



# THE IMPACT OF AUTISM IN THE SOMALI COMMUNITY IN BRISTOL UK

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## REPORT BACKGROUND

Autism Independence and Healthwatch Bristol engaged with Somali families affected by autism to find out their experiences of using health services and their understanding of the condition. Engagement built on research carried out by Bristol University, NIHR CLAHRC West and Autism Independence in 2015-2016 (<https://clahrc-west.nihr.ac.uk/research/projects/working-with-the-bristol-somali-community-to-improve-outcomes-for-children-with-autism/>). This work aimed to find out whether Somali families access adequate support from mainstream health and social care services and whether they face particular barriers in accessing care in Bristol. It aimed to find out what Somali families feel could be improved in terms of meeting the needs of their child/young person with autism and what might help their family holistically.

**AUTISM INDEPENDENCE (AI):** AI specialises in recognizing the needs of Black Ethnic Minority families affected by autism in particular the Somali community. Research suggests higher prevalence of Somali children with autism living in western countries, although there is no word that describes autism in the Somali language. AI provides parental and family education, holiday and advocacy provisions. AI aims to transform children's lives, a long term vision to optimize child/young person development to full and equal potentials. AI delivers high calibre provision with cultural understanding.

**HEALTH WATCH:** Healthwatch is the official framework through which local people can have their say about health and social care services.



# THE IMPACT OF AUTISM IN THE SOMALI COMMUNITY IN BRISTOL UK

This research aimed to capture the experiences of Somali families affected by autism in Bristol and to understand whether service providers meet the needs of their child/young person with autism. It aimed to identify whether local Somali families experience particular barriers in accessing health care and support and to identify their level of understanding of autism.

## METHODOLOGY

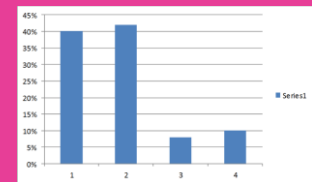
The data was gathered using mixed methods and produced both quantitative and qualitative data. This involved using a structured survey questionnaire with 7 open and closed questions and 8 general demographic questions. Each questionnaire took 20-30 minutes to complete due to interpreting time.

We consulted with 56 families. Of these, 50 (n=50) families took part and the other 6 families decided not to take part. The 6 families who did not take part had children who were newly diagnosed with autism. 51 out of the 56 families who took part are members of Autism Independence. 48 surveys were completed face to face and the other 2 were completed alone by participants. 49 female participants took part in the survey and one male. 49 families had a child/ren with diagnoses of autism and 1 family was in the process of getting an assessment. The 50 families we consulted had 51 children with diagnoses of autism and 4 children in the process of getting a diagnosis.

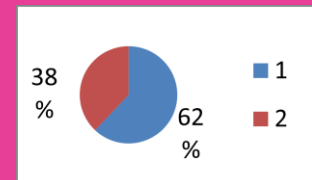
46 questionnaires were completed in participants' homes, 3 participants completed their surveys in a workshop event and 1 participant completed their survey in their work place and left it to be collected by Autism Independence staff members.

Participants were informed of their right to withdraw from the research before they started and they all gave verbal informed consent to take part in the survey. The survey was explained to each participant before the survey started. All explanations were

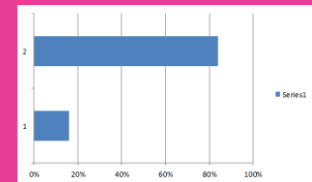
**40% OF SOMALI FAMILIES DO NOT UNDERSTAND AUTISM**



**62% OF SOMALI FAMILIES IN BRISTOL DO NOT UNDERTSNAD THE EDUCATIONAL HEALTH PLAN**



**84% OF SOMALI FAMILIES IN BRISTOL WITH A CHILD WITH AUTISM FEEL THEY FACE BARRIERS ACESING HEALTH SERVICES BEING SOMALI**



## FAMILY VOICE

**I HAVE BEEN WAITING FOR A SOCIAL WORKER FOR 3 YEARS**

**THERE SHOULD BE A WAY TO INCREASE THE UNDERSTANDING OF FAMILIES WITH AUTISM - I SEE THE BARRIER OF ALL BARRIERS AS UNDERSTANDING THE AUTISM.**

**THE COMMUNITY NEEDS HELP TO UNDERSTAND ABOUT OUR CHILDREN'S AUTISM.**

given in Somali and also sometimes in English language.

23 surveys were completed with families by staff from either Healthwatch Bristol or two members of Autism Independence who spoke Somali. The other 27 surveys were completed by one member of staff from Autism Independence who spoke Somali and English. The questionnaires were completed in the year 2016 - 2017.

## FINDINGS

### **Do you feel you understand what is wrong with your child or know what autism is? (Question 1)**

When this question was asked, 42% of parents who took part in the survey said that they understand what autism means. However, 40% of the 50 families said they do not understand what autism is, 10% percent said they think autism is being different or a problem with speaking or being disabled, and this meant that the overall concept of the condition was not really understood. 8% of families believed autism is an illness or mental illness.

One parent said: “Yes I believe autism is someone who has something wrong mentally.”

Another parent said: “It’s a mental illness which can’t be treated, because Doctor can’t do anything and there is no medication for it.”

Another parent said: “No I don’t understand autism, because it is difficult to understand the different ways autism affects my son. Communication is the biggest problem, it is only when I understood the last 2 years that my son is progressing because I started pushing for services and helped my son from home.”

Another parent said: “No (autism has) never been explained properly, I requested better explanation from the pediatrician but never received anything.”

### **What is your experience with social care/social services? E.g. do you get enough support from social services outside school hours? (Question 2)**

The question on social care support had different responses to the first question. The majority of families had an unsatisfactory experience with Bristol social care services. 50% of families we consulted said they do not have a social worker and 16% said that they did not hear back from the social worker after the assessment. 12% said they had a bad experience with their social workers, 10% said they had a good experience, 8% said social care support is minimal and 4% of families said they are new to social care services and had no experience to comment on at the moment.

Among families who had no social worker, families said the main barriers to accessing support were the fear of their children being taken away from them by social services and not knowing what support social services could offer them and their families. Others who desperately

wanted some support from Bristol social services said social workers did not contact them after the assessment was completed. Some families explained that it is over a year since they have heard from the social worker who completed their child's autism assessment or from the social services department. Somali families explained that they often do not chase their social workers due to language barriers. Others explained how there is never the same social worker and that there is always someone picking from where previous social worker left off.

Parents said the following about their experience with social care:

One parent said: "Not enough support, lack of communication the last 2 years, social worker who did the last assessment in April last year (2016) never came back to me, no paper work was sent".

Parent: "I only recently started getting social worker service, I had no idea what support I was entitled to. When social care got involved they offered me only 4 hours (support after school). Unless you ask they never help you".

Parent: "I have a social worker, but I don't always get the right support, when we need help in the house for safety they don't help".

Parent: "I have been waiting (for a) social worker for 3 years".

Parent: "No social worker, contacted them once, they said they will come back, they never did".

Parent: "I don't have a social worker as I am really scared of them."

### **What is your experience with schools and special needs provision e.g. statements and Educational Health Care Plan or EHCP (Question 3)**

The question on schools applied to all the 55 children whose families responded to the questionnaire. In terms of understanding the EHCP or the statement process, if a parent does not understand what this means for one child then they do not understand for their other children either. Understanding the EHCP is crucial for a child's progress, especially if that child has special needs. 62% of the 50 families we spoke with said they do not understand the process or the meaning of the EHCP and 38% of families said they do understand the EHCP. 20% of the families said they had had bad experiences with their child's school. 66% of families said they are happy with school and the support their child gets there. However, 56% of the 55 children/young people were attending a Special Needs School. 35% of respondents' children go to mainstream schools and 5% of the children go to other forms of education.

Parent: "My child isn't making much progress - I don't understand the process of a statement or the EHCP."

Parent: "I am happy with school's support with my child. His father deals with paper work, I don't understand the EHCP."

Parent: "My son gets one to one support; I recognized my son is different from his brother. My mother advised me, boys speak later, there is always someone in the family speaking late and they were different."

Parent: "We have no problem with school; I just don't understand the EHCP."

Parent: "Since he was in school he has learned very little. I was told he is learning but he had no skills to live with dignity. No interpreter was ever offered. School did not work for my son. There is no speech and language therapy services offered to us or occupational therapy. The social worker did not help, they asked me to stop the process of going through the EHCP because he was turning 23 years of age."

Parent: "I am involved with the EHCP process, I am happy with school."

Parent: "My daughter made so much progress; I did not understand the system before (but when I did my daughter made so much process."

Parent: "My families said don't rush for your son to have an assessment but nursery said he needs one to one (support at school)."

Parent: "I am happy with school; I don't understand EHCP, although we went to numerous meetings about the process."

#### **What is your experience with health care services? E.g. GPs, pediatricians and hospitals (Question 4)**

When the question about health was asked, 78% of families we spoke to said that they are happy with health services and 20% said they are not happy with health services. 2% said they do not know as they do not go to GP surgeries or the hospital very often. Although a large number of families said they were happy with health services, additional comments were made on how they think services could improve. One suggestion was providing a quiet area for their children with autism. Somali families with autism children said that if the waiting time for appointments was shorter, they could help when their child is anxious during their visit to healthcare settings. A large number of families spoke about how their pediatrician discharged their children immediately after diagnosis in a clinic. Somali families had expectations that doctors should have answers to their child's needs or problems. Families also said they were concerned about MMR and families had not attended follow up vaccinations for MMR as they were worried the vaccine was linked with autism.

Parent: "When they told me he has autism, I said that is it, I am not giving him any more MMR."

Parent: "I don't like the way they set up their assessment room in the clinic they diagnosed, it is overwhelming for my child."

Parent: "I am not happy with my GP, I feel the communication could be better, I don't always understand what they say."

Parent: "I am happy with the experiences I had with my doctor and the team, the process of the diagnosis. I was given adequate information such as about the Early Bird course."

Parent: "Taking blood is a big problem for us; they could've been more help at the doctors!"

Parent: "Experience with doctors has been good, they were helpful and supportive."

Parent: "My son had a sore throat and the doctors and health visitor helped!"

Parent: "My worry is families get discharge from doctors' (to soon)."

**Do you access other voluntary sector support? e.g. Supportive Parent, Contact A Family, Bristol Parent Carers, Cerebra, KHAAS, Wecil or Time to Share. (Question 5)**

When asked what services and support families received from the voluntary sector, 68% of families we spoke to said they do not get any support outside school and they do not access advocacy support. 32% of families we spoke to said they access help mainly from Cerebra and then from Bristol Parent Carers, Supportive Parents, Contact A Family, Family Fund, Barton Hill Settlement, Kids, and Caudwell Children. 2 families said they access the KHAAS holiday and weekend family support and activities. It was clear that many families did not know what support was available for their child with autism.

Parent: "Cerebra has been very helpful, I am worried now that their support has been reduced where will I go for help?"

Parent: "There is no interpreter, not with all organizations."

Parent: "I don't need help as I have my family."

**As a carer, do you access support for your family holistically because of your child with autism? (Question 6)**

The next question was asked so that we could identify if Somali families are accessing other support for their other children and also if parents are getting support to look after their own wellbeing. 90% of families we spoke to said that they do not get any support for their other children or for themselves as parents. 10% said that they get some support for our other children and for themselves.

Parent: "I had a carer's assessment."

Parent: "I don't know what is available or where to find out."



## **Do you feel that health and social services are providing a good service for your child with autism? If no how this could be improved? (Question 7)**

The majority of parents said they feel that local health and social care services could improve communication and information services. 54% of families we spoke with said that services do not get back to you when you call them and felt these services do not listen to them. Families thought information on what these services offer is not available at the locations where Somali families go or live. 22% of families said they are happy with health services and would not change the way things are run. 10% of families said they are not happy with local health care and that professionals either do not listen or do not understand them. Somali families affected by autism said they often struggle to get their health needs met (including dental problems, blood tests, not getting appointments and early discharges from clinics after a diagnosis of autism). 14% said they are not happy with social care services and Bristol City Council services are getting worse and worse. No family said they felt social care met their needs although this could be the result of a large number of families did not having a social worker.

Parent: “I want better communication with social care and health; I don’t feel they communicate with me.”

Parent: “Better understanding of autism would help so that I can better support my son.”

Parent: “I only want to see one doctor so that they understand my son. We see a new doctor every time.”

Parent: “Could be better support from doctors, parent guidance and signposting.”

Parent: “I (would) like to see social workers return my calls.”

## **Have you experienced any particular barriers when accessing health and social services as a Somali parent? (Question 8)**

We asked families whether being a Somali parent meant facing significant barriers in terms of accessing the right support for their child with autism. 84% of families we spoke to thought they did face significant barriers, including:

System barrier, language barrier and a lack of understanding of autism and how to support their children and other family members affected. The social exclusion that came with the disability meant that families felt in a disadvantaged position to access adequate support. Families felt that every service needed chasing or following up and this was just not possible because they do not speak the language and because they had a lack of understanding of the condition and right provisions. 16% of families we spoke to said they do not face barriers relating to the fact that they are Somali parents.

Parent: “Yes, system barrier, it is difficult to navigate the (health and social care) system.”

Parent: “There are so many things I don’t understand.”

Parent: “Yes, because I just don’t understand the system.”

Parent: “The impact of (having a) child with autism affects the whole family, there should be a way to increase families’ understanding of autism. I see the barrier of all barriers (as) understanding the autism. The community needs help to understand about our children’s autism.”

Parent: “Due to language barriers, I can’t access help, it is very isolating. I just don’t know my rights; if I was in Somalia I would have known what to do and how to help my child.”

## **SUMMARY OF FINDINGS**

The increased number of Somali children diagnosed with autism compare to other communities is something that raises questions in Western countries (Barnevik-Olsson et al 2010, Hewitt et al 2013, Bolten et al 2014, Fox et al 2016, Selman et al 2016.) This report aimed to gain deeper understanding by unpicking how much Somali families understand the condition and identify the specific barriers that prevent Somali families from accessing early interventions and how to best support their child with autism. Somali families felt vulnerable and marginalised in accessing services, despite increasing numbers of Somali children being diagnosed with autism, and they experience cultural barriers, system barriers and language barriers.

- 40% of families we spoke with said that they still do not understand what autism is. 8% of respondents thought autism is an illness or a mental illness and 10% thought autism meant being different or having language needs or problems. Overall, 58% of the families we spoke with did not have a clear understanding of the condition. This report found that the biggest problem for families was the lack of understanding, and this lack of understanding led on to other barriers in the development of their child, resulting severely autistic children costing society in general a fortune in the longer term..
- This report also identified that Somali families with an autistic child did not trust service providers so families were already in disadvantaged positions. 50% of the families we spoke with said they do not have a social worker mainly because they were scared this could lead to their child being taken away. 16% of Somali families we spoke with said social care do not respond to them and 10 % had bad experience. Of the families we spoke with, 76% were not accessing any social care support. This highlights a major concern and inequality in that families were not accessing services and the whole family was impacted.

- This research found that 62% of the 50 families we spoke to do not know what the EHCP means. Although this document is new to all families and local authorities, the Somali community faces extra difficulties as they do not know how to seek advice, guidance and resources to understand how they can best meet the needs of their child with autism.
- With regard to health care services, the majority of Somali families we spoke to were happy with services. Families did comment that better communication could improve the wellbeing of families as a whole. One family said that they decided not give their child anymore MMR vaccinations after the child's diagnosis: although this was only one family, this has raised alarms that service providers need to be using appropriate channels to raise understanding and to build trust. Families find it easy to believe myths and rumours when they do not have access to information and the evidence.
- The study found 68% of Somali families affected by autism are not accessing voluntary sector services and 90% of families are not accessing any support for their siblings or for themselves as carers. This meant that commissioned services for families with autism such as short break services are not very accessible for Somali children with autism. These organisations need to reach out to the Somali community to raise awareness of the support Somali families can access.
- Communication, lack of information and listening were recommendations made by families for improvement by health and social care services. 54% of families we spoke with believed this was the way to improve their child's developmental progress.
- The report found that Somali parents believe being Somali (84%) significantly affects their access to services because of language barriers, cultural barriers and system barriers. Not understanding autism, not speaking/reading English language fluently and not knowing where to seek help or information made it more difficult for them to get support and services for their child.

## **RECOMMENDATIONS**

1. Moving forward, we recommend that professionals in the health, social care, education and voluntary sector receive tailored training to build better understanding of the challenges faced by Somali families affected by autism.
2. Secondly, we recommend educating the community as a whole to raise better understanding of autism to reduce stigma, isolation and increase access to early intervention. This includes working with mosques clarifying the role of faith and the role of early intervention and treatment.

3. Public Health and/or Bristol CCG introduce workshops around the risk of Measles and other diseases. This would also need to be community specific and culturally sensitive.
4. Schools should introduce workshops on EHCP so that Somali families understand the process and to ensure that their children with autism receive support at school. This would need to be culturally friendly and tailored to Somali families' needs.
5. Social care should introduce a block of 3 sessions, each 3 hours long, for newly diagnosed Somali families affected by autism. The block of sessions can be one to one for the family in their home environment to help understand the condition, signposting to voluntary sector support and help with forms. Sessions would need a Somali speaking practitioner and be focused on building understanding of the process ahead. This could stop Somali families worrying that their child would be taken away, improve trust between the Somali community and Social Services and increase the likelihood of families seeking support early on. These families might not need a social worker at all. Sessions could include translations and pictures so that can help families continue to help their child achieve their potential.
6. Higher Education institutions should engage in research to establish whether there is a higher prevalence of autism in the Somali community and if so why.

## **Disclaimer**

This report relates to Somali families consulted at a specific point in time.

This report is not representative of all Somali families affected by autism in Bristol (only those who contributed their views during our engagement.)



## **Appendix 1: Full Results**

### **Do you feel you understand what is wrong with your child or know what autism is? (Question 1)**

Understand autism	42%
Don't understand autism	40%
Autism is being different and having language difficulties	10%
Autism is mental illness or an illness	8%

### **What is your experience with social care/social services? (e.g. do you get enough support from social services outside school hours?) (Question 2)**

Don't have social worker	50%
Did not heard back from social worker after assessment	16%
Had bad experience	10%
Good experience with social worker	12%
Social care support is minimal	8%
New to social care service	4%

### **What is your experience with schools and special needs provision? (e.g. statements and Educational Health**

#### **Care Plan or EHCP) (Question 3)**

#### **Experience with schools**

Happy with schools	66%
Not happy with school	20%

Others	14%
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**Statement or EHCP**

Don't understand Statement/EHCP	62%
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Understand Statement/EHCP	38%
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**Type of education**

Special need schools pupils	56%
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Mainstream schools pupils	35%
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Other form of education	5%
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Others	4%
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**What is your experience with health care services?  
(e.g. GPs, clinics and hospitals) (Question 4)**

Good with health services	78%
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Not happy with health services	20%
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Don't know	2%
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**Do you access other voluntary sector support?  
(e.g. Supportive Parent, Contact A Family, Bristol Parent  
Carers, Cerebra, KHAAS, Wecil or Time to Share)  
(Question 5)**

Access voluntary organisation support	68%
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Not accessing voluntary organisation support	32%
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**As a carer, do you access support for your family holistically  
because of your child with autism? (Question 6)**

Don't get holistic support	90%
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Get holistic support	10%
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**Do you feel that health and social services are providing a good service for your child with autism? If no how this could be improved? (Question 7)**

Health and Social Care services need to improve	54%
Happy with health	22%
Not happy with health	10%
Not happy with social care	14%

**Have you experienced any particular barriers when accessing health and social services as a Somali parent? (Question 8)**

Yes	84%
No	16%

## Appendix 2: General Demographics

**Do you or your partner consider yourself disable?**

Yes	4%
No	96%

**How many children do you have? Between all 50 families** 210

**Many children do you have with disability?  
Between all 50 families** 60

**Has your child been diagnosed with autism?** 93%

**Getting asses** 7%

**Gender of children with diagnoses of autism**

Boys	82%
Girls	18%

**Age of children with autism** 3-24yrs

**Gender of parents took part survey**

Male	2%
Female	98%

**Marriage or civil partnership status**

Married	62%
Separated	18%



Divorced

20%

Parent Age range

19-50yr

### **Appendix 3: Name of Social and Health Services Mentioned in Report by participants – Context!**

#### **Primary Care: GP Surgeries**

##### Bedminster Health Centre

Good experience. They can't do anything about the autism. Another participant feedback from doctor is too much to understand even with translator.

##### Charlotte Keel Health Centre

Difficult to get appointments, communication is not great, always difficult to understand Dr. One participant reported when getting medications from GP they don't make it easier

##### Eastville Health Centre

Good services

##### Fishpond Family Practice

Blood test is a problem, GP don't understand the autism

##### Gloucester road Medical Centre

Good services

##### Horfield Health Centre

No problems with service

##### Hotwells Surgery

GP and Pediatrician very supportive

##### Lawrence Hill Health Centre

Difficulty understanding GP

##### Lockleaze Health Centre

Waiting time too long

### Montpelier Health Centre

Helpful and supportive,

### Wellspring Health Centre

One participant talked about seeing too many Doctors and how it is a problem by keep repeating child diagnoses.

### **Secondary Care: Clinics**

#### Eastgate clinic

Participants said diagnostic process is too long and quite far apart. Discharge us years ago.

#### New Friends Hall

The process of getting support is too slow, it takes long to get the right support

#### Westgate House

Participants said that they had issues around their child having blood taken, appointments were too long

### **Hospitals**

#### Bristol Royal Infirmary

Happy with services, participants mention how they don't really go to GPs or doctors very often.

Southmead Hospital

St Michaels Hospital

### **Social Care services**

#### Adult Social Care/ Children and Young people

Not enough support from social workers, they don't return calls or come back when they see you. Lack of communication, Difficult to get hold of them.

## Appendix 4: Report Launch Event (12/05/2017)



On the 12 May 2017 the findings of this report was launched, over 70 participants took part including parents who participate the study, practitioners, Commissioners, Councilors, schools, health professionals, voluntary organizations and social workers. We had talks from Cabinet member for education, Bristol University and NIHR CLAHRC West, Public Health and Somali

Forum. After lunch the rest of the time was spent on workshops. The whole event was captured by drawings as shown above.

Cllr Clare Hiscott: Cabinet member for education



Solutions were explored on how to improve accessibility of services for Somali families in four areas;

### Education

Education is an area where Somali families have difficulties accessing services, during the workshop session the following three solutions were suggested;

- During initial assessment, a simple leaflet explains the condition, it can be translated, perhaps, video clips that explains the condition.
- Share and support coffee mornings in schools, chance to meet other parents to share, and practitioners can come along to talk
- Make close links with other service providers to integrate services such as AI as a point of contact

### Health

The following approaches were discussed to improve access to health services;

- Translators
- Link workers or community lead specialist organization; health visitors, GP and pediatrician's need to have better understanding of cultural perspectives



- Making pregnant women aware of what autism is so that signs and symptoms are clear to them

## Social Care

The following solutions were suggested in the workshop for social care support;

- Early intervention, these include support when a child is diagnosed so families have better understanding on how to support their child
- Access to social worker
- or a named point of contact to refer families to services

## Voluntary organizations

Voluntary organisations offer so much support and signposting however 68% of Somali families don't access these services. The following were discussed for better accessibility;

- Voluntary organisations running drop in sessions with AI so that parents are supported with language and also know what other services is available in an environment that they trust.
- A Hub to access information and find out what is available under one roof
- Enabling environment to integrate to the system

Fiona Fox: (NIHR CLAHRC West)



Mohamed Elsharif: Inner City Public Health



Abdul Ahmed: Chair of Somali Forum



## Roopindera Kaur: Health Watch



## Nura Aabe: Autism Independence





Notes from the event



Panel Discussion



More notes





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## Author

Autism Independence (AI) is a community group that supports Somali families affected by autism. Autism Independence is led by Nura Aabe. Nura came from Somalia to the UK aged eight, and has a child with autism herself. She campaigns for wider awareness of the issues surrounding autism in the Somali community. This report was written by Nura Aabe MSc and was partly funded by Healthwatch.

## Special Thanks

Special thanks to all the families who participated this study, without your support it would not be possible. Thank you to our report launch event sponsors Public Health Bristol and Ashley Housing.



