

Invisible families

Experiences of minority
ethnic families



Autism, including Asperger syndrome, is a lifelong developmental disability that affects the way a person communicates, relates to others and makes sense of the world.

People with an autistic spectrum disorder experience problems with social relationships, communication and imagination. It is a wide-ranging condition.

The common characteristics of ASD are:

- difficulties with social interaction and making friends, or appearing aloof and indifferent to others
- difficulty with communication, including not fully understanding facial expressions, gestures, or tone of voice.
- difficulty in understanding the world, social norms and others' feelings or experiences.

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compiled by
Prithvi Perepa



Foreword

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Autistic spectrum disorder is a lifelong developmental disability that affects a person's communication skills, social understanding and ability to think in a flexible way. As a mother of an autistic child I know all too well the struggles each of us has to manage often without sufficient support from educational and social services establishment. It is a wide ranging condition and not well understood within the minority community, resulting in the child not receiving the full range of services and facilities that they are entitled to.

Britain is a multi-ethnic, multi-lingual community. The latest census shows that 8% of Britain's population belongs to ethnic minority communities. Based on this figure it can be estimated that there will be about 18,800 ethnic minority families affected by autism in London alone.

With such high numbers, there are still only a few families that access

support services. I believe this happens for a variety of reasons, including language barriers which prevent comprehensive understanding of the services to which they are entitled, fear that it's a private matter and they should cope within the family, and also from a false perception that the families have access to the extended family network and support. Although there are good provisions in place to support families with autistic children, the services for ethnic minority children remain largely patchy and inadequate in meeting cultural and religious needs.

I welcome this effort of The National Autistic Society in wanting to engage families to find out what particular needs they would like addressed. The aim of this booklet is to raise awareness about the needs of families as well as to share information so that it can give confidence to those families struggling to provide the best for their child whatever the spectrum of the disorder. I hope as result of this booklet families will feel empowered to ask for services that are theirs by right.

*Baroness Uddin (of Bethnal Green)
House of Lords*

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2 Pace

Pace



Pace was our first child. When he was young he was very difficult to manage. We did

not have any idea what his difficulty was until he was three and a half. Before he got a diagnosis of autism, my wife, Ru, had never heard of the condition, and my own knowledge was limited to the film *Rain Man*.

As soon as we came to know about his condition, we started reading about autism. The diagnosis was a shock and it was difficult to get to grips with. All the literature pointed to the fact that it was a lifelong disability, and painted a depressing picture.

At that time, Pace was already in a mainstream school nursery. The school did not want to keep him without a statement (which took about a year to arrive after diagnosis). The nursery said that either one of us should come with

him or keep him at home. So for a period, Ru had to stay there every day with him along with our baby daughter. It was a very stressful time; he had to stay at home whenever his mother or sister was unwell.

We had no social networks here. My parents were in Devon and Ru's family was in China. Initially, parents of some of the children at the nursery invited us to their home. But that didn't last long. We did not feel confident enough to invite them to us in return. Our son would often scratch other children; he did not like playing with anyone. If others had a toy that he wanted, he just grabbed it.

By the time he was five, his sister, aged two by then, was also diagnosed with autism. Ru became very depressed and was referred by the health visitor to a counsellor as well as to social services. Until then we were not aware of the support services which were available.

After we had been referred to Family Link volunteer service, we found a link family who started providing respite, first for Pace, and now for our daughter, too. Before that we had paid to get some respite care, and we worked in shifts to look after the children.

As for our daughter, it was easier to get services for her as by that time we knew where to go and what to ask for. This was unlike Pace's case: although he got his diagnosis at three and half years of age, the provisions were not in place till he was five.

Family reactions

The reactions from our families were also different. While my [Richard's] parents found it initially difficult to cope with, they soon started reading about it and tried to understand. Ru's parents and family found it more difficult. There is little literature about autism in Chinese. Within the Chinese community people find it easier to accept physical disabilities. They find it difficult to accept conditions where there is no physical evidence. The community either views the parents as bad parents, or thinks that the child is just being naughty. Added to that, Ru's family was living in China and did not have sufficient regular contact with the children to understand their problems.

Having two children with special needs makes it more difficult for us. For example, they used to go to a social club with one-to-one helpers. But then the club found our daughter a bit 'challenging'

and became unwilling to keep her. We had to stop taking her and our son as well, because it was creating problems at home. Similarly, our son cannot take part in any of the after school activities, as they are not suitable for our daughter. It is not possible for us to wait for her at home and then immediately go to school, which is a long way away, to pick our son because there is only one of us at home.

Now both our children go to a specialist unit attached to a mainstream school. It has made a difference having staff who understands their needs. Before that, our son used to go to a special school; it wasn't easy to gain admission from there to the special unit. When we were struggling to get him this school placement, Autism London advised us to write letters to different people in authority, which we did. We don't know if that quickened the process. Some parents are more active and will push for services for their children. We are not like that; maybe that makes it more difficult for our children.

Richard and Ru-hua

4 Ope

Ope



I didn't know much about autism or Asperger syndrome until my son

Ope was diagnosed with autism at the age of four. As a little boy, Ope babbled and later picked up words like 'mummy, goodbye, mummy back', but then all of this stopped. His behaviour started getting strange as well.

When Ope approached his third birthday one of my friends asked me whether I thought Ope was autistic. I had never heard this word before and so mistook this for artistic.

I was slightly confused at this until my friend explained to me that autism was some sort of communication disorder. I wanted to understand this better and looked up the word in the encyclopaedia.

After reading about the disorder I came to the conclusion that my son was not autistic. Because of my confusion, I decided to contact the health visitor. This started the long process of exploring if Ope had autism.

After consultation with the GP and other professionals Ope was diagnosed with autism. Even after getting the diagnosis, I didn't speak to anyone about it. Within the African community autism wasn't really heard of, so there wasn't anyone that would really have understood what I was going through. I didn't know where to go to or who to ask for help.

Lack of understanding

Extended family members didn't understand Ope's behaviour either. Friends and family tried to reassure me that his behaviour was quite normal and it would be good for him to run riot like boys do. It was only when things didn't pick up in Ope's behaviour, that my family started coming to terms with the fact that he was different.

One of the main problems that I had was the comments passed by members of the public which were often judgemental about

Ope's behaviour. They would usually see him as a badly behaved child and not understand that he has autism.

There needs to be more education about autism so that people understand it and don't pass such hurtful judgements. I feel that communities need to be educated to create a better understanding about treatment and support.

Having just moved into Haringey, it was quite a struggle for me and my three children on our own. I did not receive any support and there was nothing at all to access. I later found a black parents' group that was set up in the local area.

Developing support

I got involved in developing the group about four years ago. It really helped me and others as there was such a need for this group. It provides support to isolated parents, and the members understand some of the cultural issues that have an impact on families.

There are also certain cultural and religious beliefs that I have encountered in my meetings. Within the African community some believe that having a child with a disability is a generational

curse, which is similar to some other cultural communities.

I feel that there needs to be more work done with black and minority ethnic communities to help them help themselves. The relevant agencies need to 'own' some of this work.

Ronke

6 Charin

Charin



When Charin, our son, got his diagnosis of autism, we went through the process of grieving. We had no family living close by and had to face it head on. Once we began to accept the situation we started to search the internet to find out about autism and PECS (Picture Exchange Communication System).

The local speech therapist visited and said that Charin would never speak, but she knew nothing about PECS. We had to pay for in-service training at our home which teachers from his school attended. So the onus was on us, Charin's parents. The local authority is always cutting costs, which is sad.

Understanding about autism within the Sri Lankan community and the wider community is very limited. We get pity from them: we certainly want empathy from

them, but not sympathy. We are ready to let go of part of our cultural roots if the wider community is also willing to take a few steps towards understanding us. Even though we are British, there is a bit of 'Sri Lankan-ness' in us. People need to place themselves in our shoes to understand this, and our needs.

We have taught Charin only in English. We want our child, even though he is autistic, to communicate in English because we live in Britain. Our son is a British Asian. For children with Asperger syndrome, English as well as their first language could be taught.

Community languages

My family is blessed in that we can stand up and talk. But if you don't talk or if you cannot, what happens then? Some families cannot speak English. How can they be reached and helped to access services? That is why we need the information in community languages.

We live in a multicultural society and in some areas minority communities will soon be in the majority. But what are the local authorities doing to provide for these families? Why is all the work

left to the voluntary sector? The Government needs to take responsibility for it. If you are from an ethnic minority, you are bottom of the bottom of the pile: when it comes to accessing services, you have to struggle even more.

Role models

Not only is there a need to provide information at grass root levels in all ethnic languages, we need role models from ethnic minority communities in the professions such as teaching, speech and language therapy. Parents need to be included in the process of education, involving interpreters if required.

We have not even started thinking about further issues in autism. What about autism and the elderly? Or autism and the workforce?

These issues will always be there as long as society as a whole cannot cope with any kind of disability. Debates on these issues need to start in 2005 to bring about changes in the attitudes of people across society. Parents, carers, and individuals with autism have to lobby to bring about that change.

Our son is part of the community now. At the beginning it was a big learning curve for all those dealing with Charin. There are very few Asians in his school, but he is accepted and loved for his character and personality. He is an inspiration to the others. The school, from having no training in autism, has turned into a centre for excellence with special facilities for children with autism. It is even building a sensory room.

Ivan and Charika Corea

8 Aaron

Aaron



My understanding of autism was limited to the film *Rain Man* until my son

Aaron received his diagnosis at the age of 18 months. With hindsight, a lot of ‘coding’ in the assessment reports suggested Aaron had autism even before he was officially diagnosed.

In a way Aaron is defenceless. For instance, if anyone mistreats him, he is not always aware of their intention. His limited understanding of language does not allow him to see beyond the words. We always need to advocate for him as he is not able to defend himself.

Currently, he is at a boarding school on weekdays and comes home on Fridays. His twin sisters enjoy seeing him when he comes home, although they are still slightly wary of him. I think this arrangement benefits everyone.

The twins benefit because they get attention from us and Aaron enjoys being at the school.

Since he is at a boarding school, he is classed as a ‘looked after child’ by social services. He has had many social workers over the years, but most of them have understood his needs. We have had more difficulties with education and health services.

The disadvantage of having so many services involved is that they are disjointed. The assessments from different services often go over the same issues and ask similar questions. This means that we have to repeat our difficulties, and live through the pain again and again. The problem is that there is too much assessment and too little service delivery.

Some procedures for assessment and delivery are also insensitive to the needs of children with autism. For example, when Aaron has hospital visits, I try to prepare him by going through a Social Story™ with him, and I inform the hospital staff about his needs but not all staff or services take this approach on board. This can end up with Aaron getting frustrated and being denied the access to services he requires.

Services need to listen to what the service users and their families have to say about their needs.

Our extended family members don't know how to handle Aaron. Some of them may want to, but don't have the physical stamina to do so. A relative asked me once: "When is he going to get better?" When I replied that he would not be 'cured', the extent of Aaron's problem suddenly dawned on this person and I could see the blood drain from his face.

Aaron is a cheeky, delightful child. I have expectations of him just as I would of any boy. I would like him to have a bar mitzvah when he is 13. Our local Rabbi understands Aaron's limitations and we are hopeful that we can help him memorize a few prayers.

A blessing

Within the Jewish community having a child with a disability is often seen as a blessing, especially by those who are particularly religious. It is a sign that God feels the family can cope. In the long term I would like my son to live in a Jewish environment. I am not overly religious but I feel that a Jewish community will provide him with community and family values,

which are sadly missing in mainstream society.

Mainstream services carry out assessments which take into account religious and cultural aspects. However, they may not have the expertise and the appropriate knowledge to deliver the required services. If the family is orthodox, then they may also have special requirements for food and prayers, for example. There is a need to employ staff from diverse cultures so that such needs are understood and respected by every service.

Whatever I have been able to achieve for Aaron has been possible only because at every stage I have explained to the service providers about our needs in very clear terms. I believe in working in partnership and have provided any information they required through emails, letters, and phone calls. However, when things did not work out, I did not shy away from making a complaint.

Robert

(Names have been changed as the family wishes to remain anonymous)

10 David

David



I have twin sons Jonathan and David who are 14 years old. We are from a Nigerian

background and live in London. My son David was diagnosed with autism quite early, when he was just three years old. Before this I didn't know that much about autism.

Having twins allowed me to compare them with each other. When the twins were three, Jonathan started picking up speech whereas David didn't: I realised that his speech was a bit delayed. I was told that twins sometimes did have some speech delay. I thought that this must be the case and there was nothing to worry about. But that was not all; there were also some problems with his hearing. Sometimes David would not respond to any sound.

At David's and Jonathan's playgroup, the staff commented

that they were quite concerned with David's behaviour. We were then referred to an Early Years Centre.

Getting information

As any parent, I tried to get as much information as possible to understand issues around developmental delay. It was by chance that I stumbled on a couple of articles in *Woman's Own* magazine regarding autism. While reading the article I recognised some of the behaviour patterns they described were shown by David, and subsequently asked at the Early Years Centre if David could have autism.

After a lot of questioning they confirmed that this could be the case. David was then referred to a specialist in children's disorders at St George's Hospital where more tests were conducted. He was given a diagnosis of classic autism.

Throughout this period I received support from the charity Contact-a-Family. By the time David was diagnosed a new autistic support group had just been started by them which was helpful.

As for my family, I still feel that my parents don't fully understand

what autism is about and they tend to focus more on the physical aspects like his speech. They will regularly ask if his speech has improved: “When will he get better?” Nevertheless, they are extremely supportive of us, and have learnt to deal with it in their own way.

Becoming an advocate

Since David’s diagnosis, I have become a full-time advocate for my son’s needs in terms of care, schooling and his future. I have also met a number of families belonging to minority communities who found it very difficult. One of the main issues regarding black and minority ethnic communities is that some families do not like to ask for help and support. Within their culture there are issues of pride and the role of the family particularly when it comes to caring.

Therefore I feel it is important that projects are set up to establish outreach in different communities to support, network, educate and raise awareness about autism. This will ensure that the information is dispersed and that families who deal with disability can be supported more within the community.

Another of my concerns is that there is a new push for mainstream schools encompassing disability and a decrease of separate specialist schools. I was worried when David was at the end of primary school that he may be sent to a mainstream school and he would not receive the care that he needs. I was worried about the danger of racial stereotyping. David could be perceived by some as a young angry black man and not as a child with autism. This could have affected him getting the support he needs and would also lead to him being unfairly labelled. Fortunately, he got a place in a secondary age special school with a unit for autism attached to it.

This is my family’s experience. Through perseverance and hard work we have helped David get through many obstacles to a point where he is happy and settled.

Tayo

Rakesh



My son Rakesh has been diagnosed with Asperger syndrome.

When Rakesh was a baby he went through all the stages from crawling at 11 months to walking at 18 months as other children do. He seemed to be okay until he got to reception class where he started having behavioural problems. Things started getting worse at the school and the headteacher blamed me for my son's difficulties. We did not receive any help from her.

Problem recognised

I decided to take him out of state education and put him in a private school for children with mixed abilities. I still did not realise that he had any major difficulties.

When he reached the age of 13 his difficulty with making and

keeping friends became clear. This is when I realised that there was a problem and I decided to take him to an educational psychologist privately.

As Rakesh grew older, things became more difficult. By the time he was 14 the situation had got worse. I had to take him out of the education system and opt for home tuition. When Rakesh reached the age of 16 he started going to a local college to do an entry level in literacy, but here again he had some problems with his peers. Eventually, he managed to settle down reasonably well.

Now Rakesh is settling down and actually has a part-time job. He also has a great passion for drama, arts and music, especially Bollywood!

Close-knit family

It has sometimes been a struggle for our family but we have got so far without any external help or support. This has been possible because we are a close-knit family and I dedicated my life to him. The only service that Rakesh uses is a counsellor for a couple of hours every three to four weeks.

Since Rakesh has been diagnosed I have realised that my mother could have been on the spectrum

as well. She has never been diagnosed. Our family and friends often treated her as an outcast, possibly because they did not understand her difficulties. It was probably easier for them to exclude her than understand her.

Rakesh will be 18 soon and I feel he needs a bit more external contact, to intermingle with his peers. Until recently we hadn't gained access to any other services. It is not as if I have not tried seeking assistance. I did try to obtain help around eight years ago, but it was not a pleasant experience. Because of the difficulties I encountered at that time, I did not try to get any help or advice for a long while.

Now I have started to access some support services like Prospects, which is the NAS employment service that specialises in finding work for people with Asperger syndrome.

Community support needed

More supportive groups within the Asian community could also have helped our family. Disability is sometimes seen as a taboo. Because of their religious and cultural beliefs, some people may interpret disability within the family as some sort of

punishment or test for the family. Education about the condition is of paramount importance within the community.

There is such a need for communities to come together and help and support each other and this could be initiated by agencies and service providers.

Aarti

(Names have been changed as the family wishes to remain anonymous)

Nathan



We can't think of any specific issues that have been different for us as parents of a child with autism because we are from an African-Caribbean community. It could be an issue if we have to think of employment for our son. It might have been an issue if Nathan was going to a mainstream school, but he has always been in a special school.

Lack of awareness

We had to push to get him into a special school. Even getting him recognised as autistic was difficult. We had difficulties with the education department as well. My husband, Les, had to sit there in the office to get what Nathan needed. They wanted to give him a statement and support in a mainstream school. But there is no way Nathan would have survived with his level of need. It was really we who had to push for him.

We have found that there is little recognition or knowledge about autism among professionals, because it is not a physical illness. As autism has been around for so many years, you would think in their training professionals would have touched on it a little bit. But when there is no physical sign like a wheelchair, they are dismissive.

We have never had to send him to respite care. When all our children were very young, we paid for a respite worker to help us out. He always had his family and friends around him. We have a few friends and relatives. There have been instances occasionally when they have not known how to look after his needs due to lack of knowledge, but basically they are very accepting.

When Nathan was young, I [Denise] worked part-time and then would take him to the language unit. Les was at home because of ill health. We had financial problems at that stage and our housing was not appropriate either. We were near a railway track, which was not safe. But we managed to push for a move by approaching all the professionals involved. It was mainly because of Nathan's autism that we got the house we're in now.

He has reached 18 and says, "I am a big man." Planning his future is our biggest worry. He will finish college next year and we have been attending reviews to plan what the next step should be. Once young people hit the age of 18 the funding stops, the support stops, everything stops. We really don't know what to do. No one has come up with any suggestions. Will Nathan be at home playing on a computer this time next year? I wouldn't want that.

His future

We're not sure he'll be able to cope in a working environment either. He doesn't always understand what he is asked to do. He can only follow simple instructions. He does gardening at the college, but would he want to do it as a career? We just don't know. His biggest talent is music and dance, but he can't make a career out of it. We'd like to find avenues where he can realise his potential. But services still have barriers and don't always take account of individual needs.

The Connexions service provides support up to the age of 25 years, but my argument is why should they stop at that age when he is going to need support throughout his life? We are not going to get any younger.

Our ideal situation for him is to be in a supported independent living home, where he can learn to live independently. As parents we don't know what is there. We want everything for him that we have – a house, employment, a relationship. I think Nathan would want to have a girlfriend, and all those things that are 'normal', whatever that is. Can services provide that? No, systems take over individual needs.

His sister and brother are very supportive of him, but we would not want to burden them with Nathan's care. It should not be left to us. We will be with him for as long as we can, but one day... and he would want to get along with life as well. We want services that fit to his needs.

Denise and Les Pilgrims

Sanjeev



My brother Sanjeev has a diagnosis of autism, along with a range of other disabilities.

Throughout my brother's 35 years, our family members have been the main carers for him. He now lives in a supported living scheme in his own home. Sadly, our mother passed away a while ago, so now I am his main carer.

My experiences have been quite difficult. I am conscious that it is my role to ensure that Sanjeev receives adequate care. I feel that many labels are put on Sanjeev rather than his being accepted as an individual. His label of 'special needs' has coloured everyone's vision: they look at his disability and miss the person in front of them. His difficulties seem to define him.

I feel that within the Asian community disability stands out like a sore thumb and the

community tends to feel sorry for the family. Some just stop and stare when I go out with my brother. Our experiences have made me realise that there needs to be some education within the community about the disability. Different services need to invest in this process so that people can get some support from their cultural groups.

My mother used to attend some cultural support groups but because of family responsibilities, she found it hard to attend such meetings on a regular basis. This was a shame because the support would have been helpful for her.

Healthcare problems

When going for Sanjeev's hospital appointments, we have been told by the social services department that the hospital would prioritise him. But this has never happened: on each of our visits he has had to wait a long time, which he cannot manage, so he leaves without getting the healthcare he needs.

Sometimes I feel that we are doubly discriminated against, firstly, because of the disability and then because of our skin colour. Some people who believe in stereotypes may think

that when I advocate on behalf of my brother to ensure that he gets the services he requires, I am trying to jump the queue because I am Asian.

Sanjeev is trying to be as independent as possible with the help of his carers and my family. I feel residential care is not suitable for my brother's needs. The majority of residential care services have been developed in a particular way which does not match the cultural values of our family. We felt the best option would be supported housing near the family home.

Sanjeev gets care on a 24-hour basis and carers come into his home. However, he now has diabetes and I feel that he needs more attention so that he eats properly. I cook his meals as the carers cannot cook Punjabi food – chapatti and curry; so really, I am still in an active caring role.

Appropriate services

My main worry is that some of the agency staff who are sent do not suit or fit the criteria needed. It is important that the carers are culturally appropriate. For example, if the carer spoke Punjabi it would be a real help. We have never been given the option for Asian carers who would make a

real difference for us. I have requested this, but I have been told that Asian people don't come forward for these kinds of caring roles.

It is important that there is a push to recruit carers from diverse backgrounds. There needs to be outreach work done within the communities to educate them about these services and carry out some positive action to encourage different sections of the community to apply.

I want more action, not just for my brother but for other families going through similar experiences and suffering as we do.

Nina Bedi

18 Afterword

Afterword

This anthology includes the stories of a range of families from just some of the minority ethnic communities resident in Britain. It offers a small sample of the issues which concern them. These stories can help us begin to understand the needs of minority communities affected by autism.

Many of the concerns covered in these stories are similar to the experiences of families in the wider community affected by autism, but certain issues deserve special consideration. Families who cannot speak English or have limited fluency in the language may not be accessing services because they are unaware of the existing services and support. Organisations will have to think about producing material in community languages to reach such families. Since not all families are literate in English or their own language, audio or video tapes may also be appropriate. As the cost of production could be high, service providers may have to think creatively about pooling their resources in producing such material.

The existing infrastructure of statutory and voluntary organisations including, for

example, education, health, religious and community centres, already have established links with many different communities. If such links do not already exist, they need to be made as the first steps to an inclusive service. These can be the channels through which awareness about the condition and about the support and services available can be conveyed. Greater awareness may help members of these communities to consider entering caring professions and specific measures could also be taken to encourage them to take up these roles. The development of outreach services working in these communities would help to break through existing barriers.

The wish for a culturally sensitive response appears in most of the stories. It is essential that all service providers have a basic understanding and training in the cultural needs of at least the established minority communities. However, it is equally important not to generalise and stereotype service delivery on the basis of ethnic background: listening to the user and matching services to the individual and family need provide the basis for good provision.

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Autism Helpline

(Language Line service available)
Tel: 0845 070 4004
Monday – Friday 10am – 4pm
The Autism Helpline provides impartial and confidential information, advice and support for people with an autistic spectrum disorder, their families and professionals.

Advocacy for Education Service

(Language Line service available)
Tel: 0845 070 4002
This service provides advice, information and support to help parents whose children are on the autistic spectrum to get the most appropriate educational provision for their child.

Branches

The NAS has 60 branches throughout the UK. To find out about your nearest branch call the NAS Development Team:
Tel: 0115 911 3360 (English only spoken)

Website

www.autism.org.uk
The NAS website offers a wide range of information on autistic spectrum disorders. Some is available in a variety of different languages.

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Baroness Uddin



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Autistic Society

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