





# **Text version of 'Access to healthcare for disabled and/or neurodivergent children and young people' poster**

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## **The Project:**

- North West Parent/Carer Forum networks and Core project team.
- Community connectors Gypsy, Roma and Traveller families: Neurodiverse and/or disabled children, young people and their families in a currently underserved community.
- Community connectors refugee and asylum seeking families: Neurodiverse and/or disabled children, young people and their families in a currently underserved community.
- Community connectors parents/carers with disability and neurodivergence: Neurodiverse and/or disabled children, young people and their families in a currently underserved community.

## **Background:**

This review of the literature is linked to a National Institute of Health Research funded project focussed on access to health care for disabled and/or neurodivergent children from under-served communities.

The project has been co-produced from the outset. The three communities focussed on were selected through ongoing consultation with the North West Parent/Carer Forums and National Institute of Health Research.

This review aimed to identify the existing evidence linked to access to health care for families within these communities.

## **Review of the literature:**

A search of health related databases e.g. PubMed, Discover More was conducted. The search located literature both within the UK and internationally. The reporting of evidence within some papers was sub-optimal, with a lack of clarity around the age of participants.

## **Gypsy, Roma or Traveller families with disabled and/or neurodivergent children:**

5 papers identified

Barriers faced within the community:

- bureaucratic processes,
- attitudes of health staff
- lack of cultural sensitivity and acceptance
- lack of consistency in research with the use of terms 'Gypsy, Roma and Travellers'
- Experiences of discrimination across the lifespan.

Solutions:

Suggested increased engagement in health services if they were run by members from their own communities.

## **Refugee and asylum seeking families with disabled and/or neurodivergent children**

6 papers identified

Barriers faced within the community:

- Confidentiality and trust issues
- Availability of interpreters

- Lack of knowledge of available services
- Worry surrounding being able to place a complaint
- Fear of being denied care
- Disbelief by staff that disabled asylum seekers could exist!

Solutions:

Health care services to be inclusive of disabled asylum seekers, to bridge the gap they experience.

### **Parent/carers with disability and Neurodivergence with disabled and/or neurodivergent children:**

17 papers identified

Barriers faced within the community:

- Feeling repeatedly deprioritised
- Feeling isolated and abandoned in managing a child's health during COVID-19.
- Child health information is typically catered to neurotypical parents - leaving parents feeling unsupported and unheard
- Misrepresentation of disabled parents due to misinformation and lack of understanding from services

Solutions:

Staff to be trained to be aware of sensory difficulties and be able to make environmental and communication adjustments to cater for them.

### **Key points:**

The review has highlighted a lack of evidence from children, young people and parents from within these communities, particularly from children and young people with additional support needs. The review has identified some common themes which make accessing health care difficult for children and young people who are disabled and/or neurodivergent from under-served communities, including;

- A lack of cultural competency within health care professionals and services.
- A lack of accessibility and reasonable adjustments within health services.
- A layered discrimination - underpinned by intersectionality.

### **The wider project:**

The project linked to this review is using multiple methods to hear from young people and their parents, including online surveys, online and in person focus groups, interviews and walk-through activities.

I attended a session at a charity advocating for young people and heard first hand how health care can be difficult to access and navigate for neurodivergent young people from under-served communities. My key learning points were:-

- How carefully the team managed the consent process and data collection to make sure that young people felt comfortable to join in or not.
- Flexible data collection methods helped the young people join in and check what they were sharing by it being written down on the large sheets of paper.
- Being a part of this project has encouraged my research development and understanding of how research projects work, and how healthcare encompasses both medical and sociocultural dimensions, which shape patients' experiences of care.
- I have been privileged to work within an amazing team that have been supportive of my goals and taken my ideas within their stride.

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