RevistaCEFAC
Current Evidence on Feeding, Audiology and Communication

eISSN 1982-0216

DOI: 10.1590/1982-0216/20252718623 | Rev. CEFAC. 2025;27(1):e8623

Original articles

Cognitive Speech-Language-Hearing Protocol for Autism Spectrum Disorder (PROFOCO - TEA)

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ABSTRACT

Purpose: to present the Cognitive Speech-Language Protocol for Autism Spectrum Disorder (ASD), that is, PROFOCO-TEA, describing its construction stages, and highlighting its practical applicability. The protocol aims to provide clear guidelines for speech-language-hearing intervention in individuals with ASD to develop and monitor their cognitive and communication skills.

Methods: the PROFOCO-TEA investigates cognitive aspects, intended for speech-language-hearing pathologists to apply to caregivers of children aged 2 to 12 years diagnosed with autism spectrum disorder. Due to the scarcity of cognitive assessment instruments available to speech-language-hearing pathologists, the authors developed this questionnaire relying on their experiences, literature review, pretesting, and an expert panel.

Results: after the modifications suggested in the pretest and expert panel stages, the PROFOCO-TEA includes questions on: 1, investigation of the regulation state, investigation of information reception, analysis, and storage, and investigation of activity programming, regulation, and execution.

Conclusion: the PROFOCO-TEA was carefully developed in stages, demonstrating its practical applicability and theoretical foundation. The protocol provides clear guidelines for speech-language-hearing intervention in individuals presented with ASD to monitor and develop cognitive and communication skills, thus helping improve the therapeutic process and clinical outcomes.

Keywords: Speech, Language and Hearing Sciences; Child Development; Developmental Disabilities; Autism Spectrum Disorder; Cognition

A study conducted at the Universidade de São Paulo - USP, São Paulo, SP, Brazil.

Financial support: This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES) – Finance Code 001

Conflict of interests: Nonexistent

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Received on: August 21, 2023
Received in a revised form on: April 15, 2024
Accepted on: October 22, 2024

Editor: Hilton da Silva

INTRODUCTION

Autism Spectrum Disorder (ASD), is a neurodevelopmental disorder characterized by deficits in communication and social interaction, as well as repetitive and restricted patterns of behavior, interests, or activities. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5 TR) (considering the need for support) and the International Classification of Diseases (ICD-11) (considering intellectual disability and functional language), currently determine the criteria for diagnosing ASD and its different impairment levels[1,2].

Individuals with ASD have widely variable cognitive profiles, with different levels of symptom severity among those with the same diagnosis[3]. Cognitive deficits also affect aspects of language and central coding processes[4]. Children with ASD have a specific difficulty in the cognitive mechanism necessary to represent mental states, posing challenges to social interaction patterns. This difficulty can directly alter patterns of symbolic play, creativity, originality, and pragmatics, which require this ability[5].

The organism's responses to environmental stimuli determine behavioral properties that ensure adaptation to different situations and behavioral individuality[6]. Biological risk factors (along with environmental and socioeconomic ones) significantly influence child development, potentially impairing cognitive skills and normal language development[7]. Sleep disorders are prevalent and persistent factors that interfere with cognitive development in ASD, affecting 44% to 83% of children[8]. Sleep is a reversible behavior characterized by a disconnection from environmental perception, necessary for maintaining physical and cognitive health[9] and sustaining life. It is when wakefulness is suspended, reducing metabolic and sensory activities, and relaxing the muscles[10]. Healthy sleep improves cognitive processes such as reasoning and language skills and plays a role in cognition and memory consolidation. It also promotes a favorable environment for the glymphatic system to remove toxic metabolites accumulated during brain activity and wakefulness[11,12]. Therefore, sleep is an active behavior that influences numerous brain functions, such as attention, reaction time, learning, and memory consolidation. In turn, sleep disorders potentially result from biological, behavioral, psychological, and environmental factors[13,14].

Cognitive-sensory impairments deserve attention, as they are common in people with ASD, interfering with their language development and social communication. Sensory changes are present in many ASD cases[15] – current estimates suggest that 45% to 96% of children with autism experience some type of sensory difficulty[16,17]. Sensory integration is a neurological process that organizes bodily sensations and external environments to produce the person's adaptive responses[18]. According to parents and caregivers of children with ASD, restrictions in sensory integration processing are limiting factors related to social interaction and participation in activities of daily living[19].

Other cognitive skills essential for interpersonal communication (critically impaired in children diagnosed with ASD from a very young age) include a lack of natural tendency to piece together parts of information to form a meaningful whole (central coherence)[20]; deficits in gaze perception (poor eye contact during communication), hindering the access to information to infer other people's mental states[21]; deficits in imitating[22] and perceiving the human voice[23]; problems and limitations in empathy (i.e., in understanding other people's mental states, such as thoughts, intentions, and beliefs – theory of mind)[23]; and impairments in executive functions, which deserve special attention here.

The literature describes executive functions as a set of cognitive skills enabling the person to perform goal-directed behaviors[24]. Research indicates that executive functions help develop the pragmatic dimension of language, as their integrated functioning maintains and updates ongoing conversation without losing relevant information as the working memory handles facts and inhibits off-topic responses. A study found that executive functions were positively correlated with the theory of mind and considered them predictors of the severity of ASD symptoms[25]. Executive function impairment in ASD, particularly cognitive flexibility and working memory, can be identified by restricted and repetitive patterns of interest and activity and absent or scarce symbolic play[26].

Hence, recognizing cognitive impairments in people with ASD and establishing their cognitive profile by assessing different skills enable personalized interventions based on individual cognitive characteristics, using more preserved ones for teaching, and strengthening deficient ones[27]. However, there are few short, low-cost, easy-to-administer and interpret instruments available for speech-language-hearing (SLH) pathologists to assess cognition in ASD.

The Ages & Stages Questionnaires (ASQ)[28] is one of the instruments currently used for assessing

cognitive aspects. It is organized by age in months and directed to the children's parents or caregivers. The questions cover Communication, Gross and Fine Motor Development, Problem Solving, Socialization, and General Questions. Although the ASQ has proven to be an easy-to-apply, quick-to-fill-out, and low-cost instrument, it is not specific for screening ASD but rather for identifying general developmental changes in children. An integrative review mentions the Child Sensory Profile 2 (CSP2), which assesses the child's sensory processing in everyday situations[29], and the Executive Functions Assessment Test (Teste de Avaliação das Funções Executivas,TAFE, in Portuguese), a computerized instrument for children aged 4 to 10 years[30]. However, none of them is specifically developed for SLH pathologists.

Thus, this article aimed to present the Cognitive Speech-Language-Hearing Protocol for Autism Spectrum Disorder (PROFOCO-TEA), describe its construction stages, and demonstrate its practical applicability. The protocol provides clear guidelines for SLH intervention in individuals with ASD, facilitating the monitoring and development of cognitive and communicative skills.

METHODS

This study was approved by the Research Ethics Committee of the Medical School at the Universidade de São Paulo (USP), SP, Brazil, under evaluation report number 6.644.283 and CAAE number 47353120.2.0000.0068. An informed consent form clarified the risks and benefits to the research participants.

The PROFOCO-TEA is a cognitive assessment tool developed in stages for SLH pathologists and ASD. The questionnaire is divided into three parts, with 25 items and 54 subitems. Its questions are closed-ended and should be answered by parents or caregivers of children diagnosed with ASD aged 2 to 12 years.

The inclusion criteria to construct the protocol were children aged 2 to 12 years, diagnosed with ASD at any level of impairment, with or without comorbidities associated with the condition.

Exclusion criteria for the PROFOCO-TEA construction included cognitive impairments in the family and caregivers that would prevent them from responding coherently to the protocol; their thought organization was assessed through speech.

Construction stages

The PROFOCO-TEA was constructed in four stages – authors' experience, literature review, pretest, and expert panel, as described in Figure 1:

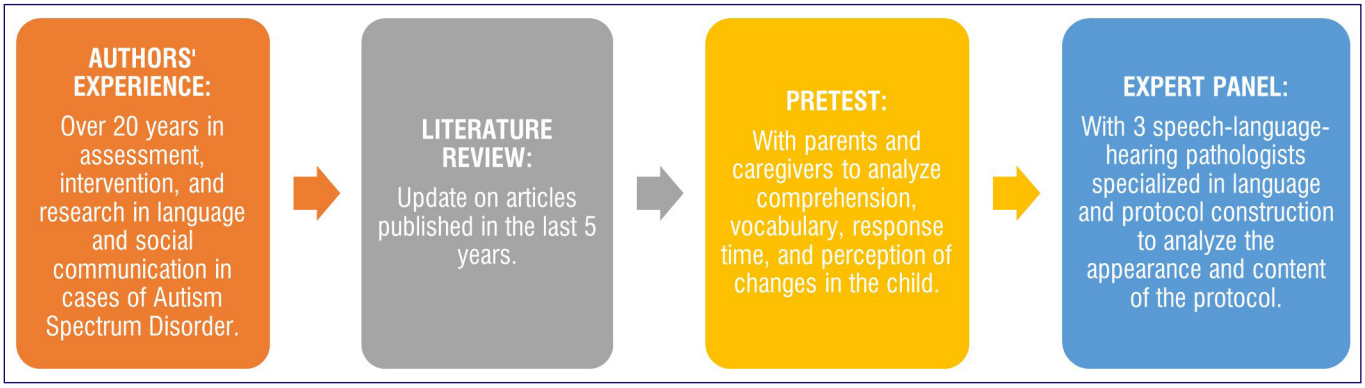

Figure 1. PROFOCO/TEA construction procedure

Stage 1: Authors' experience

The authors have more than 20 years of clinical and academic experience in therapeutic intervention related to language and social communication in ASD, as well as experience in research and protocol development as a supervisor and associate professor of the undergraduate and postgraduate programs at the Medical School of the USP. The authors' experience led them to recognize the scarcity and importance of low-cost, easy-to-administer and interpret cognitive SLH assessment tools for ASD.

Stage 2: Literature review

The PROFOCO-TEA questions were developed through updated literature on the subject, using the Web of Science, Scopus, PubMed/MEDLINE, Latin American and Caribbean Health Sciences Literature (LILACS), and SciELO databases. The inclusion criteria were articles published in the last 5 years in English and Portuguese, using the following descriptors: ASD and Cognition, Sleep and ASD, Sensation Disorders and ASD, Executive Functions and ASD, and Cognitive Protocol and ASD. The review avoided articles published more than 5 years before, although it needed some articles older than 5 years that approached diagnostic criteria.

Stage 3: Pretest

The questionnaire was developed based on the research results. Since the protocol is intended for the parents or caregivers of children with ASD, a pretest was necessary to ensure:

1. **They understood the questions** (they should be clear to facilitate comprehension).
2. **The understood the vocabulary** (it should be as simple as possible to reach the most people).
3. **They perceived the child's changes according to the questions** (parents and caregivers should be able to relate the question to their perception of the child's changes, without the need for many examples).
4. **The response time** (1 hour was used).

The study selected a convenience sample of 10 parents or caregivers of children diagnosed with ASD aged 2 to 12 years – four children requiring level 2 support, four children requiring level 3 support, and 2 participants requiring level 1 support. Responses to the pretest questions were classified as (a) no difficulty in responding, (b) difficulty in responding, and (c) did not know how to respond. All invited subjects agreed to participate in the research.

Stage 4: Expert panel

After the pretest stage, the protocol was analyzed by three SLH specialists affiliated with USP and the Universidade Federal de São Paulo (UNIFESP), based on their experience in language and protocol development, to analyze:

1. **The content of the questionnaire**.
2. **The structure of the protocol**.
3. **The vocabulary of the protocol**.

Modifications in the protocol structure and vocabulary were suggested and implemented in this phase, thus completing its construction.

RESULTS

As previously described, the PROFOCO-TEA was developed in stages, including the researchers' experience, literature review, pretest, and expert panel. Their results are described below.

Stage 1: Researchers' experience

The researchers' academic and clinical experience focused on language and ASD identified important cognitive issues to be clarified and the scarcity of low-cost, easy-to-understand, quick-to-apply cognitive assessment tools aimed at the ASD profile specificities and accessible for SLH pathologists.

Stage 2: Literature review

The literature review synthesized 65 relevant articles involving ASD and cognitive changes in ASD. Altogether, 32% of these articles focused on ASD; 11%, on compromised cognitive aspects in ASD; 15%, on sensory changes in ASD; 10%, on executive function impairments in ASD; 5%, on the relationship between sleep and cognitive disorders; and 27% on sleep and ASD.

The PROFOCO-TEA questions were based on the researchers' experience and the literature review. The initial protocol configuration had three parts with 29 items and 51 multiple-choice questions.

Regulation (9 items)	Reception, analysis, and storage of information (7 items)	Programming, regulating, and verifying activities (13 items)
• Sleep • Wakefulness • Intensity • Mobility • Adaptation to stimuli • Environment • Routine • Medication • Diet • Communicative intention	• Sensation/Perception • Perception and tracking of sensory pathways • Eye contact • Central coherence • Attention • Memory • Theory of mind	• Sensory responsiveness • Programming and planning • Imitation • Inhibitory control • Decision making • Cognitive flexibility • Inductive and abstract reasoning • Self-regulation • Emotional self-regulation • Pragmatics • Taking turns • Fluency • Prosody

Figure 2. Cognitive Speech-Language-Hearing Protocol for Autism Spectrum Disorder (initial configuration)

The first part of the protocol refers to the brain regulation state, comprising nine items with nine questions. Its second part addresses information reception, analysis, and storage, comprising seven items and 25 questions. The third part has 13 items and 17 questions focused on activity programming, regulation, and verification.

Stage 3: Pretest

The PROFOCO-TEA was applied in person to 10 pilot group participants – i.e., 10 parents or caregivers of children aged 2 to 12 years, diagnosed with ASD, at different levels of impairment, with or without comorbidities. All participants signed an informed consent form, acknowledging the research objectives, risks, and benefits.

Among the 10 pretest participants, 36% reported difficulty in understanding the questions, 28% indicated difficulty in understanding the vocabulary, and 36% indicated difficulty in perceiving the child's changes. All participants completed the questionnaire within the stipulated 1 hour.

The results indicated the need for adjustments in the content of the questions, the vocabulary, and the applicability of the instrument, which was then forwarded to an expert panel.

Stage 4: Expert panel

At this stage, three SLH pathologists specializing in language analyzed the protocol regarding its content, vocabulary, and applicability. They reached a 90% consensus on the suggested modifications to the PROFOCO-TEA, based on the specialists' detailed feedback and the analysis of preliminary results. The modifications aimed to enhance the effectiveness, applicability, and customization of the protocol for different cultural contexts.

The protocol was restructured with the modifications suggested by the expert panel, comprising three blocks with 24 items and 40 questions.

Regulation	Reception, analysis, and storage of information	Programming, regulation, and verification of activities
• Sleep • Wakefulness • Intensity of the responses to stimuli • Adaptation to stimuli • Environment • Routine • Medication • Diet • Communicative intention	• Perception and tracking of sensory pathways • Eye contact • Central coherence • Shared, alternating, selective, and sustained attention • Short-term and long-term memory • Theory of mind	• Sensory responsiveness • Programming and planning • Imitation • Inhibitory control • Decision making • Cognitive flexibility • Inductive and abstract reasoning • Self-regulation • Emotional self-regulation

Figure 3. Configuration of the Cognitive Speech-Language-Hearing Protocol for Autism Spectrum Disorder after the expert panel

The first part of the protocol refers to the brain regulation state, with nine items and nine questions. This stage aims to evaluate whether the child's brain is prepared to receive, analyze, and store stimuli, as well as to program, regulate, and execute activities. It analyzes the following items:

- ***Sleep:*** The child has an adequate amount of sleep for their age.
- ***Wakefulness:*** They quickly perceive new stimuli and respond to them.
- ***Response to stimulus intensity:*** They respond coherently to visual, auditory, tactile, and other stimuli.
- ***Adaptation to stimuli:*** They can modify behaviors to adapt to new stimuli.
- ***Environment:*** The environment provides adequate stimuli for regulation between states of sleep and wakefulness.
- ***Routine:*** The routine provides adequate stimuli for regulation between states of sleep and wakefulness.
- ***Medication:*** The use of medication interferes with the regulation of sleep and wakefulness.
- ***Nutrition:*** Nutrition interferes with the regulation of sleep and wakefulness.
- ***Intentionality:*** They have verbal or nonverbal behaviors with the intention to communicate in different contexts.

The second part of the protocol addresses the reception, analysis, and storage of information, with six items and 16 questions. It aims to assess the child's ability to perceive sensory information and interpret and store environmental stimuli through the senses. It analyzes the following items:

- ***Dominant sensory pathway perception/tracking:*** The child typically receives, analyzes, and stores information from visual, auditory, tactile, olfactory, proprioceptive, gustatory, and vestibular senses.
- ***Eye contact:*** They establish eye contact for more than 3 seconds multiple times a day.
- ***Shared attention:*** They direct attention alongside another person to a specific focus when requested.
- ***Alternating attention:*** They perceive simultaneous stimuli, analyzing them alternately and responding to the most relevant one.
- ***Selective attention:*** They direct attention to a specific focus appropriately, inhibiting irrelevant stimuli when necessary.
- ***Sustained attention:*** They typically maintain attention focused on a source of information for seconds or minutes.
- ***Short-term memory:*** They store information for a short time and can use it.
- ***Long-term memory:*** They store information for days, weeks, or years and can retrieve it when necessary.
- ***Theory of mind:*** They can perceive and understand other people's feelings, thoughts, and/or needs (empathy).

The third part of the protocol analyzes the programming, regulation, and execution of activities, with nine items and 15 questions. It aims to assess the child's ability to respond appropriately to different contexts by programming and regulating their behavior. It analyzes the following items:

- ***Visual, auditory, tactile, olfactory, proprioceptive, gustatory, and vestibular responsivity,*** as follows: within expected levels; hyperresponsive; hyporesponsive.
- ***Programming and planning:*** They can plan actions to achieve a goal.
- ***Imitation:*** They imitate by taking turns and coordinating actions and pauses with the interlocutors.
- ***Inhibitory control:*** They inhibit inappropriate responses, responses to distracting stimuli, and ongoing responses.
- ***Decision making:*** They can choose one among various options.
- ***Cognitive flexibility:*** They can change the course of actions or thoughts according to the demands of the environment.
- ***Inductive reasoning and abstraction:*** They can have abstract thinking and formulate reasoning based on observation.
- ***Self-regulation:*** They can regulate behavior in response to changes in routine and environment.
- ***Emotional self-regulation:*** They manage and control their behavior, obey demands, and regulate responses.

Protocol application procedures

SLH pathologists should apply the PROFOCO-TEA to the parents/guardians of children aged 2 to 12 years with a diagnosis of ASD. However, the professional must be attentive to the respondent's clinical conditions before applying it.

The PROFOCO-TEA application takes at least 30 minutes, and its 40 closed-ended questions are responded to with "yes" (indicating the child's potential), "no" (indicating the need for intervention), or "I don't know how to respond" (indicating the professional must evaluate further).

The protocol can be administered in person or remotely by qualified SLH pathologists, as they may need to change sentence structure to help respondents understand it better, minimizing the effect of the respondent's education level.

The researchers will develop a PROFOCO-TEA application guide before distributing it to help SLH pathologists understand its content better.

DISCUSSION

Scientific research has increasingly addressed ASD, highlighting the relationship between cognitive impairments and language and social communication aspects. Since SLH pathologists are qualified to intervene in cases of language impairment, they must have access to tools that assess cognitive aspects that may interfere with this process.

There are currently various cognitive assessment tools for ASD. However, some are costly, difficult to understand, or restricted to psychology and neuropsychology, requiring referrals to other professionals or regions, which is unfeasible for many.

Thus, the PROFOCO-TEA was developed as a low-cost, easy-to-apply, easy-to-understand tool for SLH pathologists and this population.

The PROFOCO-TEA was developed in stages, prioritizing that the questions be understood and answered in a short time. Involving parents in this process helps them identify the child's difficulties and visualize the objectives to be achieved. This provides comfort to the family, generates expectations within a real context, and, in many cases, increases family participation in the therapeutic process.

The first stage of PROFOCO-TEA question development was based on the authors' experience in clinical assessment and intervention with ASD and the academic field, with the development of language protocols. Consistent with the literature, the authors' experience led them to identify the need for low-cost assessment tools easy to apply and interpret, enabling individualized interventions based on each patient's cognitive characteristics, using the more preserved skills to teach them and strengthen deficient ones[29,30].

The second research stage involved a literature review to identify updated literature on ASD, cognitive aspects impaired in this population that are essential to developing language and social communication, and cognitive assessment tools available to SLH pathologists. This stage verified a scarcity of specific instruments for this population[28-30].

The third protocol construction stage was the pretest, in which 10 parents or guardians of children with ASD were invited to respond to the protocol's questions. This phase observed their ability to understand the questions, the vocabulary, the perception of changes in the children according to the questions, and the time needed to respond to the protocol. At the end of this stage, the researchers verified the need to reformulate the questions, the vocabulary, and the type of responses, leading to the next stage – the expert panel.

The fourth stage was the expert panel, in which experts in language and ASD suggested important

changes regarding the type of responses, the number of questions, the vocabulary, and the sentence structure. The changes suggested in this stage led the PROFOCO-TEA to be divided into three parts with 40 questions.

The first part of the protocol has questions on biological, behavioral, psychological, and environmental aspects that interfere with sleep/wakefulness regulation, such as the ability to respond and adapt to the intensity of environmental stimuli; the environment; the routine; the use of medications; the diet; and the communicative intention. According to the literature, linguistic development is associated with environmental factors, and sleep is essential for physical and cognitive health, reasoning, language skills development, attention, reaction time, learning, and memory consolidation. Knowing that sleep disorders can result from biological, behavioral, psychological, and environmental factors and that sleep plays an important role in cognitive development[6-14], the identification of impairments in the first part of PROFOCO-TEA aims to enable family and school guidance regarding the need to establish a routine and environment favorable to sleep/wakefulness regulation, medication adequacy, and interdisciplinary and multidisciplinary intervention, thus providing a better prognosis for the condition.

The second part of the protocol has questions that investigate changes in the reception, analysis, and storage of sensory information, highlighting the perception and tracking of predominant sensory pathways, central coherence, eye contact, memory, attention, and theory of mind. The questions are relevant, as the literature recognizes that 45% to 96% of children with autism present some type of sensory difficulty and deficits in central coherence, eye contact, imitation, perception of the human voice, and theory of mind. It also states that such sensory aspects are essential for learning, speech and language development, social interaction, and participation in activities of daily living[15-23]. The second part of the protocol highlights the need for referrals to professionals qualified in sensory and psychological intervention and the development of therapeutic plans aimed at fundamental aspects of speech and language development.

The third part of the protocol is based on activity programming, regulation, and verification, addressing issues related to executive functions. The literature states that executive functions are cognitive aspects that allow the individual to perform behaviors directed toward a goal and that changes in executive functions lead to significant deficits in pragmatics, communicative intention, symbolic play, working memory, and cognitive flexibility[24-26]. Thus, the questions in the third part of the protocol were directed at visual, auditory, olfactory, gustatory, tactile, proprioceptive, and vestibular sensory responsiveness; the ability to program and plan actions to achieve goals; the ability to imitate; inhibitory control; decision-making capacity; cognitive flexibility; inductive and abstract reasoning; self-regulation; and emotional self-regulation. The third part of the protocol enables the development of more specific therapeutic plans focused on the patient's pragmatics, communication, and social interaction.

The limitation of the PROFOCO-TEA development study is its sample size in the pretest stage, as its results can only be considered for the population in question. Since the objective of PROFOCO-TEA is to serve SLH pathologists from other regions and countries, future studies should include an experimental stage with a larger population and in different environmental and social contexts.

CONCLUSION

This study presented the PROFOCO-TEA, an instrument developed in stages, based on the authors' experience, literature review, pretest, and an expert panel. It was developed with three parts and 40 questions on regulation, information reception, analysis, and storage, and activity programming, regulation, and verification. The study suggests a further experimental stage to achieve its objective in different countries, this research being greatly relevant to Brazilian science, considering the scarcity of specific protocols for this population presented with ASD.

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Authors' contributions:

MVS: Conceptualization; Data curation; Investigation; Methodology; Project administration; Resources; Writing - Original draft; Writing - Review & editing.

DRMA: Conceptualization; Formal analysis; Methodology; Project administration; Supervision; Validation.

DCD: Methodology; Project administration; Writing - Original draft; Writing - Review & editing.

Data sharing statement:

We, Marcela Vieira Stilpen, Daniela Regina Molini-Avejonas, and Daniela Cardilli-Dias, from the Universidade de São Paulo, declare that we will share data from the study entitled "Cognitive Speech-Language-Hearing Protocol for Autism Spectrum Disorder (PROFOCO - TEA)". This includes

data on the protocol development. Complementary documents, such as the research protocol, will be available for consultation. The data will be accessible from October 10, 2024, and will remain available indefinitely. The data will be shared with academic institutions and researchers, through a data-sharing platform. This statement aims to ensure that data be shared ethically and in compliance with data protection guidelines. Date: October 10, 2024.