



## The experiences of marginalised families with autistic children and young people

### Executive summary

**DfE report that 2.2% of pupils in England have an autism diagnosis as their primary need. Since 2015/16 that is increasing at an average of 9.5% per year.**

Identification of autism varies based on ethnicity, language and social background:

- Children from White British and Black African communities are over-represented in the school autism population and some other communities such as Pakistani, Indian and White other are under-represented.
- On average 19% of the whole school population have English as an additional language, but only 13% of the autism school population, further suggesting that language affects diagnosis rates.
- 28% of children with autism are on free school meals compared to around 17% of the whole school population. This shows that there is higher prevalence of autism in families from lower socio-economic backgrounds. It is unclear whether this is because having a child with autism leads to financial implications for the families, or whether the prevalence is higher for some other reasons.
- There is lack of diversity within school workforce. While 64% of school pupil are White British, around 90% of teaching staff and 96% of Headteachers are White British. This could mean that school staff do not understand the implications of ethnicity for students' experiences, and do not know how to support students through school curriculum and activities to develop

a positive self-identity of their autism and ethnicity.

### Policy recommendations

1. There is a need for more professional training, more diversity in the workforce and development of appropriate resources to support education staff.

### *Local Authorities:*

2. Reduce the bureaucracy around accepting diagnosis from countries outside England so that families can receive appropriate support sooner.
3. Consider pre-diagnosis supports and interventions for families who have concerns or who are waiting for a diagnostic assessment.
4. Develop clear plans for providing translation and interpretation services support to schools so that they can support all families who require them.
5. Ensure Local authority autism commissioning and support services represent the views of marginalised groups.

### *Government Departments:*

6. **The Department for Work and Pensions:** find ways of promoting, supporting and maintaining the employment of parents and carers of autistic children and other SEND.
7. **The Department for Education:** clearer actions and targets to diversify the education workforce, especially into senior leadership roles.

## About the research

We conducted surveys, interviews and online discussions with:

- Parents of marginalised children on the autism spectrum
- Educational professionals working in schools
- Local authorities.

Focus: to investigate key challenges faced by the children and their families and to identify examples of effective working practices with these groups.

\*For this project we defined marginalised families as those: being from an ethnic group other than White-British; 2. having English as an additional language (EAL); 3. being on free school meals; 4. or children in care.

## Our findings

### Accessing diagnosis and services

- The NHS has long waiting lists which could mean that children are not being diagnosed with autism for months or years.
- Families feel they have no option but to seek a private diagnosis, which is often not recognised by authorities.
- Families from minority ethnic communities or those with English as a second language experience barriers because of their unfamiliarity with systems, lack of access to information or not speaking English.

### Lack of appropriate educational support

- 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

## The financial impacts

- Parents and carers find it difficult to maintain employment, with some having to move to part-time jobs to support their child.
- Students on the autism spectrum are more likely to be excluded from school or are on phased access, affecting a parent's ability to work.
- Families from marginalised communities experience additional financial difficulties as they are already typically on low paid jobs that offer less flexibility and as a result, they lose their jobs.

## Community impacts on families

- There is less awareness of autism in some communities. This can lead to families from such communities feeling isolated or stigmatised.
- Family support groups and training can reduce this, but professionals, parents and carers indicated that existing support groups or networks were often not accessible for parents and carers from marginalised communities due to their location, timing, language of interaction or the fact the facilitators do not understand the experiences of these families.
- Lack of time and resources has also led to family breakdowns in some situations.

Along with these challenges we also identified examples of good practice such as professionals who engage with families to build positive relationships, provide practical support, provide opportunities for families to network with each other, and raise awareness of staff and other students within schools.'

## Contact

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