The experiences of marginalised families with autistic children

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Executive Summary

Autism research has often fallen short when it comes to capturing the experiences of marginalised groups, such as those who:

▪ Belong to a minority ethnic community
▪ Whose first language is not English
▪ Come from economically disadvantaged backgrounds
▪ Are in the care systems.

The focus of this report is to understand some of the experiences of such families of the English education system and how practitioners work to support them.

A mixed-methods approach using Department for Education (DfE) data, surveys, interviews, online discussions and a workshop was used to identify some of the key challenges faced by the parents of marginalised children on the autism spectrum, as well as what support they need from schools. Education practitioners told us of the challenges they face but also where they had adopted effective working practices with these groups.

The most recent DfE data for England (2021/22) shows that 2.2% of the school population has an autism diagnosis as their primary need. Since 2015/16 that is increasing at an average of 9.5% per year. Nevertheless, some ethnic groups (e.g. Pakistani) have lower rates of autism diagnosis than one would expect; whereas other groups (e.g. White-British) have higher rates. Those children who have English as an additional language (EAL) are less likely to have an autism diagnosis. Over the last seven years of DfE data collection, on average 19% of the whole school population have EAL, but only 13% of the autism school population. More children on the autism spectrum are on Free School Meals (FSM) than the general school population. Averaged over the last seven years of DfE data, families with autistic children have a FSM rate of 28% compared to 17% for the whole school population.

We heard from marginalised families and the teachers supporting them that professional beliefs, cultural stigma, and confusion navigating the system were barriers to accessing diagnosis. Once a diagnosis is in place, challenges were experienced in navigating education systems, finding an appropriate school place, and accessing appropriate guidance and support. Families felt that this was a result of bias and racism, a lack of diversity in the school workforce and an under-resourced system. There was a sense of increased isolation for marginalised families, and difficulties faced on a day-to-day basis such as keeping their employment.

Teachers identified the current climate of budget cuts and post-Covid as being a generally challenging time that has hit marginalised groups the hardest. They felt they lacked the training and resources to support children and families from marginalised groups. Some schools found family liaison officers as particularly effective, especially if they speak other languages and/or are ethnically diverse.

The key recommendations from our study are that there is a need for more professional training, more diversity in the workforce and development of appropriate resources to support education staff. Further recommendations are presented at the end of the report.

1. Background

Marginalisation can take many forms. Our research at the Autism Centre for Education and Research (ACER), University of Birmingham, has been looking at children and young people on the autism spectrum and their families who may feel marginalised not only because of their autism but also because of their ethnicity and culture, economic status, level of English or being in the care system.

The Department for Education (DfE) data shows that attainment and outcomes vary against certain pupil characteristics. *The DfE publication Outcomes by ethnicity in schools in England – topic note 2022* reports that there is variation in GCSE performance in English and Maths by ethnicity status. The same DfE publication reports that children on Free School Meals (FSM -a variable used by DfE for deprivation) have lower academic attainment on average compared to their non-FSM peers. Not only attainment, but general educational experiences seem to vary based on children's cultural, linguistic and other socio-economic factors. For example, the Timpson review (2019) found that pupils from some minority ethnic communities, from lower economic backgrounds and children in need were more likely to be excluded from an educational setting. This can have a long-term impact in terms of life opportunities that these children and young people have in the future.

Within the government's Special Educational Needs and Disability (SEND) review green paper released by the DfE in March 2022, there was a recognition that the educational attainment and experiences of pupils with SEND are poor. The white paper '*Opportunity for all: strong schools with great teachers for your child*' suggested some sweeping changes. However, now that this bill is no longer being taken forward, it provides an opportunity to re-think how provision for children with SEND from marginalised communities should be provided.

While policies focus on single dimensions of marginalisation, there is less acknowledgement of the impact of marginalisation when more than one factor comes to play, such as children on the autism spectrum who also belong to a minority ethnic group, and/or come from a poor economic background, and/or are in care. The UK census data (2020) shows that there is a correlation between these factors. For example, families from some minority ethnic communities are more likely to belong to a lower socio-economic background. Therefore, some individuals can experience marginalisation at multiple levels. There has been a paucity of research that has focused on understanding the experiences of children and young people on the autism spectrum from such backgrounds or their families. We also know very little about the experiences of teaching staff working with such marginalised pupils and their families, nor the strategies they have put in place to provide support. The main objective of this research was therefore to understand the experiences of these families, and education staff working with such families.

1.1 What we did

This project included gathering new information as well as evaluating existing data. The DfE in England publish annual statistics on pupils and schools. Since 2015/16, this includes autism as a specific SEND category. Thus, it is possible to explore these data against other pupil characteristics, including ethnicity, language and FSM status. We used an analysis of these data to understand how such multiple factors can influence the experiences of pupils on the autism spectrum from these marginalised groups. We classified marginalised status in this project as: 1. being from an ethnic group other than White-British; 2. having English as an additional language (EAL); 3. being on free school meals; 4. and children in care. While ethnicity by itself may not marginalise a family, the interrelation with economic status and the impact of EAL in accessing resources can marginalise some families from minority ethnic communities. We therefore included this as a disadvantaged group. These four groups were also selected on the basis that they are represented in DfE data.

Along with looking at the DfE data, we conducted an online survey which was completed by 26 teaching staff working in English schools and 11 staff working for English local authorities. We conducted 20 interviews with teaching and local authority staff to provide more in-depth insights and 22 interviews with parents and carers of children on the autism spectrum. Parents and carers interviewed for the project had a child who is currently in an English school or who had recently completed education. Results from this data collection were shared with professionals via an online workshop that was attended by 30 professionals who shared more examples of good practice from their work and identified areas where further support is required.

2. Rates of autism in English schools

The most recent DfE data (2021/22) shows that 2.2% of pupils in English schools have an autism diagnosis. This is over twice the 1% prevalence rate quoted in the government's current national strategy on autism 2021-2026. Over the seven-year period of published DfE data on the number of autistic children in English schools (2015/16-2021/22), the number of pupils on the autism spectrum has been increasing on average by 9.5% per year. Compared to other SEND categories over the same seven-year period, autism has been increasing faster than Social Emotional Mental Health (4%) and Speech, language and communication (5.1%) needs. According to the DfE data the total number of pupils on the autism spectrum in English schools for 2021/22 was 182,493 and 57% of them had an Education, Health, Care Plan (EHCP), which is the highest rate of EHCPs compared to any other SEND category.

2.1. Rates of autism in children from marginalised communities

DfE data suggests that there are disparities in the rates of autism diagnosis based on cultural and linguistic backgrounds of the child. There are 18 options within DfE for ethnicity. Table One shows a selection of ethnicities, both in terms of the whole school population and for the autism population specifically.

The data in Table 1 are calculated as average rates over the last seven years of DfE data collection (2015/16-2021/22) for ethnicity in the whole school population and specifically for autism. In these data, we can see that those classified as White British make up 66.1% of the whole school population but 70% of the autism population.

Table 1: Ethnic representation in whole school and autistic populations

Ethnicity Classification	Ethnicity rates in the whole school population (%)	Ethnicity rates in the autism population (%)
Bangladeshi	1.8	1.8
Indian	3.1	1.8
Pakistani	4.4	3
Black African	3.8	4.7
Gypsy Roma	0.3	0.2
White British	66.1	70
Other White	6.4	4.5

Over-representation is seen in Black African children as well, who make up 3.8% of the whole school population but 4.7% of the autism population. Nevertheless, for other groups there may be an under-representation, for example in the Other White (6.4% whole school vs 4.5% autism), Pakistani (4.4% whole school vs 3% autism), Indian (3.1% whole school vs 1.8% autism) and Gypsy Roma (0.3% whole school vs 0.2% autism) children. The Other White category mainly consists of children from White European families.

To understand the potential impact of language abilities on autism diagnosis we explored the differences in those identified as having EAL within the DfE data in England.

Over the last seven years of DfE data collection, on average 19% of the whole school population have EAL, but only 13% of the autism school population. This suggests a lower-than-predicted percentage of autistic children with EAL.

These differences in diagnosis rates based on ethnicity and language highlight that there could be issues related to stigma of having an autistic child in some communities or lack of knowledge and understanding amongst professionals about autism in different cultural and linguistic groups. This may also highlight broader issues in accessing services, so we turn to this next.

3. The experiences of marginalised families in English schools

Parents from all the different marginalised groups in our study reported that they felt unsupported by education, health and social care systems. Our data from parents, teachers and local authority staff identified several factors that may be unique to or disproportionately impact marginalised families with children on the autism spectrum in English schools. These can be summarised as:

▪ Accessing diagnosis and services
▪ Experiences of the education system
▪ The financial impacts
▪ Family and wider impacts

3.1 Accessing diagnosis and assessment

According to the National Health Services (NHS) Waiting Times statistics, as of June 2022 there were 122,187 people with an open referral for an autism diagnosis, which is an increase of 38% compared to June 2021. By June 2022, of those with an open referral, 85% had referrals that had been open for at least 13 weeks. Anecdotal reports suggest that many individuals and their families are turning to private clinics for a diagnostic assessment (Underwood et al., 2022; Russell et al., 2022), in part because of this delay. However, this may not be an option for families from economically disadvantaged or marginalised backgrounds. Even when a family can afford such clinics, the results of these assessments are often not reported to General Practitioners (GPs) and there are challenges in terms of them being accepted by services or as part of benefit applications. Parents who are recent immigrants to the UK and had a diagnosis for their child from a different country found that this diagnosis was not accepted in the UK to provide support for their child, as stated by this parent: "*When I call up places to get him his therapies they tell me there is a nine month waiting list and then they say, well actually you can't go on the waiting list as you don't have a diagnosis from England.*"

From our survey of teachers and local authority staff, many respondents talked about the long waiting times for diagnosis and the demanding process around applying for an EHCP. These professionals felt that families from minority ethnic communities or those with English as a second language would have additional barriers because of their unfamiliarity with systems and lack of access to information, as this professional highlights: "*Some parents may not have access to a wide range of information or have self-advocacy skills which can then lead to being unable to identify and advocate for the best outcomes for their child.*"
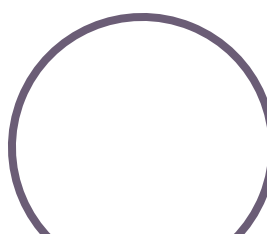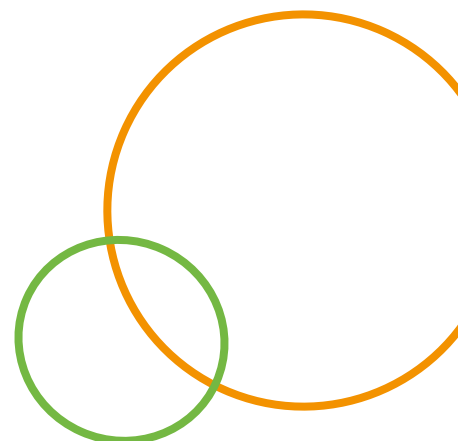
3.2 Experiences of the education system

Our survey and interview data showed that parents and carers could struggle with accessing appropriate educational support for their children for a variety of reasons. The key reasons emphasised in the findings were:

- Difficulty understanding the education system and a lack of guidance
- Funding cuts
- Difficulties in finding services and placements
- Lack of understanding from professionals
- Bias and racism from both professionals and the system
- Lack of diversity in the workforce

While parents from all the four groups faced challenges with understanding the education system and navigating bureaucracy, those who were recent immigrants or who may not have strong English found it particularly difficult to understand how the English education, health and care systems work. This was evident when it came to exclusions, as a local authority professional highlighted:

"*Exclusions due to behaviour linked to autism are frequent - instead of reflective practice and adjustments to provision for the child's needs. Again, marginalised families do not understand their rights regarding these illegal exclusions.*"

In addition, professionals highlighted that many could not get their children into the schools they wanted, as stated by this participant:

"*It is hard for many marginalised families to get their children into the school they want. It may be because of where they live or some schools not willing to take them, or funding not being available yet.*"

Parents highlighted the impact of the funding cuts for them and the provision that their child is getting. There was a feeling among some that the existing funding is not accessible to all, as articulated by this parent:

"*I think it is a postcode lottery. The funding they have in place. The numbers in that borough. Form filling and applications. So every child isn't getting the same, it is based on where they live and we've experienced that.*"

Other parents acknowledged that the local authority provided services, but what they needed was some guidance on how to make decisions, as this mother states:

"*The LA came up with options for my school to go to. But it was very hard to know what we were looking for and nobody gave me advice. I was left to figure this out myself.*"

For children in care, several complex and interrelated issues impact on access to diagnosis, waiting times and access to services, as one local authority professional highlighted:

"*Looked after children – there is confusion with attachment, so late or no diagnosis or inappropriate diagnosis; difficult to engage caregiver in targets; moving LA's means disjointed care with lots of waiting.*"

Others mentioned challenges in terms of finding the right services or placements, as well as coordination amongst agencies, as this professional commented:

"*For children with autism who are looked after, there are often too many moves in placement. This is highly disruptive for any child but the impact for children with autism is magnified.*"

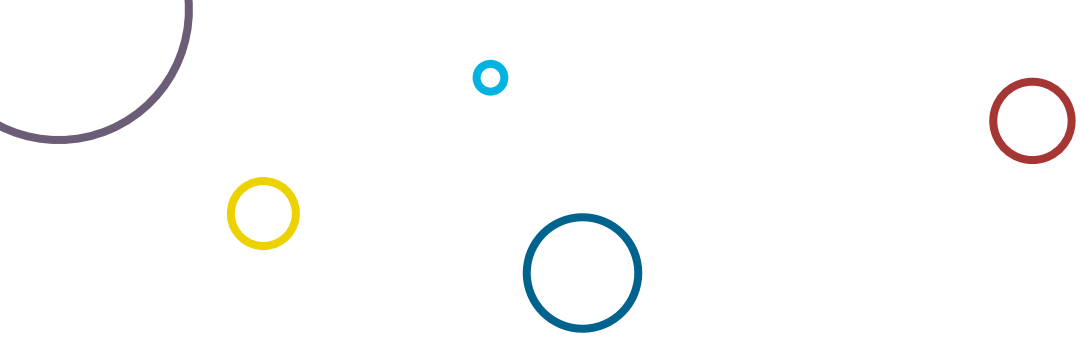Lack of support could lead to break down in service provision, as a mother who had adopted her children described:

"*He was in a foster home before us for six months. They couldn't handle him. They knew he was different but didn't find the time to learn what was going on. From my experience there is no transition planning when bringing autistic children into a foster environment but it would help a lot. They need to spend more time telling the families they are going to about the child. They don't perhaps say too much as the foster family may not take them.*"

Some of the parents and local authority professionals felt that there is lack of autism knowledge amongst educational professionals, as has been reported in previous studies (for example, Guldberg et al., 2021; Ravet, 2018). This lack of understanding led to children being ignored, misunderstood, traumatised or excluded. Along with broader understanding of autism, some educational professionals and parents and carers felt that the teaching staff do not have sufficient understanding of the difference between multilingualism and SEN, or how to recognise subtle signs of autism. This is also the case when it comes to families from deprived backgrounds or where parents are autistic. This limited knowledge or understanding can then impact how these staff perceive families from marginalised communities who have a child on the autism spectrum as this local authority professional states:

"*Some of the parents who are in need of benefits and grants are viewed differently by teachers. There are judgments made of them about being poor parents or have you seen the way the child was dressed this morning or that they are always late. They make assumptions.*"

Teachers and educators working for local authorities acknowledged that working with children from marginalised groups and their families raises specific challenges for them, and some of the time, their experiences and insights were very different from the way parents perceived things. These professionals expressed a view that because of their

culture, some families from minority ethnic communities are reluctant to accept a diagnosis of autism, as this professional explains:

"*Cultural stigma - Indian and Pakistani families try and hide their child's difficulties, I have experienced a family who kept their child hidden and would only take them out for a walk at night, families from these groups regularly state they don't want special schools as this comes with transport and they don't want their community knowing they have a child with difficulties.*"

Even when the parents accepted the diagnosis, the extended family, friends, or community may not; as some previous studies (Hussein et al., 2019) suggest. As a result, few local authority workers felt that they are unable to provide appropriate support to these families. Some professionals also considered that certain communities want less "*outside interference*" and managed the child's differences by themselves.

A view shared by this professional:

"*Some families struggle to accept support from external agencies as it is seen that their community should pull together and support one another.*" Not all parents in our study agree with these perceptions of their experiences though.

Despite the disparities in the DfE data suggesting that children with EAL are underdiagnosed with autism, there is still a large number of children with EAL in English schools who are diagnosed with autism (n=25,056). Some teachers were aware that this causes specific issues in accessing curriculum or using autism specific strategies, as identified by this teacher:

"*English as an Additional Language children struggle to access most lessons when they first begin school, so adding a condition such as autism makes this even harder.*"

However, there was little guidance or strategies on how to educate EAL pupils on the autism spectrum to support teachers in this area.

Schools found it hard to communicate with families where the parents or carers had limited English. The use and funding of translation/interpretation services was somewhat inconsistent across different schools or local authorities. When local authority staff were asked if they produced information on autism in different languages only four out of the eight who responded said they did. There was some suggestion that there were communication challenges for parents because of time constraints, mistrust or consistent negativity coming from school, as this teacher states:

"*Many of our disadvantaged groups do not communicate in a prompt manner. The families are overstretched and have lost faith in the system and so they may not respond to us so effectively or willingly. They come in already thinking their kids are in trouble.*"

Parents from minority ethnic communities or those who had EAL felt that their experiences are different because of the way professionals view them or their children; with some suggesting that this was a form of racism. One parent felt that the difficulty in accessing services showed that the system itself was racist and biased:

"*My son was the only black child at both his schools…. I had to fight the system. They were pushing me away from applying to the best school locally. They even refused to give the paperwork and gave me no reasons why. The local authority decided that my son wasn't autistic but that he was delayed because I was a refugee. So you can already see the bias.*"

Previous studies, such as Maina et al. (2018), also mentioned bias in relation to healthcare professionals and researchers and how it impacts their access to services or their voices being heard. Our data suggests that families from minority ethnic communities could hold such feelings about educational professionals as well, as this parent highlights:

"*I am aware that there is a risk that certain conscious or unconscious biases may seep down from teaching staff. There are differences in teachers picking up dyslexia for example between different races. When it came to his dyslexia application, … they tended to ignore it.*"

One parent mentioned that this internalised racism influenced her son's mental wellbeing:

"*As he has got older, he has felt that he wants to express or engage with his cultural background more. He has expressed that. Then he started self-harming. He said he didn't want to be Black anymore. I think he associated what was happening with him at school to his skin colour.*"

Lack of diversity in the work force was identified as an issue by parents and carers as well as professionals. Looking at DfE data, 64% of pupils were classified as White British in 2021/22. This contrasts with the ethnic mix of the school workforce (see Table 2).

Table 2: Educational professionals' ethnic background

Job type	Mixed background	Any other ethnic group	Asian	Black	White British
Classroom Teacher	1.6 %	0.7 %	5.5 %	2.6 %	90 %
Assistant Head	1.4 %	0.4 %	3.8 %	2 %	92 %
Deputy Head	1.1 %	0.4 %	2.6 %	1.3 %	95 %
Headteacher	0.9 %	0.2 %	1.8 %	1.1 %	96 %

Ninety percent of classroom teachers were classified as White British and this moved up to 96% amongst headteachers (DfE do not collect data on the ethnicity of non-teaching members of the school workforce). Families from minority ethnic communities were aware of this situation and felt that this resulted in staff not understanding their needs or experiences, as this parent stated:

"*The school doesn't represent our community. The only Black teacher is a TA (teaching assistant). The class teachers and headteachers are all White middle class.*"

Parents commented that this was the case in the material produced by the schools or the resources available to support their children too, as stated by this parent:

"*We had a letter come out about bring your parent to school and hear about their profession. The letter was faces with all White professionals on there. I contacted them and said that by doing this that you're only telling my son that anyone who looks like him can't do these jobs but you're also telling his friends.*"

A few parents felt this lack of cultural awareness was present in parent training sessions and workshops that were offered to them:

"*When my oldest was non-verbal I used to use a lot of PECS. There were no brown hands. There are a few Instagram pages now where you can find images like that. But you shouldn't have to search things out, it should automatically be there. It should be when you are doing a Social Story that there are brown faces there too.*"

Some of the teachers we surveyed and interviewed were aware of the impact of this lack of representation in schools as this local authority professional states:

"*….there is a reluctance to access services/ buildings as they don't see others like them represented."*

Parents from European countries felt that things have become more challenging for them since Brexit, as this mother reported:

"*Situation changed two years ago, I was being asked why am I claiming for this and accessing things because my place of birth is non-British. I am British, I have a British passport, my children are British, my husband is. But first time, twice this year, I was asked about my immigration status and had to prove I was British.*"

Some parents whose first language was not English felt that they were being judged by the professionals which could add to their reluctance to engage with professionals:

"*I find it hard, especially in a different language, to express myself. I am always going to have the Hungarian accent. I always feel like I'm misunderstood because of being a foreigner.*"

In research conducted by Gray and Donnelly (2013) they found that parents who had bad school experiences, had limited literacy or faced racism would be more reluctant to engage with professionals.

3.3 The financial impacts

The financial and employment constraints experienced by parents was highlighted as a significant issue. As one indication of this, DfE data shows that as an average over the last seven years (2015-2022) 17% of the whole school population are on free school meals against 28% of families with autistic children. Research from the London School of Economics has identified lost parental employment productivity as the second largest contributor to the overall impact of autism in childhood to the UK economy (Buescher et al., 2014). Our report on educational exclusion (Guldberg et al., 2021) found that three quarters of parents had taken time off work and half reported negative financial effects from having their children out of school. This is a significant issue for families as pupils on the autism spectrum are more likely to be excluded from schools.

In the current study too, the biggest challenge reported by the parents and carers was the difficulty in keeping employment or having to move to part-time jobs to support their child. Most educational staff acknowledged these economic pressures. Some of the reasons for this are similar to what many parents who have a child on the autism spectrum could experience, such as continuous demands from schools, as this professional suggests: "*Sometimes you may have the phone call to say that your child has been excluded and so you aren't able to work for the next however many days that child has been excluded for or that even this idea of reduced timetables. For a phased transition into a school, it is accepted as good practice within the SEND code of practice that for six weeks. That can be very, very difficult for parent and their work.*"

While impact on employment is a shared experience by many parents who have children on the autism spectrum, what made this significant for the parents and carers in this study was that some were already on low paid jobs that offered less flexibility, as this local authority professional identified: "*More likely to be working shifts so work takes priority, so then missing appointments or therapy, less likely to be able to access parenting courses. Less likely to drive, less likely to be able to financially access resources which might help, financial stress fills their life leaving no time to think about therapies, support and putting in place recommendations.*" Flexibility was also an issue for single parent families where the mothers were unable to keep the job and meet the demands made by the school. Lack of opportunities to work full-time or having to go for lower-paid flexible jobs inevitably had an impact on the financial situation of these families and their ability to engage with their child's learning. Even in families where parents have managed to keep their jobs, the financial costs of having a child who may need additional help can add extra financial pressure for some families, as this mother states: "*He has a tendency to change his clothes a lot. We've been through washing machines. He may soil himself or smear poo. So we have to clean more. Finding shoes that he can use more easily. Like finding an adult shoe with Velcro has been difficult and costs more*". Contrary to the often-heard belief that parents were electing to be on benefits, a number of parents reported on resistance to do so and the associated shame "*My mum was on benefits and I swore blind that I wouldn't be. Then I left home, went to university, got a job in the city and now I'm on benefits too. We just have very little choice.*"
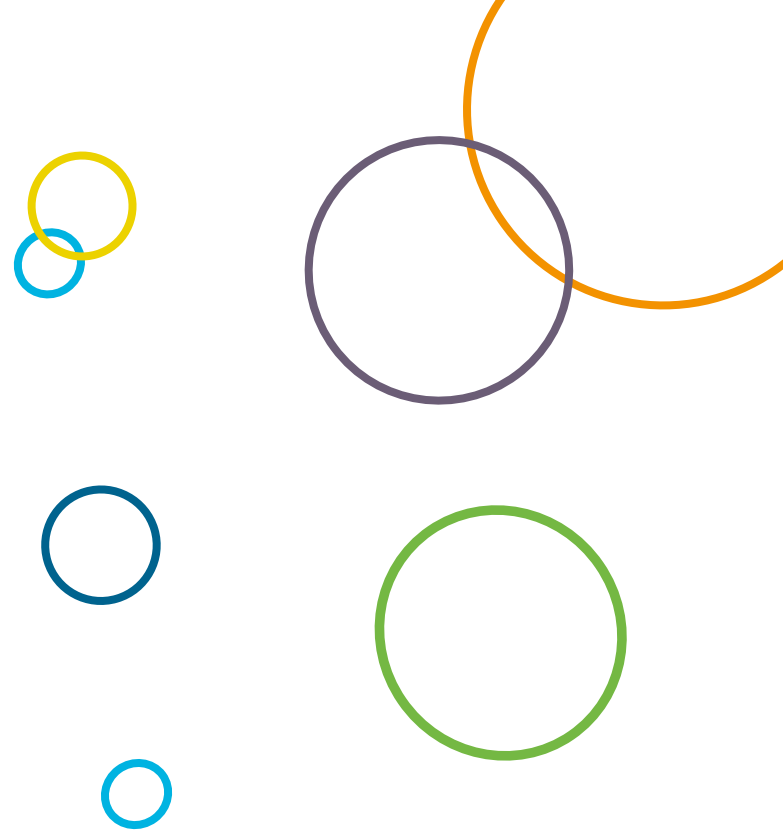
Professionals highlighted that some children and families they were working with were experiencing extreme levels of poverty where there are no toys or books for children, no beds to sleep in and little food to eat. Many highlighted that the financial impact has been exacerbated since Covid where some parents may have lost their jobs. Living conditions were specifically highlighted by some of the educators. They felt that when families are living in temporary or inadequate accommodation it influences the child's ability to learn, as this professional commented: "*If you are in short-term rented accommodation there is that instability and worry about the future. Possibly impacts on how the child feels too. There are fewer adaptations you can make to your environment for the child.*" For some families living in such conditions, this can cause extra stress with neighbours as this advisory teacher recognised: "*Some may be in hostels and have no privacy. There is a great difficulty when their children are loud, distressed or overloaded. Neighbours will complain….. Neighbours can become abusive. Families feel isolated from their community because they get a lot of negative attention.*"

All participants in the surveys and interviews were aware of how the period of austerity and the Covid-19 pandemic had impacted on the delivery of services and the cuts to budgets, against a picture of increasing demand, as this assistant headteacher explained: "*We are a small school and have so many children with a range of difficulties and have so few adults in the school, marginalised families can often be underserved. As a small school we often don't have the rooms. EAL kids often just get pushed to one side and expected to manage as best they can.*" Along

with the financial constraints being experienced by individual schools, some felt that there was a disparity amongst various local authorities as to how much funding they have for education. A few mentioned that there is a divide between urban and rural area provision, as this advisory teacher mentions: "*I work to support a number of schools in rural areas. A number of the areas are relatively wealthy but a number of areas are deprived. I think connectivity is a big one because what you inevitably have is very small primary schools, which often are doing the very best but teaching staff won't necessarily be upskilling as often as those who work in larger schools. Then parents have decisions to make about secondary, which are fewer in number and over a wider area and transport comes up often. Unless a child has those more significant needs or a EHCP, there are few options in terms of local authority support.*" There was also disillusionment about the lack of central government policies to improve the educational outcomes and experiences of marginalised families with autistic children as this assistant headteacher stated: "*They have taken away children's centres when we needed them the most to offer early support and signposting. They are making it harder for parents to get EHC plans. A government that has perpetuated casual racism and worsened everything. Demonised immigrants and refugees. Nothing good, not one thing.*"
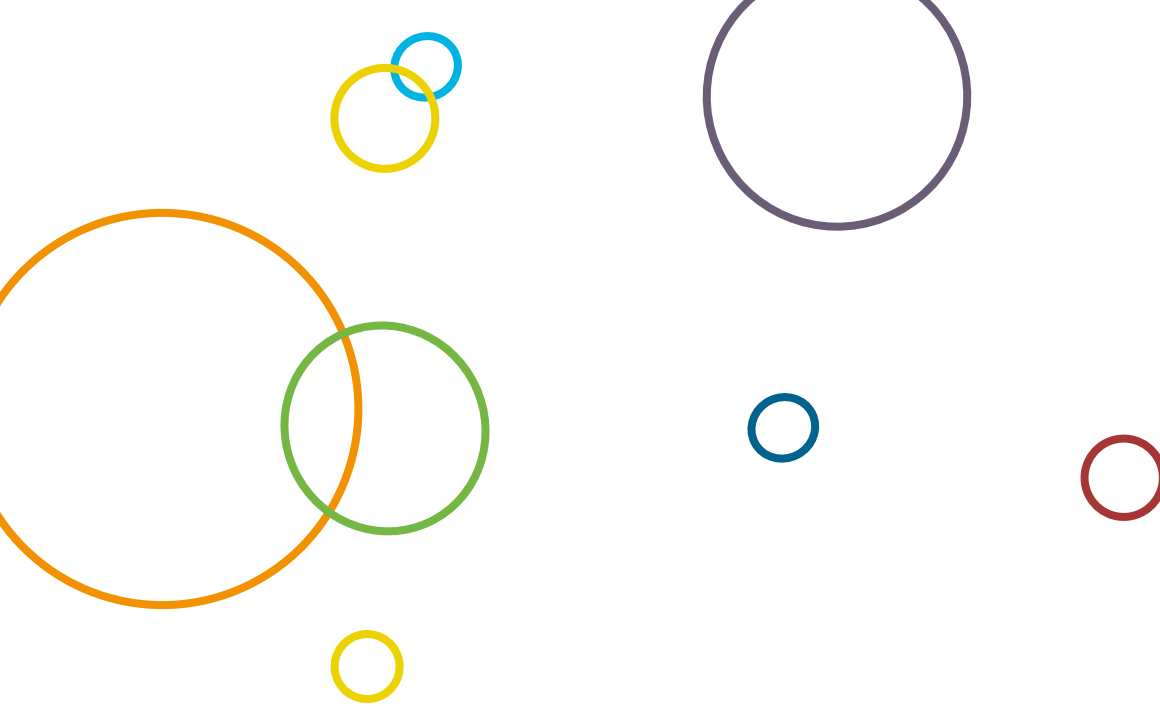
3.4 Family and wider impacts

In addition to financial impacts, parents and professionals talked about impacts on family life as well as broader community impacts. Parents reported some negative impacts on family life, such as lack of time and resources. This can especially be the case in households with more than one child on the autism spectrum, as stated by this single parent mother: "*Her main issues at school are that she is very sensitive to noise. She struggles with friendships. It really affects family life. When I look back it has been so stressful. My son is being diagnosed at the moment for autism. He is very loud. My biggest struggle is that they are not compatible with their autism, so they need to be separated. Being a single mum it is impossible to do that. I haven't got a partner who can say, I'll do something with one of the children while you're with the other. Covid hit us all, because we were even more isolated.*" A few teachers said that being aware of these situations makes them feel reluctant to suggest some of the autism specific strategies as they may not be practical for implementing in the family context, as this teacher comments: "*You can't go to a parent to suggest putting a really good structure in for bedtime when the child is having to sleep on a sofa in the living room.*"

For some parents having a child on the autism spectrum lead to family breakdowns because of the impact it had on their family life or because of cultural perceptions about disabilities, as this mother said: *"My partner was African as well. When we realised we had a child with a disability he had to leave. He would say, 'look at the child you have given me', 'I can't take him anywhere', 'he is retarded'. I had to make a choice early on. I left him the same day I was told there may be something different with my*

son." As highlighted above, single parenthood can add financial strain. There can be a link between the parents own mental health or disability and their family financial situation, as described by one professional: *"I worked with one family, who had five-year-old and three-year-old girls with autism, and a younger child who was likely to be at the more learning disabled end of things. There were 10 individuals living in a two-and-a-half-bedroom house on a council estate. The only adult who was employed was the grandmother who was a midday supervisor – on minimum wage from 11-2 every day. Mum was probably autistic but not diagnosed and struggled with the physical changes of being pregnant. They didn't eat regularly and had a restricted diet."*

Parent groups can be an important place for informational and emotional support. However, professionals, parents and carers indicated that existing support groups or networks were often not accessible for parents and carers from marginalised communities, as this local authority professional elaborates: "*Often find it more difficult to find belonging in a supportive community, can be ostracised, can struggle to leave home due to child's presentation.*" As a result, some of the parents and carers may prefer mixing with or receiving support from their own cultures or groups specifically aimed for their needs, but as this advisory teacher states such networks are difficult to find: "*…opportunities for parents to meet other parents in a similar position but who share the same ethnicity is much more limited.*"

4. Sharing good practice

Although a number of challenges were identified by the professionals and parents/carers in our study, they also provided examples where appropriate support has been provided. Sadly, there were fewer examples of positive experiences shared by parents and carers who participated in our research. However, local authority professionals and teachers, as well as those who took part in our online workshop, shared some examples of strategies that were effective in their practice.

4.1 Practical support

The most common strategy mentioned by educators as being effective in supporting marginalised families was providing them practical support. This included signposting parents to appropriate services as well as providing a wide range of services within the schools, as this example by a teacher highlights: "*Our family liaison officer has to refer a lot of families to foodbanks and there is another thing called the Family Fund. She will meet with parents to help them apply. Some of our families don't have beds and the children sleep on the floor. So she will apply with them to the Family Fund to buy a new bed. She's very good at finding pots of money.*"

Some teachers highlighted how their school is being creative to provide such support, often drawing from school budgets: "*Our headteacher decided to fund a family support service attached to the school. There are two people full-time. It comes out of the school budget, not the LEA….If one of our families is about to lose their house, their child's education is not number 1 it is keep a roof over their head. They help advise with families who have high need.*" These examples show that some schools and professionals are thinking more holistically about the child and family experiences and not just focusing on educational elements. However, these practices are not the norm as this advisory teacher comments: "*I do know a couple of good schools who will look to use non-SEN budget to pay for taxis. But that is the more progressive secondaries that do that.*"

An example of practical support provided by some of the educators was the provision of language and interpretation support: "*We have employed our own bilingual social worker to help families access services. We have many bilingual staff, and we try to be as flexible as possible with meeting different needs.*" Almost all the educators who provided language and interpretation support as an example were using resources available within their school, such as a member of staff, other parents, or siblings, to act as interpreters. Only a couple of them came up with imaginative ideas such as this one identified by a local authority professional: "*One of our schools has set up a young interpreter network. If it is something simple to translate, like remember the school lunchbox, then you can ask a pupil. They've got an interpreter in the front office as well.*" While these are creative ways to solve an issue, they also raise the question about confidentiality and the level of language skills these informal translators or interpreters have for technical issues such as explaining autism or EHCP process.

Some schools have started considering multilingualism within their teaching practice as this teacher explains: "*In our school we would try to have a glossary of terms in different languages. I started training four years ago and the schools I was in didn't have a curriculum in the different languages we should have been teaching in.*" In addition to practical support, participants emphasised the importance of building good relationships based on trust and collaboration. We turn to this next.
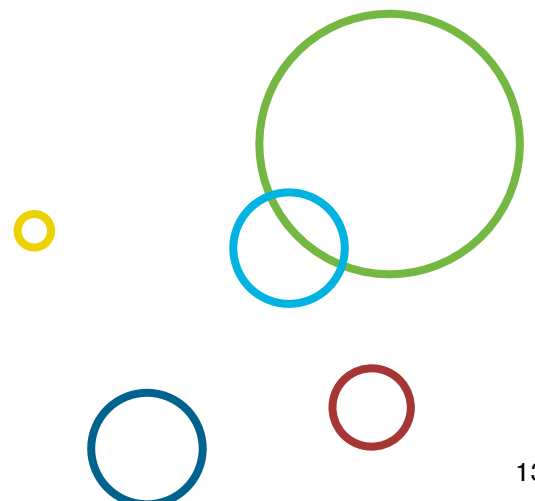
4.2 The importance of understanding, empathy and building positive relationships

Having empathy was considered as key for developing good relationships with the families. This professional expands on this: "*Staff need to have an appreciation of where the family are coming from and what might be difficult for them in that situation. We can say, 'well your child is on the autism spectrum, so you need to provide routines and visuals' but actually is anyone taking time to understand what the routines of the family are. We make assumptions based on our own experience 'well in my house we get up at such and such time'. Some people's lives aren't like that.*" While there might be challenges in empathising with parents and carers when a teacher is unfamiliar with such contexts, some of the professionals in our study were saying that this can be achieved, as this outreach teacher mentions: *"I think the schools who have family engagement officers are making a big difference, even when the child doesn't have a diagnosis there is someone they can build a relationship with and there is more of an understanding."* This highlights the importance of close working relationships between parents and professionals. Those we interviewed and participants in our online workshop highlighted the importance of building trust, particularly in the early stages of meeting parents. These professionals were achieving this by being flexible in terms of when they meet the parents/carers and providing them an option to meet in person or online.

Parents and carers particularly felt that there needs to be more collaborative work between the schools and them. They felt that this can be facilitated by having better means of communication and professionals believing what they say about their experiences. This mother shares her feelings when such opportunities are in place: "*Now I feel in a good place because they are talking to me and they are treating us as partners. We have a mission. A joint mission. They are asking me and continuity. They ask me about his evenings. Just communication. I know it is small and obvious. But it is huge.*" Some teachers and local authority staff felt that this collaborative working pattern can be facilitated by using different ways of communication, such as using technology, to support parents and carers who cannot attend meetings in person: "*They could do more to help families stay in work. You know, using technology for example, to keep families updated or communicate or get advice from families.*" Participants in our online workshop also spoke of working in partnership with families – such as in the co-production of materials, joint training initiatives and co-organising coffee mornings in school.

In addition to collaborative working, the most common thing that was considered as contributor to better experience for their child by the parents and carers was that their child's individual needs were considered, as this father shares: "*Our son was treated as an individual. His whole education*

has been through the lens of the label of being autistic. But within that very defining label he was treated as an individual with very specific needs. They looked at whether members of staff were compatible with him." Parents and carers mentioned that it was often individual staff members who made the biggest difference to them or their children: "*When they thought about the vocabulary they were using in class, and I could programme it onto his talker (communication aid), that helped. Oh, there was one teacher who took responsibility, knew he needed written communication, so when they had a group session, before they went to the work-stations he had a whiteboard and he wrote and spoke. That was an amazing year for him. Work was at the right level*". A couple of parents mentioned that once the professionals understood their children, they were able to adapt the teaching and the educational setting to meet their child's needs. Listening to the child's voice was important for developing this individual understanding, as this mother states: *"First, they took time to listen. Nobody rushed him. When he was trying to say something with his difficult speech, they listened. There was no rush. Then, they respected his voice. He'd never experienced that. He flourished immediately."*
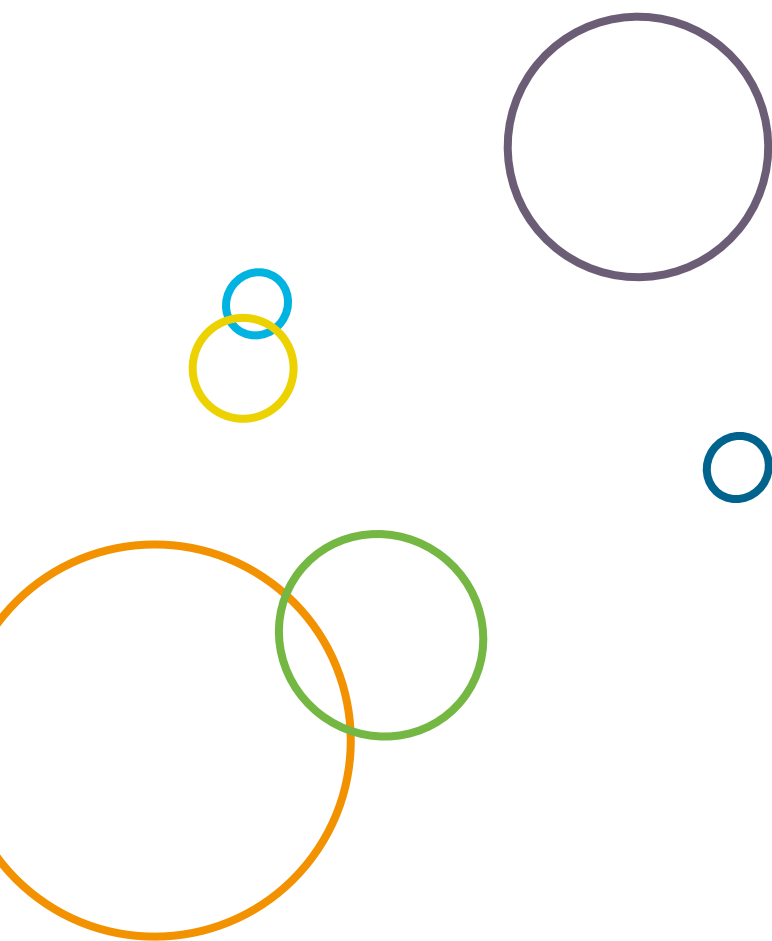
4.3 Parent support and networks

Some schools and professionals create parent networks by offering training and having parent events such as coffee mornings: *"We have a family support service as part of our school that supports all families. We have begun parent training with a member of staff translating that has enabled us to reach some of our more marginalised families."* Parents valued these opportunities to develop their knowledge and their networks, as stated by this parent: *"I think the thing that has helped me the most was going on a local course which was for adopted teens. It is very hard to get on but was over multiple weeks and I got to meet other parents and also be given strategies."* In addition, a couple of settings were offering a wide range of parent or carer networks as this outreach teacher explains: *"A big part of the work we do is with families. We run daytime and evening workshops, post-diagnostic support, we run regular drop-ins – one for dads, one for grandparents, one for parents who identify as autistic, one for those questioning their gender identity. We also have a parent surgery to support families."*

Along with these general networks, more personalised opportunities such as buddy systems are also being used in some schools: "*We have also explored buddy systems. It might be actually that that parent, can support that parent. It may be that the whole group is too overwhelming for them. I've had parents that have found it too intense. If they have a partner from a similar cultural background they may have shared values and language.*" These networks could then provide another source of information for the parents.

4.4 Acceptance in the wider community

There was a recognition in some schools that relationships with peers need to fostered. Two parents specifically mentioned the efforts their child's school made to create peer-awareness to help their child to feel accepted within the setting, as this mother says: *"What worked in my younger two's school, is making pupils aware that there are others who are in a similar boat to you. Reducing the embarrassment."* Raising peer-awareness can facilitate inclusion of the pupil within the wider school community.

As was indicated earlier, teaching and local authority staff both felt that a lack of understanding and stigma from local communities was a significant challenge for families. However, this did not translate into strong evidence of good practice in schools to overcome these barriers. A few schools seem to be doing outreach work with local communities, such as by engaging with other parents in the school, police or local religious and cultural groups. It was acknowledged that as part of this work with other communities it is important to be open to learn about other cultures, as highlighted by this teacher *"Listening to the needs of families… and making the effort to learn about multiple cultures without judgement".*

There was also a call for holistic approaches to increase awareness of neurodiversity within and outside of school settings and adopting a strengths-based approach. This example was provided by a teacher: *"In a school I used to work in we did a project on Makaton. We did it for all parents. Because we thought what was the point in us doing it for those kids who would use it, if those around them didn't know. That got a conversation going. It created more of a community and parents of children who didn't have special needs supporting those that did."*
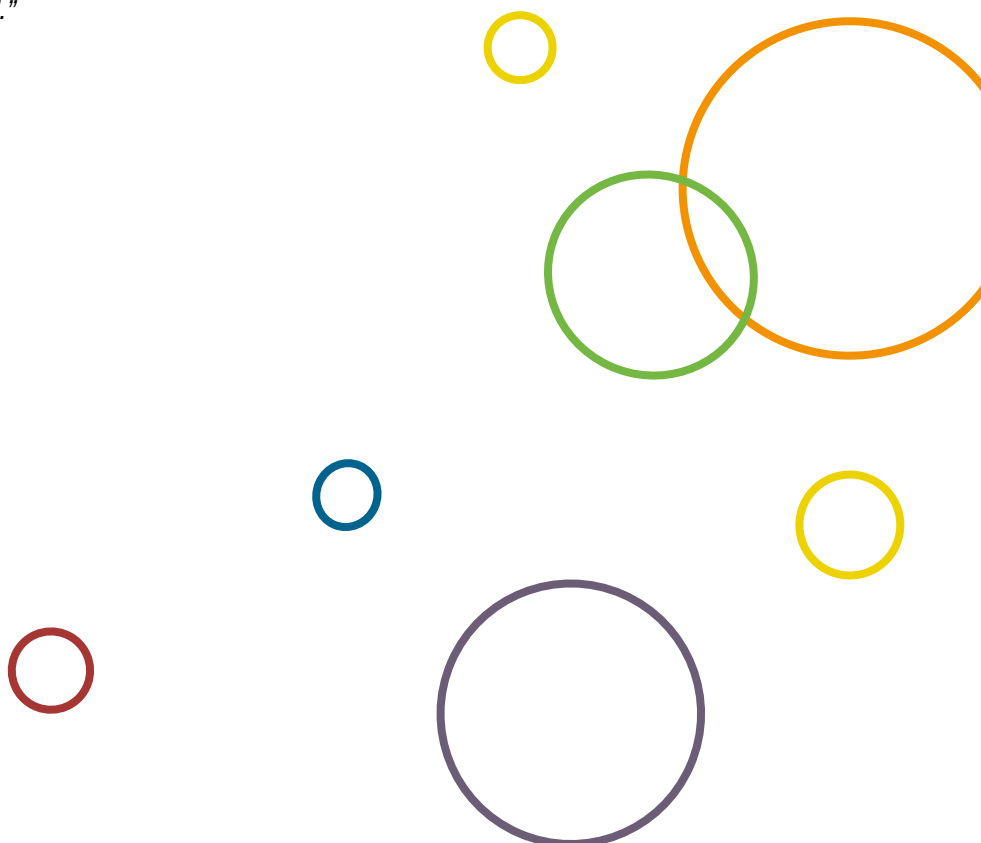
4.5 Developing staff awareness

Two advisory teachers mentioned the steps they are taking to encourage schools to understand the complex experiences of the students they teach and their families: *"With dual language children we would support teachers where there is that dual need and we would encourage them to look through their autism lens as well as their EAL lens and to try to draw apart what is the picture we are seeing here. We may suggest using the pupil profile."* One of them mentioned how they are developing specific resources to help the school staff with this: *"We created a booklet for schools to support their working with neurodivergent parents. Following the same principles in many ways as to how they should be working with the children. The implicit, explicit; use visuals; no ambiguous statements etc."*

A couple of educational professionals felt that there needs to be more representativeness in terms of the parent voices which are being heard in educational settings and in research: *"we need to hear from you what's working, what's not working and we hear from the same families and the services get shaped according to their needs and again we miss out on those whose families we rarely hear from. Best way is to go into those communities and meeting them there."* These professionals are trying to raise this awareness amongst other educational professionals in schools.

4.6 Multi-agency working

A theme that came through particularly in the online workshop was the benefits felt by families when agencies were well coordinated and regularly communicating. They identified that this was useful as it reduced the need for families to be constantly repeating themselves. Effective multi-agency working was also seen as a good way to expedite families getting a diagnostic appointment and subsequent support; although there was a call not to wait until diagnosis is in place before support is provided. Lastly, effective multi-agency working was identified when there was clear communication – particularly for marginalised families – around pathways and *"who does what"*.

What is required?

While there were some excellent examples of innovative and sensitive practice, professionals and parents/carers highlighted several things that needed to be developed and provided to effectively meet the needs of marginalised children on the autism spectrum and their families. These included teacher and other agency training; support for parents; resources and assessment tools that are sensitive to cultural and linguistic differences; and encouraging greater diversity in the workforce.

Training for professionals was one of the most popular recommendations from the participants in this project. In the survey, when asked specifically about training, no school staff had received training on autism and marginalised families, and this was echoed in teaching staffs' interviews: *"Practices do not appear to reflect the fact that children can inhabit more than one marginalised group….As practitioners, we have received no training/awareness building around these issues - all children with SEND are lumped together".* Therefore, along with general autism training, participants in this research felt it was important that professionals understand how diversity may impact the experiences of children and their families as this parent argues: *"If they could make themselves aware of different cultures, it would help a lot. They should be more aware that some things are expected or not expected in different cultures."* The importance of understanding the experiences of children in care was also raised, for example by this teacher: *"Training for teachers as well. These are children who have often had very early traumatic experiences and so they need supporting differently."* The online workshop participants called for universal training, so that there was a consistency of messaging across schools and authorities.

Support networks for parents/carers/local communities: Participants suggested a range of ways in which parental support can be provided, which included offering workshops and training as well as creating networks as this mother comments: *"We need to have workshops in schools, where we can talk together from our cultural background."* The importance of training was highlighted against a backdrop of the need to provide tailored courses to parents and carers from different marginalised groups, such as for carers of looked-after children on the autism spectrum, as stated by this professional: *"There isn't a network of foster carers with autistic children. They don't get together that much. It's all kept more to itself."* A view shared by this foster carer: *"We looked very early on to see if there was specific help for parents of autistic children who have been adopted and there is nothing out there – that I could find anyway. An online group, local or national charities developing awareness and linking families together would really help."*

Participants in our online workshop also highlighted more work to be done to support local communities in terms of their understanding of autism. This included creating allies and networks across and within communities, targeted awareness raising activities, programmes and workshops as part of outreach and the increased use of autistic people who are from marginalised groups in training and awareness raising.

Appropriate resources: Professionals felt that there was a need for more educational resources that are appropriate for pupils from marginalised communities. They felt that services and interventions can only be inclusive when they involve the voices of these children and their families in service development. There were also suggestions that the assessment and diagnostic tools should be adapted to be sensitive to the needs of children from marginalised groups as identified by other researchers (e.g., Davies et al., 2021).

Diversity in the workforce and improved representation: Teachers and parents/carers felt that there should be greater diversity in the school workforce so that it reflects the makeup of pupils and the local community. This would increase an understanding of the lived experiences of pupils and families. They argued that to achieve this there is a need to change the perception of some of the communities about the status of teaching as a profession, but also creating an environment within the education sector which embraces and encourages diversity as this Black ex-teacher states: *"… so that children can see themselves in the staff. I was a teacher for seven years. There is a challenge for ethnic minority teachers in school and them remaining in their posts. There is racism and a lack of support. The school culture is often set up so different cultures are pitted against each other. The opportunities for progression are also more difficult for ethnic minority teachers – part of that is down to funding issues in the sector."*

There was also a call for a systemic change to improve representation of the diversity within autism discussions. For example, a member of our online workshop highlighted how systems, including within our collective autism community, are broadly speaking built on a "white, British, middle-class" mindset. There needs to be greater discussion about how we create systems and spaces that meet the needs of all individuals and families from diverse social, economic and cultural backgrounds. However, participants also highlighted that improved representation can often be met by a box ticking exercise and so a holistic and systemic approach to the issue is required.

Recommendations

The following recommendations emerged from our research:

1. Professional Development

▪ Universities and teacher training organisations should develop autism training for teachers that provides an understanding of the impact of marginalisation on children and their families and how to support them.
▪ Curriculum resources should be developed by the DfE that include material for supporting culturally and linguistically different children on the autism spectrum.
▪ The Department of Health and Social Care should include specific sections within the current autism training being delivered to health and social care professionals that focus on the issues of marginalisation and providing support.
▪ The National Health Service should provide additional training for diagnosticians in identifying autism in children from diverse cultural, linguistic and social backgrounds.

2. Schools

▪ An audit of the makeup of staff may indicate whether senior leadership need to adjust recruitment to reflect the pupil and local community demographics.
▪ Where possible, schools should look to create at least one family liaison post. This member of staff should have training in and experience of autism and marginalised families.
▪ Schools should provide a range of options for developing parental/carer networks. Ideas for appropriate support should be developed in collaboration with families accessing their setting.
▪ Where possible, schools should engage in autism awareness raising within their local communities.

3. Policy

▪ Local authorities should consider reducing the bureaucracy around accepting diagnosis from countries outside England so that families can receive appropriate support sooner.
▪ The Department for Work and Pensions should consider ways of promoting, supporting and maintaining the employment of parents and carers of autistic children and other SEND.
▪ The Department for Education should have clearer targets as to what they are doing to diversify the education workforce, especially into senior leadership roles. This should include providing appropriate support to enable them to stay in their roles and to progress.

▪ Given the delay in diagnosis, specifically affecting marginalised families, local authorities could consider pre-diagnosis supports and interventions for families who have concerns or who are waiting for a diagnostic assessment.
▪ Local authorities should have clear plans for providing translation and interpretation services support to schools so that they can support all families who require them.
▪ Local authority autism commissioning and support services should represent the views of marginalised groups.

4. Charities

▪ Charities could assess how they represent the whole of the autism community in the UK and look to develop specific ways of supporting and networking marginalised families.
▪ Charities could audit their staff, their materials, their training and their communication so there is greater representation of marginalised families.
▪ There could be greater diversity in the autistic voices that are promoted, so that role models from across communities are represented.
▪ Funding could be secured so that resources and training are delivered in a greater range of languages.

5. Research

▪ Research funding organisations should include in their grant awards that recruitment of a diverse range of participants is necessary.
▪ Given the paucity of research of autism and marginalised families in the UK, as well as the lack of tailored interventions and support, funding organisations must prioritise this field.
▪ Scotland, Wales and Northern Ireland should consider conducting comparable research on their own populations.
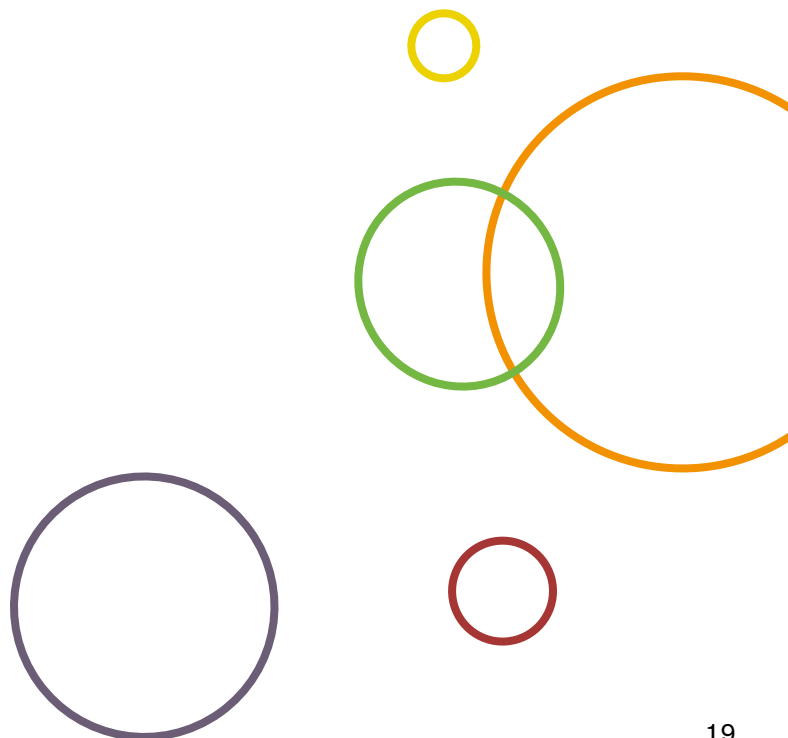
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