

2021-2022



Autism
Independence

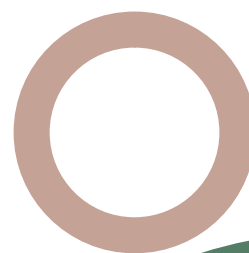


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**Lived experience of
people with learning
disabilities and/or
autism from minority
ethnic groups, using
health services**



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**Bristol, North Somerset
and South Gloucestershire**
Integrated Care Board

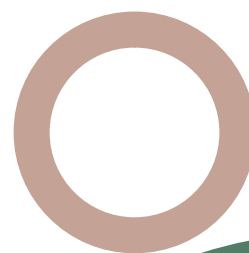




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Introduction

People with learning disabilities and/or autism experience health inequalities. Those from ethnic minority groups are further disadvantaged and underrepresented as users of learning disability health services (Fox et al 2016).

We want to address these inequalities in access, experience and outcomes.

The project was funded by Bristol, North Somerset and South Gloucestershire Integrated Care Board (BNSSG ICB).

This project included a range of approaches, such as focus groups, community discussions, individual and family discussions and meetings with existing groups to gather lived experiences and individual stories of the support people need and how people access learning disability or autism services. It included action research to test different approaches to improving access, experience and outcomes.

It required liaison and information gathering from professionals such as Health Visitors, GP's, Community Nurses and Community Learning Disability Teams working within communities on what support is available.



This project sought to better understand if and how people and families access health services:

- How accessible is information about care and services?
- Are people registered with a GP? Is the person on the LD register at their practice?
- Are people in contact with the Community Learning Disability Teams? E.g., do they see a speech therapist, a physiotherapist or an occupational therapist?
- Could services be delivered in ways that better meet needs?
- Do families and individuals have specific needs that are not being met?
- Are people seeking support from other individuals/organisations?
- Are there approaches that we can build upon to improve people's access to support, experience and outcomes?

The project wanted to hear people's stories and experiences of supporting an individual with a learning disability and/or autism and find out their recommendations on how support might be improved.

Project methodology

This project aimed to explore the lived realities and experiences of young people aged 16 years+ in accessing health services, and their views on the transition process to adult services.

The project team aimed to recruit the participants through a range of methodological research perspectives to reflect their potential communication, learning, physical and sensory needs. This project adopted a mixed methods approach.

The first part of the data collection constitutes an online survey which was promoted and disseminated through a range of platforms, including: social media, direct contact with a variety of organisations and charities supporting individuals with learning disabilities and autism and their families, and the communities supported by Autism Independence. The total number of individuals participated in the survey was 42 (n=42).

Relationship status

The survey data reveals that 19 participants (n=42) were registered with a GP and 2 were not. 20 participants (n=42) stated that their son or daughter was registered on the doctors learning disability register.

All the questions in the survey questionnaire were designed to allow the participants freedom of choice in participating in a part, some, or any questions at all. This method was applied to increase the number of participants in the study and to accommodate their individual potential needs and wishes.

The consent page question was the only one which forced the answer to progress further in the questionnaire. Hence the evidence of number disparity across a range of questions.



Impact of Covid pandemic on project.

The team set a clear plan for the field work, data collection and data analysis. The project initially began on time with an online survey dissemination in May 2021. The research team experienced significant difficulty with participant engagement and completion of the questionnaire. Some of the difficulties were identified as follows:

1. Participants experienced challenges associated with access to the internet and with access to the technological devices to take part with an online survey. The research team had initially been scheduled to release the outcome of this study in the form of a report at the end of September 2021. The implications of lockdowns (Covid-19 pandemic) and their impact on digital poverty has slowed down data collection significantly. The research team has been actively reaching out to the communities and recruiting participants to take part in semi-structured interviews, focus groups and the survey. This resulted in identification of the substantial challenges experienced by the communities we were working with.

These difficulties were mainly concerned with:

A) Access to the devices supporting participation in all pathways to contribute to the research. (See digital poverty below).

B) Digital poverty compromises family access - poor internet access limits the participants ability to use technological devices for the purposes of essential day-to-day activities: booking doctor's appointments, learning platforms for the children and young people living in the same households, the significant time spent on telephone conversations with support services, family members and significant others. Sometimes only one device is used by the whole family for their different needs.

C) Time challenges also affected the participants in contributing to the research project, as many of the individuals were working from home and looking after their children/young people. This significantly impacted on the efficiency effectiveness of the contributors. The research team confirmed many cases of previously scheduled interviews, timeslots and focus groups that had to be rescheduled which caused significant delays in the field work. The research team was also required to stop/pause and cancel many interviews/focus groups due to the childcare challenges experienced by the participants. This caused significant interruptions in the completion of the project.

D) The research team also found young people were hesitant in expressing their views through the online platform. The qualitative data recorded on the survey was of a limited quality as the research team had no direct impact on supporting the participation, as would have been possible during face-to-face data collection accommodating the needs of the sample participation in the study.

2. Project recruitment has proven challenging despite the research team's wide network opportunities within the participant's pool. The Covid-19 pandemic restrictions imposed by the Government were still in place for many weeks. The participants had difficulty understanding the scope of the rules which limited opportunities for the research team to engage with face-to-face support in filling in the questionnaire, semi-structured interviews, and the focus groups. The participants also experienced personal challenges with childcare arrangements, transition difficulties, illness (Covid and other health problems), stress and anxieties directly linked to Covid-19 and to the impact of pandemic restrictions, financial struggles, and other personal struggles.

3. Participants' disengagement from research was impacted by a general feeling of helplessness, tiredness and a lack of hope. E.g.: most interviews were rescheduled several times.

Findings - thematic analysis

The qualitative information gathered from the interviews and the survey has been included in the analysis below which identifies a number of themes emerging from our findings.

Diagnosis process

Participants often reflected on their experiences of a diagnostic process with the health services (Aabe 2017)

Participant 1 explains:

"I do have learning difficulties: dyslexia, ADHD and autism. I have been at university trying to get my degree for the last seven years. Because I only just was diagnosed, I never really had the chance to take the specific support available. If I knew, I could use that into finishing my study. Now, I had to suspend it again."

"The diagnostic process was a very, very long and tedious journey. I guess, possibly if you've got language barriers as we had you might not even think these people and services exist. I couldn't understand the referral process. We did not have any assistance there. I can imagine some people might have given up by the time you get your referral..."

Impact of learning disability and/or autism on everyday life

The participants were also keen to share how their conditions affect or impact on their everyday life (Overcoming Barriers 2019).

Participant 1:

“Before my diagnosis, I had to take time off from work for six months in the middle of the pandemic and it just hit me that, you know what, I can't just be depressed and anxious my whole life. I just knew there is something not right and I had to look for the solutions...”

Participant 3:

“I have a 16 year old son who received diagnosis as of age 4. He suffers with high anxiety which then affects his ability to process information. He has been probably suffering from IBS for the majority of his life. If he has a really high levels of anxiety he turns into a different person. He's unable to process information and retain it. He can get quite frustrated because of his anxiety levels, and it stops him from being able to do anything. He usually needs someone else with him all the time, whether that is a friend that's slightly more socially mature or me.”

And it continues:

“I expect a phone call from the school, from the police, from anyone really every single day. It is impacting on my professional life and on my mental health. I am unable to plan anything for myself.”

Other mental health conditions:

“I was diagnosed with depression and anxiety when I was in Uni. I spoke to many mental health professionals. One of them told me that: ‘you don't really want to be labelled with a diagnosis. no-one wants this on their records...’”

“...it is the amount of trauma that I experience every day because of me being so black and white... I am very honest and straightforward. People don't like this.”

Unmet needs in educational settings

Although this project did not intend to explore participants experiences of their educational provisions, all of the participants wished to express their view on the impact of schools on their challenges associated with autism and/or a range of learning disabilities.

It was clear that the participants felt it was essential to apply a multi-dimensional and multi-organisational model to receive a quality and effective support provision and good outcomes for young people.

Participant 1 notes that schools are the first potential source of identifying difficulties and for a referral to the paediatricians, diagnostic teams, and a range of support services.

Therefore, they play a crucial role in the outcomes of quality of life for young people with learning disabilities and for their families.

“If that [the conditions] have been explored at an early point, I probably would've flipped back. I can't believe how negative professionals in education are. They don't understand the importance of finding the right diagnosis which means that you can do something about it.”

Participant 2 who is neuro-divergent himself expresses his views on education:

“I did not like secondary school. I was bullied a lot. Teachers did not understand me, they did not like me. But I am now in college studying IT- it is better. I like it.”

“I was punished by my teachers for not being able to memorise things or read and comprehend or just remember what I read out. It was like a very turmoil of my life because there were all these emotions which I carried all these years when I believed that everything was my fault.”

Participant 3 further expressed that:

“We carried out our usual annual review with the educational authority this year identifying the colleges he was looking at going to and the support he would need in place. We had a confirmation from one of the colleges to inform us that his needs can be met. Unfortunately, it appears the college is not aware that he has an educational healthcare plan in place!”

Parents also expressed that despite their children having an EHCP (Education, Health, care plans), these were not implemented in their support plan effectively:

“My son has education health care plan but doesn't have any access to education.”

“Parents are never listened to. It is hugely traumatic. I lost my trust in the effectiveness of the EHCPs.”

Multi-dimensional support

“After I processed all my emotions, I knew I needed support because at that point in my life I associated more of my problems with my autism. And not the other conditions. It is not because I don't have strong traits of ADHD or dyslexia but the primary thing which affected my quality of life it's all to do with my interaction with others. I was rejected time after time.”

“As a brother of an autistic person, I often go with him to support. You know: to explain things. Also I go with my mum as she does not speak any English. So, most of my work leave time is spent on supporting my family. I am OK with this. But we are kind of forgotten...”

Participant 3:

“You can imagine it's extremely stressful for all of us, not just myself and [the name of the young person]. For my parents, too. They tried to provide me support as well and all my friends, of course. But there is not so much important effective communication within the services: the NHS, the educational provisions, social services. It is like we need to constantly convince everyone. It is very tiring for us all.”

“The inconsistencies with information. Medical professionals, education, and other professional bodies. Everyone says something very different. There is no effective information system. It does not work.”

“I worry about the future. What happens when I'm not here? You can insure yourselves up to the hills which I have done but what happens when I'm not here? He has no siblings. What happens when I'm not here is my biggest worry. There is no support system; that failed us massively. I do not trust any support systems. It is not effective. It does not exist.”

The participants also expressed their concerns in the survey about joint system working and services not working together, stating that:

“The GP and disability services tend to not sympathise with the disabled children's problems and assume that their problems can be easily fixed. Therefore, I would like for them to have a better understanding of the girl's problems and give strategic answers and solutions.”

Accessing Health Services

“There is a lack of understanding and awareness in all services, especially in crisis services which we all have begged to help us.”

There was also a consistent pattern emerging in relation to the legislative inconsistencies in the service providers guidance acknowledging and responding to the notions of: privacy, confidentiality and anonymity in regard to young people with a range of learning disabilities.

Participant 1 who is neuro-divergent expressed her concerns regarding accessing mental health services:

“It is impossible. I suffer from a serious anxiety. I did not have any support at all. My mood is very low all the time. I needed help so many times. Nothing was ever done for me.”

Some participants expressed their positive views on accessing GP services as a part of a regular check-ups:

Participant 2:

“I have asthma and I need to see my GP often. I am very independent, and I am ok to go and see my doctor on my own. But now with Covid, I was not able to see my GP.”

And another family member who was present during the interview further asserts that:

“I need to be available to support my family. To take them to the doctors as my family struggles to communicate in English.”

Additionally, a participant taking part in the survey notes that:

“My son has mental issues but the health services don't value my input.”

And another participant continues:

“I had the worst experience ever. As a woman of ethnic minority having severe complex mental health issues, and then to be diagnosed with dyslexia, ADHD, ASD, and dyspraxia in the last 8 months... And there is no support whatsoever. When I reached out to the local autism service for accessing post diagnostic treatment, they turned me away saying, they don't think I am autistic and that NHS is massively overstretched and underfunded and they have no resources to provide me the services I need.”

Additionally, a few participants expressed their concerns in regard to limited access to alternative therapies, such as: art therapy, music therapy, or drama therapy.

“My daughter has a massive sensory challenge. The only way she responds well is music. We had two music therapy sessions through the NHS before lockdown and it stopped. We never had any communication related to a continuation of the provision remotely, or if this will be available for her after pandemic.

The meltdowns and her challenges continued. In fact, now we are financing privately music therapy for our daughter.”

Another participant continues:

“My son had art therapy at school provided by the art teacher. It was amazing as she understood his sensory needs and challenges. He likes getting messy. He loves water, this is what makes him calm. Art was offered by the school as a form of alternative provision with a TA being trained to continue his art sessions. I mentioned this to my GP and to the paediatrician during one of my visits. None of this was followed up. I was told these services are not offered through the NHS.”

Worries for the future

Many of the participants expressed their worries for future support. Often, they were worried about the independent lives of their children with learning disabilities/autism.

“I really worry about the future. What is going to happen to my son when I am not here anymore? I am the only person fighting for his provisions, his rights, his wellbeing... (Silence) There is nobody else who would do that for him.”

Whilst many participants were focused on addressing the current needs of their autistic children/those with learning disabilities, the majority also were clear on their uncertainties relating to future support provisions.

The Covid-19 pandemic accelerated the anxieties of most of the participants:

“What if I suddenly died? What if I caught Covid and died? I am unprepared. There is no one else who can look after my child. Suddenly, it became real. I am very worried.”

“I mean... This whole pandemic made us think massively. People are dying all the time from Covid. It could be me next time, it could be my son. I don't know what is going to happen to him when I am not around. He has only me. He has complex needs - nobody wants that.”

Eastern European participants who reside in England and who took part in this study also expressed their concerns regarding their entitlement to access any services after Brexit.

They were unsure how Brexit will impact on their opportunities to engage with support services, the NHS, social services and education:

“I have no clue what this [Brexit] means for us who have not British citizenship. I never thought about getting British citizenship as it is so expensive. All my savings are for supporting my daughter, as I had to use private services in the past. And suddenly, I don't even know if I am able to continue living here, at my very own home in Bristol. It really disturbs my sleep at night.”

“I feel massively guilty to ask for help. The NHS is under such pressure. And, of course, I am Polish - told so many times I am not welcome here, that I only use and abuse the services... The NHS is for British people, I was told. I feel embarrassed to engage NHS in supporting my family. I also don't know if I am still entitled...?”

“Brexit changed everything. I have been living here, in this country for over twenty years. I felt at home. Not anymore. I was abused on the streets for speaking Polish, I was told I am not welcome here and I should 'go home'. This is my home, in fact I bought one! It is very hard to know if I am still going to receive any support from the NHS, from social services, from schools. It is very stressful and I was considering to go back to Poland, even though I don't even have anyone there ...”

Cultural influences

Many participants also articulated the impact of cultural influences on their experiences in getting or accessing the support they wanted and needed. These cultural differences were mainly associated with: family upbringings, religion, or linguistic challenges.

“We autistic girls use masking to understand the social reality around us. That's one thing but if you're a woman of colour and if you live a life when women are punished for everything, that is a very different story. I was told I am nobody and it would be better I was not around.”

So I tried to kill myself when I was six. I ate a whole tube of toothpaste as I thought it would make me die. I take everything literally. My family have never accepted any diagnosis I have. Everything was and is always my fault, especially that I am a woman. This is ingrained in my culture.”

“When I was in year 10, I used to have like a small chain around my neck. Nothing protruding or anything, but for me that was some way of stimming - I had to have it around my neck, you know? I was asked to take this off at school, it was a very religious school. When a woman wears chain on their neck, it tends to get the attention of males. It was not allowed.”

Participant 3 expressed that:

“You see... The fact that you actually speak to other people who haven't experienced this [autism, or learning difficulties] and they think you're not telling truth, or that you haven't tried enough ... Or that you're being a bit stupid. I have been explaining myself all the time because our skin is darker. People don't think you can have a great career in life, and they treat you as you are stupid. They actually don't want to believe what is going on in our life.”

“I was worried my child will be taken away from me. Nobody explain that social services are here to support you. We were sure we will be labelled as ‘bad parents’ because of our culture. It was terrifying.”

“Gosh! Sometimes I am being spoken to ‘slowly and loud’ as people don't anticipate me being a fluent English speaker. This is so very frustrating. I do understand terminology I am being communicated by the NHS staff. I am medically trained myself, in fact! I am not stupid and I don't want to be treated as a second tier citizen because my accent is a little different...”

Further on, a participant expressed the view that:

“Services need to be culturally competent. Generally, there is a lack of awareness and training of the issues families face.”

Transition

There have been ongoing debates and discussions in regard to the notion of a ‘transition’ concept in relation to autistic people and individuals with a range of learning disabilities. The impacts of transitional daily difficulties are present often in the form of day-to-day tasks, such as: transitions from home to school; school to bus; bus to home; etc.

However, for the purpose of this project a transition was defined to the participants as a long-term impactful change in one's life and further explained as a transitional process from children's services to adulthood medical and care services.

The majority of the participants expressed their concerns highlighting the communication inadequacies during this process, misinformation and general experiences of a lack of provision.

As one participant noted:

“What transition? There is nothing to be transitioning into!”

“It does not exist. These are words which have no concrete meaning.”

Most participants felt worried for the future of their children as their experiences of accessing services was poor in the past. The participants often did not feel supported and they felt the needs of their children were not met in the past.

“I don’t think there was any service in the area that I was trying to access. Not only for myself but also for other people. Most of them did not give any support. This is very scary.”

Here one participant expresses:

“This may be a fine line, yet, as a parent carer I have experienced unnecessary blockages from service providers where they give priority to confidentiality over the health needs. For example, I have a 19 year old son with autism whose condition has an adverse affect on his current developmental stage. He is physically big but emotionally more vulnerable, yet service providers are giving more priority to his privacy than his wellbeing.

As a carer, I am the one who is picking up the pieces when he breaks down which is on daily basis truly speaking. Yet, when I bring him to service points, especially health services, I get excluded from the discussion unless he allows me to do so.”

Cross-service failures

“Because of my experiences, I have seen more and more people with learning difficulties, with autism and with brain injuries in prisons, in the institutions where they shouldn’t be. Do you know what? It starts with schools. We are seeing very young children ending up in isolation rooms. I spoke to a teacher the other day when a child was put in isolation for a day awaiting a decision of a teacher whether a child was an instigator of a fight! This is so very, very wrong.”

“My child has been let down by everyone. He is now under Police investigation of gang membership. I have liaised with everyone: probation services, divergent teams, mental health teams, social services, lawyers. Everyone. Nothing happened. There is a lack of awareness of autism in all of the above services. This is shocking.”

Capturing stories and experiences

Some participants were willing to share their concerns with the systemic issues underlying the problems with accessing the services in general.

They clearly specified that there are challenges with the communication system underpinning all support services, including: health and education. The participants expressed their worries in respect to educational quality for their children and young people with a range of neurodevelopmental conditions.

There was a clear and explicit view that the teachers are not equipped to undertake inclusive interventions in their classroom as they are not being trained to understand the very distinctive factors in the neurodevelopmental conditions. They simply do not know how to manage and cope in neurodiverse classrooms.

Participant 2 expressed that:

“There is a serious issue with autism awareness. Let’s look at schools. Only a few teacher training providers have special educational needs modules, others don’t. So we have teachers in our classrooms that have got no experience in special educational needs. Last time I checked data, it was one in four people with some sort of SEN needs. How can we have staff in a classroom who cannot understand our children? I don’t come from an uneducated background.

[The name of the child] is my first child and we didn’t have a clue what was wrong with him at all. I foolishly saw teachers back then as experts in young people. I thought they would give me advice and guidance. I was foolish.”

There is an overwhelming thematic pattern of a lack of trust emerging from the data in this study. All the participants who have taken a part in sharing their stories exclaimed that they do not trust any support services. This includes the health, social, educational and judicial services. The participants believed that there is ‘no reason why they should trust anymore’ (Participant 5) as they have been ‘let down so many times’ (Participant 4).

Furthermore, participant 1 talks about the dismissive nature of the health services, in general:

“I had to take my child to the A&E many times as he hurt himself on so many occasions. He has complex needs and each time I was told there is nothing they can do to help me, as his needs are so complex. The staff were unable to check his injuries as he wasn’t allowing anyone close to his body. There was no one NHS practitioner trained in sensory integration and sensory difficulties. These were his main issues!”

Another participant talks about the nature of the system's rigidity and the poor integration of linguistic options to represent the communities the health system serves. Participant 6 says:

“I am the lucky one, to be honest. English is my first language, everything [all documents] is in English. I have a good education level. I'm also confident enough to be able to ask questions and to questions the answers. But seriously, I cannot imagine the potential scenarios if I wasn't speaking English well...”

There is also a clear indication that social services are not fit for purpose in supporting the underlying complexities of the clients they aim to serve:

“I know many families that have suffered in silence where they have an autistic child with learning difficulties that can occasionally lash out physically. Because they have other children at home, social services are really cruel and unfair at situations like this. I know people who were told that we're gonna have to take that child away because your other children are at risk. There is no support. There is an isolation.”

There were also voices expressing that the health practitioners do not understand the difference between mental health difficulties and developmental conditions, such as autism and other comorbid difficulties.

Participant 5 expressed that:

“There is so much misunderstanding. Quite often people mentioned to me [the child's name] got mental health problems. What did they actually mean? I tell them he has autism. I say: hold on! Autism is not a mental health problem. Perhaps making sure the right information is being circulated, would help. The more people accept it, the better for us all.”

Racial stereotyping

The participants expressed clear views about racial inequalities and the direct impact of this on the effectiveness of the services they sought to get support from. The participants in this study expressed their explicit views that their skin colour was portrayed in a stereotypical and often judgmental way. One mum expressed ongoing challenges experienced for years in supporting her son. She, as a black woman who also has been a single mum raising her autistic son, was challenged on multiple occasions in relation to her 'status'.



She expressed that:

“Let’s look at our first school... The head applied racial stereotypes and decided that the behavioural challenges at school were rooted at issues at home! No one explored our home situation. And my son was referred to the social services! This unfortunately was a start of our journey. It was the battle. First proving that they referred my son to the unnecessary authorities. It was a waste of time for the school to blame me as a parent for the challenges with behaviour. No one recognised his autism because my skin is darker. I was assumed to be a ‘trouble’ parent. It has taken some time and we were finally successful.”

The above participant is a successful, financially independent woman with an in-depth academic knowledge of neurodiversity. Despite that, her household was viewed as a ‘troubled family’ where the causes of the challenges experienced by her son were believed to be rooted in ‘inadequate parental skills’. These were dismissed after years of ongoing court trials.

Another participant expressed the view that there is an ongoing lack of awareness of autism and learning difficulties within a range of support services, including: education, health and police/judicial services.

She says:

“It probably further complicates things for us that we are people of colour. It is difficult to understand, I know! So the health and educational services, judicial system is also riddled with discrimination. It is ingrained into our everyday lives. My son was stopped and searched twice in the last few years. He was handcuffed by the police. When he asked a question why this happened to him, he got threatened with a Taser! Autistic people need to understand what is happening. There is no multidirectional understanding, or support as we speak. There is no autism or learning difficulties awareness. That’s it.”

Participant 3 confirms once more the narrative patterns emerging from the interviews which are directly linked to stereotypical views of race. Furthermore, the participant strongly believes she is not alone in this belief and confirms that her experiences of racial discrimination are shared by many others with similar life experiences:

“I think the experiences I had will be common for a lot of people of colour. Race hasn’t been recognised as a part of human intersectionality here. We do not have a conversation about diversity here. We talk about the stereotypes, especially on racial stereotypes and racial discrimination. This is so, going back to the very start of our unfortunate journey...”

Racial discrimination has been also recognised by the participants as ingrained in a lack of a cultural awareness in the health services.

Participant 4 expresses that:

“You see, it is difficult to exclude the cultural differences from our origins. I remember many occasions when feeling tired due to my Ramadan fasting, my parental skills were questioned, and I was indirectly and directly blamed on my lack of understanding of autism condition. Gosh, I read all books available to me to understand my child better. I took all training available to me. I know my child inside out. I still was treated like I have no clue what I am talking about. None of my queries and worries I expressed to the GPs and health practitioners were taken seriously.”

Engagement with men

A strong narrative pattern emerging from this study was directly linked to a lack of men in the journey to support a child/children with autism and learning difficulties. This topic has been emerging in many different contexts. For example, participant 5 strongly implied that a lack of male presence in raising autistic males is a real issue, especially in respect of giving them a platform to rely on, reflect on and learn good social examples from as young men:

“Something needs to be done about men, really. If there is any behaviour issue, or whatever, it always seems to be the woman that picks all of this up which is really hard for the boys who are autistic because they don't really want a woman doing these things. They need a role model to rely on. They are very literal often. They need a man in their lives who they can shadow and follow. It is very important.”

Another participant had strong views on the role women play in the social world nowadays, especially with respect to raising a child with a disability as a single mother. She expressed her views on stigma and the extra challenges associated with being a single mum, especially a mum ‘of colour’.

“It is not easy to be a woman nowadays, especially a single mother. Things are often swept nicely under the carpet when you are trying to be honest. There is a real stigma with single mums. Especially if your child has some form of difficulty, or disability. You are simply blamed for this by everyone: by your close family, your (ex)friends, by the father of the child if he is around at all, by the services you try to seek support from. Single mums are often dismissed and not taken seriously. And we are heroes, you know?! We need even more support.”

One male participant who took part in this study expressed his frustrations that there are not enough men supporting their families, their wives and partners who are raising a child, or children, with disabilities.

He exclaims:

“I am so angry most men are hiding from their responsibilities. Why would they think it is allowed? My wife is a rock to me because she showed me how to help her in raising our child together. It is not easy; my son has complex needs and he can be very challenging at times. But he is my son and I carry the same responsibilities. I have chosen to be a dad. That’s it. My son is autistic and has many other disabilities. My job is to support my family and to show my other sons how men should behave as a father and as a partner.”

Another participant says that she knows she cannot rely on her husband to care for their autistic child as his culture won’t ‘allow it’:

“I am responsible for all domestic, child-raising duties. My husband’s culture would not allow him to take an active part in our family life. I clean the house and look after the children. One of our sons is severely autistic. He doesn’t talk and has complex needs.”

Identity

“I know it’s a really awful thing to say but a lot of these young people [autistic] are really struggling with their identity. And quite incorrectly [name of the child] thinks his disability is the reason why he struggles. I’m trying to explain that it is not your disability, this is the system which is failing people with your type of disability. It is not your disability’s fault; it’s the label you were given and people do not understand it correctly.”

“Young people with autism and learning differences have been experiencing exclusions forever. All those young people are being excluded from different spaces, they are made think they are not worthy, they don’t fit in; they are challenging and difficult. They feel rejected all the time. I mean, it all started somewhere. We are experiencing a multi-dimensional problem here. Issues with our communities; communication problems that cause challenges. It’s multi layered and ineffective communication is at heart of it.”

Autistic people themselves who contributed to this study also expressed their own understandings of ‘who they are’. In fact, there was a clear parallel suggesting that they were struggling with identifying their identity(s).

For example:

“When I was younger, I tried to be a good girl. I masked my own feelings and learnt how to dissolve myself in a crowd. Not anymore. However, it is very hard as I am struggling with understanding who I am in in so many aspects of life. I follow the ‘gender stuff’ but I don’t like it and don’t agree to this. So, I get myself in trouble a lot. I have a boyfriend - he is very supportive, but I am unsure about him. I don’t know if this is where I want or should be. I also have an autistic friend who is trans as he is completely overwhelmed with this ‘identity’ thing.”

“I always struggled with food as I had massive sensory problems with food texture. I did not enjoy eating food, it was never a pleasure for me. It was a necessity. I eat very little of healthy foods, as they made me feel sick. I understand I should, but I can’t. So, even I eat very little, I eat very unhealthy food and I struggled with my weight.”

“My daughter has always struggled with food. To be honest, as a mum I found meal times incredibly stressful and anxiety provoking. I knew I need to ‘force’ some healthy food to my daughter. She could live on crisps her entire life. But then, I looked at myself. I am undergoing an autism diagnosis myself as a grown up women who suffered from anorexia and bulimia throughout my life. Food was always a difficult thing for me. I have so many sensory challenges which do not allow me to enjoy my food.”

Conclusions

Although this project had a well-defined ethics and conceptual framework and it was wrapped in a clear time scale, the process of completing this research was complex. The research team faced many unexpected challenges which were uncovered by the Covid-19 pandemic and its implication on peoples’ lives. The field work proved to be incredibly challenging. The participants often had their children and other dependants at home whilst committing their time to domestic and professional work. All participants needed to reschedule the time set for an interview or a focus group (which was particularly challenging) at least twice. At times, the interviews were cut short and were continued at different time slots and days.

The research team also encountered challenges associated with the participant’s opportunities to access the internet. This was not anticipated and brought many difficulties with reaching out to potential participants and also in dissemination of the research objectives across the population sample specified for the aims of this project. This is a clear indication for a future change associated with technological advances in inviting people to seek support/access services/raise a problem through a remote platform which is directly dependent on internet access. The recommendation here is to offer alternative opportunities for reaching out for support and for communicating their needs, to the communities affected by adversity, financial disadvantages and poverty.

There is clear indication of a substantial risk to gathering evidence from misrepresented and hard-to-reach communities.

In addition, there is strong evidence from the thematic analysis process suggesting that autistic individuals and their families are negatively affected when accessing support by the limited opportunities of linked-up services across provisions; this includes: the NHS, social services and education. The participants clearly stated they feel tired of repeating their stories and their needs each time they are facing a challenge. The years of ‘fighting’ to access any help urgently needed for their child or themselves have left the participants feeling that their trust in NHS services is partially but fundamentally broken. There was an overwhelming sense of disappointment and hopelessness resulting from the participants’ past engagement when seeking support from the NHS and any support services.

Another clearly emerging theme was access to mental health support services, as progressively participants described them as failing and impossible to access. This was particularly evident in the context of young people transitioning into ‘adult services’ which often was described by the participants as ‘non-existent’.

There is a clear indication for the need for a future unobstructed, unbiased and transparent structural transformation within support services for autistic individuals and people with a range of learning disabilities to access the help they and their families need.

Much of the frustration from the participants was expressed in relation to a lack (or very limited awareness) of understanding of autism and other conditions which can result in learning needs, by ANY of the support staff at ANY provision. This was highly impacting on the accessibility of the services, participants’ trust and their negative perceptions on seeking help in the future. The research team recommends a range of compulsory trainings related to autism, comorbid conditions and learning disabilities (as an ongoing process/refresher) for ALL NHS, social services and educational staff as an urgent matter.



Summary of Themes and Findings

•Diagnostic process•

The participants clearly stated their dissatisfaction with the diagnostic process. In fact, the majority of those who contributed to this study described this process as: 'painful', anxious and lonely. All participants felt the waiting time for an assessment was very lengthy and that it directly impacted on their children's ability to access any early years interventions. Educational settings and other support services were unable to offer any support with no evidence of a diagnosis. Parents/carers and young autistic people/individuals with learning disabilities consistently view this as negatively impacting on their ability to engage with all aspect of their lives (Selman 2017).

•Difficulty accessing services•

All participants in this study referred to the challenges associated with accessing any sort of support services. These challenges were mostly related to: cultural differences, linguistic challenges and political issues (such as Brexit). Many participants have expressed their troubles linked to waiting times, a lack of transparency in the referral process, suitability, availability, eligibility, and possibilities to seek/access support. Some people were affected by linguistic challenges and cultural discrepancies impacting on their trust when seeking support. These often were affected by their historic experiences when accessing any kind of help (Seale 2022).

•Cultural issues•

Issues with men's engagement in family life and involvement with their understanding of their disabled/autistic child. We had three male participants who took part in this study; one expressed his frustrations that there are not enough men supporting their families, their wives and partners who are raising a child, or children, with disabilities. Some participants also expressed their frustrations and concerns related to negative (often viewed as non-sensitive) responses to their cultural intersectionality, including religious views and language (Aabe 2019) .

•Translation services•

Linguistic barriers. All participants had children in a range of ages (8-25 years old) with a diagnosis of learning disabilities/autism. Some had physical disabilities as well. Most participants spoke Somali language with a few participants from Polish and Eastern European communities residing in BNSSG.

Some of our participants felt that they were being ridiculed for their accent which affected their trust when accessing the provisions, they needed. Some participants also noted that a request for translation services would substantially lengthen their waiting times to be seen by practitioners and other support provisions (Fox et al 2016).

•Impact of learning disability/autism on everyday life•

All participants (parents/carers and individuals with a range of learning disabilities) stated that the support services made little difference in their everyday functioning. Autism and/or learning disabilities made a significant impact on all participants' lives. This included their families, education, physical and emotional health, mental health and wellbeing, and affected their confidence, motivation and social engagement. The participants felt isolated, frustrated, hopeless and worried about the future. All participants stated that their condition or disability impacted negatively on their mental health which significantly limited their opportunities to develop coping strategies and lead their lives independently.

•Racial stereotyping•

There was strong evidence suggesting that the participants felt that their race or their ethnic identity considerably influenced the quality and the effectiveness of support they were requesting. Participants in this study felt the practitioners often used stereotypes associated with race and ethnicity which directly impacted on their opportunities to access support services.

For example, one participant who was requesting critical mental health support was offered advice stating that perhaps her understanding of ill-mental health is mistaken with 'a bad attitude' and a limited knowledge.

The participant explained clearly that she is able to express openly her emotional states and she understands how to verbalise her emotions. She added she is an undergraduate student completing her course despite her multiple diagnosis of a range of developmental conditions. Another participant was 'not taken seriously' by a range of support services as 'she looks like a single mum who might have limited skills to raise her son'. She was offered parenting courses instead of support (Selman 2017).

•Multi-dimensional support – joint working across systems•

Services not working together or cross service failures. Frustrations with the quality of multi-dimensional support. One participant expressed: “I would my daughter to be taught life skills. All aspects of life skills. Things like, safety: crossing the road, going on transport, going on a bus... She is not safe anywhere.”

Another participant added: “Lack of basic social skills are my main concern and the biggest struggle. There needs to be support from other services to help teach our children to live around others. I do not have many Somali people where I live, and it is very difficult. I have nowhere to take him (autistic young person) and nobody understands my child.”

•Transition to adult services•

All participants expressed their negative view on the quality of the transition process from children’s services into adult support. In fact, a few participants stated that adult services ‘are not existent’.

Most of the support the parents/carers were offered for their children was not available in adult services. Some participants had their help (mostly associated with mental health challenges and educational provisions) taken away which made a considerable negative impact on their lives. Some parents expressed they had to leave their jobs to look after their children with complex needs after they reached adolescent years.

Some parents were worried about coping with challenging behaviours exhibited by their disabled children at home which affected their own wellbeing and the family dynamic.

All participants simultaneously stated that adult services are not fit for purpose and they are letting vulnerable people and their families down.

(Transition work is being addressed in the project funded by the Bristol Impact Fund)

Recommended Actions

- 1. Extensive staff training in relation to a range of communication methods and platforms with parents and carers by health professionals, practitioners and support staff (including administrators, cleaners, etc).**
- 2. Training directly targeting men's participation in supporting their family members and young people's health care, especially for young men with disabilities. There is a need to involve male trainers/facilitators to actively engage in training activities. This also would be an opportunity to accommodate an outreach worker to get males/fathers involved in training.**
- 3. Effective access to translation support during appointments and meetings (face-to-face and remote).**
- 4. Accessible and accommodating Regular Health Checks for parents/carers (including mental health checks) who have a son or daughter with learning disabilities/autism and physical disabilities. Adequate preparation in advance of the appointment indicating what the young person can expect on the day.**
- 5. Implementation of a Care Navigator/Bridging Worker role directly supporting access and signposting parents/young people from ethnic communities in accessing health services. Initially as a pilot with a view to establishing as a permanent role within the NHS.**
- 6. Life skills training for people with learning disabilities/autism from ethnic communities.**
- 7. Cultural awareness and competence training for staff co-produced with families with lived experience and trainers from ethnic communities.**
- 8. Destigmatising mental health in the form of accessible support services fit for purpose and directly responding to the parents'/carers and young people's needs. To be accommodated partially by training providing the therapeutic teams with a range of communication tools and inclusive neurodiversity practice.**

Appendix 1

Demographic data - interview participants

	Gender	Age	Nationality	SEN status
Participant 1	Female	24	Mutual nationalities: American, Moroccan, British	Young person with Autism and ADHD, anxiety disorder
Participant 2	Male	23	British and Somali	A brother of autistic young person
Participant 3	Male	20	British and Somali	Young, autistic person
Participant 4	Female	40	British, Somali	Mum of a young autistic person
Participant 5	Female	37	Polish	Mum of a young autistic person
Participant 6	Female	47	British	Mum of a young autistic person
Participant 7	Male	49	British, Somali	A father of an autistic young person

The following table evidences participants registration with a range of health services:

#	Question	A parent/ carer		A young person		Total
1	Social care services	55.56%	5	44.44%	4	9
2	Mental health services	0.00%	0	100.00%	3	3
3	Learning Disability community services	33.33%	2	66.67%	4	6
4	Occupational Therapist	0.00%	0	100.00%	3	3
5	Speech and Language Therapist	16.67%	1	83.33%	5	6
6	Physiotherapist	0.00%	0	0.00%	0	0
7	Counsellor/ Mental Health Therapist	0.00%	0	100.00%	2	2

And their satisfaction/ dissatisfaction in accessing the health services

#	Question	Very satisfied	Satisfied	Neither satisfied, or satisfied	Not satisfied	Very unsatisfied	Total
1	GP	2	5	2	4	1	14
2	Social Care services	1	1	3	2	2	9
3	Mental Health services	0	0	2	2	2	6
4	Learning Disability community services	2	2	1	3	2	10
5	Occupational Therapist	0	0	2	2	1	5
6	Speech and Language Therapist	1	1	2	4	0	8
7	Physiotherapist	0	0	2	1	1	4
8	Counsellor/ Mental Health Therapist	0	0	4	2	1	7

Appendix 2 - Project analysis

Table 1. The ratio of a parent/carer contributions recorded in the questionnaire.



Table. 2. Participants national identity.

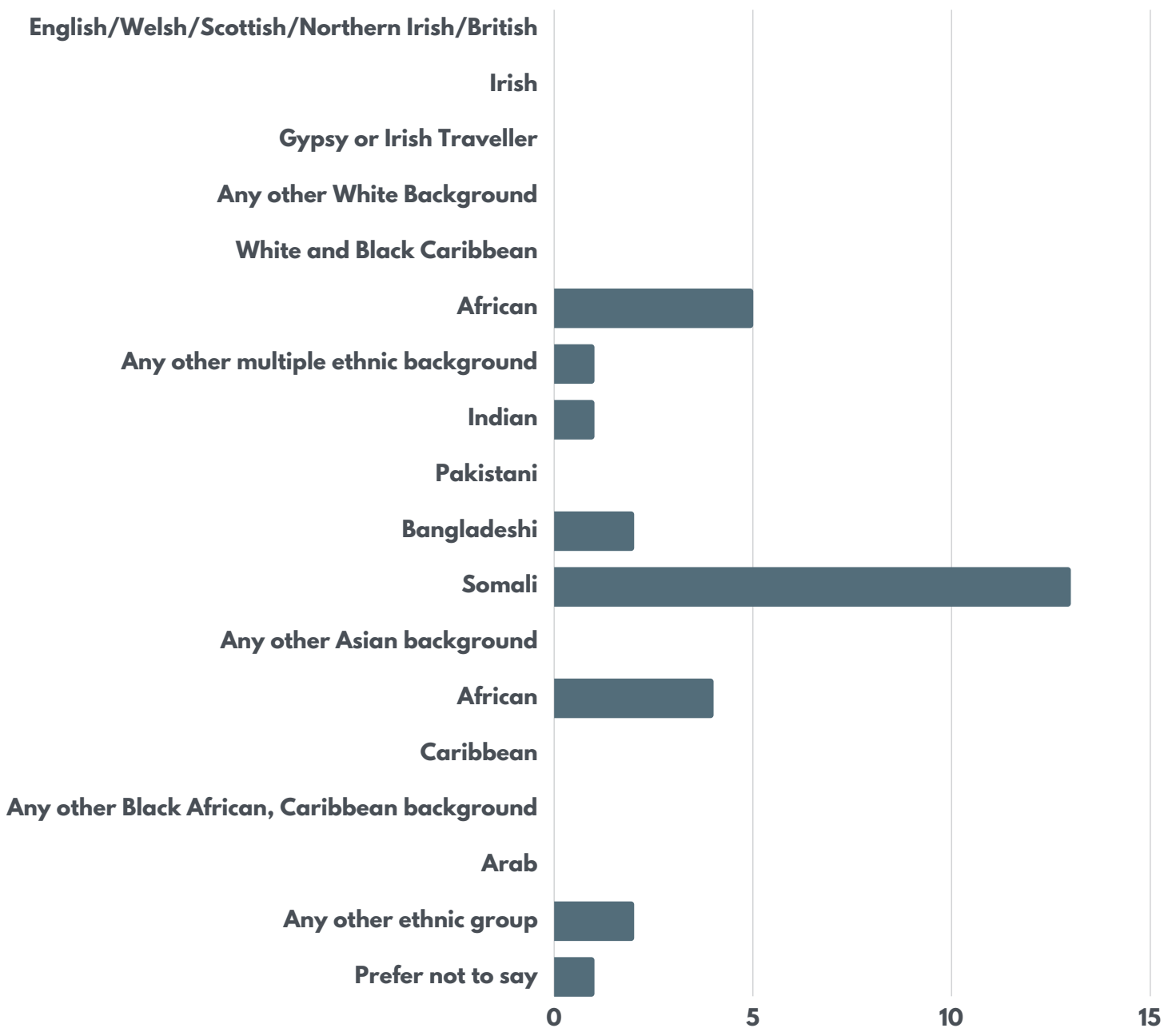
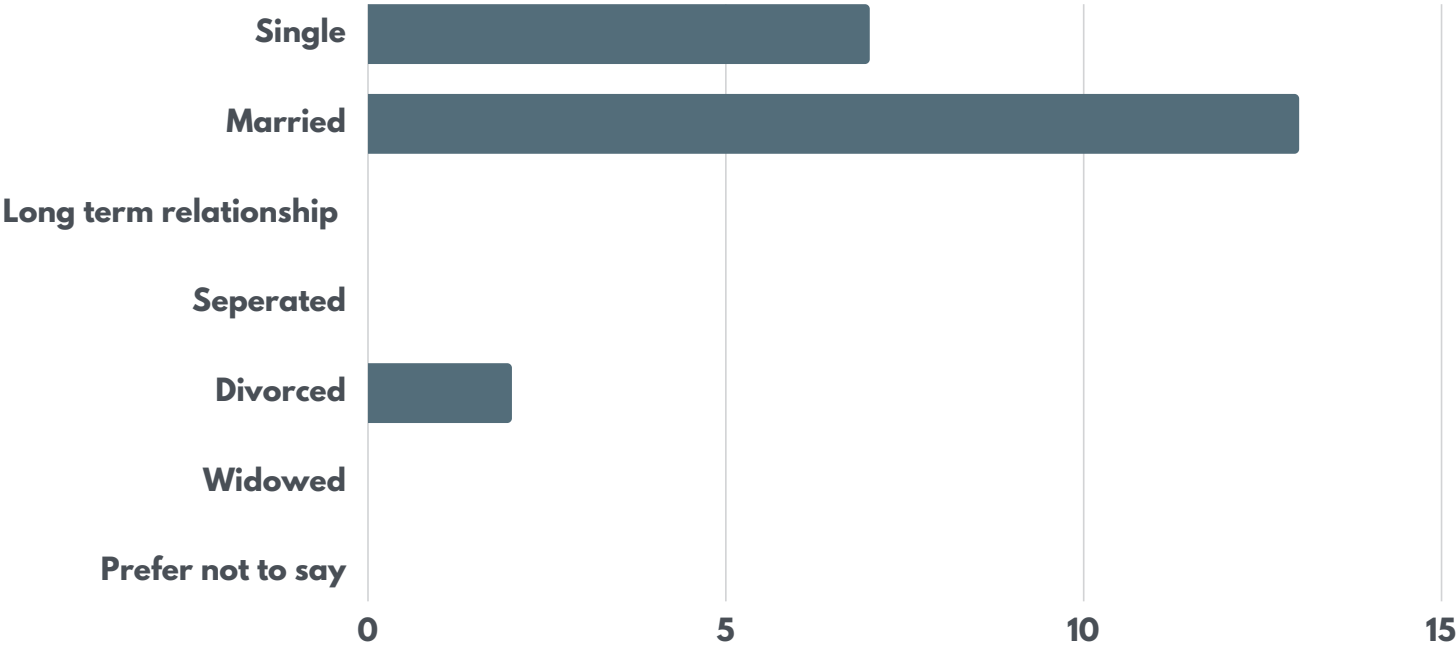


Table. 3. Participants marital status



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