

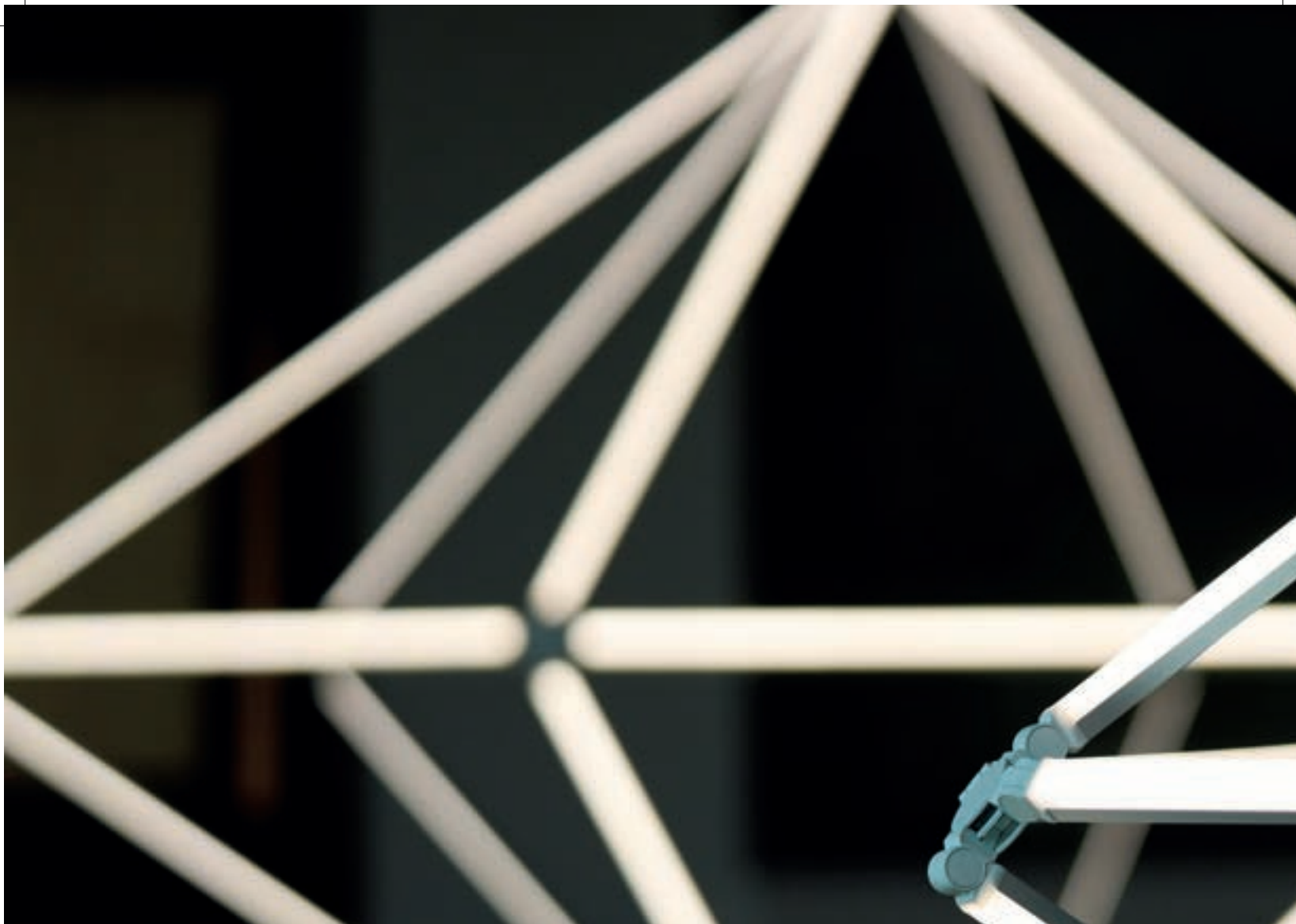


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Developing communication and clarity between stakeholders



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This leaflet is a result of a panel discussion between a parent and educational professionals. It is designed to support parents and carers to navigate the educational setting, pre, during and post an autism diagnosis.

Parents and carers can use this booklet as a guide to develop their understanding of the educational setting, and a tool to build their language for specific support strategies to engage with educational staff and foster positive relationships.

There are six main sections to this booklet:

- Recognising autistic characteristics and professionals to contact
- Local support services to network with pre, during and post your child's diagnosis
- A parent (Akum Ibekwe's) experiences and steps towards developing communication and clarity between stakeholders
- Questions to ask educational professionals
- Legal processes educational professionals follow to support students with additional needs
- How to engage with educational professionals to request for additional support for your child.



The stakeholders that contributed to the panel discussion are:

Akum Ibekwe, Parent

Amanda Hind, Autism & SEND Consultant

Dr Siya Mngaza, Educational Psychologist, University of Birmingham

Sylvia Ikomi, PhD Researcher, University of Leeds

Sonia Gannon, Lead teacher, Drumbeat Outreach

Dr Eli Ashong, Economic Social Research Council Postdoctoral Fellow,
University of Birmingham

Abbreviations and Glossary

CAMHS – Child and Adolescent Mental Health Services

EHC plan – Education, Health, and Care plan

SENCo – Special Educational Needs Co-ordinator

SENDIASS – Special Educational Needs Information Advice and Support Services

SEND – Special educational needs and disability

Reasonable adjustments – changes schools and teachers can make to remove a disadvantage related to a student/child's disability.

*This leaflet uses identity-first language

You can watch the Panel discussion on the ACER website
https://youtu.be/_LIXYMJarM



Background

The online panel discussion is an impact activity resulting from Eli Ashong's (nee Gemegah) doctoral research on Black parents' experiences of their autistic children in the United Kingdom (UK). Immigrant Black parents have shared similar experiences of the educational and local authority system as other parents of autistic children. The panel discussion occurred on the 6th June 2023 to discuss the specific and unique challenges Black parents and Black autistic children experience in educational settings.

The doctoral research identified three main barriers to parents and their autistic children's educational experiences:

- limited knowledge of specific, personalised, and complementary educational support beneficial for their autistic children
- difficulties navigating the education system to support their child's needs
- difficulties getting EHCP and understanding why it is needed.

Parents face barriers because of:

- limited knowledge and awareness of autism
- complex health, education and care systems after their child's diagnosis
- the intersection of race, gender and length of time in the UK

Recognising autistic characteristics and professionals to contact

Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.

Black mothers from the research noticed some of these behaviours that caused concern:

- not responding to their name
- delayed physical and speech development
- limited speech or non-verbal
- watching spinning items and their hands for long periods of time
- not meeting developmental milestones typical for their age group,
- behavioural meltdowns, tantrums such as banging heads and hyperactivity

**This is not an exhaustive list of autistic behaviours. For more detailed information about autism, visit the National Autistic Society website.*



Do not know what to do after your child's autism diagnosis?

Here are some local area networks:

- Attend parent support groups
- Contact SENDIASS in your local authority
- Contact the SEND officer at your child's school

Local support services to network with pre, during and post your child's diagnosis

Do you think your child is autistic?

Contact these professionals within your local authority:

- General practitioner (GP)
- Your child's school SENCo
- CAHMS
- Paediatrician

Akum Ibekwe

Hello, my name is Akum. I am a single mother of four children, one of them has severe autism and severe learning disabilities. We moved from Italy to the UK when my autistic son was 12. It took us more than seven months to get a school for him then the main challenge is communication. Initially communication was a big problem - we tried to understand them but educational professionals will not try to understand us. I decided that we would use a communication book. They will write something in the communication book but what they would communicate to us was completely different. The communication gap became a big challenge to understand us, to know what we wanted and how to support us properly. Another problem is, educational professionals not having a listening ear, not working together with the family for holistic support. This has lingered and affected us in many ways.

We want professionals to:

- Listen to us, work together with us as the family, because we know our children more than professionals. We know what works well for our autistic children and how to approach them and eliminate triggers
- Identify and apply reasonable adjustments in practice not as a tick box exercise
- Provide holistic support and care for the family.



Questions to ask educational professionals

Parents, be empowered to meet with education professionals (SENCo, Form tutor, Pastoral head, Head of Year) Questions to ask Education professionals:

- Can I have a meeting with the SENCo or SEND officer for the school?
- Is my child on SEN Support?
- How is my child's academic attainment? Is he/she doing better in some subjects than others?
- What is their rate of progress for all subjects: steady, slow, fluctuating?
- What is the school's perception of the nature and extent of my child's needs?
- May I share some of my child's behaviours at home with you?
- Does my child also present these behaviours at school?
- What methods are you using to monitor my child's progress in school?
- What methods of support are available for my child's wellbeing?
- What are the reasonable adjustments you make for autistic young children?
- What professional support can I request for? For instance, an Educational Psychologist, Occupational Therapist, Speech and Language Therapist?

**What educational systems are in place to support your child whilst waiting for a diagnosis?
Additional support:**

- Request meetings with your child's school SENCo, form tutor, specific subject teachers
- Ask whether your child is on the SEN register for SEN support
- Discuss your child's challenges and the support systems available
- Request for the SEN officer to assesses your child's current needs and support required
- Ask about interventions and subject specific support
- Ask about Reasonable Adjustments for your child's particular challenges (e.g., leaving class 5 minutes before the bell, having a scribe, a personal laptop, hall passes, lunch time clubs).
- Parents to collaborate with school staff to explore and review the strategies

Legal processes educational professionals follow to support students with additional needs in educational settings: nurseries, schools and college

Teachers:

- Develop relationships with autistic children that establish trust
- Support for autistic children and young people:
- Have a clear strategy and support for autistic children in and outside organised settings (e.g., the classroom, lunch times, before and after school)
- Engage in collaborative teamwork with teachers, parents, support staff and SENCo to identify individual triggers; embed and implement principles, strategies, and practice for supportive strategies

Educational settings are legally required to follow this process to ascertain the child's needs

School processes: Assess, Plan, Do, Review to support child's needs

- Assess – schools evidence how they assess a child's needs
- Plan – SENCo and support staff plan how to make provision, adapt, or differentiate for your child's needs
- Do – school staff apply, embed, and monitor some provision/intervention over a period
- Review – SENCo evaluates the impact of the provision on the child's progress to evidence that a child has needs over and above what can be provided through a quality first approach.

*Education, Health, and Care (EHC) Plan is

A legal document for children and young people (0-25years) that identifies your child's educational, health and social needs, challenges and strengths. The plan identifies and provides relevant support to develop those needs.

Who is eligible for an EHC plan?

To get an EHC plan, you will need to show that the child has additional needs that require more support for them to achieve academically and the educational setting is currently unable to provide adequate support to meet the child's needs. Parents and carers can apply for an EHC needs assessment to their local authority. SENDIASS can help with this application. EHC plan applications that have been denied can be appealed.

Note: having an autism diagnosis does not automatically result in have an EHC plan.

Who can apply for an EHC plan?

- Parents and carers
- School SENCo
- SENDIASS





For more information about autism related research, contacts, courses, resources, visit the Autism Centre for Education and Research at the University of Birmingham.

Here is a list of autism organisations:

- Ambitious about autism
- Autism Alliance
- Autism Education Trust
- Autistic UK
- National Autistic Society – autism.org.uk
- Resources for Autism

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