the *Current-Prior* and *Prior-Current* groups ( $p=.150$ ), but there was a significant difference on NVIQ ( $t(60)=-.852, p<.021$ ). When the *Typical* sample was included in a multivariate ANOVA, there were no significant differences on (VIQ ( $p=0.72$ ) and NVIQ ( $p=0.639$ )).

To directly test the question of whether the order in which a caregiver discussed autism symptoms in their child impacted their scores on the ADI-R, a univariate ANOVA was performed with the dependent variable of diagnostic algorithm domain totals and the between subject factor of group (*Current – Prior* and *Prior-Current*) VIQ, NVIQ and age of the child at the time of the ADI-R were entered as covariates.

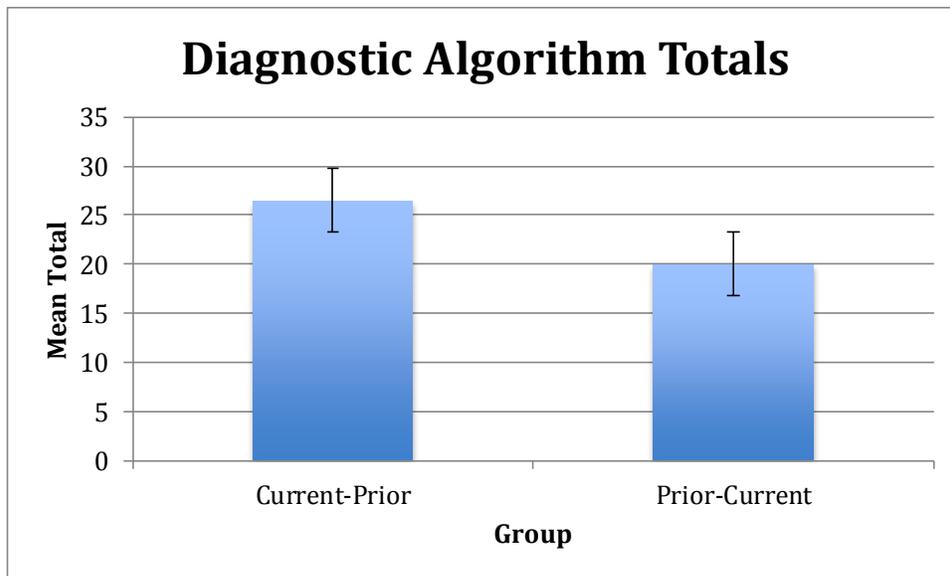


Fig 1: There was a significant difference between *Current-Prior* and *Prior-Current* on the Diagnostic Algorithm totals ( $F(1, 57)=4.398, p<.040$ ). There were no other significant interactions.

A second univariate ANOVA was performed to analyze differences in current algorithm totals. The Algorithm totals were the dependent variable and a between subject factor of group (*Current-Prior* and *Prior-Current*) and age of the child at the ADI-R, NVIQ and VIQ were entered as covariates.

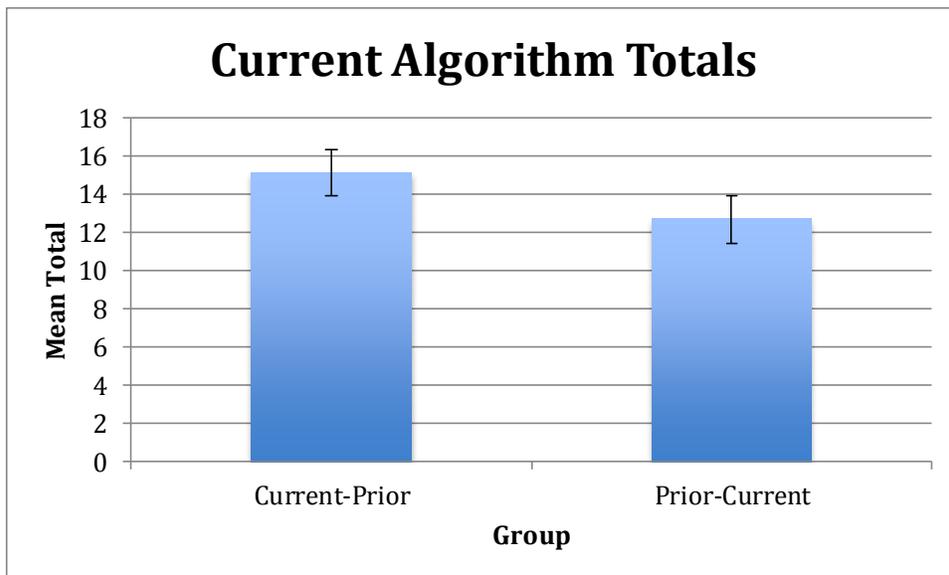


Fig 2: There was a significant difference between *Current-Prior* and *Prior-Current* groups on the current algorithm totals ( $F(1,57)=4.767, p<.033$ ). No other interactions were significant.

In order to determine how the two samples of caregivers who received the ADI-R questions grouped in time may differ from how the ADI-R is typically administered another set of analyses were performed. Specifically, two univariate ANOVAS were

performed; this time comparing *Current-Prior* and *Prior-Current* diagnostic algorithm and current algorithm totals to that of the *Typical* group. The dependent variable to compare prior history and current questions was diagnostic domain totals and current algorithm domain totals with a between subject factor of group (*Current-Prior*, *Prior-Current* and *Typical*) and covariates VIQ, NVIQ and age ADI.

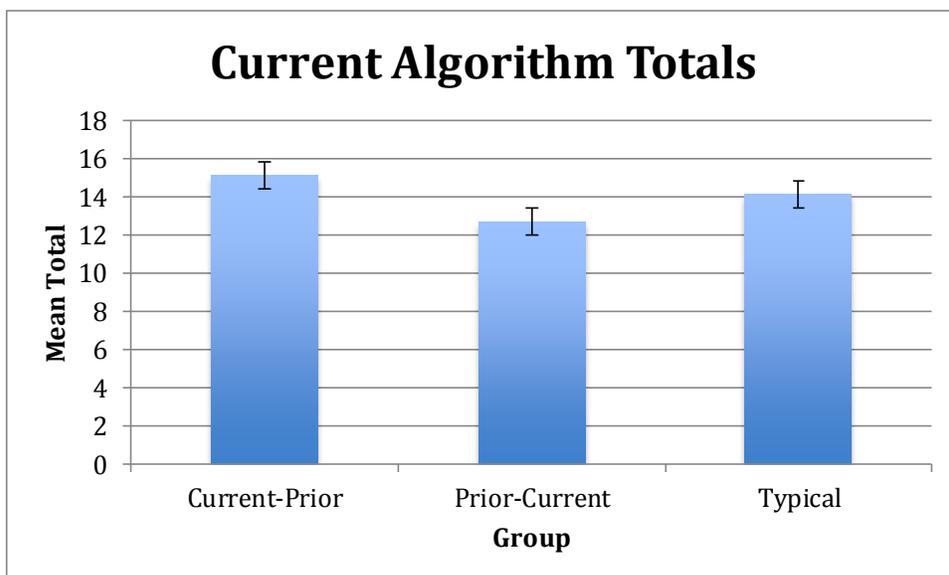
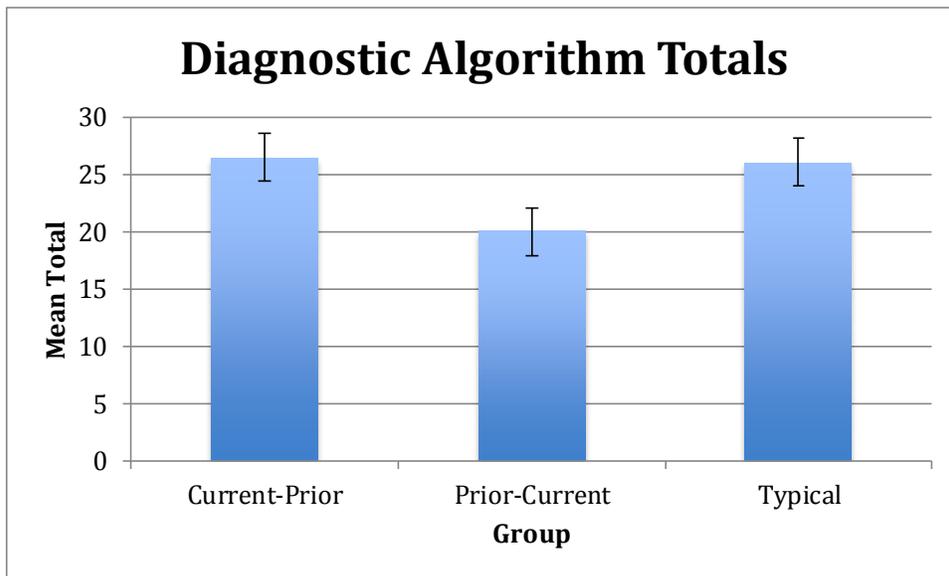


Fig 3 and 4: There was a trend of a significant difference between the three samples ( $p = 0.069$ ). There was no significant difference for the current algorithm totals ( $p = .295$ )

This study was the first to directly test whether caregivers alter their description of their child's autism symptoms based upon when they are asked in time to remember the autism behaviors. Furthermore, this experiment was novel in that it altered the order of symptom questions on the ADI-R in order to test whether both sets of symptoms (current and prior history) were needed to provide accurate information. There were significant differences in both diagnostic algorithm totals and current algorithm totals between people who received prior history questions first and those who received current behavior questions first. People who received the current behavior questions first had elevated current totals and diagnostic totals compared to those who had received the prior behavior questions first. This suggested that caregivers inflated the amount of autism symptoms in their child in the past when they were asked to first recall the present behaviors. From these two comparisons it was unclear whether hypothesis one or two was being proved correctly. Asking current behaviors first could have increased the severity of scores, but it was also possible that asking prior history questions first was decreasing the severity of the ever scores, or a combination of such was occurring.

The analyses between the three caregiver samples were performed to use the *Typical* group as a baseline. The data suggests that the *Current-Prior* group mirrored the scores of the *Typical* group, but it was the *Prior-Current* group that was significantly different. Although there was no significant current algorithm total difference among the

three groups, there was a significant difference on the diagnostic algorithm totals. The diagnostic totals of the current behavior group were significantly higher than the ever group, but they matched the *Typical* group, showing that they were not inflated. This suggests that without current questions to anchor how caregivers report symptoms report that they will deflate their report of prior history symptoms.

### **Limitations/Future Research**

Consistent with findings from previous studies (Krosnick and Alwin 1987), response-order effects, or change in report due to framing, were seen in this research. Following the principle of memory bias, the set of symptoms that were presented to caregivers first became the framework and comparison for the latter set of symptoms. For example, the group that didn't receive current questions first reported understated symptoms, where as the group that received the current questions first had a better anchor or framework to remember symptoms. This research and the framing effect highlight the importance not only using both sets of symptoms on the ADI-R (Hus et. Al 2007), but also using various diagnostic tools to diagnose autism. In a study by Huerta in 2012, it was found that a combination of caregiver report and direct clinical observation provided a more accurate diagnosis of autism than using only one test (Huerta et. al, 2012). In concurrence with Huerta et. al, our research suggests that parent report can be easily influenced by design of the ADI-R, and thus to obtain the most accurate diagnosis an array of tests should be implemented.

Due to time constraints the test could not be expanded, however including more participants and expanding the sample size would provide more accurate results. In addition this study did not assess the condition of parents, for example, their level of stress or mood while taking the ADI-R, and if it could have affected the way they reported symptoms that day.

There has also been discussion regarding new DSM 5 autism diagnostic criteria, which will be published in 2013, and a movement to focus diagnosis on more current behaviors than the DSM 4 manual. (Huerta et. al 2012). However, in light of this study, more careful consideration of the weight of caregiver symptom report in diagnostic criteria should be considered as valuing one set of symptoms in time over the other could result in a misdiagnosis.

## **Conclusion**

This research proved that prior behavior symptoms cannot be reported accurately when independent from current questions. Current questions are needed to provide the framework or act as an anchor for caregiver report. Therefore prior behavior and current symptoms are necessary for ADI-R diagnosis and a best estimate of diagnosis by a clinician.

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