Project Title

Access to healthcare for disabled and neurodiverse children and young people from under-served and underrepresented communities

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Plain Language Summary

Neurodivergent and/or disabled children and their families from under-served communities have less access to healthcare services, and have poorer health and life expectancy. Many children and families facing discrimination are not involved in healthcare decision-making and are less-heard within research. We wanted to hear from these groups in North West England, to understand what they find difficult accessing and using healthcare services, what would make things easier, and how to reach out, work with, and learn from them. Children and parents made key decisions and co-produced the project's four stages.

Stage 1: Parent Carer Forums identified communities facing the greatest challenges in accessing healthcare. The communities were; neurodivergent and/or disabled young people, asylum seeker and refugee families, Gypsy, Roma or Irish Traveller heritage families, and parent carers who are themselves neurodivergent and/or disabled.

Stage 2: researchers found and worked with trusted 'community connectors' and families from the communities, to develop accessible and culturally acceptable ways to hear from them.

Stage 3: researchers used online surveys, face-to-face and online interviews, group discussions and activities to hear from 65 young people and 159 parent carers from the four communities.

We heard accessing healthcare was challenging, with difficulties; making and getting to appointments, navigating services, communicating with professionals, overwhelming environments, feeling judged, dismissed and discriminated against, due to a lack of understanding about disability, neurodivergence, culture and language. Services often caused more harm than good; this led to experiences of trauma, avoiding services, and accessing healthcare in alternative ways.

Stage 4: Researchers shared findings with communities in group discussions and 'agreed ways forward' including priorities for future work, and co-wrote summaries of the findings.

This project has discovered important priorities for neurodivergent and/or disabled children and young people and their parents from under-served communities, to drive further research and service change.

Summary of Research Findings

This project has been collaboratively developed and delivered between parent carer (PC) representatives from the National Network of Parent Carer forums (NNPCF), Contact (a national charity), Alder Hey Children's Hospital, and Edge Hill University.

The work focuses on access to health services for neurodiverse and disabled children and young people, who are particularly vulnerable to experiencing inequitable access to healthcare (Ofsted 2021, LeDeR 2022). This is exacerbated in communities who are currently under-served and under-represented in decision-making forums. This project aimed to address ongoing disappointment in influence and 'voice' held by neurodivergent and/or disabled children and young people and parent carers from under- served communities where strategic and operational decisions are being made about health service delivery and improvement.

We chose not to use terminology associated with medicalised/ deficit-based models of disability e.g. impairment, disorder, condition, instead choosing the terms neurodivergent, disabled and additional needs. Neurodivergence is part of a wide spectrum of hidden neurological conditions, including 'Autism, Dyslexia, Dyspraxia, Tourette's and social anxiety' (The Donaldson Trust 2022). The UN Convention on the Rights of Persons with Disabilities (UNCRPD, 2006 pg1) states 'persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.' Neurodivergent was not a term familiar to many of the CY&P and families, they asked us to use 'additional need'. We did not require children and young people or parent carers to have formal diagnoses of neurodivergence or disability.

The four phases of the project was underpinned by a commitment to the 'National Framework for Children and Young People's Participation in Decision making' (Department of Children, Equality, Disability, Integration and Youth 2018) based on the Lundy Model of Participation's (2007) four concepts of; space, voice, audience and influence.

Phase 1 'Scoping and Mapping'; involved hearing from PCF leads across the North West region (n=23 with a reach of over 30,000 families, who have a role to represent the views of parent carers in their areas working with local services), to map current known networks and gaps in access to health service linked to disabled and/or neurodivergent children and young people. NNPCF and Contact's work with PCFs suggested they were well placed to understand which groups experienced high levels of difficulty in accessing health services, but under-served in terms of strategic influence. PCF members with lived-experience were invited to consultation activities, to identify three under-served communities for the focus of the work; Gypsy, Roma or Traveller heritage (recommended by NIHR) , Asylum Seeker and Refugees, and Neurodivergent and/or disabled parent carers. This phase enabled the identification of individuals and organisations with established and trusted relationships within the communities.

Phase 2 - 'Reaching out'; involved the team carefully seeking out 'community connectors' working at grassroots level from within statutory, voluntary or charity based organisations. Previous work highlights that many communities have a lack of trust in health services and researchers and so we prioritised building trusted relationships with connectors to gain cultural competence in our approaches. Evidence shows the importance of working with 'community connectors' (Shommu et al 2016) to ensure greater cultural understanding, language skills, and contacts in the community (NIHR BAME Toolkit, Dunstan 2020). This phase involved working with community connectors to reach neurodivergent and/or disabled children and young people and neurodivergent and/or disabled parent carers to co-produce bespoke methods to support recruitment and gather data. We were invited 'in' to existing meetings and events as opposed to the research team arranging meetings. The team met with experts working with unaccompanied child refugees, who highlighted their extreme vulnerability and the ethical tensions associated with safeguarding neurodivergent and

unaccompanied refugee minors.

Phase 3 -'Listening and learning'; involved working with connectors to directly hear from neurodivergent and/or disabled children and young people and their parent carers. Data collection focussed on identifying barriers and facilitators to accessing healthcare for the children and young people and their parent carers, whilst exploring what could improve access and identifying research priorities. It became apparent that neurodivergent and/or disabled children and young people and their families had many intersecting identities and 'pigeonholing' people according to one identity was problematic. Whilst this work discusses 'communities', we recognise that people within a community are not homogenous and experience layered inequalities.

Methods and findings

Recruitment and data collection methods were bespoke for each community which led to four mini-projects which gained ethical approval individually from the Health Research Ethics Committee at Edge Hill University. Specific issues relating to access to healthcare were reported for each community including challenges and enablers which spanned across all the community members we heard from.

Neurodivergent and/or disabled YP aged 16-25 years. We worked with YP from Greater Manchester Youth Network (GMYN) to design recruitment information and short anonymous online surveys, online interviews and walk-through group activities. 42 YP with a range of additional needs and intersecting identities described encountering many difficulties in accessing healthcare, including making and travelling to appointments, understanding which services to access and when, communicating their needs to professionals and struggling to feel heard and respected. They also discussed where they had been made to feel 'less than human', disregarded and judged. They disliked having to re- tell 'their story' every time they saw a professional and struggled with overwhelming healthcare environments which were not sensory friendly. Some YP had developed trusted relationships with professionals and identified longer appointments and flexible communication improved accessibility.

Neurodivergent and/or disabled parent carers whose child was neurodivergent and/or disabled. We worked with a panel of four neurodivergent and/or disabled parent carers to design recruitment information and anonymous online surveys, online interviews, online group discussions and walk-through activities. We heard from 138 neurodivergent and/or disabled parent carers (113 mothers, 18 fathers, 7 did not include their gender); 96 completed surveys, 14 took part in an interview, 28 joined group discussions (17 online, 11 in person). The parent carers who took part lived with physical disabilities, learning disabilities, neurodivergence and/or long-term conditions. Interview and group discussion questions were forwarded, conversations were paced to support processing and online sessions were supported through the chat text function. parent carers shared the multiple challenges they faced in accessing health services for their child. Their neurodivergence and/or disability increased the difficulty they experienced trying to access and use health services for their neurodivergent and/or disabled child. This could cause them and their child trauma and more harm than good. parent carers encountered difficulty in making and getting to their child's appointments, many neurodivergent parents struggling to make telephone calls. parent carers found sensory environments within services extremely difficult for them and their child, faced challenges in communicating with professionals, and often felt judged, dismissed and treated disrespectfully. parent carers were distressed at re-telling their child's history at appointments with their child and reported that reasonable adjustments were often not made for them or their child. Difficult experiences led parent carers to avoid accessing healthcare services for their child and/or struggling to fund access to independent/private services.

parent carers reported access to healthcare services could be improved by the provision of sensory friendly environments, flexibility and choice of online or remote appointments (or at home), a known contact and number to text or call services, professionals reading their child's notes before appointments and for flags to identify their and their child's needs. Professionals required greater

patience, humanity and compassion towards parent carers and their children, paying attention to parent carers' expertise of their child and not labelling, judging or dismissing their concerns or accounts. Specifically, parent carers noted professionals needed more knowledge and skills relating to neurodivergence, disability, and reasonable adjustments.

Asylum seeker or refugee parent carers and neurodivergent and/or disabled YP. We interviewed 10 parent carers (9 mothers and 1 father) who have disabled and/or neurodivergent children. 4 children and young people took part in a 'walk-through' activity at a GMYN meeting for young asylum seekers or refugees. Parents and the YP had experienced many different journeys before arriving in the UK, some involving trauma and loss.YP told us they struggled with healthcare appointments, waiting for appointments and language barriers with healthcare staff. The phone and navigating hospital environments was problematic, an extra person helped them at appointments, but were not always available. YP told us staff were often rushed which prevented them asking questions and made them feel staff did not care or were angry with them. parent carers also struggled with healthcare environments, navigating different health services, barriers and long delays in accessing diagnostic pathways for their child and registering for physical healthcare services e.g. dentists or GPs due to their refugee status. Families struggled to navigate services, access equipment e.g. wheelchairs, get financial support and schooling for their disabled children. They described feeling rushed and not heard, experiencing issues with language barriers due to poor access to interpreters, lack of translated leaflets, and accessible legal information. Local NHS appointments were easier to travel to. Parent/carers and children and young people suggest their access and confidence is often impacted by their language skills, needing an individual they can rely on to help navigate information and services.

parent carers and neurodivergent and/or disabled CY&P from Roma, Gypsy or Irish Traveller heritage. A community connector, parent and two children and young people helped design culturally sensitive methods to hear from children and young people and parents. The project team underwent Roma Gypsy heritage, culture and language training prior to contact with families, enabling insight into historical prejudice and misunderstanding associated with Roma, Gypsy and Traveller communities. Data collection sessions in a primary school and secondary school used music and storytelling. children and young people were initially reticent to share their views, particularly with the researcher who was an 'outsider' and the presence of the community connector and school staff being asked to leave the room were fundamental in developing trust and engaging with the children and young people. One session in a community centre engaged with children and young people who were educated outside of the school setting. Nineteen children and young people aged 7-16 years with a range of additional needs participated; 15 from Roma or Gypsy heritage and 4 of Irish traveller heritage. We conducted interviews with 11 parents and 2 caregivers from 7 families (4 fathers, 7 mothers and 2 extended family members), 3 from Irish Traveller heritage and 8 from Gypsy Roma heritage. Interviews were conducted in family homes with Roma Gypsy parent carers facilitated by the community connector translating into Romanes.

The children and young people and parent carers told us that many professionals they had interacted with did not understand their culture and heritage and they had experienced discrimination. Poor experiences and lack of trust caused them not to go back to specific professionals and services or avoid using health services, even when they needed to. They were scared that professionals would contact social services over minor injuries and concerns.

children and young people often had to translate letters or interpret for their parents and family members at appointments and parent carers described how interpreters often did not speak Romanes which excluded them from conversations about their child. parent carers described if they needed prescribed medicines for their sick child, they may buy these 'under the counter' rather than going to the GP and many would travel to their 'home country' to access healthcare. The parent carers also described how they often felt isolated within their communities and this impacted on their mental health.

Access to healthcare was identified as being helped by; information and letters offered in audio form, Romanes interpreters being available, professionals having greater understanding of Gypsy, Roma or Irish Traveller culture and people from these communities being involved in decision-making forums relating to healthcare.

Core themes across the communities highlighted a lack of understanding of neurodiversity, disability, reasonable adjustments and cultural needs, leading to services being inaccessible Several of the communities had more than one 'protected characteristic' as highlighted in the Equality Act (2010) and these intersecting identities corresponded to the layering of negative experiences and marginalisation.

Phase 4 - 'Agreeing a way forward'; Grounded in the Lundy model, we were committed to developing culturally sensitive ways, supported by the community connectors, to feedback the findings to community members to co- produce research priorities. This phase acknowledged the importance of not 'leaving the field' without providing parent/carers and children and young people with the opportunity to share their views and further develop trusted relationships. The priorities identified differed for each community, but as above there were also commonalities spanning all the communities.

Neurodivergent and/or disabled parent carers. Researchers and parent advisors presented the project findings to a NW event of PCF representatives and NHS commissioners. 31 parent carers identified five priorities, for professionals to;

- have greater understanding, patience, humanity and compassion towards parent carers and children.
- read a child's notes before an appointment.
- have training in neurodivergence, disability, and reasonable adjustments.
- listen and pay attention to parent carers' expertise of their child and for parent carers not to be labelled, judged or dismissed.
- place flags on health notes to show what support is needed.

Neurodivergent and/or disabled children and young people. 4 children and young people helped identify priorities, highlighting the most important things as:

- For professionals to gain skills in how to care for and communicate with children and young people with additional needs (neurodivergent and/or with disabilities).
- For healthcare services to be disability and sensory friendly.
- For health systems and records to flag the support needs of children and young people.
- For there to be more flexible ways to book appointments with health services e.g. text/online chat. Asylum Seeker and Refugee parent carers. 2 parents helped identify priorities, highlighting a need for improved;
- access to entitlements and funding for children with a disability to attend appointments
- communication with children and young people and families through access to interpreters and accessible information eg leaflets
- support to navigate healthcare systems, understand what was available, where and who to go to Roma, Gypsy or Traveller Heritage parent carers and children and young people. A parent and community connector identified the following priorities;
- Information and letters from health services to be offered in audio form and be easier to understand.
- Romanes interpreters need to be available.
- Professionals need greater understanding of Gypsy, Roma or Irish Traveller culture and heritage.

- parent carers and children and young people from Gypsy, Roma or Irish Traveller heritage should be supported by charity workers to join decision-making forums relating to healthcare.

Discussion

This will be structured according to the two main aims.

What facilitates equitable access to healthcare for disabled and neurodiverse children and young people from under-served communities?

The United Convention on the Rights of the Child (United Nations 1989) is clear that every child as per Article 24 has the right to access 'health' and 'healthcare'). Findings above show children from the communities involved experience unequal access to healthcare, experiencing difficulties with appointments, navigating services, communicating with professionals, overwhelming environments, and feeling judged and discriminated against due to professionals and services lacking understanding about neurodiversity, disability, culture and language. Services often caused more harm than good; this led to experiences of trauma, avoiding services, and accessing healthcare in alternative ways. Proposed solutions from the communities included offering a variety of communication formats, making reasonable adjustments, ensuring staff have a greater understanding of disabled and/or neurodivergent children and young people needs, and working with communities to ensure their voices are heard in service design.

How can meaningful partnerships and working practices be developed to gain insight into the views, perceptions and needs of diverse communities?

This programme development grant has enabled an important co-produced piece of work to be delivered to hear from families within four under-served communities. Early in the project, our parent carer lead KB noted: 'Co- production looks 'messy' because it is. If it's messy we are doing it right.' (Bromfield, K. 2023). On occasions throughout the project, we adapted our approaches to ensure we gave ample weight to the voice of lived-experience, allowing more time or opportunities to consult with and hear from parent carers and children and young people. We have been supported and challenged throughout by the parent carer co-apps and our steering group to go further than developing relationships with under-served communities, but to gather tangible evidence to inform future work.

Trusted relationships took time to establish with community connectors, parent/carers and children and young people. Once connections had been made, it became difficult to 'not complete' as promised, leading the team to apply for additional time and funding. We faced challenges as some data collection was planned for Summer 2024, when there were public riots and certain communities including asylum seekers and refugees experienced attacks. This meant some parent/carers and community connectors did not feel safe to engage and we respected this and worked sensitively during this time.

The team carefully considered the recruitment, consent and data gathering methods, avoiding collecting unnecessary personal data from some communities who view authorities with scepticism due to past trauma. This led to closer working with councils and organisations than researchers had anticipated, due to their important role in recruitment and safeguarding arrangements. The flexibility to work with and recompense key partners not named on the grant application was key to the research success.

In co-designing and consulting children and young people and parent/carers across the communities we asked open questions; 'how could we design this in the right way?', 'how could we hear from people in a group discussion or interview?'. This approach encouraged thoughtful, open responses and challenged the team to design the bespoke methods and mini-projects for each community.

Recognising the emotional toll of the work, we took steps to support individuals in the team, by ensuring check-ins to keep researchers psychologically safe and documenting lessons learnt along the way.

Patient and Public Involvement:

PPI has been at the core of the research. All phases of the study have been co-produced and developed as below. Overall the co-production and engagement work was more resource intensive and took longer than originally anticipated, in part due to the four mini-projects and also because of external factors such as the Summer 2024 riots, and factors relating to communities requiring greater planning, extensive preparation for recruitment and trust building work with communities.

Phase 1 'Scoping and Mapping'; involved Parent Carer Forum (PCF) leads across the North West region (n=23) mapping existing networks and organisations linked to disabled and neurodiverse children and young people. Current known networks and gaps in engagement were identified. The project was presented at a PCF regional network meeting to enable forum members to be involved and have the opportunity for forum leads to share services and known engagement activities. A regional meeting with the project team and parent carer forum members willing to share their knowledge was arranged. This phase drew heavily on the lead roles of Kath and Carolyn (co-apps) who lead within the Forum network and facilitated this work within existing meetings and events. The scoping and mapping exercise identified communities that experience high levels of challenge in accessing health and social care services and are under represented in strategic decision making. The first phase identified current networks, individuals and organisations already working within communities associated with lack of voice and rights to participate. This included Parent Carer Forum members recognising and acknowledging gaps and challenges in representative engagement of diverse communities within existing disabled and neurodiverse networks. This phase identified three under-served communities.

Phase 2- 'Reaching out'; making connections, trusted partnerships and identifying 'community navigators'. This phase identified and invited 'community connectors' within each community to work alongside the team. The connectors were already trusted community members or employed within services who had established meaningful relationships in supporting disabled and neurodiverse children and young people. This phase took significant time and involved building trusted and respectful relationships with connectors to avoid the risk of the study acting as a barrier for families engaging with services. This work helped the team to identify potential barriers and specifics around developing culturally sensitive communication at an individual, family and community level. Community connectors worked with the core team and members of each community (public advisors) to develop methods and approaches to hear the views, experiences and opinions from disabled and neurodiverse children, children and young people and their families. We worked with:

- 4 neurodivergent and/or disabled parent carers advisors who advised on recruitment, methods, questions asked, analysis of the findings, writing of the lay summary, presentations and workshops linked to the study

- 2 children and young people from Gypsy, Roma heritage and one parent who advised on the school workshops, methods and questions to ask. One parent from Roma heritage who helped interpret the findings and agree on priorities going forward.

- 4 children and young people from GMYN helped advise us on recruitment, data collection methods, interpretation of findings and crafting of the lay summary.

- 5 children and young people and 3 parents from Asylum Seeker and Refugee communities who advised on recruitment, data collection methods and 2 parents who helped to prioritise the findings.

Phase 3 -'Listening and learning'; involved hearing from disabled and neurodiverse children and young people and their families within the communities. This phase built on the consultation information gained during Phase 2 from community connectors, children and young people and families. A range of methods and approaches were designed and received ethical approval. This involved submission of approvals for each community based on the bespoke requirements identified.

Phase 4 - 'Agreeing a way forward'; The final phase of the study co-produced key research priorities and outcomes from each of the communities. This phase focused on drawing together the information collected and the development of culturally sensitive ways to 'share back' with community members the key findings and the identification of their priorities and 'ways forward'. This phase involved the use of methods developed in phase 3. Accessible methods of communication were used to share and gain consensus on key concerns and the co development of priorities moving forward.

This phase aimed to acknowledge the important contribution of community connectors, and enabled the team to develop lessons learned, agree dissemination plans with community members. It ensured the team fed back results from families sharing their views, consolidating the trusted relationships already formed. The participation framework (Lundy, 2007), includes materials to facilitate critical evaluation from people involved (project team, connectors, steering group, children and young people and families) of the work and outcomes of the project.

Data sharing statement - See link [https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253] for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

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