



Research Report:

Understanding the rise of Autism in the Somali Community of Sheffield

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Introduction

This report explores the prevalence and perception of autism within the Somali community in Sheffield, United Kingdom (UK). Autism, referred to as 'Maan Qaar' in Somali—meaning “Mind of its Own”—has become an increasingly prominent concern for Somali families, particularly those living in Western countries.

Autism, or autism spectrum disorder (ASD), is a developmental condition that influences how individuals communicate and engage with the world around them. It is not a disease or illness, but simply a different way the brain functions. As a spectrum disorder, autism affects each person differently and to varying extents. Figure 1 below shows; Autism Spectrum Disorder in a chart.

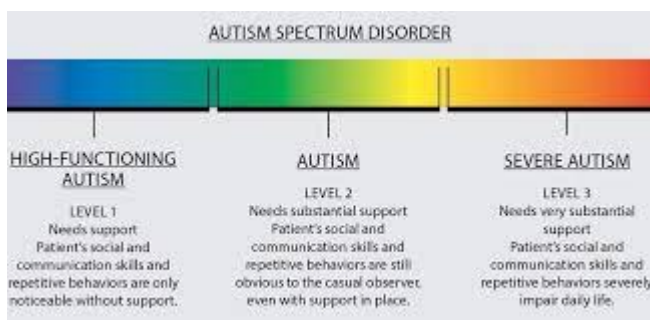


Figure 1. The three-level framework for Autism Spectrum Disorder (ASD)

The research aimed to engage the Somali community in discussions about autism, raise awareness of the challenges faced by families, and foster a collaborative approach to developing solutions.

Purpose of the Study

There has been a noticeable rise in autism diagnoses among children in the Somali community, particularly those in Western nations (Bashir, 2025). It has been echoed within the Somali community that in Sheffield, nearly every Somali family is to have at least one child with autism, with some families having two or more children affected.

A definitive statement supported by data is lacking, as no research has been conducted on the number of Somali families affected in Sheffield. However, the participants in the group expressed agreement with this observation.

Often, these children develop typically until around age two, after which they begin to lose speech, make less eye contact, and display other signs of autism, often becoming non-verbal. The sudden regression is alarming and remains largely unexplained. Nevertheless, the Somali community is predominantly devoted to the Islamic faith and holds the belief that all events occur in accordance with the will of Allah (God).

However, many Somali families feel overlooked and misunderstood by healthcare and educational institutions. Due to limited resources, schools, special needs services, and speech and language therapists are struggling to support the growing number of autistic children in this community. Additionally, there is a prevailing belief among some Somali families that autism is a “Western disorder,” as it is rarely observed in Somalia itself.

This study aimed to:

- Understand community experiences and perceptions of autism.
- Share expert insights with the Somali community.
- Empower families to participate in the design of community-based research.
- Identify gaps in services and areas for improvement.
- Engage with different professional who share their expertise and knowledge on aspects related to ASD.

Project Timeline

The initiative consisted of weekly support group meetings with Somali mothers of children with special needs. These meetings took place every Thursday from January 9 to February 27, 2025. During these sessions, a range of professionals—including researchers, doctors, psychologists, pharmacists, well-being coaches, and special needs transport staff—were invited to contribute. Their role was to share expertise, listen to parental concerns, and collaborate on potential research directions.

These sessions were facilitated by a bilingual coordinator (FI), who provided translation to ensure accessibility and engagement in both English and Somali.

Funding and Support

This community-focused research project was supported and funded by multiple partners:

Funding: Provided by the Working South Yorkshire Community Fund and Working Together in Research.

- Key Supporters:

- Deep End Research Alliance (DERA)
- NHS
- University of Sheffield
- Sheffield Hallam University
- Reach Up Youth (a charity organisation actively engaged in research and social support projects, including collaboration with Prince William's Homeward Project to tackle homelessness)

Reach Up Youth played a pivotal role in facilitating and hosting the project and is recognised by Sheffield University as a trusted research partner.

In this research, the author translated Somali language content, including cultural expressions and sayings, into English. As Somali is a highly poetic language, direct translations are not always possible. However, the closest equivalent meanings in English have been used to ensure accuracy and preserve the intended context.

Consent and ethical permission:

All ten participants provided their consent to take part in this research at the beginning of our first session. They also agreed to have their pictures taken and to be recorded if necessary.

Ethical, cultural, and religious values were fully respected throughout the research process.

Research Methodology

Study objectives

- To investigate the increasing prevalence of Autism Spectrum Disorder (ASD) within the Somali community.
- To facilitate public engagement with healthcare professionals and members of the Somali community, in Sheffield in relation to autism.

Methodology

The methodology incorporated primary and secondary research, thematic analysis, and public engagement with a focus group of Somali mothers raising children diagnosed

with autism. This study utilised a mixed-methods approach combining both qualitative and quantitative research.

Qualitative and quantitative research methods

Qualitative data provided a nuanced understanding of the lived experiences of Somali mothers, aligning with Denscombe (2012, pp. 231–276), who emphasises the strength of qualitative methods in exploring personal experiences. Quantitative data included structured questionnaires and measurable statistics to ensure reliability and scientific depth, as highlighted by Luck (2017, pp. 63–64).

Primary and secondary research

Primary data were collected from a focus group of ten Somali mothers through interviews, focus group discussions, and questionnaires. Secondary research involved the analysis of existing academic literature, including peer-reviewed journal articles, books, and reliable online sources. As Bell and Waters (2018, p. 129) describe, secondary research reanalyses existing knowledge to support new investigations.

Thematic Analysis

Thematic analysis was employed to interpret qualitative data gathered through sessions and interviews. This allowed for the identification of recurring themes related to autism perceptions and causes within the Somali community. Thematic analysis is a useful approach in community health research because it helps researchers find and interpret patterns (or themes) in qualitative data. This method offers a deeper understanding of people's experiences, views, and the different factors that affect health in a community. It is especially helpful for exploring complex health issues and can guide the development of focused interventions and practical policies (Saunders et al., 2023).

Public engagement activities

Public engagement involves activities that link the public with research, innovation, and higher education. It is a two-way process that not only shares research findings but also actively involves the public in the research journey, promoting mutual learning and benefit. Rather than simply distributing information, it focuses on meaningful participation and open dialogue (University of Oxford, 2024).

The public engagement component began on 9 January 2025 and ran for seven weekly sessions (excluding a half-term break). Each two-hour session included:

- Hour 1: a professional guest speaker presented information relevant to autism and public health.
- Hour 2: the researcher facilitated discussions with mothers, exploring causes of autism and related themes.

Topics for each session were co-developed through prior consultations (via phone or in-

person) with participants in December 2024 to ensure cultural relevance and community alignment.

Session environment

To ensure inclusivity and cultural sensitivity, the following considerations were made:

- Location: the Verdon Centre in Sheffield (which services people from the Pitsmoor/Burngreave area) was chosen for its accessibility and significance within the community. This location was selected due to its proximity to Pye Bank Primary School, where eight out of the ten participating mothers regularly brought their children. The Verdon Centre was therefore a convenient and accessible venue for the focus group discussions. Location plays a critical role in community health research, as it substantially influences health outcomes. The physical and social environments in which individuals reside affect access to essential resources, exposure to environmental risks, and the nature of social interactions—all of which contribute to overall health and well-being. A thorough understanding of these place-based determinants is essential for developing effective public health interventions and addressing health inequalities (Buck, Wenzel & Beech, 2021).

- Time: sessions were scheduled on Thursdays from 9:30–11:30 a.m. to accommodate mothers' childcare responsibilities. This time was selected to accommodate the needs of the mothers participating in the focus group. As previously mentioned, the majority of these mothers dropped their children off at Pye Bank Primary School, located adjacent to the Verdon Centre. Scheduling the session shortly after drop-off allowed them to attend conveniently. Additionally, four mothers were able to participate before collecting their children from nursery at 11:30 a.m.

- Cultural Appropriateness: Somali tea and coffee, pastries, and fruits were offered to reflect hospitality norms of the Somali culture.

Figure 2 below shows: Refreshment.



Figure 2: The images display the refreshments that was provided for the participants during the sessions.

- Safe space: efforts were made to create a non-judgmental, supportive environment to encourage open discussions. This was particularly important, as participants were reassured that there were no right or wrong answers. Equally significant was the provision of a women-only space, which fostered a sense of comfort and encouraged mutual understanding among participants. Lastly, an essential principle of the session was the respectful consideration of differing viewpoints.

Session summaries

Session 1

Dr. Kate Fryer from the University of Sheffield introduced public health and community-based research. Dr Fryer provided an overview of the history of community health research and highlighted the importance of community involvement in the research process. The session also covered the researcher's motivations and the epidemic-like rise of autism within the Somali community.

Session 2

Cynthia Brooks a professional nutritionist and well-being coach discussed the relationship between diet and energy levels. The discussion then shifted to possible causes of autism, including genetics, vitamin and mineral deficiencies, immunisations,

and diet. Participants compared development patterns in Somalia and Western environments.

During the second hour, we began by exploring how this research could benefit the mothers. At the end of the session, we identified four main topics to focus on in the upcoming sessions: genetics, vitamins, vaccination, and stress/trauma. We also discussed the desired outcomes of the research. Participants shared a range of ideas, including the need for a larger-scale study to explore and explain the apparent rise in autism within the Somali community.

Session 3

Somali psychotherapist Salma Mohamed explored autism's psychological and familial impacts. Mothers elaborated on previous topics and shared deeply personal experiences. Discussion also covered responses from educational and therapeutic professionals. Salma was able to share her experiences and knowledge as a psychotherapist with the mothers while drawing on her own cultural background and understanding as a member of the Somali community. The mothers' enjoyed this session.

In the second session, we explored the topic genetics.

Session 4

Pharmacist Stephen Morris from Leeds Deep End Research Alliance discussed medication and its effects. He was able to respond to the mothers' questions regarding the pharmaceutical industry, and the participants expressed their appreciation for his session.

In the second hour, a questionnaire on vitamin deficiencies revealed high prevalence of deficiencies in Vitamin D (100%) and iron (100%) among participants' children, indicating a potential area for further research.

Figure 3: below shows the fourth session.



Figure 4 shows the fourth sessions that was accompanied by Mr Stephen Morris a pharmacist from Leeds.

Session 5

Special needs transport escort Hinda Euge discussed support systems and logistics for children with ASD. Hinda shared information about holiday activities available for children with ASD, centres that promote independence and social inclusion and guidance on accessing transport services for children with special needs.

In the second hour the mothers expressed their concerns regarding vaccines and immunisations, openly sharing their thoughts and worries—a sentiment that is widely echoed within the Somali community. Participants completed a questionnaire in which they were asked to indicate, by ticking a box, any childhood immunisations they believed might be associated with autism. The results of this activity are presented in the findings section of this research.

Session 6

Dr. Anna Calvert, a paediatrician from Sheffield Children's Hospital (NHS), addressed autism diagnosis, medication, and immunisation. The session also facilitated information sharing from the mothers, contributing valuable community insight to academic researchers. A significant portion of this two-hour session was dedicated to discussing stress and trauma. The mothers found the session both enjoyable and beneficial.

Session 7

Figure 5 below shows the final session.



Figure 5 displays an image of our final session which was a celebratory of this research project.

The project concluded with a community celebration featuring Somali food, research presentations by the lead researcher (Fardusa Isse) and Dr. Rebecca Mawson (on female hormones), and distribution of certificates to participants and community organisations. The event marked a successful engagement with the Somali community in the Burngreave/Pitsmoor area of Sheffield.

Research findings

Figure 6 below display a scribe.

The occurrence of autism in Somali communities



Figure 6 show a scribe summarising all the topics and some quotes of the sessions.

A study conducted in the United States of America (USA) has shown that autism amongst four-year-olds is 1 in 53. However, in the Somali community it is 1 in 16, indicating that autism in the Somali community is significantly higher than in other communities. In particular, the Somali community experienced autism with intellectual disabilities - 40 percent had autism with intellectual disabilities, requiring basic life skills and lifelong care (PBS News, 2024).

This was reiterated by research that was done in Sweden where the findings suggested that autism is 4 or 5 times higher in Somali children than non-Somali (Duale and Gele, 2024). In the Somali community, autism is understood as a western disease because it is something that occurs more in Somali people in western countries than in Somalia (PBS News, 2014).

Indeed, this research revealed that autism in the United Kingdom and other western countries was perceived to be high – much higher than in Somalia. All the Somali mothers participating in this research were born in Africa but migrated to the UK, and so, were able to compare experiences and observations of life in Somalia with those in the UK. These comparisons are interwoven in this research. One mother, Fatima said; *“autism is rare back home (Somalia) and here almost every family has one or more child with autism”*. Another mother Rahma commented; *“autism in Sheffield was very rare 15/20 years ago, now there is an autistic child in almost every Somali family”*. All ten mothers who participated in the seven focus groups (in total) had at least one child with autism spectrum disorder and three of them had two children who had the complex neurological condition.

The severity of autism experienced in the Somali community was stressed by another mother, Fatima explained, *“I think in our Somali community autism is severe.”* The symptoms of severe autism include: considerable challenges communicating; significant difficulty interacting with others; and severe behavioural problems.

In this study, four significant factors emerged during the focus group discussions and interviews with Somali mothers that could be related to the high occurrence of autism in the Somali community. Those four factors are: vitamin deficiency, genetics, vaccination, stress/ trauma. Whilst there is a lack of evidence on the exact cause(s) of the high rates of autism in this specific community, the mothers’ experiences, perceptions and concerns influenced the further exploration of these factors.

Vitamin deficiency

Research conducted by Liverpool University by a Somali researcher Mohamud, Mohamed Osman Mahamud shows that the lack of vitamin D in the Somali community is significant and on a concerning level (Mahamud, 2004). Given the high prevalence of vitamin D deficiency within the Somali community, we can now proceed to examine the next study, which explores the relationship between vitamin D levels and autism spectrum disorder (ASD).

A study in the USA found that children with autism had a higher vitamin D deficiency than children without (Bener, Khattab and Al-Dabbagh, 2014). The study found that children with autism exhibited a higher prevalence of vitamin D deficiency compared to neurotypical children. It also suggested that vitamin D supplementation during infancy may be a safe and potentially effective strategy for reducing the risk of developing autism.

Given that vitamin D and iron intake are the lowest among the Somali community (Mahamud, 2004). There are potentially serious consequences for health. At least two Somali mothers participating in our research study attributed a deficiency in vitamins and minerals during pregnancy to their children being autistic. The mothers have completed a questionnaire where they filled in which vitamin deficiency they have/had. The results are:

- Vitamin D 100%
- Vitamin A 20%
- Calcium 40%
- Vitamin C 50%
- Vitamin B6 30%

- Iron 100%
- Vitamin B12 50%

Kalthum shared, *“I have five children, and I forgot to take a pregnancy supplement with my child that has ASD, and I believe that this has contributed towards my child's ASD”*. Another Somali mother Hafsa commented, *“I lack vitamins and iron, and I believe that this has contributed towards autism in my child.”* This was a perception of the other mothers too.

A deficiency of vitamins and minerals in the Somali mothers' diets emerged as a prominent finding during the focus groups. A healthy diet was recognised as providing adequate nutrition for the body; however, it was not always possible for mothers to have a healthy diet. They described that they often forgot to eat themselves because they were so busy meeting their family's needs. Kalthum explained, *“I grab whatever the kids have left behind because I feel guilty to waste the food. Often, I am too tired to make myself a nice plate”*. Most Somali mothers who had five children or more with a special need child described the struggle surviving each day. Whilst sharing their challenges, the mothers explained that they were trying to improve their family's and their own vitamin and mineral deficiencies by taking over the counter supplements. Despite the numerous struggles and challenges they face, the mothers in the focus group expressed deep gratitude for their lives and demonstrated strong dedication to their families.

Genetics

The Somali mothers shared that genetics could play a big part in the increase of ASD. Kauthar perceived genetics as playing a big part in ASD because ASD was common in her family. Rahma commented,

Our genetics [in the Somali community] are not made for the western environment. When we were living in Somalia ASD was very rare. The food and climate are completely different and our bodies have been accustomed to that environment.

In the final session, the Somali mothers were joined by Dr Rebecca Mawson from the School of Medicine and Population Health, University of Sheffield. She discussed inborn errors of metabolism - an inherited metabolic disease when a single genetic mutation affects biochemical pathway(s). The next part explains what Inborn Errors of Metabolism is.

Inborn Errors of Metabolism (IEMs)

Inborn Errors of Metabolism (IEMs) are genetic conditions that affect how the body processes nutrients and chemicals. These disorders occur when the body lacks certain enzymes or when these enzymes do not function properly. Enzymes are crucial proteins that speed up chemical reactions involved in metabolism, such as breaking down food, building cells, and eliminating waste (Cleveland Clinic, 2024).

Causes and mechanism:

IEMs are caused by mutations in genes that provide the instructions for making enzymes. When these instructions are flawed due to a genetic mutation, the resulting enzyme may be missing, present in too small an amount, or not work correctly. Since enzymes control chemical reactions, any defect can disrupt a metabolic pathway.

This disruption leads to two main problems:

1. **Toxic buildup:** Substances that are normally broken-down start to accumulate in the body to harmful levels, potentially damaging organs.
2. **Deficiency of needed substances:** If the enzyme is also responsible for creating essential molecules (like energy or building blocks for cells), the body can suffer from shortages that impair function and growth (Cleveland Clinic, 2024).

Inheritance:

Most IEMs are inherited in an **autosomal recessive** pattern. This means that both parents must carry one copy of the mutated gene, even if they show no symptoms. A child who inherits a defective copy from each parent will develop the disorder. Less commonly, IEMs can be inherited in other patterns, such as X-linked or autosomal dominant (Jeanmonod & Jeanmonod, 2020).

Examples of Common IEMs:

- **(PKU):** In this condition, the body cannot break down phenylalanine, an amino acid found in many protein-rich foods. Without treatment, it builds up in the blood and causes brain damage and intellectual disabilities.
- **Maple Syrup Urine Disease (MSUD):** Named for the sweet smell of affected individuals' urine, this disorder involves a failure to break down specific amino acids, leading to a toxic buildup that can cause brain damage and death if untreated.
- **Galactosemia:** A defect in metabolizing galactose (a sugar in milk) can lead to liver damage, developmental issues, and even death in infants if not managed early with a lactose-free diet.
- **Lysosomal Storage Disorders:** These result from problems with enzymes in lysosomes, the "waste disposal" centres of cells. Without these enzymes, waste accumulates inside cells, damaging organs like the brain, liver, and heart (Jeanmonod & Jeanmonod, 2020).

Symptoms:

Symptoms vary depending on which enzyme is affected and how severe the defect is. They can appear in newborns, during infancy, or even later in life. One of the symptoms include:

- Developmental delays, such as late milestones in walking or speaking. This is an interesting finding as it resembles autism.
- Feeding difficulties, vomiting, and poor appetite
- Lethargy or low energy levels
- Seizures
- Unusual body odors, such as sweet-smelling urine
- Liver problems, including an enlarged liver
- Growth issues, like failure to gain weight or height (Cleveland Clinic, 2024).

Diagnosis:

Early detection is critical. Many countries screen newborns shortly after birth with a **heel-prick blood test** to check for certain IEMs. If an IEM is suspected, doctors may conduct:

- Blood and urine tests to detect abnormal chemical levels
- Genetic testing to identify the exact mutation involved (Cleveland Clinic, 2024)

Treatment:

While most IEMs cannot be cured, they can often be managed with ongoing care:

- Specialised diets: Avoiding specific foods or nutrients that the body can't process (e.g., low-protein diets for PKU).
- Medications and supplements: Used to replace missing substances or enhance residual enzyme activity.
- Enzyme Replacement Therapy (ERT): In some cases, synthetic enzymes can be given through IV to replace the missing ones.
- Emergency treatments: During metabolic crises, patients may need hospital care to remove toxic substances from the body and stabilize vital functions (Cleveland Clinic, 2024).

After participating in Dr Mawson's session, and exploring Inborn Errors of Metabolism, some Somali mothers identified a potential link between IEM with high levels of autism

in Somali communities, because of the developmental delay. One mother Shams explained the following:

I do believe that my son could have IEM because of how he was developing 'normal' and started losing his speech and eye contact by the age of two. He was able to say grandma and grandad in Somali language. He was also saying words in English and making eye contact. That is now all gone. Another symptom is that he vomits very easily. I believe that screening in heel prick would be a great step and much needed.

Another mother, Aisha stated that, *"I do believe that this [IEM] could be something that explains the high level of autism in the Somali community, because IEM is a fault in the genetics. It would be fantastic that it could be screened in the heel prick"*.

Vaccination

This research has found that within the Somali community there is a big anti-vaccine community. This is because many Somali people believe that the measles, mumps and rubella (MMR) vaccination, in particular, plays a significant role in the development of autism in infants. The mothers have completed a questionnaire where they filled in which immunisation they think are related to autism. The results are:

60% 8 weeks DTaP/IPV/Hib/HepB and MenB

60% 16 weeks DTaP/IPV/Hib/HepB and MenB

80% 12 months Hib/MenC PCV Booster, MMR, MenB booster, LAIV

60% 3/ 4 years dTaP/IPV

10% 12/13 HPV

It is the timeline of receiving the MMR vaccination that has caused most concern. Many Somali mothers in the focus group described their child(ren) developing at a 'normal' rate in terms of social abilities, but at around the age of two – three years their child(ren) started showing signs of ASD Aisha reported the following:

My daughter was saying ball, kick, apple and other words, she was also making eye contact when I was talking to her and all of that disappeared when she was two years going to three. It was the same time as she received the MMR. I am convinced that the immunisation triggered the development of ASD in my child.

Even Though there have been many studies done to prove that this is not the case (see Hotez and Caplan, 2018; National Health Service, 2024) many people in the Somali community are unconvinced. The Somali mothers suggested that it could be useful to consider the timeline of the immunisation schedule instead. Mothers in the focus group were unanimous in agreeing that the immunisation schedule of the UK is short. Some

Somali mothers explained that they had purposely delayed the MMR vaccination for their child(ren) or avoided it altogether. As one of the mothers share Kauther *“I skipped the MMR vaccination for my other children. I believe the MMR triggers ASD”*.

Indeed, when comparing the UK immunisation schedule with other western countries such as the Netherlands, the timeline of all immunisations in the UK is less spread out (Vaccination Schedule 2025 | Rijksvaccinatieprogramma.nl, 2025). The Somali mothers requested that this narrow timeline for babies and children immunisations change. They stressed that their children should be older and more mature when they received subsequent vaccinations. Fatima shared that she intentionally missed appointments because she perceived the schedule of immunisations as being tight. Perhaps the healthcare profession could solve the problem of the anti- vaccination community in the Somali population, albeit partially, through their responsiveness to such suggestions – suggestions that have emerged directly from the community.

Stress and Trauma

Stress and trauma and the connection between autism emerged as an important finding from the research. The Somali mothers discussed both stress and trauma in depth during one focus group, although the subject of stress and trauma was brought up in several other focus group discussions. One of the mothers, Deqa shared, *“I was going through stress when I was pregnant with my autistic child”*. Other mothers participating in the focus group discussion concurred that stress and trauma were related to giving birth to a child with autism. Hafsa explained that she was moving house while having difficulties during her pregnancy. Another Somali mother commented that she was going through a difficult time and felt lonely during her pregnancy, and she perceived this as contributing towards her child having ASD. Hafsa reported, *“that with stress eating habits change and we start missing out on giving our body nutritious food”*- nutrition that is necessary for giving birth to a healthy baby. Clearly, the mothers identified stress in pregnancy as a major contributory factor to ASD.

There has been much research on antenatal maternal stress and the effect on children once they are born. One research project (Beverdors et al., 2020) focused on mothers who were pregnant during the Louisiana storm and followed up the children's development once they were born. A link was established between children with ASD who were exposed to antenatal stress because of the storm. In particular, there was a strong link between autism and stress in the mothers who were 5/ 6 months pregnant during the storm (Beverdors et al., 2020).

On the sixth session of the research the Somali mothers were accompanied by Dr Anna Calvert(Paediatrician from Sheffield Children’s Hospital) Dr Calvert explained, *“sometimes trauma during childbirth such as lack of oxygen received by the baby can mimic autism”*. This can occur when the child is born with an umbilical cord around his/

her neck or the baby gets stuck in the birth canal (Beam Legal Team, 2025). So, it is important that the child gets diagnosed correctly by looking at the possible cause of the symptoms. Dr Calvert also explained that many children were diagnosed with autism who were exposed to the Covid-19 era. Interestingly, five Somali mothers had their child(ren) (seven in total) diagnosed with ASD, during the Covid-19 pandemic. Research has suggested that ASD increased by 300% due to Covid-19 (Thinking Autism, 2021). As we reflect on the restrictions experienced during the COVID-19 pandemic, it is important to recognise that many babies born during that period did not have the opportunity to engage in the social interactions essential for the development of social skills.

Recommendations

The key recommendations to arise from this research include the following:

Firstly, undoubtedly, there is a need for further research into the rise of autism within the Somali community and potentially extending this to include other East African communities. To better understand the scale and root causes of what is perceived as an epidemic, a large-scale study should be conducted, similar to the Born in Bradford project, which involved over 60,000 participants since its launch in 2007 (Born in Bradford, 2018). That research provided valuable insights into what supports child health in Bradford. A comparable study focusing on Somali (and potentially East African) families could investigate the prevalence and causes of ASD, ADHD, and other neurological disorders that appear to be in large numbers common in these communities.

Secondly, it is important that there is follow-up activity to further advance this research. Too often, research projects are completed, and the very communities it is focused on receive little information about any outcomes or developments beyond the initial findings. This project should not be a dead end but rather be the beginning of a longer-term commitment to uncovering the causes and potential solutions to ASD in Somali communities. More ASD specialists should be engaged to support this effort.

Lastly, and perhaps most importantly, it is recommended that we listen closely to the Somali mothers who participated in the focus groups, as they represent many voices within the community. One of their major concerns relates to the timeline of childhood immunisations. Many mothers expressed a desire for longer intervals between vaccine doses. Addressing this concern and normalising the option of spreading out vaccines – without judging parents who request this – could reduce vaccine hesitancy within the Somali community.

Reflections of the research

This research highlights a pressing health issue within the Somali community – an issue that has been recognised and examined by the community itself.

There have been many positive outcomes, which are summarised under three headings:

For the Community

Figure 7 below displays Somali food from the local business.



Figure 7 displays Somali food provided by local catering business Zurbiyani.

One of the key outcomes of this research is that it has helped bridge connections between the research world (universities, funders) and the Burngreave / Pitsmoor community. While this area is often associated with poverty and crime, it is also a vibrant melting pot of cultures. This research has helped bring that richness to light. Even local businesses, such as Zurbiyani, participated by catering for participants and guests on two occasions.

A major benefit was the recognition received by the charity Reach Up Youth (in Verdon Centre, run by Safiya Saeed), which received the funding to conduct this research. This organisation was acknowledged by the University of Sheffield as an active research partner in addressing health inequalities through the Deep End Research Alliances (DERA) project.

I initially started with Deep End Research Alliance, with a women focus group run by Dr Mawson and Aaishah Javeeds- Aslam. Dr Kate, Dr Rebecca and Aaishah who are all part of DERA has supported me through this journey.

Almost all the individuals involved in this research (aside from a few professionals) were members of the Burngreave/ Pitsmoor community with children attending a local primary school.

For the mothers

Figure 8 below shows the participants.



Figure 8 displays the focus group mother with their participation certificate at the end of session 7.

The mothers from the Somali community shared that they often felt unheard, misunderstood, and neglected, particularly regarding their concerns about their children's ASD. Kauthar said, *“I felt heard (in this focus group). My opinion was valued. I felt comfortable sharing personal experiences. Normally when we go to professionals to talk about our child’s ASD, we are quickly dismissed”*.

They also highlighted the long waiting times to see a specialist – often over two years. One mother shared her relief and confidence after participating in a session with Dr Calvert, stating, *“My son was prescribed this medication a while ago. I was too afraid to give it to him. But after the session, I felt confident to give my son this calming medication”*.

The mothers gained a great deal from talking with each other and the professionals who joined the sessions. One mother, Deqa stated, *“There were many things I would not*

discuss with anyone else about being a mother to a child with ASD, but in this group, I felt that I was not alone, and it was comforting to share these experiences.”

These examples represent only a few of the positive outcomes; there are too many to list here.

For Myself

As for myself, I am a Muslim, Black, Somali, and niqabi (covered from head to toe except hands and eyes) woman who began this research journey in April 2023 after five years of teaching. I was introduced to research by Aaishah Javeed- Aslam (Project Manager at DERA Leeds). At that time, I was unaware of what community health research entailed. I joined as a PPI (Public and Patient Involvement) member of the Women's Health Focus Group organised by Aaishah Javeed-Aslam and Dr Rebecca Mawson. They introduced me to a world I had never known or experienced.

I quickly realised the value that public health research can bring to underrepresented communities. Leading my own focus group gave me the opportunity to connect different communities with researchers—especially those who are often overlooked.

This research project on the rise of autism in the Somali community has brought many personal benefits, including:

- Securing a management position as a result of the research experience.
- Undertaking meaningful research conducted by someone within the Somali community.
- Learning that with patience and hard work, there are no limits to what one can achieve through research.

Acknowledgments

Firstly, I would like to express my sincere gratitude to Working Together in Research for providing the funding that made this research possible. I would also like to express my sincere gratitude to all the mothers who participated in this research. Each played a valuable role, and without their involvement, this study would not have been possible. I am also especially grateful to Safiya Saeed, CEO of Reach Up Youth and currently the Lord Mayor of Sheffield, for her unwavering support throughout the entire research process—from its inception to completion.

I would also like to extend my heartfelt thanks to all the professionals who participated in the sessions and generously shared their expertise and knowledge with the participants. I am especially grateful to Nadia Bashir (Senior Research Fellow, Sheffield Hallam University) for her invaluable support in supervising the write-up of the report.

Finally, I would like to express my deep appreciation to the DERA team for their continued support throughout the course of this research.

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