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

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Overview

This paper will:

- 1) Reflect on progress in autism understanding and provision in the UK
- 2) Describe research into the situation of people with autism and their families in Ethiopia
- 4) Discuss an integrated health worker training initiative
- 5) Draw conclusions from this cross-cultural perspective



Autism in the western world: initial steps

1940s

- Autism first identified by Leo Kanner (USA) and Hans Asperger (Austria)

1960s

- First children diagnosed in the UK (but no separate autism criteria)
- Understanding and availability of services and treatment minimal:
‘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”’ (Michael Baron, father of Timothy)¹
- Stigma due to ignorance and ‘parental blame’ hypothesis:
‘We were told that it's the parents and the parents are cold and the parents were blamedthat was the sort of fashionable view that you know it was your fault.’ (Hannelore Braunsberg, mother of David)¹

1) The Autism Puzzle 2002



Pioneering parents and charities

Since the 1960s, UK parents have played a pioneering role in:

- combatting stigma
- founding pressure groups campaigning for diagnosis, interventions, educational provision and support services
- The National Autistic Society founded 1962
- The first specialist school -Sybil Elgar School, London- founded 1965

Key Northern Ireland groups include:

- Autism NI - founded 1990 as 'Parents and Professionals and Autism'
- National Autistic Society – NI office opened 2005
- Both have launched key initiatives with the NI Assembly



Autism in 21st Century UK

- Diagnostic, educational and intervention services, but *not always readily accessible*
- Research insights into cognition, behavior, brain function and long term outcomes
- Under-diagnosis in females and adults recognized
- Economic burden of autism recognized
- Neurodiversity and advocacy: autism as a difference

Legislation includes:

- Autism Act UK 2009, focusing on adult needs
- Autism Act NI 2011, focusing on supporting individuals and families

Setbacks

- NAS and Autism NI (2016) report failure to implement NI legislation strategy and action plan
- National Autism Project (2017) reports UK-wide failure to deliver services and to source evidence-based cost-effective interventions



Autism worldwide

UK

- Estimated population prevalence: 1.1 in 100 (2011)¹

Worldwide

- Estimated population prevalence: 0.6 in 100 (2012)²

Many Lower and Middle Income Countries (LMIC):

- Prevalence low (or unknown)²
- Sparse awareness, diagnosis, professional training, services³
- Pioneering parents have contributed to progress in some countries e.g. India ⁴

Sources: 1) cited by National Autistic Society 2) Elsabbagh et.al.(2012) 3) Bakare & Munir (2011) 4) Feinstein (2010)



Autism in Ethiopia

- Sub-Saharan African country
- Population almost 100 million; 50% children
- Autism prevalence unknown
- 2 child psychiatrists, based in Addis Ababa (capital)
- 2 specialist schools, also in Addis
- Majority of the population rural

Milestones

- 2003 post graduate psychiatry training
- 2012 National Mental Health Strategy



Sources The Lancet 2016; Tekola et.al. 2016

Stigma and exclusion

- Stigma is prevalent ¹
- Primary: directed at/experienced by the child
- Secondary: directed at/experienced by parents, families and associates

'..when I take him out to enjoy, people point at him, then I cry and take him inside' ²

'Some people say: 'It is because of her sin, her cruelty that this happened to her boy...'²

'Later when I came with (my son) the woman renting the house said she didn't want to rent to me' ²

'..first they promise to teach him but as soon as they came to know about his condition they told me to take him out...'³

- Stigma may be more common in context of traditional beliefs such as possession¹

Sources: 1) Tilahun et.al. 2016; 2) Nehemiah Centre 2011; 3) Tekola et.al. 2016



Pioneering parents

The two first schools for children with autism founded by parents in Addis. Founders and fellow parents are active in awareness raising and campaigning for funds and services



Zemi Yunus
Joy Centre
opened in 2002



Rahel Abayneh
Nehemiah Centre
Opened in 2011



Rural health provision

- Rural medical services very sparse
- 2004: launch of community service delivered by Health Extension Workers (HEWs)
- 38,000 HEWs have received a 1 year training for work in rural areas
- Two HEWs are assigned to each kebele (community of around 5000) and based at a health post
- HEW tasks include health promotion (e.g. promoting knowledge of HIV); health prevention (e.g. vaccinations); outreach to community members



Open University (OU) health work in Ethiopia

- Health Education and Training (HEAT): upgrade materials for HEWs by OU and AAU* experts with Ethiopian Ministry of Health
- 13 health modules designed for further training of rural Health Extension Workers (HEWs)**
- 12 modules on adult and child physical health
- Part of 1 module: mental health module
- Child material includes Intellectual Disability (ID) and a brief description of autism

*Addis Ababa University

**Resources available for download:

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



HEAT+ project

- 1st Ethiopian autism research project
- OU and AAU team led by Dr Rosa Hoekstra (now at KCL) funded by Autism Speaks

Aims:

- Document the situation of autistic children and their families in Ethiopia
- Evaluate impact of the HEAT mental health module on rural HEWs' awareness and attitudes, especially to autism and developmental difficulties
- Develop enhanced (HEAT+) training materials including augmented focus on autism and developmental difficulties
- Evaluate the impact of the enhanced training materials



Situational analysis

Findings from qualitative interviews with service providers, stakeholder meetings and public documentation:

- Sparse knowledge and understanding among general public
- Stigma, exclusion and negative perceptions
- Low awareness and lack of specialist training among health professionals
- Lack of diagnostic and screening tools appropriate for culture and context
- Inadequate mental health services
- Lack of funding; competing health priorities
- Shortage of schools; education and interventions inaccessible
- Lack of research studies

Source: Tekola et.al. 2016



Impact of HEAT mental health training

Structured interviews with 104 HEWs who had studied the HEAT curriculum:

- Highlighted HEWs' interest in the mental health training, and self-rated improvements in knowledge of child mental health, ability to identify cases and provide services

In-depth qualitative interviews with 11 HEWs complemented these findings:

' [...] Generally the training was very important; I gained knowledge about developmental disorders... When I compare myself from previous, I learned many things....'

- However, the need for more extensive and targeted resources was identified:

' ... The (mental health) module covered very little on child developmental disorders and autism. It would be better to include the symptoms of developmental disorders, including autism and details on how to make diagnosis, identify causes and provide treatment'

Source Tilahun et.al. (2017)



Developing the HEAT+ training materials

Aim: to meet HEWs' need for further training through extended specific resources

Mental Health Pocket Guide – adult and child material including sections on autism and intellectual disability (ID)

5 videos modelling how to interview the parent of a child who may have autism or intellectual disability

Essentials of the approach

- appropriate to cultural context; realistic about local resources
- guidance on identifying problems; *not* a diagnostic manual
- address traditional beliefs and practices with sensitivity
- practical strategies for ready use by HEWs and parents
- help HEWs to tackle low awareness and stigma in their community

English text and video scripts translated to Amharic (official language); examples checked for cultural relevance by Ethiopian team members



Mental Health Pocket Guide: examples of guidance

Identification

Look out for and listen to talk about a child who:

‘Is usually kept in the house’

‘Does not speak or respond like other children of the same age’



What to tell the family

‘Developmental disorders are due to the brain working differently. It is not the child’s fault and not your fault’

‘Neglecting or punishing the child for being slow or having difficult behaviour is likely to make things worse’

Simple strategies to give parents

‘Make sure the child is stimulated e.g. sing to him, take him for walks and name trees, flowers and animals’

‘Notice all the child’s skills, and make sure he has the chance to practice these on his own’

Source: Mental Health Pocket Guide, Open University



Videos

5 scenarios modelling HEW conversations with women in the kebele:

- Detecting Intellectual Disability ID
- Supporting a parent of a child with ID
- Detecting Autism
- Supporting a parent of a child with Autism
- Supporting a mother with many social problems



HEWs viewed videos and received their own
Mental Health Pocket Guide as part of in-class education

Videos available for free download via:

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

Mental Health Pocket Guide available soon

Further steps

- A questionnaire compared beliefs, attitudes and 'social distance' preferences of untrained, HEAT trained and HEAT+ trained HEWs towards children with autism and their parents
- Impact of the HEAT and HEAT+ training resources was evaluated: findings forthcoming (Tilahun et.al. submitted)
- Training videos (OpenLearnCreate) are attracting interest for use in other LMIC settings; Mental Health Pocket Guide to be added soon



Conclusions

- Autism is a global problem with cross-cultural disparities in awareness and service provision depending on geographical area and development status
- Nonetheless stigma and inadequate access to diagnosis, services and support are common problems for autistic individuals and families worldwide
- Throughout autism's history parents have played a key role in combatting stigma and promoting change
- Training also plays a crucial role in awareness raising, capacity building and service provision; the cascade approach outlined has potential for various contexts
- Resources within the OU educational framework offer effective training materials with potential for mass impact through collaborations in developing countries and online distance teaching



Further OU Autism resources

'Understanding the Autism Spectrum'

20 week 15 pt. undergraduate course at Level 1; final presentation Nov 2017

<http://www.openuniversity.edu/courses/modules/sk124>

Badged Open Course (BOC)

Free 8 week online course, available worldwide; forthcoming 2017

OpenLearn materials and quiz

<http://www.open.edu/openlearn/body-mind/health/health-sciences/what-autism>

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Knowledge Exchange Seminar Series (KESS)

...is a forum that encourages debate on a wide range of research findings, with the overall aim of promoting evidence-based policy and law-making within Northern Ireland