Autism: a cross-cultural perspective on service provision and capacity building

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What is autism?

Autism is a lifelong, developmental condition affecting how a person thinks, communicates with and relates to other people, and interacts with the world around them.

Recent prevalence estimates suggest that around 1.1% of people in the UK, including children and adults, are on the autism spectrum (Baird et.al. 2006; Brugha et.al. 2009; Brugha et.al. 2012, cited by the National Autistic Society). The same figure has been proposed for Northern Ireland and the other UK nations. However, some estimates give a higher adult figure for Northern Ireland, and a recent estimate for Northern Irish school-children is particularly high at 2.3% (Department of Health NI 2016).

The exact causes remain unknown, but there is evidence that subtle atypicalities in brain function may lie behind the differences in thinking and behaviour. It is also clear that autism is highly genetic. The genetic mechanisms involved are not fully understood, but multiple genes seem to be involved, with different gene combinations indifferent families or individuals (Persico and Napolioni 2013).

The autism spectrum

Because of the striking variation in the way autism affects individuals, it is treated as a spectrum (Autism Spectrum Condition). Around 50% of people on the spectrum have profound social, communication and intellectual difficulties. Another major group have no obvious language problems and are intellectually capable or exceptionally bright, while remaining inflexible, bound by routines and struggling to interact with others. This variant has previously been diagnosed as Asperger syndrome. However, current trends in diagnosis and

clinical practice favour a continuous spectrum without 'sub-groups', individual variation being represented by severity scores and profiles of strengths and weaknesses.

Diagnosis

•   The most recent framework for diagnosing autism (American Psychiatric Association 2013) identifies two main areas of difference from 'neurotypical' behaviour. The first concerns social communication and interaction. Language differences range from no language, to late language development to having problems with social and communicative aspects of language despite verbal fluency. People with autism also find it hard to interact socially with others or to make friends

•   The second area of difference is 'non-social': people with autism tend to have narrow or unusual interests, such as accumulating information about just one type of dinosaur. Some individuals repeat the same activity, ranging from constantly rocking backwards and forwards or flicking the fingers, to always eating the same foods, or repeatedly watching the same video. Such differences are collectively known as Repetitive and Restricted Behaviours and Interests (RRBIs). Finally, most people with autism have atypical sensory responses, such as being overly sensitive to particular sounds, sights or smells, or, in contrast, seeming insensitive to loud noises or pain.

While diagnosis is based on these social and non-social differences, many people with autism also have enhanced skills such as good attention to and memory for detail or facility with numbers or IT. A very small proportion of autistic individuals have outstanding talents in fields including art and music.

Social, language and sensory challenges mean that people with autism may find it hard to function in a mainstream school or workplace environment. Yet with the right support they can flourish, and employers are beginning to realise the benefit to the workplace of attributes such as mathematical and IT skills, persistence and attention to detail, as well as other skills less stereotypical of autism. Organisations such as 'Specialiststerne' have played a pioneering role here (Lam 2016).

See Roth et.al. (2010) for more information covering these topics.

Autism in the developed world: milestones

Leo Kanner and Hans Asperger were the first to recognise autism as a clinical entity in case studies published in the early 1940s. It was Kanner's work, published in the US, which first triggered the very gradual development of awareness, identification of cases, and ideas about intervention. However, it was not until the 1960s that the first cases of autism were diagnosed in the UK. One of those was Timothy Baron, son of Michael Baron, who has recalled:

'There were doctors saying "This child is hopelessly handicapped and the best thing for him is to go into a hospital. You should get on with your life and forget all about him"' (from 'The Autism Puzzle 2003)

Michael Baron was one of a small group of parents who refused to take this advice 'lying down'. Instead, in 1962 the group established the pressure group which became the National Autistic Society, with Baron as the founding president. Another group member, Hannelore Braunsberg, whose son David grew up to become a talented artist, has described the way Bettelheim's corrosive and fundamentally unsound theory of maternal blame (Bettelheim 1967) affected parents at that time:

 'We were told that it's the parents and the parents are cold and the parents were blamed ….that was the sort of fashionable view that you know it was your fault.' (from 'The Autism Puzzle 2003).

Among the many tasks which this group of parents took on was to challenge this highly stigmatising view of themselves, as well as campaigning for diagnosis and services for their children. It was parents themselves who founded the first specialist school for autistic children, and the pioneering role of parents has been repeated down the years in many countries including, as will be demonstrated, Ethiopia. Although the substantial progress in the autism field rests crucially on developments in diagnosis, scientific research into causes and advances in interventions, it is fair to say that parents, and the charities which they have founded down the years, have stimulated and underpinned much of this progress (see Feinstein 2010 for further accounts of pioneering parents).

In Northern Ireland, the founding of autism organisations has happened later than in other parts of the UK. Autism NI was established in 1990 and has both lobbied and worked with the NI Assembly over the years, achieving a number of notable successes. The National Autistic Society opened their Northern Ireland office in 2005. Both charities played a key role in instigating legislation for autism services and support. The Autism Bill NI 2010 became the Autism Act NI in 2011.

Autism in 21st Century UK

In considering the current situation for people with autism and their families in developed countries such as the UK nations, it is important to recognise how far things have improved from the early days, notwithstanding major gaps and deficiencies in infrastructure and services. Only a few key points can be mentioned here. Firstly, autism diagnosis now follows internationally agreed criteria and standard procedures - it did not do so in the 1960s. However, there are deficiencies and delays in the accessibility of diagnosis. Secondly, a range of educational strategies and interventions are in use, with some measure of success. Again, though, access to schools and specialist centres with the resources to implement best practice is often extremely patchy. Thirdly, research over the last decades now offers a wealth of insights into cognition, behaviour and brain function in autism, as well as long term outcomes. Yet there are huge gaps in this understanding. Moreover, a recent survey indicates a strong consensus that the top priorities for research should be areas such as effective intervention, support and service provision (Autistica 2016). A fourth positive step is the recognition that autism often goes undiagnosed, notably in females (Mandy et.al. 2011), and also in the adult population. However, rectifying this problem, and meeting the needs of adults with autism generally, remains a challenge.

In the last three decades there have been significant changes in public awareness and perceptions of autism (Roth et.al. 2010; Silberman 2015). Autistic people have themselves played a major role in this shift. High-profile advocates like Temple Grandin and Ari Ne'man in the US and Wenn Lawson, an Australian and Open University graduate, have helped to shift discourses about autism. The media has played a mixed role, raising public awareness but often favouring stories about the minority of autistic individuals with exceptional talents.

The passing of autism legislation such as the Autism Act UK (2009) and the Autism Act NI (2011) are further significant signs of progress. However, the NAS and Autism NI joint report entitled 'Broken Promises' (2016) highlights failure to implement the autism strategy and action plan set out in legislation Similarly, a report by the National Autism Project (2017) documents the UK-wide failure to deliver services and to source evidence-based cost-effective interventions.

Autism in Lower and Middle Income Countries

The situation for people with autism and their families in many Lower and Middle Income Countries (LMIC) reflects, at considerably greater scale, the problems experienced in developed areas of the world, along with other cultural, political and economic challenges. (Saraceno et.al. 2007; Wallace et.al. 2012). In many LMIC countries public and professional awareness of autism has only recently begun to develop, and few diagnoses

have been made. Even where diagnosis is available, it may be hampered by inadequate professional training and the need to use western-oriented diagnostic tools. Cultural differences in expectations about development and behaviour mean that diagnostic criteria and tools developed in the West may be inappropriate for different cultures. (Matson et.al. 2011). Moreover the stigma which frequently surrounds mental health and developmental problems may cause parents to sequester their children and avoid or delay seeking help (Bakare and Munir 2011; Kishore and Basu 2011). A recent worldwide autism prevalence estimate of 0.6%, which falls well below estimates for developed countries, is more likely to reflect such factors, than worldwide differences in the incidence of autism (Elsabbagh et.al. 2012). Wallace et.al. (2012) highlighted the need for internationally coordinated efforts to tackle autism worldwide. Some recent key milestones towards this global initiative include resolutions by the United Nations (2007) and World Health Organisation (2014) and the Autism Speaks 'Global Autism Public Health' (GAPH) initiative (2008).

The Ethiopian project presented in this seminar highlights a striking example of the LMIC picture just outlined.

Health and the Health Education and Training (HEAT) programme in Ethiopia

Ethiopia is in Sub-Saharan Africa, with a population of almost 100 million, of whom around 50% are children, and 85% based in rural areas. Despite strong growth in the last decade, Ethiopia remains one of the poorest countries in the world, with a per capita income of $590 (World Bank 2016). Historically, health provision was centralised and fragmented, a recognised barrier to effective and democratic health provision (Saraceno 2007). In 1992, the Ethiopian government developed a new decentralised health policy, and in 2004, it launched the Health Extension Programme, designed to train health extension workers (HEWs) to deliver primary health care, especially in rural areas, where health facilities of all kinds are very sparse. To date 38,000 HEWs have received a 1 year training for work in rural areas. 2 HEWs are allocated to each 'kebele', an administrative unit of 5000 people. They work from a health post, typically a simple building with an office and some basic treatment facilities.

In 2010, under the umbrella of The Open University's Health Education and Training (HEAT) programme for Sub-Saharan Africa, Ethiopian and OU health experts joined forces to develop an upgraded training programme for HEWs, receiving £4m funding from Unicef, and support from the Ethiopian Government, World Health Organisation and AMREF. In all, 13 written modules were developed, with a predominant focus on physical health. Part of one module (equivalent to two week's full-time study) was devoted to mental health, including one session addressing childhood developmental problems and a brief description of autism.

The programme was launched in Ethiopia in 2011, and to date 12,700 HEWs have received the HEAT training. The materials are also made freely available online for use in other LMIC countries

http://www.open.ac.uk/africa/heat/heat-resources

Mental health and autism in Ethiopia

The small proportion of the HEAT materials devoted to mental health reflected the predominant focus of Ethiopian health policy at the time, with AIDS, malaria and other physical diseases being of special concern. Mental health had been a much lower priority, with child mental health and developmental problems particularly poorly served. Even to date, there are only two fully qualified child psychiatrists in Ethiopia, both based in Addis Ababa. One positive development occurred in 2003, when postgraduate training in psychiatry commenced as a joint initiative of the Toronto and Addis Ababa medical schools. A second was the launch of Ethiopia's first National Mental Health Strategy in 2012. (Federal Ministry of Health 2012).

In the 2000s, the serious plight of Ethiopian children with autism was beginning to emerge. In 2003, Zemi Yenus, parent of one of the few children to have been diagnosed, could find no school to take her own autistic

son. The Nia Foundation Joy Centre which she established now provides for around 80 children, and offers advice, support and training to parents. In 2010 another parent, Rahel Abayneh, established the Nehemiah Centre, also in Addis and catering for around 60 children. Both parents campaign vigorously to raise public awareness, combat stigma and mobilise practitioners and policy makers. The trajectory, with parents as key pioneers, is remarkably similar to that in 1960s UK. Just in the last years, a handful of autism schools have opened outside the capital (Burton 2016).

Stigma evoked by conditions like autism is prevalent in LMIC regions such as Sub-Saharan Africa (Bakare and Munir 2011; Tilahun et. al. 2014). It may take complex and varied forms. Stigma may be directed at the autistic individual and their family and/or experienced by them- for instance a mother may feel shame at her child's slow and atypical development. Stigma may be either or both primary - directed at, or experienced by, the autistic individual, or secondary- directed at the individual's family, friends and associates. In the majority of cases where autism remains undiagnosed and the label itself is unfamiliar, stigma is likely to arise nonetheless because a child's slow development and unusual behaviour makes them stand out as different. Traditional beliefs can have an especially stigmatising effect: children may be thought possessed by a spirit, and parents may believe they are being punished for a sin (Tekola et.al. 2016; Tilahun et.al. 2016; Tilahun et.al. 2017). One HEW gave the following account:

'I have got one child in our survey; he does not talk. His parents were hiding information about him. They thought that this type of disease is cured through traditional or spiritual means. They said [his illness was] due to spirit possession-likift-because someone had given him some potion. When I saw the child he was very pale and […] chained…..'. (Quote from Tilahun et.al. 2017 p.7)

The HEAT+ project

In 2012 Dr Rosa Hoekstra (now at Kings College London), led an Open University and Addis Ababa University (AAU) initiative constituting the first research project on autism in Ethiopia, with an integrated training component. Building on the ongoing HEAT training initiative already outlined, the aims were to:

- Document the situation of autistic children and their families in Ethiopia

- Evaluate the impact of the HEAT mental health materials on rural HEWs' awareness and attitudes, especially to autism and developmental difficulties

- Develop enhanced (HEAT+) mental health training materials including an augmented focus on autism and developmental difficulties

- Evaluate the impact of the enhanced training materials

The situational analysis (Tekola et.al. 2016) drew evidence from qualitative interviews with service providers, stakeholder meetings in Addis Ababa, and public documentation. The picture confirmed and extended the broad picture outlined earlier for LMIC countries, highlighting low levels of awareness and high levels of stigma among the public, poor specialist training, sparse mental health services and inadequate funding in the context of other health priorities. There was a lack of schools, educational provision and interventions. An important feature of the findings was the call for culturally- appropriate diagnostic and screening tools. In other words, even if professional training and diagnostic services were enhanced, the diagnostic instruments would need adaptation. A further study (Tilahun et.al. 2017), using questionnaire-based interviews with care-givers of children diagnosed with developmental disorders (either autism or intellectual disability), confirmed and extended these findings, shedding particular light on links between traditional beliefs and stigma.

Since Health Extension Workers play a pivotal role in rural health care, it was important to evaluate whether those HEWs trained on the HEAT programme had improved their understanding of mental health, especially

childhood developmental problems and autism. In one evaluation (Tilahun et.al. 2016), 104 of these trained HEWs undertook a structured interview exploring their reactions to the study material. Most HEWs rated the materials as interesting and important, over half reported using them regularly in their work. A significant proportion felt they were providing better services as a result, and had organised mental health awareness-raising meetings in their kebele. In-depth interviews with 11 HEWs broadly complemented these findings. However, in both forms of interview, HEWs strongly endorsed the need for more extended and specific study materials to assist them in identifying and addressing childhood mental health and developmental problems. The HEWs saw thorough training as essential to their frontline role in delivering healthcare.

The HEAT+ training materials

In response to these findings, the HEAT+ team developed further mental health training materials, including specific sections about developmental problems and autism. The materials comprise:

 A 'Mental Health Pocket Guide', covering both adult and child mental health, and developmental problems including autism

Five training videos modelling HEW interviews with women in their kebele- two of these deal with autism and two with intellectual disability.

It was essential that these materials were appropriate to the cultural context and realistic about local resources. For instance, since HEWs were to be guided in identifying likely cases of autism, but would be unable to provide formal interventions, they needed to be equipped with simple practical strategies to offer parents straightaway. HEWs also needed guidance on tackling low awareness and stigma in their communities, while operating sensitively in addressing stigmatising traditional beliefs. Further details of the pocket guide and videos are provided on slides 16 and 17. The videos are now available for free download from the OU International Development Office website, and are beginning to attract interest for use in other LMIC settings. The Mental Health Pocket Guide will shortly be added.

http://www.open.edu/openlearncreate/mod/oucontent/view.php?id=51898

To fully assess the beneficial effects of both HEAT and HEAT+ training, a further questionnaire study compared beliefs, attitudes and 'social distance' preferences of untrained, HEAT trained and HEAT+ trained HEWs towards children with autism and their parents. A full report of the findings (Tilahun et.al.) is forthcoming.

Conclusions

This presentation has discussed the situation for children with autism and their families in the UK and Ethiopia, highlighting striking disparities in awareness, attitudes, infra-structure and service provision. At a time when families throughout the UK nations are experiencing serious gaps in provision, it might be tempting to shelve the even greater problems that prevail elsewhere. Yet, stigma and inadequate access to diagnosis, services and support are common experiences across these different settings, and there are also some important 'bridging' factors. Notably, awareness of autism and access to services and support is often particularly low in ethnic minority communities living within the UK. Corbett and Perepa's 'Missing Out' report for the National Autistic Society (2007) showed that black and ethnic minority children with autism were particularly likely to miss out on educational opportunities. Different cultural expectations for development among ethnic minorities (Perepa 2014) may lead to delays in detecting a problem, and stigma, may, as in Ethiopia, deter some parents from seeking help. On the other hand, parents worldwide have played pioneering roles in getting autism services going, and in campaigning for change.

The presentation has also highlighted the contributions of training and education on a mass scale as elements within capacity building. In Ethiopia, the OU's distance learning model has been adapted to provide materials suited to culture, learning style and local resources. The materials are nonetheless sufficiently generic to be adaptable other LMIC settings, and thus are offered online for free download. The OU also offers an autism-specific online undergraduate course (Understanding the Autism Spectrum - chaired by the present author), which has been studied by well over 6000 students to date, including many who care for and/or work with people with autism. Between 2012 and 2014, around 500 students in Scotland studied the course funded by the Scottish Government Strategy for Autism Group. As this course approaches its last presentation starting November 2017, the present author is leading the production of a new 8 week online 'Badged Open Course', offered worldwide for free study, to be launched later this year.

The Northern Ireland Assembly has a long track record of initiatives in the autism field, as well as a special interest in international development through its All Party Development Group, which has a particular focus on Uganda. It is hoped that this presentation has contributed to the arguments for sustaining these important priorities.

Ilona Roth, March 2017

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