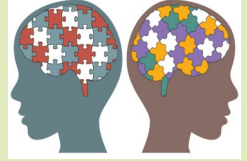# Exploration of the process of the diagnosis of autism spectrum among black children in England

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BACKGROUND

A number of people affected by autism is dramatically increasing while the cause are still unknown with different interpretations (Szatmari (2003).

There are 100,000 children with autism in UK (Approx. 1 in 100). They have rights to live in a society that listens and understands them in order to provide quality services according to their needs. Children with autism deserve to benefit from the best possible education that prepares them for adult life with opportunities (beyondautism.org.uk).

A growing number of European researchers especially those from Nordic countries suggest an increase rate of autism among children of immigrant parents (Keen, Reid and Arnone, 2010).

FACTS ABOUT CHILDREN WITH AUTISM IN UK

- Despite reliable tools, autism is remains frequently a mis-, or delayed diagnosis. This situation of delayed and missed ASD diagnosis may be the problem to a medically undeserved communities, particularly racial and ethnic minority in England. The delayed and missed ASD diagnosis dilemma has caused concern to parents especially those of black children where diagnosed are regardless of race, language, ethnicity and culture considerations (Ghoroury et al, 2012)

- Parents of black children, who notice signs of ASD in their children, are unable to speak out to health services fearing future negative consequences. Hence, the need to examine the process of diagnosis of ASD and challenges faced by affected black children and their families is essential.

UK AUTISM POLICIES

- **Adult autism strategy: statutory guidance. (2015). London: HMSO.** This guidance informs the public services what actions should be taken to meet the needs of people on the autism spectrum living in their area.

- **Children and Families Act (2014). London: HMSO. Young Person's Guide.** Act which amends existing legislation and services for children and young people, including those with special educational needs, in England.

- **Parents and carers (2014). London: Department of Education.** Explains how the system that supports children and young people with special educational needs and disability (SEND) works

AIMS

- To analyse the protocol used to diagnose autism spectrum disorders in black ethnic and minority children

- To qualitatively analyse the caregivers' perspectives on autism spectrum disorder screening and referral practices of black children

METHODS AND METHODOLOGIES

This project will use a qualitative method throughout the study that will be divided into four sub-studies;

First, through ontological approach, the study will be carried out in African Communities (AC) with parents of black children diagnosed with ASD about their understanding of the ASD diagnosis process through semi-structured interviews

Second, semi–structured interviews will be carried out on black children with ASD about their experiences living with the condition

Third and fourth, an epistemological approach, using discourse analysis will emphasise educational, medical and health professionals' knowledge about the factors and symptoms considered through process of the diagnosis of ASD in black children.

Data collection

The data collection will be carried out through participants' responses using audio-recorded face- to- face semi-structure interviews including visual aid [Pictor technique] (Brooks et al, 2013). The qualitative audio recorded face to face interviews will be translated into the written texts with codes and under randomly names (Hardy & Firth, 2012)

Data analysis

The data will be analysed through four stages using manifest and latent techniques (Gary & Densten, 1998): Through the de-contextualization stage, by using manifest analysis technique, the researcher will create an ode list and writing down what has been said and what was intended to been said by using a coding system of inductive and deductive (Lassen, 2009)

Through re-contextualization stage, the researcher will compare the texts and what has been written in original data through literature review (Nissi & Lehtinen, 2015).

In categorisation stage, the researcher will bring all texts together using a triangulation analysis (Santiago & Martínez, 2007). Finally, compilation stage, the researcher will draw a small realistic conclusion based on key words to stay close to text and context (Chambers (2002)

Sampling and recruitment

The study will focus on children, parents and caregivers' perspectives on the process of the diagnosis of ASD. The study will be subdivided in four small studies that will be linked together to respond the purpose of the research. The study will recruit 33 participants based in England.

Expected outcomes

Through the reliability, validity, credibility and patterns matching between the outcomes and original contribution to the project, the findings will determine whether there are lack of race, language and ethnic factors in ASD diagnosis; lack of appropriate practice, lack of proper awareness of symptoms in black children and a lack of support to black families and children affected by ASD in diagnosis process.

References

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Conclusion

The study will provide insight into race , language and ethnicity factors in ASD diagnosis process and will inform medical professionals the strategies to follow in improving the ASD diagnosis in black children towards early intervention