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Community engagement with individuals with lived experience of autism and intellectual disability to promote awareness and service utilisation for early identification and intervention: A scoping review

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Abstract

Community-based early detection and intervention for NDDs has increasingly received prominence in public health research. Despite diagnostic opportunities, limited awareness of child development, social support and standardised care pathways delays diagnoses and access to services. Engaging lived experiences builds trust, improves quality and access to care. However, there is limited synthesised knowledge on involving lived experiences, especially those of autistic individuals and their caregivers, in conceptualising community awareness to promote service utilisation. This scoping review reports on community-engaged research methodologies employed within community-based programs to build awareness to promote early identification and intervention. Studies after 1980 were included to follow the advocacy movement following deinstitutionalisation. Fifteen thousand and six hundred and seventy-three abstracts were screened, of which 66 were selected for full-text review and 16 met eligibility criteria. Studies were from the United States of America, the United Kingdom, Canada, Australia and Bangladesh. Caregivers supported identifying knowledge gaps and information preferences, while autistic voices amplified authentic experiences. Most studies used community-based participatory research and half utilised collaborative partnerships. Interviewing was used in six studies. Cultural adaptation for marginalised or underrepresented communities.was a key focus. With engagement occurring across disciplines, the nomenclature varies. Standardising community-engaged practices across community-based programmes may ensure appropriate representation across a range of cultural contexts.

Lay Abstract

There is an increasing number of community-based programmes for recognising early signs of autism and increasing access to interventions. However, despite the same, limited awareness of child development milestones, lack of social support and difficulty in accessing care pathways lead to a delay in finding the right help. Engaging with people who benefit from health programmes – including beneficiaries, people with lived experiences and related stakeholders before implementation has been suggested to improve programme engagement. However, there is little condensed knowledge about how to engage people with lived experience, especially those who are autistic or are caregivers of autistic adults in building awareness and subsequently lead to programmes that help with detection and intervention. This particular scoping

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review reports on studies that have successfully done this and asks and answers (to an extent) critical questions about – what level of engagement currently exists, how to engage (approaches, methods and tools), and when to engage. Currently, lived expertise is largely included after research priorities are already set, for example, designing interventions that researchers feel the need for a benefactor or population. This often leads to mismatched priorities for beneficiaries and excludes them from the design of programmes that directly benefit them. This paper suggests that stakeholders need to come together to build a taxonomy that ethically and meaningfully engages lived experience at different stages of research, whilst acknowledging the level of engagement possible and using appropriate approaches, methods and tools while building programmes for early detection and intervention.

Keywords
autism, community engagement, stakeholder navigation, community-engaged research, public health

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Introduction

Globally, an estimated 52.9 million children under 5 years have a developmental disability with – autism and intellectual disability, resulting in high costs to individual and family functioning (Baxter et al., 2015; Global Research on Developmental Disabilities Collaborators et al., 2018; Krishnamurthy, 2008). Researchers increasingly recommend task-sharing models that use community resources to address the gap between increased reporting of NDDs and the costs of availing detection and intervention services (Bhavnani et al., 2022). Community-based screening has been effective in identifying NDDs in low-resource settings (Stewart & Lee, 2017). Despite the implementation of community-based programmes, stigma related to disclosing concerns related to NDDs persists, with low awareness of child development, limited social support and inconsistent practices in care pathways resulting in delays in seeking timely care or interventions when they exist (Divan et al., 2021; Turnock et al., 2022). Furthermore, following the deinstitutionalisation of individuals with disabilities in the 1980s, understanding choice and agency among families of children with NDDs became essential to improve health outcomes (Dyer et al., 1990; Minihan & Dean, 1990; Stancliffe et al., 2000). In response, community-engaged research strategies, which are “the process of working collaboratively with groups of people affiliated by geographic proximity, special interests, or similar situations to address issues affecting their well-being” offer researchers opportunities to create an environment of trust and improve quality and access to care (Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011, p. 21).

Community engagement broadly aims to involve and incorporate the perspectives of those being impacted by research and its outputs (Luger et al., 2020; Ohmer et al., 2022). Actively involving community members in research processes assists in developing practices that serve the needs of the community in conjunction with researchers (Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011; Kok et al., 2016; Kwon et al., 2018; Yardley et al., 2015). This, however, has gained limited momentum in autism research and as put forth by Cullingham et al. (2025), such an approach needs to be “grounded in iterative action oriented research and practice”. Adams et al. (2024) outline three levels of engagement: (i) involvement (one-way sharing from lived experience experts (LEE) to the researcher), (ii) consultation (two-way communication and LEE have input on decisions), and (iii) partnerships (LEE and researchers share decision-making). While community-engaged research is new in the field of NDDs, it has been used to design mental health interventions (Edwards et al., 2024), communication aids (Zolyomi & Snyder, 2023) and for autistic individuals, and in building awareness through advocacy research (Schuck & Fung, 2024).

This review aims to understand if these approaches can be scaled to support community programmes that promote service utilisation. Moreover, community engagement research methods are reportedly flexible and rely on case studies, qualitative inquiry or literature review (Luger, Hamilton & True, 2020). Thus, with the research question: “*What community-engaged strategies are employed to involve lived experiences of autism and ID toward building awareness resources that lead to early intervention service uptake?*” this review aims to report methodologies used in community-engaged research and programs to raise awareness through leveraging lived experiences to improve service utilisation for early identification and intervention.

Method

Protocol Registration

The protocol of the current review was created in adherence to PRISMA-ScR guidelines (Tricco et al., 2018) and was registered on the Open Science Framework (Malhotra et al., 2025; https://doi.org/10.17605/OSF.IO/XJRPA).

Table 1. Search Terms.

Autism and Related Methods of Awareness Building	(((“autism Awareness” OR “autism Knowledge” OR “community Health” OR “public Awareness” OR “community Awareness” OR “public Knowledge” OR “public Involvement” OR “community Involvement” OR “sensitization” OR “community Engagement” OR Stakeholder OR Participatory OR “health Promotion” OR “psycho?education” OR Inclusion OR Empowerment OR “shared Decision?making” OR Engag* OR Advoc* OR Outreach*) AND (strateg* OR Tech* OR Tool? OR Approach* OR “Co-Design”) OR (“best Practices” OR “community?based” OR Delphi OR “patient?centred Care” OR “community Participation/methods” OR “Community-Based Interventions” OR Story*))
Making use of lived experiences	AND ((autis* OR “autistic adults” OR “Intellectual disability” OR “autistic community” OR “parents of children with autism” OR “neuro?developmental disab*” OR “peer mentors”)))
Excluding those studies based on biomedical or basic science research:	NOT (“animal model*” or “genetic*” or “molecular*” or “cellular*” or “neurobiolog*” or “pharmacolog*” or “drug*” or “medication*” or “biomarker*” or “imaging”) AND ((english[Filter]) AND (1980:2024[pdat]))
Language and year limit	((english[Filter]) AND (1980:2024[pdat]))

Search Strategy

Four databases were selected (PubMed, Scopus, Web of Science, and Ovid for PsycInfo and PsycAPA articles) and helped to identify relevant keywords related to community awareness, community engagement and involvement methods, autism and intellectual disability. Initial results were saturated with information about biomedical and pure science studies, and hence, served as an exclusionary basis for further refining the strategy (Table 1). Full search terms for all databases are found in the supplementary section (Table S2 in the Supplementary materials).

Inclusion and Exclusion Criteria

Studies were included if they met the following inclusion criteria:

(a) Published since 1980, (b) involved relevant stakeholders, with a focus on autistic individuals and their caregivers in the conceptualisation of awareness strategies, (c) reporting on the use of awareness strategies toward the promotion of early detection or intervention services. Beginning of deinstitutionalisation in the 1980s which led to advocacy for the needs of individuals with NDDs, especially focusing on choice-making, and finally involving individuals with lived experience to inform interventions developed for them and their community (Dyer et al., 1990; Minihan & Dean, 1990; Stancliffe et al., 2000). Studies were excluded if (a) recipients of interventions were above 18 years, (b) not in English due to a lack of resources for translation, or (c) purely biomedical or pure science studies.

Study Selection

BM and SP searched all four databases which can be found in the supplementary file. Consensus was achieved in getting the same results, and all identified references were uploaded into the *Covidence systematic review software* (Veritas Health Innovation, n.d.). The abstract screening comprised 5 reviewers, namely BM, SP, MM, RM and SS. Since COVIDENCE considers inter-rater reliability by default, disagreements on including an abstract were resolved in consultation with the entire team, with BM and SP as the deciding vote. BM, MM, RM and SS then proceeded to screen the full texts of selected abstracts. The included full-texts were extracted by two reviewers charting data and a third reviewer checking for data accuracy.

Few studies had the same authors, but it was unclear if one study preceded the other to inform CE. However, upon clarification by BM through email correspondence to these authors, as well as discussions with RR, it was understood that these were independent studies.

Data Charting

The Population, Concept, Context framework was adopted to chart data (Peters et al., 2015). Furthermore, the review will refer to the definitions in the Stakeholder Engagement Navigator Tool (Kwon et al., 2018) designed to guide researchers on suitable stakeholder engagement methods for translational and clinical research. This included:

1. Approaches: Organising frameworks used to define and understand stakeholders’ roles in decision-making, as well as in the conceptualisation, conduct, and dissemination of research.
2. Methods: Specific tools, techniques, and processes that are employed to achieve “high-level” engagement. This involved identifying and convening stakeholders, creating reciprocal relationships (to level the playing field), engaging in bi-directional

Table 2. Example of an Extraction.

Approach	Method	Tool
Community-based participatory approach – CBPR (Community members and academics have an active and equitable role in shaping the research)	Community-campus partnerships and Boot Camp Translation (BCT), Active learning strategies (Engage community members in partnership to aid the translation of evidence-based medical guidelines by co-developing messages and materials about "what", "who" and "how".)	Expert presentations, small group discussions, teach-back strategies, conference calls and reflection sharing.

communication, eliciting perspectives, and making collaborative decisions over time.

3. Tools: Specific activities for gathering information, facilitating group discussions, brainstorming, etc., utilised by the research teams.

An extraction sample is shared in Table 2 for the study: Community-Engaged Research to Translate Developmental Screening and Referral Processes into Locally-Relevant, Family-Centered Language (Magnusson et al., 2020).

Additional methods and tools not included in the engagement navigator – such as workshops, interviews, consultations, and community health events – were also considered for a comprehensive understanding of engagement practices.

Role of Funding Source

The funding source had no role in the design, execution, analysis or interpretation of this research.

Results

The search yielded 23,961 references, of which 8286 were duplicates, leaving 15,673 abstracts (Figure 1). The study selection process was visualised using a PRISMA 2020 flow diagram created with an online tool (Haddaway et al., 2022). After screening, sixty-six abstracts underwent full-text review, of which 50 studies were excluded as they lacked an awareness strategy or focus on service promotion. Sixteen studies across design research, public health, community psychology, child development, anthropology, technology and disability health were included for final synthesis.

Population Characteristics

Stakeholder groups: All 16 studies included in this review reported engagement with multiple stakeholder groups.

(i) Including autistic individuals and caregivers, that is, Lived Experience Experts (LEE)

Five out of 16 studies involved LEEs in different capacities; as advisors ($n = 1$) (Magaña et al., 2021) as participants ($n = 1$) (Gilbert et al., 2023) as co-researchers only ($n = 1$) (Ha et al., 2022), one study involved them in both an advisory and participatory capacity (Singla et al., 2024), and one involved LEE both as advisors and partners (Rutherford et al., 2021)

(ii) Including caregivers

Fifteen out of 16 studies included caregivers in different capacities; in a participatory role only ($n = 5$), (Gilbert et al., 2023; Grinker et al., 2015; Islam et al., 2018; Magnusson et al., 2020; Milgramm et al., 2022), as disclosers of autobiographical lived experience narrative in the form of video or other media ($n = 2$) (Codd et al., 2018; Johnson & Van Hecke, 2015), in a partnership role only ($n = 2$) (Brookman-Frazee et al., 2012; Peacock & Lin, 2012). The remaining six studies engaged caregivers in more than one capacity; as participants and partners ($n = 2$) (Wagner et al., 2023; Aabe et al., 2019), as advisors and partners ($n = 2$) (Rabba et al., 2020; Rutherford et al., 2021) as participants and advisors ($n = 2$) (Magaña et al., 2021; Singla et al., 2024)

Caregiver characteristics: fifteen of the 16 studies engaged caregivers, such as mothers, fathers, grandparents or families of children with NDDs; five studies involved mothers only (Aabe et al., 2019; Codd et al., 2018; Gilbert et al., 2023; Grinker et al., 2015; Wagner et al., 2023), two involved both mothers and fathers (Rabba et al., 2020; Singla et al., 2024), and one involved mothers and grandmothers (Magnusson et al., 2020). One study consisting of four programmes included mothers, fathers and grandmothers (Magaña et al., 2021). The study by Gilbert and colleagues also included unspecified female caregivers (Gilbert et al., 2023). Six did not report on the sex of the caregivers (Brookman-Frazee et al., 2012; Islam et al., 2018; Johnson & Van Hecke, 2015; Milgramm et al., 2022; Peacock & Lin, 2012; Rutherford et al., 2021). Only three studies reported the ages of the caregivers (26.1–54 years) (Gilbert et al., 2023; Islam et al., 2018; Singla et al., 2024).

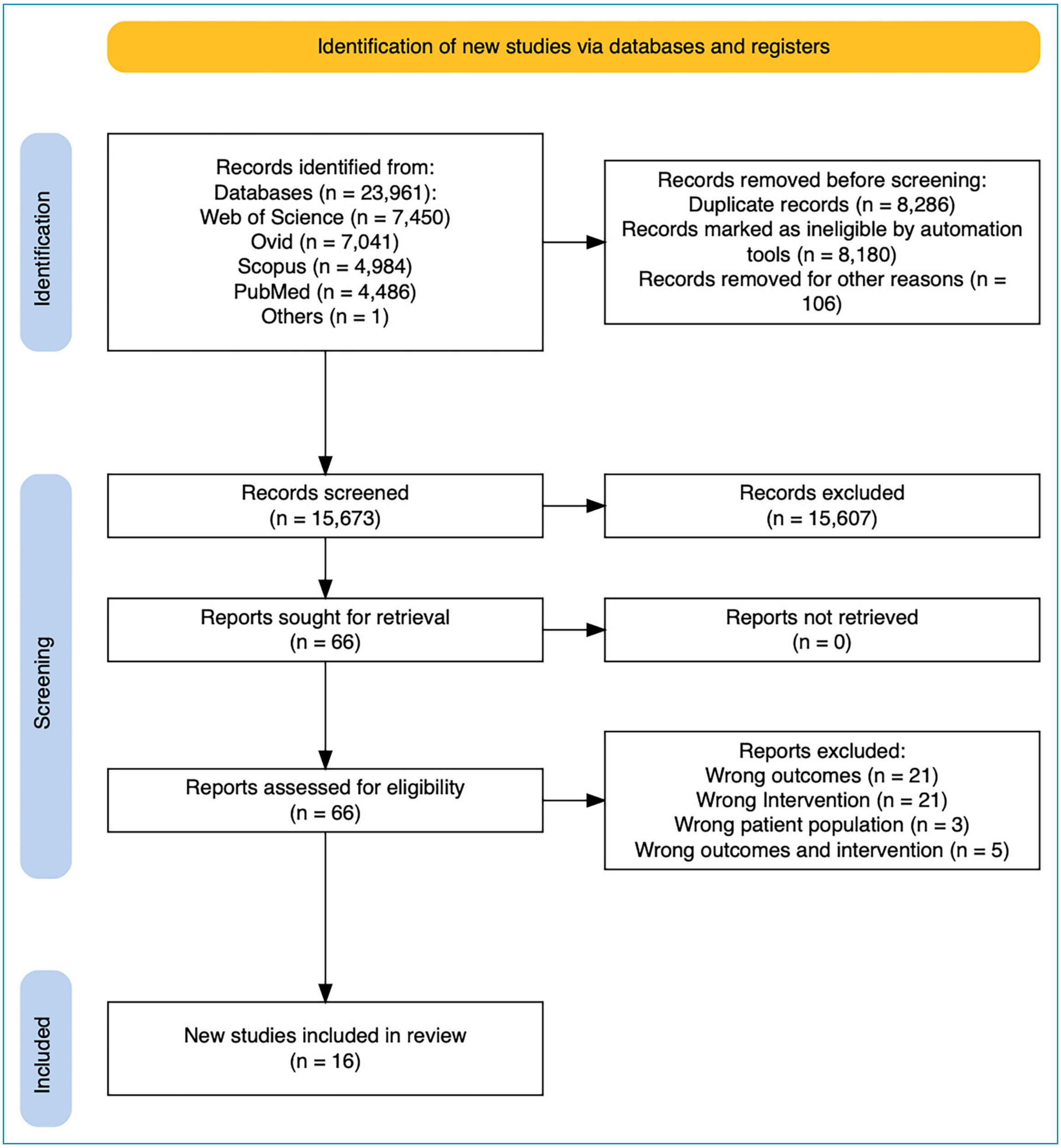

Figure 1. PRISMA Flow Chart for engaging individuals with lived experience of autism and intellectual disability towards developing community awareness to promote service utilisation for early identification and intervention.

Studies within HICs also focused on racial or ethnic minorities such as the Korean-American community in New York (Grinker et al., 2015), the local Somali community in Bristol, UK (Aabe et al., 2019), members from the black community in the USA (Johnson & Van Hecke, 2015) and caregivers from multiple communities were represented in one study.

Concept

All studies report on either approaches, methods, tools or all three, to engage relevant stakeholders. Based on these, they were also classified at the level of engagement they offer, as shown in Table 3.

Approaches. CBPR was the most frequently utilised approach, appearing in three studies (Aabe et al., 2019; Brookman-Frazee et al., 2012; Magnusson et al., 2020). One study used cultural adaptation in addition to CBPR and the Ecological Validity Framework across four programmes (Magaña et al., 2021). Out of 16 studies, two attempted to approach their objectives by keeping culture/cultural relevance at the fore, for example, by using cultural

Table 3. Levels of Engagement.

		Level of User Engagement		
S. No	Study Information	Involvement	Consultation	Partnership
1	Islam et al. (2018); Bangladesh	Conducted needs assessment with parents, teachers and community members to understand attitudes and opinions about autistic children and services for autism toward building a mobile application.		
2	Rutherford et al. (2021); Scotland		Convened multiple advisory boards to develop a multidisciplinary neurodevelopmental assessment and diagnosis pathway for children and young people.	Partnered with a group of lived experience experts to define study priorities and directions
3	Magnusson et al. (2020); USA		Consulted parents, grandparents, mental health specialists, home visitors, nurses, teachers, health care professionals using Boot Camp Translation method to identify, prioritise and disseminate recommendations for developmental screening and early intervention services.	
4	Codd et al. (2018); England	Created a digital story featuring a parent's lived experience as a patient education resource.		
5	Grinker et al. (2015); USA		Consulted study participants for cultural adaptation of outreach materials in the language and definition suitable to the demography.	
6	Brookman-Frazee et al. (2012); USA			Built a research-community partnership through joint leadership structures to improve early intervention for young children at-risk for autism. The research team convened an "Operations group" which included a researcher, the community provider that initiated the project and a parent to oversee research tasks, and these members served as co-investigators for the collaboration.

(continued)

Table 3. Continued.

		Level of User Engagement		
S. No	Study Information	Involvement	Consultation	Partnership
7	Rabba et al. (2020); Australia		Consulted parents provided input on what type of resource it should be, how it may be developed, used, disseminated as well as foreseeable barriers and recommendations in its development and use by intended recipients.	Collaborated with study participants and a professional advisory group to identify the most appropriate participatory design methodology for the development of a website for families of newly diagnosed children with ASD.
8	Milgramm et al. (2022); USA	Conducted needs assessment with families for developing a parent education program supports awareness for uptake of early intervention services.		
9	Gilbert et al. (2023); Australia	Conducted training needs analysis with caregivers, autistic adults and maternal and child health workforce to inform the design of a professional development programme.		
10	Ha et al. (2022); USA			Teamed-up with an autistic student researcher who contributed to the development of the autism knowledge video and the preparation of the manuscript.
11	Johnson and Hecke (2015); USA	Used a pre-existing video of an African-American autistic child for creating a training module to improve autism knowledge and attitude for an awareness session among inner-city churches health ambassadors.		
12	Magaña et al. (2021); USA & Canada			*PTA development and pilot study* Created a Community Advisory Committee to establish research priorities related to autism awareness and education.
		Parents Taking Action (PTA) for Black Parents Conducted needs assessment with black families and elicited advice on best practices to recruit and engage parents of Black autistic children for a parent education intervention for autism.	*PTA for Black Parents* Established and elicited input from the Community Advisory Board (CAB) to intervention design for the parent education intervention for autism.	

(continued)

Table 3. Continued.

S. No	Study Information	Level of User Engagement		
		Involvement	Consultation	Partnership
		PTA for Chinese Immigrant Parents Invited review and feedback from parents on the translated curriculum and support cultural adaptation of the parent education intervention for autism.		
		ASD Screening and Parent ENgagement (ASPEN) Intervention Program Tested and elicited feedback from parents on delivery of psychoeducation, training on the coaching strategies, and the sample materials of the psycho-educational tools developed.		
13	Peacock and Lin (2012); USA			Held regional summits with stakeholders including parent advocates for brainstorming toward building awareness for autism.
14	Singla et al. (2024); Canada	Conducted needs assessment with multiple stakeholders including individuals with lived experience for building Coaching Assistant for Medical/Health Information (CAMI) to provide information about trusted resources covering core knowledge and services for Neurodevelopmental delays and disabilities, including early intervention and detection.	Conducted a nationwide consultation with individuals with lived experience; Established an advisory group which provided direct feedback on the project and recruitment of participants for testing the ideas or chatbot prototype.	
15	Wagner et al. (2023); USA	Conducted focus group discussions and field testing with families and caregivers to identify barriers and facilitators to utilise early intervention (EI) services.		Established a partnership with a parent with extensive experience in navigating the EI system to provide guidance, assist with recruitment, provide suggestions related to a potential app, and reviewing the focus group interview guides.
16	Aabe et al. (2019); England	Conducted interviews with parents to explore the experiences of Somali families in the UK who have children with autism		Led by Nura Aabe, a parent and co-researcher who had decision-making roles in study conceptualisation, participant recruitment, data collection, analysis and dissemination.

consensus (Grinker et al., 2015; Johnson & Van Hecke, 2015). Eight out of 16 other approaches included participatory action research (PAR) (Brookman-Frazee et al., 2012), Medical Research Council Framework (Rutherford et al., 2021), "Consulting End Users About Their Needs to Target the Needs of Potential Users" (Singla et al., 2024) identifying participants' experiences (Gilbert et al., 2023) community involvement (Ha et al., 2022), patient-centredness (Codd et al., 2018) and Consolidated Framework for Implementation Research (CFIR) (Wagner et al., 2023). Three studies did not elucidate their approach to engage stakeholders (Islam et al., 2018; Milgramm et al., 2022; Peacock & Lin, 2012).

Methods. Half (8) of the studies used collaborative partnerships: including advisory boards (Rutherford et al., 2021), multistakeholder partnerships (Aabe et al., 2019; Rabba et al., 2020), community partnerships with campus researchers (Brookman-Frazee et al., 2012; Magnusson et al., 2020), advisory boards alongside multistakeholder partnerships including LEEs (Magaña et al., 2021), advisory boards and lived experience consultations (Singla et al., 2024), and lived experience consultations with community partnerships with campus researchers (Wagner et al., 2023).

Three studies utilised needs assessment/analysis (Gilbert et al., 2023; Grinker et al., 2015; Islam et al., 2018) and two sought feedback from stakeholders for strategy refinement (Grinker et al., 2015; Ha et al., 2022). Other methods included: Boot Camp Translation (BCT) in conjunction with active learning strategies (Magnusson et al., 2020), regional summits (Peacock & Lin, 2012), and ethnographic inquiries (Grinker et al., 2015). Two studies involved LEEs by using an autobiographical narrative (Codd et al., 2018; Johnson & Van Hecke, 2015).

Tools. Six studies used interviews: two mentioned interviews (Codd et al., 2018; Magaña et al., 2021), two mentioned in-depth interviews (Aabe et al., 2019; Grinker et al., 2015), one reported using individual or group, semi-structured interviews (Rutherford et al., 2021) and one reported cultural consensus modelling interviews alongside unstructured interviews (Grinker et al., 2015). Grinker et al. (2025) also used free-listing, ranking and piles-sorting.

Five out of 16 studies reported using group formats to facilitate engagement; two studies employed small group discussions (Magnusson et al., 2020; Rutherford et al., 2021) with Magnusson et al. (2020) additionally using problem-based learning and teach-back strategies, and conference calls, and three studies used focus group discussions (Gilbert et al., 2023; Magaña et al., 2021; Wagner et al., 2023). One study reported using iterative participatory design workshops through individual and/or group meetings, engaging in knowledge translation sessions through group and individual meetings, alongside feedback cycles on the output developed in the study (Rabba et al., 2020). Other tools reported in five out of 16 studies included documenting an autobiographical video (Johnson & Van Hecke, 2015), personal communication (Brookman-Frazee et al., 2012; Rutherford et al., 2021), expert presentations alongside interactive discussions and logic model development (Peacock & Lin, 2012) and peer review and participation (Ha et al., 2022). Brookman-Frazee et al. (2012) additionally utilised a collaborative process committee as a tool.

Context

Fifteen out of 16 studies were from high-income countries: ten were from North America (USA and Canada), three from Europe (UK), and two from Australia. Only one study was based in an LMIC, in South Asia (Bangladesh).

Discussion

Lived experience involvement is increasingly considered a good research practice, with the UK's National Health Service requiring research applications to explain this across methodologies and disciplines (Wright et al., 2010). While this is an important approach, it can also lead to a tokenistic representation of service users if they do not fit in with the needs of the research. To ensure relevant representation, the global health community focussed on neurodiversity needs to consider the following questions toward fair and equitable community-engaged research:

> Whose lived experience is involved in building community-engaged awareness materials towards service uptake?
>
> How are people with lived experience involved?
>
> When is lived experience included in the research cycle and whose interest is prioritised?

Whose lived experience is involved in building community-engaged awareness materials towards service uptake?

Currently, as parents/caregivers are the first point of advocacy in autism and neurodevelopmental disabilities, this population is widely approached and involved in designing awareness efforts towards improving uptake of detection and intervention services. Autistic adults and children are also involved in studies. During our search, we did not limit ourselves to the global north. However, as with most public health studies, the studies included in the current review focussed on White, Educated, Industrialised, Rich and Democratic populations, which represent only 12% of the global population (Henrich et al., 2010). All but one study came from an HIC, with only four out of the 15 studies (Aabe et al., 2019; Grinker et al., 2015; Johnson & Van Hecke, 2015; Magaña et al., 2021) focussing on disadvantaged racial and ethnic communities in the USA, Canada, and England. Greater investment is needed to support LMIC-based researchers in conducting research in their local context, which goes beyond "parachute research" that is, "drop into a country, make use of the local infrastructure, personnel, and patients, and then go home and writes an academic paper for a prestigious journal" (The Lancet Global Health, 2018). For health to be truly global, equitable and representative, researchers need to build partnerships with LEEs, LMICs and LEEs in LMICs to bridge knowledge gaps, address disparities in health service provision, and lack of infrastructure and resources.

How are People with Lived Experience Involved?

Researchers' have dominantly involved lived experiences to fit into their research question or programme requirements rather than as stakeholders who may drive research priorities. For example, Johnson and Van Hecke (2015) recorded an autistic child to improve content relevance for training inner-city church ambassadors on autism knowledge and attitude for an awareness session.

However, in the backdrop of the evolving neurodiversity movement, we see active involvement of LEEs in leading and partnering with academicians. LEE-led partnerships may be involved to serve as a bridge when cultural differences exist between researchers and the study population, as demonstrated by Magaña et al. (2021), Grinker et al. (2015) and Aabe et al. (2019). Advisement and feedback from LEEs with intersecting identities based in sex, culture, disability, immigration experiences may be involved to build relevant local adaptation of interventions and study materials to improve service utilisation, such as by Magnusson et al. (2020), and Singla et al. (2024), Rutherford et al. (2021), Rabba et al. (2020). LEEs may be involved as participants sharing their internal and subjective experiences shaping the resources that may be used by researchers to support community building, promoting services that lead to service uptake, as seen in the studies by Gilbert et al. (2023), Ha et al. (2022) and Johnson and Van Hecke (2015).

When is Lived Experience Included in the Research Cycle and Whose Interest is Prioritised?

In the current review, studies utilised lived experience at the **planning stage**, that is, the very start of the research cycle in the form of partnerships to help build relevant research questions, at the **conduct stage** through advisory boards that review recruitment and data collection strategies, and during the **dissemination stage,** that is, sharing outputs and findings with other community members. Very few studies also included lived experience during the **interpretation stage,** that is, meaning-making and understanding implications of the data collected for community members (Adams et al., 2024). To the authors, this seems like a lost opportunity to test and revise outputs before dissemination, and it can be a key factor in addressing gaps in service uptake. From the current review, we see that stakeholders such as academicians, government bodies, and clinical experts from the global north largely drive the research priorities even when involving lived experiences.

Co-production of global research with representation from the Global South and marginalised identities can help build relevant programmes and services which align with community priorities and lead to service uptake.

Partnerships of this kind offer deep and meaningful engagement with the community. Combining the researcher's expertise and lived experience enriches the process and outputs for all stakeholders. Considering the subjectivity of community-engaged research, researchers should reflect on the choices made in the research design, including which population was involved, how they were recruited, and how these choices impacted data collected and dissemination (Wright et al., 2010).

For example, Aabe's co-researcher reflects within the study reported:

> I felt reassured that her lived experience would be critical to bridge the gap between myself, an unknown researcher, and Somali parents affected by autism.

The review also brings forth questions on methodology toward building these partnerships and involving community members. Our findings corroborate with our introduction, that is, community-engaged methodologies are flexible in nature. However, studies with different nomenclature often report on the same process. For example, the process of Singla et al. (2024) consulting with end users, that is, final beneficiaries throughout the research is resonant of community-based participatory research (CBPR) as an approach (Collins et al., 2018). Building a taxonomy of approaches, methods and tools across fields such as design research, public health, community psychology, child development, anthropology, technology and disability health, can help researchers determine the level of engagement throughout the research cycle. An example of such a taxonomy based on this review is exemplified in Table S5 attached in the supplementary file.

Limitations

While the stakeholder navigator tool helped conceptualise current practices using approaches, methods and tools, these definitions are still susceptible to diverse interpretation based on one's lived experience or career exposure. The authors note that the current review does not consider grey literature or published reports about public and community engagement. Additionally, the current review is set within the context of Neurodevelopment and Autism in South Asia: Treatment and Evidence (NAMASTE) programme and is focused on service utilisation for early identification and intervention. Future research may benefit from identifying engagement practices to include lived experiences for community awareness for a variety of outcomes such as inclusion and intervention development as per community priorities.

Conclusions

In the current review, studies have reported on different strategies, which the current review has classified as approaches, methods and tools. Equitable decision-making is facilitated by using CBPR, involving lived experience advisors and experts, and the lived experiences of primary caregivers improve the design of research studies, enrich participant recruitment, research activities and dissemination activities. Researchers may benefit from building a taxonomy of community-engaged research strategies based on levels of engagement and corresponding methodologies (approaches, methods and tools) to answer critical questions underlying power sharing within community engagement.

Abbreviations

NDD	Neurodevelopmental delays and disabilities
ID	intellectual disability
LMIC	low- and middle-income country
HIC	high-income country
CBPR	Community-based Participatory Research
PAR	Participatory Action Research
BCT	Boot Camp Translation
MRC	Medical Research Council
CFIR	Consolidated Framework for Implementation Research
LEE	Lived Experience Experts.

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Ethical Approval and Informed Consent

No ethical approval was required, considering it was a scoping review and did not involve direct participation of human subjects.

Author Contributions

Bhavya Malhotra contributed to conceptualisation, data curation, investigation, methodology, visualisation, project administration, and writing–original draft preparation; Sweta Pal contributed to conceptualisation, investigation, methodology, and writing–review and editing; Manya Mishra contributed to data curation and investigation; Riya Mitra contributed to data curation and investigation; Sanjna Shukla contributed to data curation and investigation; Kathy Leadbitter contributed to supervision and writing–review and editing; Jonathan Green contributed to supervision, and writing–review and editing; Gauri Divan contributed to conceptualisation, supervision, and writing–review and editing; Reetabrata Roy contributed to supervision and review and editing.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability

All data are available in the manuscript and supplementary files.

Community Involvement

The first author (BM) identifies as a neurodivergent individual with lived experience of ADHD.

Supplemental Material

Supplemental material for this article is available online.

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