

The continuing role of ICNA in Africa: how to tackle autism?

There are no published data on population-based estimates of autism spectrum disorders (ASD) from Africa. Indeed, in an ASD detection program for 18- to 36-month-old Zulu-speaking children in South Africa, ASD was found to be underdiagnosed and rarely reported in clinical or educational records.¹ The limited literature regarding ASD in sub-Saharan Africa suggests some similarities and several differences from data outside of Africa. Like other parts of the world, there are higher numbers of males than females affected. There is evidence for a number of genetic disorders associated with ASD in Africa, including tuberous sclerosis, Rett syndrome, and fragile X, although the identification of these disorders is low. Comorbidities reported to be associated with ASD in Africa include intellectual disability and epilepsy.²

However, features of ASD in Africa that differ from many non-African nations include: (1) older age at diagnosis; (2) increased proportion of non-verbal cases; (3) possible infectious aetiologies; (4) lack of recognition by health care workers; and (5) attributing ASD to traditional (spiritual) causes. In a review of case studies and case series from Africa, Bakare and Munir found six studies reporting the age of the child at first presentation to 'orthodox clinical practice' (one from Tunisia, one from Tanzania, one from Kenya, three from Nigeria).³ Most of the cases presented for the first time 'well above 8 years of age.' In a study from Tanzania, 71% of the ASD cases were non-verbal,⁴ compared to only about 25% of nonverbal cases in developed countries. A third theme from the literature is the potential role of malaria infection. In 2006 Mankoski et al. described three children (from a cohort of 14) with ASD in Tanzania who showed ASD symptom onset following cerebral malaria. Studies from Kenya reported an association between severe malaria and language impairment, describing children with a semantic pragmatic pattern similar to children with ASD.⁵

In the West, a number of studies have shown that medication is effective in the treatment of maladaptive behaviors associated with ASD. Furthermore, expert panels in the West have agreed that children with ASD should have access to at least 25 hours per week of comprehensive intervention to address social communication, language, play skills, and maladaptive behavior. Recommended treatments with demonstrated efficacy included applied behavioral analysis, integrated behavioral and developmental programs, the Picture Exchange Communication System,

and various social skills interventions. But there is virtually no literature regarding the management of ASD in Africa. There is no information regarding treatment with medications. Access to behavioral intervention is available only to a small number of children at private schools, instituted by parents of children with ASD.

Bakare et al. have published a series of papers examining the knowledge of health care workers regarding ASD in Nigeria. Using questionnaire methodology, they found that knowledge of autism was lacking in primary health care workers, as well as in final-year undergraduate medical, nursing, and psychology students. A similar knowledge gap was reported in a study of health care workers from tertiary facilities in Nigeria. Interviews of families found that in addition to biomedical explanations of ASD, people also had spiritual explanations of ASD, including retribution from a higher power, curses, and magical forces such as witchcraft or juju. Similarly, among health care workers surveyed in southeastern Nigeria, 27% gave supernatural and 14% gave preternatural explanations for ASD.⁶

In 2014, the International Child Neurology Association (ICNA) will hold a workshop in West Africa to analyze the current state of pediatric ASD diagnosis and management in sub-Saharan Africa through participation of delegates from 30 sub-Saharan African nations.

The ICNA workshop will have the following goals: (1) establish guidelines to facilitate development of infrastructure to ascertain and diagnose ASD; (2) establish practical guidelines for medical management of ASD; (3) establish practical guidelines for behavioral management of ASD; and (4) identify key viable research approaches to increase understanding of prevalence and etiology of ASD in Africa.

We anticipate that this ICNA workshop on ASD in Africa will provide a framework to estimate the prevalence of ASD in African countries, to facilitate increased detection, and to address the needs of children with ASD in order to improve their care.

CHARLES R NEWTON¹ | DIANE C CHUGANI²

¹ ICNA Executive Board Member, KEMRI-Wellcome Collaborative Programme, Kilifi, Kenya; ² Children's Hospital of Michigan Autism Center, Wayne State University School of Medicine, Detroit, MI, USA.

doi: 10.1111/dmcn.12150

REFERENCES

1. Grinker RR, Chambers N, Njongwe N, et al. "Communities" in community engagement: lessons learned from autism research in South Korea and South Africa. *Autism Res* 2012; 5: 201-10.
2. Bakare MO, Ebigbo PO, Ubochi VN. Prevalence of autism spectrum disorder among Nigerian children with

- intellectual disability: a stopgap assessment. *J Health Care Poor Underserved* 2012; **23**: 513–8.
3. Bakare MO, Munir KM. Excess of non-verbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa - a trend possibly resulting from late diagnosis and intervention. *S Afr J Psychiatr* 2011; **17**: 118–20.
 4. Mankoski RE, Collins M, Ndosi NK, Mgalla EH, Sarwatt VV, Folstein SE. Etiologies of autism in a case-series from Tanzania. *J Autism Dev Disord* 2006; **36**: 1039–51.
 5. Carter JA, Murira GM, Ross AJ, Mung'ala-Odera V, Newton CR. Speech and language sequelae of severe malaria in Kenyan children. *Brain Inj* 2003; **17**: 217–24.
 6. Bakare MO, Agomoh AO, Ebigbo PO, et al. Etiological explanation, treatability and preventability of childhood autism: a survey of Nigerian healthcare workers' opinion. *Ann Gen Psychiatry* 2009; **8**: 6.

Mac Keith Press



www.mackeith.co.uk/guides.html

Children with Neurodevelopmental Disabilities

the essential guide to assessment and management

Edited by Arnab Seal, Gillian Robinson, Anne M Kelly, and Jane Williams

- Covers the wide spectrum of problems associated with paediatric disability (both transient and life-long).
- Provides knowledge about conditions such as cerebral palsy, autism spectrum disorder, attention problems, and genetic disorders and how to manage them.
- Practical advice includes templates for letters, reports, and care plans.



240 x 170mm / 743 pages / Paperback / March 2013 / 978-1-908316-62-2 / £65.00

T: 0800 243407 (FREE PHONE, UK ONLY) or +44 (0)1243 843294

F: +44 (0)1243 843296 / **E:** cs-books@wiley.co.uk