

# Administration of the Autism Behavior Checklist: agreement between parents and professionals' observations in two intervention contexts

## Aplicação do Inventário de Comportamentos Autísticos: a concordância nas observações entre pais e profissionais em dois contextos de intervenção

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### Abstract

**Objective:** To determine the agreement between responses on the Autism Behavior Checklist by mothers and healthcare professionals. **Method:** Twenty-three mothers of children from the autism spectrum (DSM-IV-TR, 2002) were interviewed. The children were part of an educational program of the Autistic Friends Association-SP. The healthcare professionals in charge of the children at the institution filled out a questionnaire regarding the method for observing behavior. For comparison purposes, an additional 15 mothers of children from the autism spectrum were interviewed at the speech therapy clinic of Universidade Federal de São Paulo, and the speech therapists responsible for the children filled out the questionnaire on the observation method. The Kappa index was employed to obtain the frequency of agreement between mothers and healthcare professionals' observations on the overall Autism Behavior Checklist, as well as its individual components. The Student's t-test was used to assess differences or similarities between the Kappa results. **Results:** The agreement index was low for the total score, with a statistically significant difference between both groups ( $p < 0.001$ ). Agreement was also low for each Autism Behavior Checklist components, but there was greater agreement in the group treated at the public service in the Language, Body and Use of Objects components ( $p < 0.001$ ). **Conclusion:** There was disagreement between the observations in both intervention contexts, but agreement was better at the public service than at Autistic Friends Association.

**Descriptors:** Autistic disorder; Behavior; Evaluation studies; Questionnaires; Reproducibility of results

### Resumo

**Objetivo:** Verificar a concordância das respostas no Inventário de Comportamentos Autísticos de mães e de profissionais de crianças pertencentes ao espectro autístico. **Método:** Entrevistou-se 23 mães de crianças do Espectro Autístico (DSM-IV-TR, 2002) inseridas em programa educacional da Associação dos Amigos do Autista-SP. O profissional da instituição responsável pelas crianças preencheu o questionário sob forma de observação de comportamentos. Para comparação, entrevistou-se 15 mães de crianças do Espectro Autístico (DSM-IV-TR, 2002) do ambulatório de fonoaudiologia da Universidade Federal de São Paulo e os fonoaudiólogos responsáveis pelas crianças preencheram o questionário sob forma de observação. Empregou-se o Kappa para obter a frequência de concordância entre as observações das mães e do profissional no total e nas áreas do Inventário de Comportamentos Autísticos, e teste T-student para avaliar diferenças ou igualdades entre os resultados de Kappa. **Resultados:** No escore total, o índice de concordância foi baixo, com diferença estatisticamente significativa entre os dois grupos ( $p < 0,001$ ). Para cada uma das subáreas do Inventário de Comportamentos Autísticos, o índice de concordância também foi baixo, mas teve maior concordância no grupo atendido no serviço público, nas áreas de Linguagem, Corpo e Uso de Objeto, e Relacionamento ( $p < 0,001$ ). **Conclusão:** Houve discordância entre as observações nos dois contextos de intervenção; porém, no serviço público, a concordância foi melhor do que na Associação dos Amigos do Autista.

**Descritores:** Transtorno autístico; Comportamento; Estudos de avaliação; Questionários; Reprodutibilidade dos testes

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## Introduction

The conditions that make up the autism spectrum are characterized by severe, invasive impairment to social development, communication and interest.<sup>1</sup> The atypical behavior that characterizes the autism spectrum is manifested in a heterogeneous fashion, with considerable variability in clinical presentations and different levels of severity. We can find children who speak and others who do not; children without any kind of social contact and others with atypical relationships. Some children may exhibit mental retardation, whereas others can have an intelligent quotient within the normal average range.<sup>2,3</sup> The clinical assessment of subjects pertaining to this spectrum includes interviews with family members, direct and indirect observations and the correlation of recorded behavior with knowledge on cognitive, relational and communicational manifestations described in Pervasive Development Disorders (PDD).<sup>1,4</sup> Based on clinical observations regarding development, it is possible to determine the severity of the condition, as well as design interventions, measure progress and compare different individuals.

Interviews involving parents and caregivers<sup>5</sup> scales and checklists for the assessment of behavior among children belonging to the autism spectrum are also useful. Such instruments tend to be quite detailed, thereby providing numeric data that make observations more objective and enable the information obtained to be used in other contexts.<sup>6</sup> The characteristics of scales and checklists depend upon the psychometric measurements of reliability and validity,<sup>7</sup> which are necessary so that a more reliable use of an instrument in both clinical practice and research can be obtained. The term reliability is generally used to refer to the stability or reproducibility of an assessment instrument or screening scale.<sup>8</sup> Thus, reliability is an indicator of the quality of information and is understood as the agreement between information provided by different observers or even a single observer performing distinct measurements.<sup>8,9</sup> Thus, there are two types of agreement that can be considered more important: inter-observer agreement, when a single individual is evaluated by two different observers; and intra-observer agreement, when a single individual is evaluated by a single observer on different occasions.<sup>7,10</sup>

Few studies have included agreement information between different observers during the development of field collection or even during clinical treatment. This fact can lead to errors in the interpretation of results. Agreement studies are carried out with various proposals, from the drafting of assessment instruments to the determination of the accuracy of the results obtained from a particular instrument. However, all are concerned with determining possible sources of disagreement that could result in incorrect or inaccurate information.<sup>11</sup>

One common procedure to obtain better assessments when gathering information on child development is the comparison of reports from professionals and parents.<sup>12</sup> Such reports enable the estimation of reliability measurements and the use of information provided by parents, who are considered secondary informants. Reliability studies with data obtained from parents and professionals have demonstrated high levels of agreement for permanent physical characteristics,<sup>13</sup> but the same does not occur with regard to subjective dimensions, such as most psychological behavior symptoms.<sup>14-16</sup> Due to their greater closeness with their children, mothers are generally the most often used secondary informants in information agreement studies.<sup>11</sup> However, some studies have found that fathers generally observe and report more behavioral problems with their children than mothers, with the exception of symptoms of depression.<sup>15</sup>

A study on respiratory symptoms,<sup>10</sup> symptoms of depression, changes in sleep patterns and problems in the neighborhood or at school estimated the level of agreement between information obtained from 10 to 14-year-olds and their mothers in a health inquiry. Interviews were first held with each of the children in their respective homes. On a second visit, the mothers were asked to answer a similar questionnaire applied by a blinded interviewer. Reliability was higher among boys than among girls for all variables except changes in sleep patterns. The results revealed that information obtained from 10 to 14-year-olds does not agree with that provided by their mothers. It was also observed that socioeconomic, demographic and environmental variables influenced the level of agreement between responses.

Another study was carried out with the aim of determining agreement between parents and professionals regarding intervention practices addressing children with diverse disabilities, especially those practices considered ideal.<sup>17</sup> The results indicated that agreement was high with regard to both current and ideal practices. Although both groups considered most of the practices essential, more than half were not applied in practice. The authors stressed the importance of the combined view of parents and professionals in order to facilitate the modification of intervention programs according to the needs of each family.

Reliability studies are also carried out to determine the stability and reproducibility of instruments used in the assessment of individuals with autism. The reliability of the Perceptions of Children's Theory of Mind Measure was demonstrated.<sup>18</sup> The aim of this scale is to map children's skills regarding the theory of mind. Caregivers of children of the autism spectrum responded to the instrument on two separate occasions. The score demonstrated high test-retest reliability and high correlation with verbal mental health and performance on theory of mind tests. Another reliability test on the Childhood Asperger Syndrome Test (CAST) was carried out.<sup>19</sup> CAST is a questionnaire made up of 37 items filled in by the parents. The aim of the questionnaire is to perform screening for children with autism who have high levels of functioning in situations of epidemiological research. CAST demonstrated good accuracy as a screening instrument, but the results indicated moderate test-retest reliability for use, evidencing the need for further research.

The correlation between the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS) was determined using 129 children and adolescents between 7 and 18 years of age diagnosed with autism.<sup>20</sup> The individuals received a diagnosis of autism based on the ADI-R. Discriminant analysis revealed adequate agreement between the ADI-R and the ADOS, with 75% of the participants correctly classified by the ADOS. The findings suggest that when there are discrepancies in the information given by these instruments, an adaptive function assessment may reduce diagnostic errors.

Few psychometric scales for autism are used in Brazil. Studies on the validation of assessment scales regarding the spectrum of autism disorders are also scarce. The Autism Screening Instrument for Educational Planning (ASIEP-2) was translated to our field of knowledge.<sup>21</sup> The validation of the Autism Treatment Assessment (ATA) was carried out, and it found a cutoff point of 15 ( $p = 0.05$ ) and Cronbach's alpha coefficient of 0.71; reliability was 0.27; external validity exhibited low agreement ( $\kappa = 0.04$ ) and internal validity was 100%.<sup>22</sup> In all patients assessed, the clinical diagnoses agreed with those determined by the scale. The correlation index was 0.42, proving specific to autism conditions.

The Autism Behavior Checklist (ABC) is a list containing 57 atypical behaviors.<sup>23</sup> In Brazil, the checklist was translated, adapted and pre-validated with the name of *Inventário de Comportamentos Autísticos* (ICA).<sup>24</sup> The list was designed for the initial screening of children suspected to have PDD and was standardized through teachers' observations of the children. Some studies have used the questionnaire in interview form with parents and caregivers.<sup>25-26</sup> The aim of the ABC/ICA is to assist in the differential diagnosis of children suspected to have PDD and refer them to appropriate intervention processes.

The ABC is one of five subtests that make up the ASIEP-2.<sup>23</sup> It is most often used during the initial diagnosis process on individuals suspected of having autism. The ABC/ICA contains 57 atypical behaviors that are typical of the condition, organized in five domains: Sensory, Relating, Body Concept, Language, and Social & Self-Help. There is a protocol for recording the child's behavior. Each item is scored from 1 to 4, statistically determined according to the degree of association to pathological behavior. The scores for each of the five domains are tallied, giving a partial score for each domain, as well as an overall score. When the overall score reaches 68 points or higher, the child is classified as autistic;<sup>23,27</sup> scores between 54 and 67 indicate a moderate probability of autism; scores between 47 and 53 are considered dubious for the classification of autism; and scores below 47 indicate that the child is typical. The checklist has been widely used in a number of countries by professionals both in research and clinical practice due to its ease of application and low cost.

In recent years, the psychometric properties of the ABC/ICA have been investigated and evaluated.<sup>28-32</sup> Although these studies dispute the cutoff point determined by the authors of the ABC, the checklist has been considered useful in screening children suspected to pertain to the autism spectrum. The psychometric properties of the ABC/ICA were addressed in a preliminary validity study.<sup>33</sup> The authors demonstrated that the instrument is capable of identifying children suspected of having childhood autism and proposed a score of 49 as a cutoff point with high sensitivity and specificity in identifying such cases in the general population.

The reliability of the ABC/ICA has been determined in some studies.<sup>33-35</sup> In these studies, the mothers of children diagnosed as pertaining to the autism spectrum responded to the questionnaire in the form of an individual interview, and the professional caregivers from the institution responsible for the follow-up of the children filled out the same questionnaire based on behavior observations. The cutoff point of 68 was maintained to separate children with autism from other groups of children.<sup>27</sup> It was concluded that intra-class reliability was satisfactory (ICC = 66%) when considering the cutoff point originally proposed by the authors of the instrument, but when assessing the presence or absence of each behavior, there was disagreement between the mothers' observations and those of the professionals (Kappa = 0.23).

Another study on the reliability of the ABC/ICA found that mothers and teachers were in agreement in relation to 30 (52.63%) of the behaviors, all of which coincided with those considered as having a greater associative degree with the pathology (scores 3 and 4).<sup>33</sup> The items for which there was no agreement (47.27%) were those with a low association with autism according to the American standardization of the instrument. The atypical behaviors the children with autism exhibited and which were perceived by different observers were presented as indicators of the condition in different contexts. Despite the existence of disagreement, the test proved adequate for the screening of autism, regardless of the observer.

Therefore, behavior assessment scales or checklists (each with its own particularities) have proven quite useful in the identification of autism. However, they are merely complementary instruments for the diagnosis of this syndrome and are unable to perform the diagnosis alone. The aim of the present study was to determine the agreement in ABC/ICA responses from mothers and professionals involved in the care of children pertaining to the autism spectrum and treated at a public service of a teaching clinic and a specialized institution.

## Method

### 1. Study design

The present reliability study was approved by the Research Ethics Committee of Universidade Federal de São Paulo, with due authorization from the institutions involved and signed terms of informed consent from the guardians (CEP no. 316/01).

### 2. Participants

Mothers of children pertaining to the autism spectrum, who were diagnosed by the multidisciplinary team according to the criteria of the DSM-IV-TR and CID-10,<sup>1,36</sup> participated in the study along with professionals involved in the children's care. Both the mothers and professionals were part of the following intervention contexts: the Friends of Autism Association at a specialized school in the city of São Paulo; and the Laboratory of Phonological Investigation of Language in PDD at the Teaching Clinic of the Sector of Human Communication Disorders at the Department of Speech Therapy and the Childhood and Adolescence Reference Center of the Psychotherapy and Psychodynamics Sector in the Psychiatry Department of Universidade Federal de São Paulo.

As inclusion criteria, only mothers with children between 4 and 12 years of age were considered. The children were of both genders and needed to attend school and receive therapeutic care. The mothers and professionals were divided into two groups. Group 1 was made up of 23 mothers of children with autism and the professionals responsible for the children at the Friends of Autism Association of the city of São Paulo. Children's mean age was 7 years and 5 months and they were enrolled in an educational program in the specialized institution. The mothers belonged to the middle and lower-middle socioeconomic classes. Their mean age was 38 years and they had an average of 9 years of schooling. Group 2 was made up of 15 mothers of children with autism and the speech therapists responsible for the treatment at a public service of a teaching clinic in the outpatient clinic for human communication disorders at Universidade Federal de São Paulo. Children's mean age was 9 years and 7 months. The mothers belonged to the middle and lower-middle socioeconomic classes. Their mean age was 37 years and they had an average of 8 years and 7 months of schooling.

### 3. Procedures

Both the parents and professionals who participated in the study, whether teachers at the specialized institution or speech therapists at the teaching clinic, were informed regarding the task they were about to perform. The mothers of the children from both groups responded to the questionnaire in the form of an interview carried out by trained professionals in order to control the schooling variable. The professionals responsible for the children at the specialized institution and the speech therapists responsible for following the children at the public service of the teaching clinic filled out the same questionnaire based on observations. Thus, each case had one questionnaire filled out by the mother and another filled out by

the professional who directly took care of the case. Responses were classified as presence/absence of each of the 57 behaviors.

#### 4. Statistical method

For the analysis of the results, the Kappa index was employed for the overall score and for each domain in order to obtain the frequency of agreement between the mothers' observations and those of the professionals at the two care facilities. Kappa values allow us to compare two qualitative variables. Greater values indicate a higher level of agreement between the observations made by the parents and professionals. The minimum Kappa value should be equal to or greater than 0.60.<sup>37,38</sup>

### Results

#### 1. Description of the sample

Group 1 (G1) of the study sample was made up of 21 boys (91.3%) and two girls (8.7%). Their mean age was 7 years and 5 months. Group 2 (G2) was made up of 13 boys (86.7%) and two girls (13.3%). Their mean age was 9 years and 7 months. The mothers' mean age was 38 years in G1 and 37 years in G2. The mother's average schooling was 9 years in G1 and 8 years and 7 months in G2. Regarding average monthly income, the mothers in both groups belonged to the middle and lower-middle economic classes. There were no significant differences between groups regarding any of these variables.

Regarding the overall ABC/ICA score, agreement between parents and professionals was low for both groups. The difference between groups was statistically significant ( $p < 0.001$ ). Agreement was also low for each of the ABC/ICA domains, but G2 demonstrated a higher level of agreement between the parents and professionals than G1, especially in the Language, Body Concept and Relating domains. The difference between the two groups was statistically significant ( $p < 0.001$ ) (Table 1).

**Table 1 - Kappa values for agreement between responses from parents and professionals in the different ABC/ICA domains**

ABC/ICA domains	Kappa values	
	Public service	Specialized institution
Language	0.559	0.313
Body concept	0.520	0.350
Relating	0.416	0.151
Social and self-help	0.387	0.321
Sensory stimuli	0.329	0.051
Total	0.460	0.265

#### Discussion

The results reveal that agreement was generally low between the mothers and the professionals from both the specialized institution and the public service of the teaching clinic. For each of ABC/ICA domains, as well as the overall score, the group from the public service of the teaching clinic (G2) demonstrated a higher level of agreement between mothers and professionals than the group from the specialized institution (G1), especially in the Language, Body Concept and Relating domains. This is an interesting finding, as the professionals in G2 were speech therapists who focus their evaluations and interventions specifically on these aspects.

It occurs to us that this fact may also reflect the differences between the two groups of observers working with children with autism. Mothers and professionals certainly interact with children in different manners and this interaction is influenced by the roles they play in childcare. We believe that the lack of agreement may have been influenced by the differences in the meanings mothers

and professionals attribute to children's behavior. It appears that professionals are able to detect subtle progress in the behavior of children with autism. For parents, however, atypical behavior is often more evident. We should also consider the fact that care facilities provide systematized, organized situations for the children, which can lead to a decrease in atypical behavior. However, professionals are not always capable of dealing with all the behaviors described in the ABC/ICA. Children spend a far greater amount of time at home, where situations are not always planned and controlled, which may more frequently make atypical behavior evident.

Disagreement between the responses of different informants does not necessarily imply a lack of attention or care on the part of one informant over another. Individuals express their own perspective in a unique context of culture, values and representations. Mothers and professionals differ in their reports based on sensitivity, perception and tolerance to different problems. The discrepancies in the observations may therefore be the result of different points of view. Mothers are recognizably more prone to perceiving behavior they consider irritating, such as disobedience, inattention and inactivity. As in other studies,<sup>14-16</sup> discrepancies were found in the present study between the observations of the mothers and professionals. This suggests that with regard to subjective dimensions and most psychological behavior symptoms mothers and professionals have different views regarding the children – views that are likely influenced by social, affective and cultural aspects.

The assessment of reliability based on different levels of schooling is important to self-applied questionnaires, as the level of schooling can affect the comprehension of items and thereby affect the response as well. We attempted to control the schooling variable by using a trained professional to fill out the questionnaire during interviews with the mothers. For this type of instrument with items related to the pathology, it is considered suitable to take into account the stability of particular questions. Another important aspect concerns the results regarding the reliability of the ABC/ICA from the pre-validation of the instrument.<sup>34</sup> Agreement was low between the responses from mothers and professionals regarding the presence or absence of behavior for all items. However, a later study found satisfactory agreement between the responses from mothers and professionals when analyzing the items of greater association with the pathology.<sup>33</sup> These results led the authors to question the understanding of particular ABC/ICA items by both mothers and professionals that work with children with autism.

The present findings contribute indispensable knowledge for the use of screening behavior scales or checklists in clinical contexts that are founded on issues related to enhancing the sensitivity of mothers of children pertaining to the autism spectrum. Although the mothers' responses were not similar to those of the professionals, they express values, feelings and needs, offering pertinent information concerning their experiences, the validity of which should be the object of future studies. The evidence of differences in the descriptions of the behavior reported by parents and professionals leads clinicians to overlap both observations.

In our study, the mothers demonstrated a higher level of agreement with the professionals who care for their children at the public service of the teaching clinic. This may be related to the fact that the mothers had been guided throughout the therapeutic process in an effort to explain atypical behavior. Thus, parents learn how to recognize atypical behavior as expressing difficulties the child is having and differentiate it from other types of behavior, such as laziness. Furthermore, as parents are present during the sessions,



they are more sensitized with regard to the clinical management, as well as the progress and limitations of the children.

Direct intervention with the child provides a better planning and execution of activities that favor the adequacy of behaviors. Mothers who spend most of their time caring for their children can establish a more intensive exchange of information with professionals both informally and during the structured work of family guidance. Another aspect to be considered regarding the public service of the teaching clinic is the fact that periodic reevaluations are performed. These occasions stimulate the analysis of the progress

of the treatment by both professionals and parents, who are always re-interviewed. Furthermore, it is a characteristic of this service to observe the children from a developmental perspective, which allows caring for and understanding their needs and not just the remission or substitution of atypical behavior.

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\* Modest

\*\* Significant

\*\*\* Significant. Amounts given to the author's institution or to a colleague for research in which the author has participation, not directly to the author.

Note: UNIFESP = Universidade Federal de São Paulo; CAPEES = Coordenação de Aperfeiçoamento de Pessoal de Nível Superior.

For more information, see Instructions for authors.

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