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Barriers to health care for autistic people

There has been much discussion recently as to whether autistic people are disadvantaged in accessing healthcare. This article will suggest that these disadvantages do not occur overnight and could start at birth, and in some cases, continue throughout a person's life. Not quite the "cradle to grave experience" that was envisioned by Aneurin Bevan in the mid-1940s (Rivett 1998). The situation is significant enough that research studies are estimating premature mortality to be up to 10-times higher among autistic people compared to the neurotypical population (Hirvikoski et al 2016). So what is going wrong and is there solution?

Setting the tone

A child may face healthcare barriers for the early part of their life until a diagnosis has been given. A diagnosis often will not be acquired until the child is 8-11 years of age (Bogdashina 2006, Attwood 2006). Even if interventions are available the delayed diagnosis can be significant.

Problems can occur in the very early stages whilst attempting just to see a health professional. A child may be seen as being "disruptive" in waiting rooms due to perceived tantrums or non-compliance with treatment, when in fact these behaviours might be that the result something entirely different, for example an unrecognised sensory sensitivity - the smell of the surgery, the touch of a doctor, lighting etc...

These experiences might mean that a person doesn't go back for treatment because the experience is worse than the health issue, especially if it is a preventative issue such as vaccinations or check-ups. Early detection, diagnosis and intervention is key in order to prevent this situation occurring as is autism training for staff so that they may pick up issues quicker and have strategies that help.

Making appointments

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First of all it can be very difficult for an autistic person to make an appointment (Dern and Sappok 2016), as speaking to a stranger and using telephones is an issue for some people (Kim 2014).

Some autistic people may not realise they need a doctor's appointment as they do not feel or compute pain in a typical way. Autistic people may not be able to communicate that they are in pain. This may at least in part explain why Hirvikoski et al (2016) found higher mortality rates in autistic women with a co-occurring learning disability.

Texting/emailing to make appointments is one option (Kim 2014). Another alternative is for surgeries to have an "autism champion" receptionist who people can request to speak to on the phone - someone who has had autism training.

GP waiting rooms

Once an appointment is made there is the waiting room to contend with. These can often be very noisy places with loud talking, babies crying or mobile phones going off. These sounds can be painful or stressful for an autistic person. A relative of mine has been fortunate in that his GP has given him permission to take a chair into the corridor to wait, and ensures that an early morning appointment is available so that the building is generally quieter. This is a strategy that is cost-free and would be easy for others to follow.

There are "autism friendly" theatre performances so why not autism friendly GP sessions, once a week with quiet waiting rooms, no mobile phones and longer appointment times to take into account slower processing times (Dern and Sappok 2016). Should the entertainment industry be ahead of health services in terms of meeting the needs of autistic people?

The consultation

Some healthcare professionals have very limited experience of working with autistic people so will be unaware of sensory differences, for example not feeling pain or being very sensitive to touch (Kim 2014).

The person may answer in a very literal way. During a hospital admission a relation of mine was asked "what have you come in with?" Their response - "a bag" - was perceived by staff as "obstructive".

Every autistic person is an individual, therefore a doctor who has come across autism previously may not have experienced certain issues. The same relation was refused repeat medication as the locum GP observed shaking, sweating and delayed responses

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Organisation: Specialist Report Writing Services
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(Soraya 2014, Kim 2014). The patient now has these symptoms highlighted in their notes so that GPs have that information prior to the appointment- a low cost benefit for all.

Conclusion

Nickaladis et al (2012) indicates that there is a significant problem with the way that healthcare is provided to autistic people, and access to health services does not guarantee effective and appropriate treatment. There are small but positive steps forward with some health professionals receiving autism training and adapting their services and communication in order to meet the needs of autistic people, but this is far from common practice and needs to be standard for all. In addition to this, there are still great health discrepancies based upon socio-economic status (Nursing Times 2012), so until the education and employment disadvantages for autistic people are addressed there will continue to be health inequalities for autistic people.

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