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Barriers to mental health services for children and adolescents with autism spectrum disorder in Brazil: protocol for a qualitative evidence synthesis and citizen panel (BARRIER-Free-BR Project)

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ABSTRACT

Introduction The perspectives of stakeholders directly affected by mental health services for autism spectrum disorder (ASD) are essential for the quality of these services. However, it is crucial that these perspectives are informed by the best available evidence and adapted to the local context. This study aims to analyse barriers related to mental health services for children and adolescents with ASD from the perspective of families and caregivers, considering social, racial and gender aspects.

Methods Three steps will be taken: stakeholder engagement through an online meeting to refine the research question and understand the magnitude of the problem; (b) qualitative evidence synthesis using five databases and grey literature to identify studies that have collected and analysed qualitative data on barriers to mental health services for children and adolescents with ASD in Brazil. Only studies conducted in Brazil that consider the perspectives of family members and caregivers will be included. (c) A citizen panel with families of children and adolescents with ASD will be used to discuss and validate the synthesis findings.

Ethics and dissemination We will provide a set of evidence-informed and stakeholder-experienced barriers to mental health services for children with ASD in Brazil. This represents an effort to engage stakeholders in evidence descriptions to inform policy. We plan to disseminate the findings through various means, including peer-reviewed journal publications, presentations at national conferences, invited workshops and webinars, patient associations and academic social media platforms. The project was approved by the Ethics Committee for Research at the University of Sorocaba (approval number 78747224.7.0000.5500).

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STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study will use a qualitative evidence synthesis based on multiple databases and grey literature.
⇒ Stakeholders will be engaged early to refine the research question and priorities.
⇒ Focusing on Brazil may limit the applicability of results to other settings.
⇒ The study will incorporate social, racial and gender considerations, adding depth to the planned analysis of barriers in mental health services.

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterised by persistent deficits in communication and social interaction, along with restricted and repetitive patterns of behaviour, interests or activities.[1] The most recent estimates of ASD prevalence indicate that approximately 1 in 36 children aged 8 years in the USA has been diagnosed with the condition, according to data from the Centers for Disease Control and Prevention.[2] In Brazil, the most up-to-date data come from the 2022 Census conducted by the Brazilian Institute of Geography and Statistics, which identified 2.4 million people with a diagnosis of ASD, corresponding to 1.2% of the Brazilian population.[3] The Census also showed that ASD diagnoses are more prevalent among younger individuals, with children and adolescents aged 0–14 years accounting for 1.1 million diagnosed cases in the country.[3]

Programmes and policies related to the identification and care of children with ASD are affected by social and ethno-racial

disparities.[4] In Brazil, a country with continental proportions, these disparities represent a significant challenge to health policies and guarantee comprehensiveness and equity.[5] In the context of ASD, this discussion has gained prominence, as delays in the provision of mental healthcare can result in worse outcomes.[6] In Brazil, the National Mental Health Policy advocates for community-based care through the implementation of multidisciplinary services, Child and Adolescent Psychosocial Care Centres and specialised centres, all within the framework of the Brazilian Unified Health System (SUS).[7] As a universal coverage system, the SUS ensures that healthcare is a right for all individuals, regardless of their socioeconomic status.[8] Although these spaces face structural challenges and chronic underfunding, they welcome children and adolescents with ASD, as well as their families, for mental healthcare.[9]

Several barriers to accessing services under Brazil's National Mental Health Policy have been identified in previous studies, leading to an increasing need for family activism in support of ASD, particularly through individual initiatives to seek diagnostic and care services.[10] This search represents a significant factor of strain and illness for families during caregiving, particularly for mothers.[11] Nevertheless, there is a lack of systematic understanding of how these barriers intersect with social markers such as gender, economic class and ethno-racial factors.[10] Health policies in Brazil for ASD focus on family-based care, leading to an increasing burden on families and caregivers, particularly women, to whom caregiving has been socially delegated.[12]

No qualitative evidence synthesis with a methodologically robust approach has considered the barriers to mental healthcare for children and adolescents with ASD from the perspective of families and caregivers in Brazil.[10] Moreover, the latest synthesis of findings related to mental health services for individuals with ASD did not consider social, gender or ethnoracial markers of barriers to these services.[10] Barriers to accessing mental health services for children and adolescents with ASD are shaped by historical structures of gender, racial and class inequality, whose intersections profoundly influence family experiences and the organisation of care.[13] Recognising that multiple systems of oppression and inequality operate simultaneously, access to services can be understood as both a situated and structural process that directly affects the quality of care received by children and adolescents with ASD.[14]

This study aims to analyse barriers related to mental health services for children and adolescents with ASD from the perspective of families and caregivers, considering social, racial and gender aspects.

METHODS AND ANALYSIS

Patient and public involvement

Patients and the public will be actively involved in the design and conduct of this study. A stakeholder workshop will contribute to the refinement of the research questions, ensuring that the study addresses relevant concerns from the perspective of families and caregivers of children and adolescents with ASD, policy-makers, healthcare professionals and researchers. Additionally, a citizen panel will be held at the end of the study to disseminate the findings and to validate the results of the qualitative evidence synthesis against the daily experiences of families of children and adolescents with ASD. The results will also be shared with relevant community organisations through plain-language summaries and virtual conferences. Further details of these steps are described below:

Study design

This qualitative evidence synthesis is organised into three stages (figure 1): Stage 1— stakeholder engagement to refine the research question for the qualitative evidence synthesis; Stage 2— development of the qualitative evidence synthesis to identify barriers to mental health services for children and adolescents with ASD in Brazil; Stage 3—a citizen panel with families and caregivers in Brazil to discuss and further explore the barriers to mental health services identified in the synthesis. This study began in July 2025 and will end in September 2026.

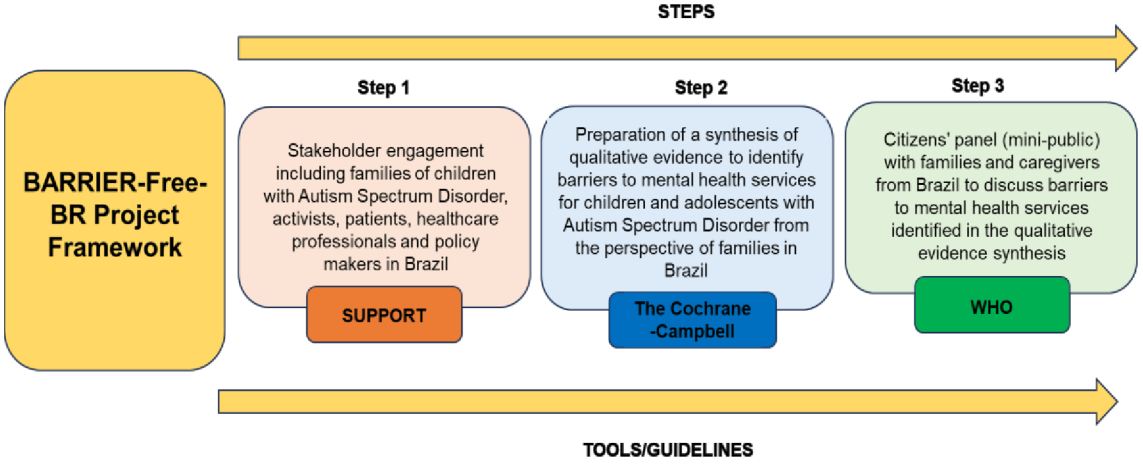

Figure 1 BARRIER-Free-BR Project Framework. SUPPORT, Supporting Policy Relevant Reviews and Trials.

Step 1: Stakeholder engagement through a workshop for refining the research question

We will engage stakeholders through an online meeting to refine the research question, understand the magnitude of the problem and gather suggestions on relevant data to be extracted in the qualitative evidence synthesis.[15] The workshop will include families of children and adolescents with ASD, healthcare professionals working in mental health services for ASD in Brazil, researchers on the topic and policy-makers. We limit participation to up to 10 stakeholders to ensure the involvement of all parties.[16] We will identify these stakeholders through contact with patient associations, mental health services and recommendations from the Ministry of Health of Brazil. A facilitator will present the research question and the methods of the qualitative evidence synthesis, and the stakeholders will share their perspectives on the topic on three central aspects: (1) the magnitude of the problem; (2) methodological adjustments and (3) relevant outcomes to be extracted from the included studies. Online supplemental material 1 presents the proposed schedule for conducting this workshop.

The workshop will be recorded in full with the participants' consent, and the feedback will be transcribed and analysed through thematic analysis.[17]

Step 2: development of the synthesis of qualitative evidence

We will follow the recommendations of The Cochrane-Campbell Handbook for Qualitative Evidence Synthesis in developing the qualitative evidence synthesis.[18] This protocol adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Systematic Review Protocols (online supplemental material 2).[19] A protocol was developed a priori and is available on the Open Science Framework.[20]

Eligibility criteria

We have systematised the research question for this synthesis according to the acronym population, phenomenon of interest and context (PICo):

Population

We will include studies that used qualitative methods for data collection (eg, focus group interviews, individual interviews, participant observation) and data analysis (eg, content analysis, discourse analysis, structural analysis, grounded theory) that consider the perspective of families and caregivers of children and adolescents (0–18 years) with ASD regarding mental health services. Mixed-methods studies or studies with mixed populations were included when it was possible to extract only qualitative data.

Phenomenon of interest

The phenomenon of interest in this synthesis will be the experiences and barriers to mental health services for children and adolescents with ASD.

Context

We will include only studies that evaluated mental health services for children and adolescents with ASD in Brazil. Multicentre studies will be included as long as the results for participants from Brazil are presented separately.

Search strategy

We developed and validated a search strategy (online supplemental material 3) with a specialised librarian in the following databases: Scielo Brazil, MEDLINE (via PubMed), Embase, PsycINFO and the Regional Portal of the Virtual Health Library. Grey literature will be consulted through the Brazilian Digital Library of Theses and Dissertations.

Study selection

Before study selection, we will conduct a calibration with the reviewers to refine the eligibility criteria. The calibration consists of a pilot exercise with a random sample of studies to better understand the eligibility criteria. We will select first by title and abstract and then by full text using Rayyan. These stages will be carried out independently by two reviewers. Discrepancies were resolved through the judgement of a third reviewer.

Data extraction

For data extraction, similar to selection, we conduct a calibration. Data will be independently extracted into an Excel 2016 spreadsheet by pairs of reviewers. Discrepancies were resolved by consensus or with the assistance of a third reviewer. The data to be extracted are summarised in online supplemental material 4.

Assessment of the methodological limitations of the included studies

We will evaluate the methodological limitations of the included studies via the Critical Appraisal Skills Programme (CASP) Checklist.[21] This phase will be conducted by two trained reviewers via the tool. Any discrepancies were resolved by consensus; if necessary, a third reviewer was consulted. No study was excluded on the basis of the CASP assessment results.

Summary of findings

We will conduct a thematic synthesis to identify codes and prominent themes in the included studies.[22] Line-by-line coding of first-order constructs (participants' quotations) and second-order constructs (authors' interpretations) will be performed following the thematic synthesis approach to develop both descriptive and analytical themes.[22] The thematic analysis will be conducted in an iterative, critical and interpretative manner.[23] Analytical categories will not be predefined but will instead emerge through engagement with the data, based on close reading, negotiated meaning among the research team and active listening to the experiences narrated in the included studies. The analysis will aim to capture not only what was said, but also how experiences were discursively constructed, within specific social and institutional

contexts, and with what effects. Coding will occur in multiple rounds, with team meetings held to validate interpretations, revisit categories and challenge normative understandings of care, disability and inequality. The process will be documented in a shared, reflexive journal, where analytical and ethical decisions will be continuously discussed. Descriptive themes will be developed to stay close to the findings of the primary studies, followed by the generation of analytical themes, providing new interpretative explanations or hypotheses that go beyond the descriptive synthesis and inform the design of future research and interventions.[22]

To prevent the national scale from obscuring the territorial and social asymmetries that shape access to mental health services, the synthesis results will be stratified whenever possible according to regional divisions (North, Northeast, Central-West, Southeast, South), also taking into account whether the included studies are located in urban, periurban or rural areas. Results will be presented and analysed separately according to participant type, distinguishing between people with ASD and caregivers. When studies present data or narratives directly involving racialised populations or specific groups (eg, Indigenous families, quilombola communities or residents of favelas), these voices will be highlighted as autonomous analytical axes, ensuring they are not subsumed under a generic category of the 'Brazilian population'.

We will develop statements related to barriers to mental health services for individuals with ASD in Brazil on the basis of the perspectives of families identified in the included studies. The analysis of findings will be guided by an intersectional lens,[24] with attention to the interconnections between race, territory, gender, class and disability in the production of barriers to care. This approach will be essential to understanding how racialised geographic location—where neighbourhoods, cities and states function as markers of exclusion—influences access to, quality of and continuity in mental healthcare. Rather than seeking national-level generalisations, the synthesis will aim to map zones of invisibility and exception within the national territory, where the promises of public policy are either interrupted or precariously realised. This process is carried out in the following stages[25]:

- Familiarisation with the data: A review author with expertise in qualitative research will read all included studies in full to become familiar with them and gain a deeper understanding of the data while noting any initial thoughts.
- To generate initial codes: Researchers independently identify codes from a selected corpus of articles, drawing on new insights and findings to refine and expand the coding process. The review authors compared the identified codes via a Microsoft Excel results database to reach a consensus on the appropriateness and terminology of each code. This process results in the development of a shared coding framework, which is applied to subsequent articles. The framework will be continuously refined as new studies are synthesised.
- Identifying themes: Two reviewers with expertise in qualitative research will group codes into potential themes, gathering all relevant data for each theme. At this stage, the review authors interpret the underlying meaning of the data and examine the relationships among the codes, themes and thematic hierarchies. This process involves regular discussions to reflect on emerging new themes.
- Report production: A review author with expertise in qualitative research will develop a narrative of findings for each theme, integrating vivid illustrative quotes from the families of interlocutors featured in the included studies. This narrative will be shared with the research team for feedback.

Assessing our confidence in the review findings

Two reviewers will assess the confidence level for each finding (theme and/or subtheme) via the confidence in the evidence from reviews of qualitative research (GRADE-CERQual) tool.[26] This tool evaluates confidence in the findings on the basis of the following components: methodological limitations of the included studies, coherence of the review's findings, adequacy of the data supporting a review finding and relevance of the included studies to the review question. All findings begin with a high level of confidence and are downgraded if there are significant concerns regarding any of the CERQual components. After assessing each of the four components, we judge the overall confidence in the evidence supporting the review's findings and report it as high, moderate, low or very low. Our final assessment will be based on consensus among the reviewers.

Step 3: citizen panel with families of children and adolescents with ASD in Brazil to discuss and validate the findings

We will conduct a virtual citizen panel with families of children with ASD in Brazil.[27] We included only families and individuals with ASD to ensure firsthand insights, prioritising lived experiences with mental health services in Brazil. To maintain ongoing stakeholder engagement, families from step 1 will also be invited to join the citizen panel. Participant recruitment will not rely exclusively on convenience sampling, but will follow a mixed strategy involving engagement with support networks for families of children with ASD, social movements and community leaders, with a focus on territories historically marked by exclusion and limited reach of public policies. Efforts will be made to ensure the inclusion of individuals whose voices are systematically marginalised in deliberative processes, such as Black and Indigenous women, families from rural and peripheral regions, caregivers with low levels of formal education and people with disabilities. The aim is not merely to achieve 'descriptive diversity', but to build a composition that can actively contest dominant meanings of care, rights and access.

Following the WHO guidelines for mini-publics, we will include up to 15 participants, ensuring a diverse profile of families in terms of race, gender and geographic location.[27] We agree on a date and time with the families 30 days before the citizen panel. After the panel, we encourage families to provide feedback on the importance of their participation. Online supplemental material 5 outlines the planned activities for conducting this stage.

We acknowledge that participatory engagement initiatives, such as the citizens' panel described in this protocol, risk becoming performative exercises if not accompanied by explicit strategies for power redistribution and the attentive listening to voices that have been systematically silenced.[24] We, therefore, hold that participation is only meaningful when it is accompanied by epistemic justice.[28] That is, when inequalities in the production and reception of knowledge are explicitly recognised. This protocol, accordingly, aims not merely to consult citizens but to co-construct situated forms of data interpretation and to develop recommendations that are sensitive to lived experiences of exclusion.[29]

An online, anonymous form will also be provided at the end of the experience to collect feedback on its strengths and limitations.[30] The citizen panel will be recorded, transcribed and analysed via thematic analysis.[22] The results are organised into categories and emerging themes according to the families' narratives.

Reflexivity

As researchers engaged in a qualitative synthesis of studies on access to mental health services for children with ASD in Brazil, we recognise that our social positions, institutional affiliations and personal trajectories inevitably shape the ways we listen to, analyse and interpret the findings.[29] We, therefore, frame the knowledge produced in this synthesis as situated, acknowledging that ways of knowing emerge from bodies marked by race, gender, class and geopolitical location. Some members of the research team have direct experience in the care of children with ASD, while others work in public policy, research and social movements related to mental health. This diversity enriches the analysis but also introduces potential limitations, which will be continuously reflected on throughout the analytical process.

DISCUSSION

In this protocol, we describe a synthesis of qualitative evidence aimed at analysing barriers related to mental health services for children and adolescents with ASD from the perspective of families and caregivers, considering social, racial and gender aspects. We will conduct this work in continuous dialogue with relevant stakeholders, both at the initial stage to refine the research question and during the validation of the findings. The systematisation of these barriers and the ongoing interaction with Brazilian stakeholders underscore the importance of this study.

Essential internationally recognised methodological tools will guide all stages of this project and may encourage other countries such as Brazil to implement these approaches in building strong, equitable health systems and evidence-informed policies for ASD. The BARRIER-Free-BR Project framework can assist future studies aiming to evaluate barriers to mental health services for individuals with ASD from the family perspective. Through the findings of this methodologically robust qualitative evidence synthesis, we will be able to assess the performance of the Brazilian healthcare system in providing mental health services for children and adolescents with ASD. This could promote changes in the organisation of these services to expand access and mitigate barriers and serve as a comparison with other studies conducted in low-income and middle-income countries, strengthening evidence-informed policy formulation.

The findings of this work could shed light on areas of mental healthcare for children and adolescents that require more significant effort. Validating the results with families could serve as a foundation for overcoming these challenges with appropriate strategies relevant to those directly affected by Brazil's national mental health policy. Additionally, it could represent an evaluative project framework to inspire other low-income and middle-income countries, such as Brazil, to use international tools in evidence-informed policies.

Limitations in identifying Brazilian studies that address barriers to mental health services for children and adolescents with ASD from the families' perspective, considering aspects such as race, gender and geographic location, may be encountered during this study. Additionally, engaging families with diverse characteristics to ensure a broad range of stakeholders in the citizen panel may pose challenges. To mitigate these risks, we will use the gaps in the evidence as an opportunity to propose new studies, suggest appropriate methodological designs for future research, and contact ASD patient associations to raise awareness and engage stakeholders. If the search yields three or fewer eligible studies after full screening, a contingency plan will be activated with the following steps: (1) transparent documentation of the number, type and characteristics of the included studies; (2) a justified transition to a scoping review design, maintaining the central objectives while expanding the inclusion criteria to encompass qualitative and mixed-methods studies with relevant components and (3) a revision of the planned analysis, employing conceptual mapping and narrative synthesis methods,[31] prioritising a descriptive yet critical approach to the available findings.

Although this synthesis is limited to studies conducted in Brazil, we acknowledge that the country does not constitute a homogeneous unit of analysis. Brazil is marked by profound regional inequalities, historically shaped by processes of racialisation, land concentration, uneven urbanisation and fragmented public policies. Access to

mental health services is therefore inseparable from territorial determinants such as the presence or absence of the Unified Health System (SUS), the strength of community mental health services and the selective privatisation of care. These elements will be treated as central analytical dimensions in the interpretation of the findings.

Finally, although this research focuses on identifying and analysing barriers related to mental health services for children and adolescents with ASD in the Brazilian context, it may also provide a roadmap for other nations and regions to consider the perspective of families when evaluating health policies.

ETHICS AND DISSEMINATION

We will provide a set of evidence-informed and stakeholder-experienced barriers to mental health services for children with ASD in Brazil. This represents an effort to engage stakeholders in evidence descriptions to inform policy. We plan to disseminate the findings through various means, including peer-reviewed journal publications, presentations at national conferences, invited workshops and webinars, patient associations and academic social media platforms. This protocol has been submitted and approved by the Ethics Committee of the University of Sorocaba (approval number 78747224.7.0000.5500). Participants in all stages of the study signed an informed consent form and were guaranteed the confidentiality of the team's responses and respect for informed consent.

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Contributors All authors (LPNL, LdSB, ACFM, AR-S, VPM, FCA and LCL) made substantial intellectual contributions to the development of this protocol. LCL is the guarantor of the study. LPNL is the principal investigator, responsible for writing the draft protocol. The review question was developed by LCL and refined by LPNL and LdSB. LPNL and FCA tested the search strategy. All authors (LPNL, LdSB, ACFM, AR-S, VPM, FCA and LCL) participated in writing the manuscript, critically reviewed the content, approved the final manuscript and agreed to be responsible for the manuscript, ensuring the accuracy and integrity of the work.

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Competing interests None declared.

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