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Development of a participatory research strategy involving autistic people with different levels of support needs

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Abstract *This article describes the development of a participatory methodological study involving autistic people with varying levels of support needs in the design and validation of an instrument devised to assess the effects of social isolation during the COVID-19 pandemic and the strategies used to cope with the crisis. The development of the instrument involved the following stages: Definition of the domains to be assessed (researchers in consultation with experts and autistic people); Design of the instrument (researchers with the co-participation of autistic people); Validation of the instrument (by experts and autistic people, led by the researchers); and Final approval of the instrument (co-participation between researchers and autistic people). In addition to making the instrument more robust, the participation of autistic people in the design and application of the instrument reinforced the importance of strategies to include autistic people in research as both study participants and co-researchers.*

Key words *Autism, International Classification of functioning, disability and health, Communication, Evaluation, Validation studies*

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Introduction

Despite a progressive increase in the volume of literature on autism, this field of research[1] remains characterized by divergences[2]. One of the main points of controversy in this area is the prioritization of the perspective of family members, caregivers, and professionals to the detriment of autistic people[3]. A common characteristic in this group, communication difficulties should not be seen as an obstacle to research but rather a challenge to be overcome. In this respect, it is important to develop strategies to enable the participation of autistic people with varying support needs in studies, including nonspeaking people.

The motivation for this study emerged during the first wave of the COVID-19 pandemic, against the backdrop of the resulting psychosocial, economic, political, ethical, and health crisis. In this anxiogenic situation[4], autistic people required special attention, yet this need was largely ignored by different spheres of government and society[5]. It is worth highlighting that the pandemic magnified existing inequalities[6], with the neglect of autistic people being associated with the vulnerabilities resulting from the neuronormativity of our social structure, which is insensitive to body and neurological diversity[7]. This gave rise to the need to analyze the effects of the pandemic and social isolation on this population, while seeking to veer away from a reductionist logic that ignores subjectivities and autistic people's right of self-determination.

Despite public policies designed to promote the inclusion of autistic people, an apparent paradox has emerged as actions to promote the active participation of members of the autistic community in research as co-researchers and study participants are lacking[8]. It is widely agreed that valuing the different subjects involved in the process of health production is crucial for the development of effective humanized strategies[9]. However, little consideration is given to issues such as self-determination, protagonism, shared responsibility, and building bonds of solidarity when it comes to certain population groups, including autistic people[10-14].

Though still sin the early stages, there is a growing movement of academics and activists who strive to engage the autistic community in research[15]. Cassidy *et al.*[16], for example, developed and validated a questionnaire to assess the likelihood of suicide involving the autistic community. Similarly, Pavlopoulou[17] conducted a participatory study to investigate sleep facilitating factors among autistic adolescents. The involvement of autistic people in these studies enabled the authors to gain unique insights into the experiences of the autistic participants, contributing to the reliability and relevance of findings. Without detracting from the importance of listening to parents, caregivers, and professionals, the small number and limited visibility of such studies reveals an unconscious bias underpinned by the mistaken presumption of incapacity[3]. Moreover, even studies like those mentioned above encounter difficulties involving individuals with language impairments, with communicative normativity amplifying the exclusion of people with autism from the research and knowledge production process[18,19].

This article describes the development of a participatory methodological study involving autistic people with varying levels of support needs in the design and validation of an instrument devised to assess the effects of social isolation during the COVID-19 pandemic and the strategies used by autistic people to cope with the crisis.

The study is a step forward for participatory research with autistic people insofar as it proposes a strategy to include people with different support needs[8] regardless of language impairment, promoting their participation in the production of knowledge concerning autism. This article is also unique because it draws on the neurodiversity paradigm for its theoretical framework, providing visibility and opening up other epistemic possibilities in this field.

Methodology

Study design

We conducted a participatory methodological study involving joint working between researchers and partners from the community[20]. The hierarchy of community participation in research can be defined on three main levels. In non-participatory research, members of the community contribute only as participants (*Doing to*). At the intermediate level, partners from the community act as consultants who may influence decision-making, with researchers maintaining full control over the final decision (*Doing for*). At higher levels of participation, academic and community partners work collaboratively, taking joint decisions (*Doing with*). The development of the present study involved the collaboration of experts as consultants and the co-participation of autistic people.

The study is underpinned by the assumption that autism brings together a broad spectrum of possibilities of existence. We therefore adopted an assessment based on levels of support[21], where autism is classified as follows:

a. Level I - Requires support, in the absence of which there are social problems, difficulties initiating interaction, staying organized, and planning, and inflexibility of behavior;

b. Level II - Requires substantial support, with apparent social problems, limited ability to initiate and maintain interactions, inflexibility of behavior, and difficulty coping with changes to routine;

c. Level III - Requires very substantial support, with severe challenges in social communication as well as extremely inflexible behavior, and extreme difficulty coping with changes to routine.

Despite common misconceptions, these levels are not an equivalent classification of “mild”, “moderate” or “severe” autism. This understanding is important to avoid reductionist and fallacious analyses. The idea of “mild” autism often carries the mistaken assumption of the absence of support needs, while the notion of “severe” autism reinforces the assumption of incapacity, amplifying the deficit of adaptive strategies[20].

The instrument

To facilitate understanding of the following sections, below we provide a general description of the instrument in question, which consists of an online questionnaire.

The first section of the questionnaire consists of sociodemographic questions about age, gender, marital status, color/race, nationality, municipality of residence, level of education, level of education of the caregiver (when applicable), and language impairment.

For respondents with language impairments, the following alternatives are proposed: continue with the written questionnaire or schedule the application of the questionnaire using Augmentative and Alternative Communication (AAC) techniques. AAC is an assistive technology that brings together different sets of procedures, resources, and strategies to maximize communication, complementing or replacing speaking and/or writing using visual-graphic symbols and gestures[5]. AAC frequently uses devices, which can be either low-tech (simple and low-cost) or high-tech (computers or other electronic devices)[22]. Effectiveness is not dictated by the complexity of the device, which should be suitable for the demands of the user[5,22]. For the present study, we used boards that translated the topics using pictograms.

The sections that come after the sociodemographic questions are organized into seven domains: education, family routine, work/paid activity, family income, health/associated conditions, treatments/therapies, and daily routine/social network.

Before the education, work/paid activity, health/associated conditions, and treatments/therapies domains, the following yes/no questions are asked first to ascertain applicability:

- Are you studying at the moment or were you before the social isolation measures were introduced?
- Are you working or doing a paid activity at the moment or were you before the social isolation measures were introduced?
- Do you have an autism-related condition that requires support?
- Are you undergoing therapy or treatment at the moment or were you before the social isolation measures were introduced?

Respondents who answer no are directed to the next section.

The questions used to characterize each domain are presented in the results section of this article.

After the questions used to characterize the domain, the respondent is asked about the influence of the period of crisis on that domain. The question is answered using a Likert scale with the following response options: had a positive influence; had a more positive than negative influence; didn’t have an influence; had a more negative than positive influence; had a negative influence.

The following open-ended questions are asked after the Likert scale:

- What positive and/or negative factors has social isolation brought to [DOMAIN]?
- What do you attribute the positive aspects to?
- What do you attribute the negative aspects to?
- With regard to [DOMAIN], did you need any additional support during this period?
- Did you develop or put into practice any new strategies to ease difficulties during this period? If yes, which?
- How do you define your reaction to [DOMAIN] in the current context?

For the domains education, work/paid activity, and treatments/therapies, we asked if these activities were disrupted by the crisis and whether the respondent continued activities remotely. Respondents who answered yes then responded the Likert scale and open-ended questions related to the subtopics.

Design of the instrument

The instrument was designed between January and March 2020 and the data were collected between April and June of the same year. During this period, strict social isolation measures were imposed across multiple states in Brazil. This situation was aggravated by lack of knowledge about the disease and uncertainty regarding the development of vaccines (which began to be made available only in December 2020).

The development of the instrument involved the following stages:

1. Definition of the domains: formulated by the researchers in consultation with experts and autistic people;
2. Design of the instrument: researchers with the co-participation of autistic people;
3. Validation of the instrument: by experts and autistic people, led by the researchers;
4. Final approval of the instrument: co-participation between researchers and autistic people.

Definition of the domains

The definition process began with the analysis of the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), focusing on "autism spectrum disorder" (ASD). It is important to note that, while we used the DSM classification, we have sought to avoid using the term ASD in the present study. This decision was made by the co-participating autistic people and represents a view shared by a large part of the autistic community in Brazil and other countries[23]. The objection to the term stems from the use of the word "disorder" and the semantic field it evokes. The words that one chooses to use or not use spell out the underlying ideology of the discourse[24]. Autism is not a disease, but rather a psychosocial disability that may or may not be coupled with other disabilities (such as intellectual or language impairments)[25-27]. This means that this neurological condition requires adaptations and therapies tailored to each person's specific needs to promote the development of the individual's potential and minimize limitations. Conversely, the word "disorder" is bound to the idea of "disease" and a "problem to be solved or cured". We therefore believe that – despite the fact that autism is a disability – the choice of the term "disorder" is a reflection of the structural and systemic body and neuronormativity rooted in our society[7].

After reading the DSM-5, the study proposal and preliminary domains were presented to three experts in autism (a psychiatrist, psychologist, and neuroscientist). After discussions with the experts, the domains were presented to three autistic people: two with level I autism, without language or intellectual impairment, and one with level II autism, with spoken language impairment, without intellectual impairment, and who uses written language and an AAC application.

The final domains were defined based on the new suggestions.

Design of the instrument

The first version of the instrument was designed by the researchers based on the domains defined in the process outlined above. The version was presented to the three autistic people who participated in the domain definition stage. The domains were agreed jointly and the instrument was modified in a participatory manner. The researchers and participants communicated using a virtual communication app due to the imposition of social isolation measures.

Validation of the instrument

The validation stage involved both expert and autistic judges. The judges were selected by searching the *Plataforma Lattes*, a curriculum platform run by the National Council for Scientific and Technological Development (CNPq). The following selection criteria were used: people with a master's degree or PhD with research, publications in indexed journals, theses or dissertations, and practical experience in a relevant area of interest (clinical, education or research) and in the theme of study.

Ten of the 12 people selected accepted the invitation to be a judge, one of whom was autistic.

The autistic judges were selected using convenience sampling to ensure the inclusion of people with varying levels of support needs and who use different forms of communication. Ten autistic people participated, as follows:

- four with level I autism, without intellectual or language impairment;
- two with level II autism, without language impairment and with intellectual impairment;
- three with level II autism, without intellectual impairment and with language impairment and who use AAC tools;

- one with level III autism, with intellectual and language impairment.

We used AAC boards with the two participants with level II autism and language impairment and with the participant with level III autism. This stage was crucial for the creation of AAC boards that adapted the instrument questions. The other participants were able to read and respond the questionnaire in spoken or written form.

Percentage agreement between the judges was calculated using the Content Validity Index (CVI) and Cronbach's alpha. The CVI per item was calculated by dividing the number of judges who rated the item as adequate by the total number of judges, resulting in the proportion of judges who rated the item as valid. The overall CVI was the sum of each item CVI divided by the total number of items. The following values were considered acceptable: item CVI≥0.75[28] and Cronbach's alpha ≥0.6[29]. The items were categorized using a 4-point Likert scale as follows[30]: 1 = inadequate; 2 = needs major revision; 3 = needs minor alterations; 4 = adequate.

For each item, the judge was able to express an opinion in an open field, explaining his/her decision and making suggestions.

The participant with level III autism answered the items of the questionnaire using pictograms on a personal AAC board or by typing on an adapted keyboard with the help of his mother. The validation process with this participant occurred over three encounters, with the participant signaling which questions he had difficulty responding or a special need.

Approval of the instrument

After validation by the expert judges and incorporation of their suggestions, the instrument was represented to the autistic judges four times, until unanimous approval was given.

Application of the instrument

The link to access the questionnaire was publicized using social media and a virtual communication app between April and June 2020. Data collection was interrupted at the beginning of the easing of social isolation measures in most states across the country. Forty-four people responded the questionnaire. Of these, 40 filled in the online version and four opted for scheduled completion with the help of assistive technology.

Ethical aspects

The study protocol was approved by the University of Fortaleza research ethics committee (reference No. 4.028.756). The study was undertaken in accordance with the principles and guidelines set out in Resolutions 466/2012 and 510/2016, respecting the dignity and autonomy of participants and assuring confidentiality during all stages of the research. All participants or parents/guardians signed an informed consent form.

Results

The preliminary domains, suggestions and modifications based on the suggestions made by the expert and autistic judges are shown in Chart 1.

The replacement of the "family" domain with "family routine" was justified by the need to differentiate feelings for people from issues related to the routine of relationships. The domain "health and support needs" was understood to be two separate topics by the autistic judges. Based on the suggestion of the autistic judges, the domain was replaced by "health and associated conditions" and "support needs" was diluted across the other domains. The domain "work" was altered to "work and paid activities" to include autistic people who undertake informal activities of varying complexity. The domain "daily routine and social network" was added due to the importance of routine for creating and maintaining predictability.

Based on the readings and discussions with the expert and autistic judges, the following common characteristics of individuals with autism and respective adaptations to the instrument and strategies were defined (Chart 2).

An online questionnaire format was chosen because it allowed the researchers to mix closed, Likert, and open-ended questions, provided predictability (by enabling the "show progress bar" option), and directed respondents to specific sections based on answers to preliminary questions.

The questions used to characterize the domain are summarized in Chart 3. The items in bold are those modified after validation by the judges (stage detailed below).

Each judge assessed and made suggestions on the introductory text and all 18 items of the questionnaire. Of these, seven were considered totally equivalent, two obtained a CVI of 0.85, and nine obtained a CVI of 0.75, as shown in Table 1.

Chart 1. Preliminary domains, suggestions made by the experts, and modified domains.

Domains defined by the researchers	Suggestions made by the expert judges	Final domains after incorporating suggestions and approval by the autistic judges
Education		Education
Family	Replace with family routine	Family routine
Work		Work and paid activities
Family income		Family income
	Include health and support needs	Health and associated conditions
Treatment and therapies		Treatment and therapies
		Daily routine and social network

Source: Authors (2022).

Chart 2. Common characteristics of individuals with autism and respective adaptations to the instrument.

Common characteristics of individuals with autism	Adaptations to the instrument
Rigid thinking	Prioritization of direct questions
Alexithymia	Add a quantitative Likert-type question to assess the influence of the study phenomenon on each domain (the initial idea was to use only open-ended questions) Avoid questions about how the person feels in relation to each domain
Language impairment with limited or absence of oral language or speech	Enable participation by using AAC tools or answers written by the autistic person or with help from a facilitator who acts as an interpreter of the language used by each person
Persistent deficits in social communication and social interaction	Allow remotely delivered asynchronous responses
Inflexible adherence to routines or ritualized patterns of verbal or non-verbal behavior	Provide predictability concerning the number of domains and questions Avoid questions about domains that do not apply to the person (for example, don't ask non-students about education) Guide open-ended questions using a preliminary yes/no question

Source: Authors (2022).

The items that needed alterations were modified and represented until they were unanimously approved by the autistic judges. Chart 4 shows the alterations made in response to the judges' suggestions.

Of the 44 respondents, 20 (45.5%) were cisgender women, 18 (41%) were cisgender men, three (6.8%) were transgender or non-binary people, two (4.5%) were gender-fluid people, and one (2.2%) was an intersexual person who was assigned female at birth. Of the 19 respondents with spoken language impairments, only four opted to schedule the completion of the questionnaire. The others were able to read and express themselves through writing.

The respondents who completed the online form answered all the questions they were directed to. The answers to the open-ended questions were mostly well-detailed. The four respondents who scheduled the completion were able to understand the questions adapted using the AAC boards. Three used their personal AAC to answer the open-ended questions with the help of their caregiver. One respondent had concomitant apraxia of speech, vocalizing responses in a unique manner, which were translated by the person's mother. The empirical results and analysis will be presented in a future publication.

Reflections on the process

Considering the epistemic innovations proposed by this study, the following reflections on the research process help provide an understanding that goes beyond the objective aspects of the phenomenon of interest.

In participatory autism research, the connection with the autistic community is fundamental and presents the first challenge. Insistence on

Chart 3. Questions used to characterize the domain.

Domain	Questions
Education	Is your school: a. Public? b. Private?
	Do you receive some kind of study grant or funding that covers all or part of your tuition fees? **You can choose more than one option if necessary.** a. No because my school or course is free. b. No, although my school or course is not free. c. Study grant for private middle or high school. d. Full ProUni grant. e. Partial ProUni grant. f. FIES. g. University grant or scholarship (research, monitor, extension, work grant, technical support). h. Bank loan.
Family routine	Where and with who do you currently live? a. In a house or apartment, alone. **b. In a house or apartment, with parents or relatives or another person (caregiver).** **c. In a house or apartment, with parents or relatives, without any relationship of care or dependency.** d. In a house or apartment, with spouse and/or children. e. In a house or apartment, with other people. f. In another type of individual or collective accommodation (hotel, lodgings, guest house, other).
	How many people live with you in your residence?
Work and paid activities	Which of the following options best describes your current occupation or paid work (except work experience or grants)? a. I stopped working or undertaking paid activities during the **pandemic** of my own choice. b. I lost my job during the **pandemic**. c. I can't do my paid activity during the period of isolation. d. I am currently working or undertaking a paid activity.
Family income	What is your total family income including your income? a. Up to 1 minimum wage **(R$ 1,045).** b. Between 1 and 2 minimum wages **(between R$ 1,045.01 and R$ 2,090).** c. Between 2 and 4 minimum wages **(between R$ 2,090.01 and R$ 4,180).** d. Between 4 and 10 minimum wages **(between R$ 4,180.01 and R$ 10,450).** e. Between 10 and 20 minimum wages **(between R$ 10,450.01 and R$ 20,900).** f. More than 20 minimum wages **(over R$ 20,900.01).**
	Which of the following options best describes your financial situation? a. I don't have an income and my expenses are totally funded by my family or other people. b. I don't have an income and my expenses are totally or partially funded by government programs. c. I have an income, but I receive assistance from government programs. d. I have an income, but I receive financial help from my family or other people to pay my expenses. e. I have an income and don't need help to pay my expenses. f. I have an income and help support the family. g. I have an income and am the family's main breadwinner.
	If you chose b or c in the previous question, what type of assistance do you receive? a. *Bolsa Família.* b. *Benefício de Prestação Continuada* (continuous cash benefit program). c. Child Labor Eradication Program (PETI). d. *Garantia-Safra* (harvest guarantee program). e. *Seguro Defeso* (closed season benefit program for artisanal fishermen). f. Unemployment benefit. g. Allowance. h. Pension. i. *Auxílio Emergencial* (emergency assistance during the pandemic).

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Chart 3. Questions used to characterize the domain.

Domain	Questions
Health and associated conditions	Which autism-related conditions do you have that require support?
Treatment and therapies	Which treatments and/or therapies do you undergo/were you undergoing before the social isolation measures were introduced?
	How are these treatments and/or therapies paid for? a. In full by the SUS. b. Privately. c. Health insurance. d. Partly by the SUS and part privately or by health insurance.
Daily routine and social network	**Did the need to socially isolate influence your relationship with your social network and friends?** **a. I reduced contact with my friends and my social network a lot.** **b. I reduced contact with my friends and my social network a little.** **c. Nothing changed because my social interactions were already mainly remote.** **d. Nothing changed because I didn’t adhere to social isolation.** **e. I increased contact with my friends and my social network a little.** **f. I increased contact with my friends and my social network a lot.**
Final question	Is there anything I didn't ask that you would like to talk about? Feel free to write whatever you like.

Source: Authors (2022).

Table 1. Frequencies of responses of the judges regarding the instrument items.

Item	Needed alterations		Adequate		CVI
	N	%	N	%	
1	3	15	17	85	0.85
2	5	25	15	75	0.75
3	0	0	20	100	1
4	5	25	15	75	0.75
5	0	0	20	100	1
6	5	25	15	75	0.75
7	3	15	17	85	0.85
8	0	0	20	100	1
9	5	25	15	75	0.75
10	0	0	20	100	1
11	5	25	15	75	0.75
12	5	25	15	75	0.75
13	5	25	15	75	0.75
14	0	0	20	100	1
15	5	25	15	75	0.75
16	0	0	20	100	1
17	5	25	15	75	0.75
18	0	0	20	100	1

Note: Mean CVI: 0.86; Cronbach’s alpha: 0.85.

Source: Authors (2022).

using refuted theories (such as the “refrigerator mother”), the use of demeaning and patronizing language, tokenism, and the hegemony of neuronormativity that underpins most analyses has contributed to growing distrust of research proposals by autistic people[15].

It is therefore worth highlighting some factors that help increase the capillarity of research.

Chart 4. Alterations to the instrument items suggested by the judges.

Suggestion	Alteration
Add the estimated questionnaire completion time (suggested by 1 expert and 3 autistic judges).	The autistic judges were asked to respond the questionnaire and say how long it took. The average time (18 minutes) was informed in the introduction to the questionnaire.
Leave the question about gender open-ended considering the multiple possible responses (suggested by 1 expert and 4 autistic judges).	Open-ended question.
Do not use the wording "How would you describe your feelings in relation to" due to the high frequency of alexithymia (suggested by 2 expert and 4 autistic judges in all domains). Specify that the question refers to the current context (4 autistic judges).	**How would you define your reaction** in relation to [DOMAIN] **in the current context?**
Not all autistic people who live with their parents have a relationship of dependency. It was suggested that this response option was divided into two (4 autistic judges).	Where and with who do you currently live? a. In a house or apartment, alone. **b. In a house or apartment, with parents or relatives or another person (caregiver).** **c. In a house or apartment, with parents or relatives, without any relationship of care or dependency.** d. In a house or apartment, with spouse and/or children. e. In a house or apartment, with other people. f. In another type of individual or collective accommodation (hotel, lodgings, guest house, or other).

Source: Authors (2022).

Three of the researchers who conducted the present study are mothers and one the aunt of autistic people, one is on the autism spectrum (level I without intellectual or language impairment), is twice-exceptional and has *high abilities*, three are members of the Brazilian Association for Action for the Rights of People with Autism (ABRAÇA, acronym in Portuguese that means "embrace"), and one is neurodiverse, being diagnosed with dyslexia. Thus, three of the authors belong to a group recognized by the autistic community. Hence, the study was not conducted from the "outside". In this regard, it is important to highlight that the autistic community is sensitive to the colonialities that structure the modes of production of knowledge and therefore researchers who adopt a participatory approach face the challenge of evening out traditional power imbalances.

Another important factor was that the questionnaire was made accessible to members of the autistic community, resulting in necessary alterations. This integration with the community helped make the questionnaire accessible to people with intellectual impairments and communication challenges. In addition, the difficulties in promoting the participation of these individuals were significantly reduced due to the researchers' prior experience with using AAC. In this regard, it is worth highlighting that the main obstacle to the participation of autistic people with language impairments is not autism in itself, but rather the lack of social investment in these people. Unfortunately, the use of assistive technology to support and enhance communication remains limited, contributing to the underrepresentation of this group. These problems however should not be used to justify the perpetuation of the exclusion of these people from the knowledge production process. Quite the contrary, they should act as a stimulus to continue the development of strategies to adapt and disseminate AAC techniques.

Discussion

The active participation of autistic people in the design of the methodology of this study contributes to the demystification of the fallacy of presumed incapacity and breaks with hegemony of hierarchical models of scientific research.

Participatory studies like the present study optimize methodological qualities, reduce interpretation bias of non-autistic researchers, and frame the results in a real-world context. Without detracting from these benefits, it is important to make clear that being participatory is not enough. Research needs to break away from structural and systemic neuronormativity. Unfortunately, this posture is still rare, as Cos Michael[31] illustrates after having collaborated with multiple studies: “Were we there because they valued our input, or were we tokens, useful for ‘authenticity’ and snippety quotes, to validate the researcher’s inclusive credentials?”.

In this sense, the present study reinforces the neurodiversity paradigm that is emerging within the autistic community[25,26]. This paradigm proposes an alternative functional analysis to replace conceptions of neurological impairment[27]. Unlike the claims of some critics, the paradigm does not deny intellectual and/or psychosocial impairment coupled with conditions such as autism, ADHD (attention deficit hyperactivity disorder), dyslexia, dyscalculia, and dyspraxia[8,27]. Without denying support needs, neurodiversity approaches advocate that therapies should focus on maximizing skills, providing socioemotional support, and developing strategies to deal with individual and environmental demands rather than seek a cure for conditions that are an expression of human diversity[32].

It is also worth stressing that autistic people with language and/or intellectual impairments also participated as judges, using AAC tools or written language with the assistance of an interpreter. This experience exemplifies the social model approach to disability, which focuses on limitations linked to social barriers – such as lack of structural adaptations or limited investment in forms of AAC – instead of focusing on the impairment itself[33].

Final considerations

This study is unique insofar as it proposes the epistemological decentering of hegemonic scientific knowledge, opening up opportunities to build more plural and (neuro)diverse knowledge and practices. This article illustrates a positive participatory research experience originating from members of the autistic community that emphasizes the importance of valuing the role of autistic participants in research, shared responsibility, and fostering a connection between members of the autistic community. The study involved autistic people with varying levels of support needs, including those with language and/or intellectual impairments. The participation of autistic people in the design and application of the instrument and data collection helped highlight the importance of AAC techniques and inclusion strategies designed to ensure autistic people’s right of self-determination, regardless of support needs.

Collaborations

LMA Filgueira: development of methodology, writing and content analysis. AVM Brilhante: research advisor, theme development and methodological approach, content analysis and textual completion. AR Sá: methodological conduction, content collection and analysis, writing contribution. MSF Colares: contribution with writing, development of discussion and final considerations, methodological collaborator.

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