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Autism stigma and the role of ethnicity and culture

Stigma can be broadly viewed as the product of negativity towards a target group. This can take the form of:

- negative attitudes (e.g. authoritarianism, malevolence)
- negative knowledge (e.g. misconceptions, stereotypes)
- negative behaviours (e.g. discrimination, avoidance)

Stigma also has a number of other guises such as [courtesy stigma and self-stigma](#) (Papadopoulos, 2016).

The impact of stigma

The damage stigma causes is unnecessary, preventable, complex and extensive. As such, autism related stigma is an issue that needs careful and urgent attention. We know from compelling research evidence outlined below that autism stigma impacts upon a wide range of psycho-social phenomena.

Employment stigma and discrimination

This is a highly prevalent and dangerous problem. Redman et al (2009) reported that only 15% of autistic adults in the UK are in full-time employment, while 79% of those on incapacity benefit say they want to work. Further, an independent survey commissioned by The National Autistic Society in 2012 revealed that more than a third of those who have secured employment experienced workplace discrimination or bullying (Bancroft et al, 2012).

Social and emotional loneliness

The Bancroft et al (2012) survey also revealed that 24% of autistic adults said that they have no friend while 66% of adults also said that their main friends are their family or carer. For autistic individuals with a learning disability, one third reported that they have no friends at all.

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Hate crime

The 'Living in Fear' project from 2014 reported that just under half of all surveyed research participants experienced some form of victimisation. Those interviewed in more depth revealed harrowing narratives associated with their hate crime experiences, and the psychological impact this had both on themselves and their carers (Beadle-Brown et al, 2014).

Mate crime

A report from Wirral Autistic Society (2015) revealed that mate crime, a phenomenon whereby someone falsely befriends a vulnerable person and then uses that friendship to manipulate or bully, was identified among 80% of surveyed autistic individuals aged over 16, while 13% of children aged 5-11 years had experienced online bullying.

Mental health problems

We also know that those who experience stigma are at a far greater risk of experiencing other problems such as depression and suicidality (Rusch et al, 2014). The result is therefore a double stigma, since mental health problems themselves remain highly stigmatised.

The role of ethnicity and culture

In the complex and what will likely be long battle against autism stigma, focusing on the roles that ethnicity and cultural context play in the production of stigmatising attitudes could be a particularly effective avenue. This is for several reasons outlined below.

Stigma and ethnicity

There is compelling evidence from the domain of mental illness stigma research that ethnicity and culture play key roles in moderating stigmatising attitudes. For example, Anglin et al's (2006) study of nationally representative American samples found that African Americans held significantly stronger stigmatising attitudes towards mental illness compared to Caucasian Americans, even after controlling for age, political views, family income, and education.

Service provision

According to Grinker et al (2011), larger and more competent service provisions are in general more likely to exist within communities where there is a relatively greater level of understanding and awareness towards autism, compared to contexts where awareness is lower.

Therefore in particular cultural contexts where autism service provision is lower than compared with, for example, Western contexts, we should expect to find a relatively greater prevalence of stigma. This issue likely reflects and contributes to the problematic understanding of autism within particular cultures.

Collectivist cultures

Previous stigma research has found that collectivist cultures (which place priority on community interdependence and shared group norms and values) are generally more likely than individualist cultures (which place priority on personal independence, goals and values) to stigmatise people who deviate from the norm. This is partly because such people are more likely to be identified in the community due to high surveillance levels, which such cultures rely upon in achieving their goals of interdependence and group conformity (Papadopoulos et al, 2013).

There are two major consequences of this:

- those who are identified as deviating from group harmony are vulnerable to being devalued, rejected and stigmatised
- families fear such stigmatisation and consequently hide their circumstances from their community. This in turn has a range of harmful consequences.

Health inequalities

We know ethnicity is a key determinant of health inequalities in England, where Black, Asian and Minority Ethnic communities face poorer access to healthcare (The Kings Fund 2015) including autism services (Slade, 2014). If minority groups access services but experience poor cultural awareness from service providers, they may reject these services. Health care and autism service providers may also be unable to identify and diagnose autism due to language and cultural differences.

With progress hampered, services lose the opportunity to engage with the community, raise awareness and understanding of autism and mitigate against the production and effects of stigma.

Religion

Religion is an important component of culture. In the mental illness research domain we have empirical evidence that particular groups with higher levels of religious faith are more likely to stigmatise (Wisneski et al, 2009; Tzouvara & Papadopoulos 2014). This may be because greater levels of religious faith are found in communities where services are less available, inaccessible and/or distrusted (sometimes due to poor cultural awareness).

This has been highlighted by Nwokolo (2010), who argues that within the Nigerian culture the influence of religiosity upon autism is particularly evident among rural communities where so few services for autistic children exist. Exorcism represents a more common intervention as a result of this.

Bankole (2016) agrees, arguing that in many African cultures autism is conceptualised as resulting from witchcraft and poor parenting. Similarly, Alqahtani (2012) has shown how Saudi Arabian parents tend to rely on cultural interventions involving religious healers, and attribute autism to the 'evil eye' which ascribes one's misfortunes to "envy in the eye of the beholder" (Spooner 1970, p. 312).

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While it is clear that autism stigma may exist across all socio-cultural contexts (Obeid et al, 2015), it is also reasonable to argue that the severity and means to which autism stigma occurs varies across different cultures. There are a range of practical measures that the autism community can employ that are likely to have an immediate positive effect. Some of these are described by [Bankole \(2016\)](#), such as professionals familiarising themselves with different cultures before meeting families and viewing themselves as partners who care.

However in tackling this area I believe that we need to heed the lessons from the mental illness stigma domain, and produce further rigorous research in order to better understand the theoretical propositions described above, and also to add to them. Only then can our interventions and policies be underpinned with strong theory and evidence, thus being best placed in the campaign against stigma.

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