Looking for Way Forward with Autism: Educational Partnerships & Research

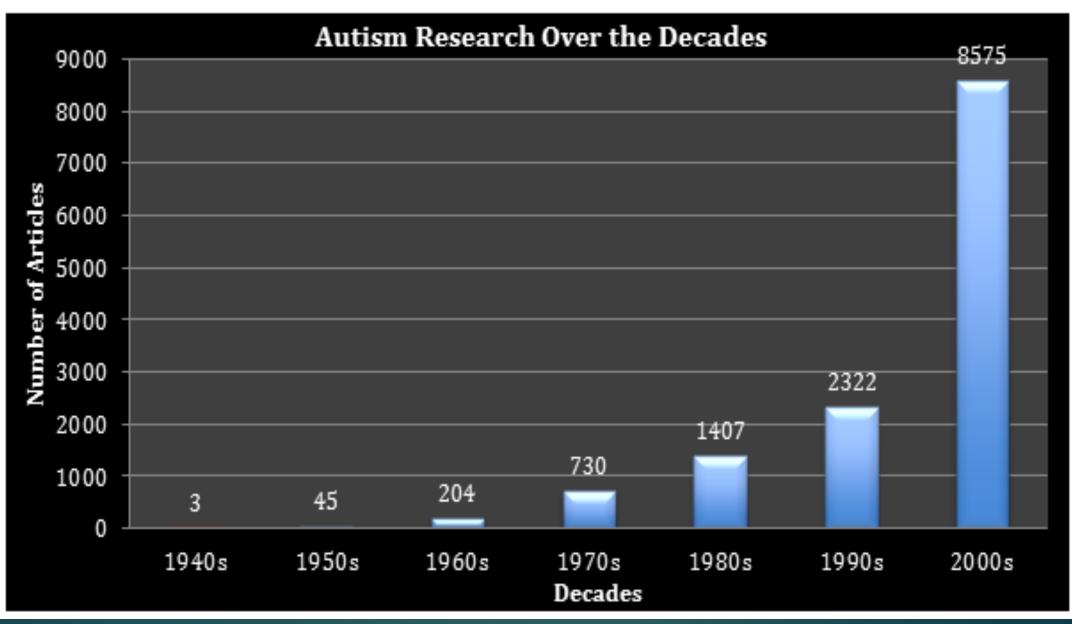


Recent Findings

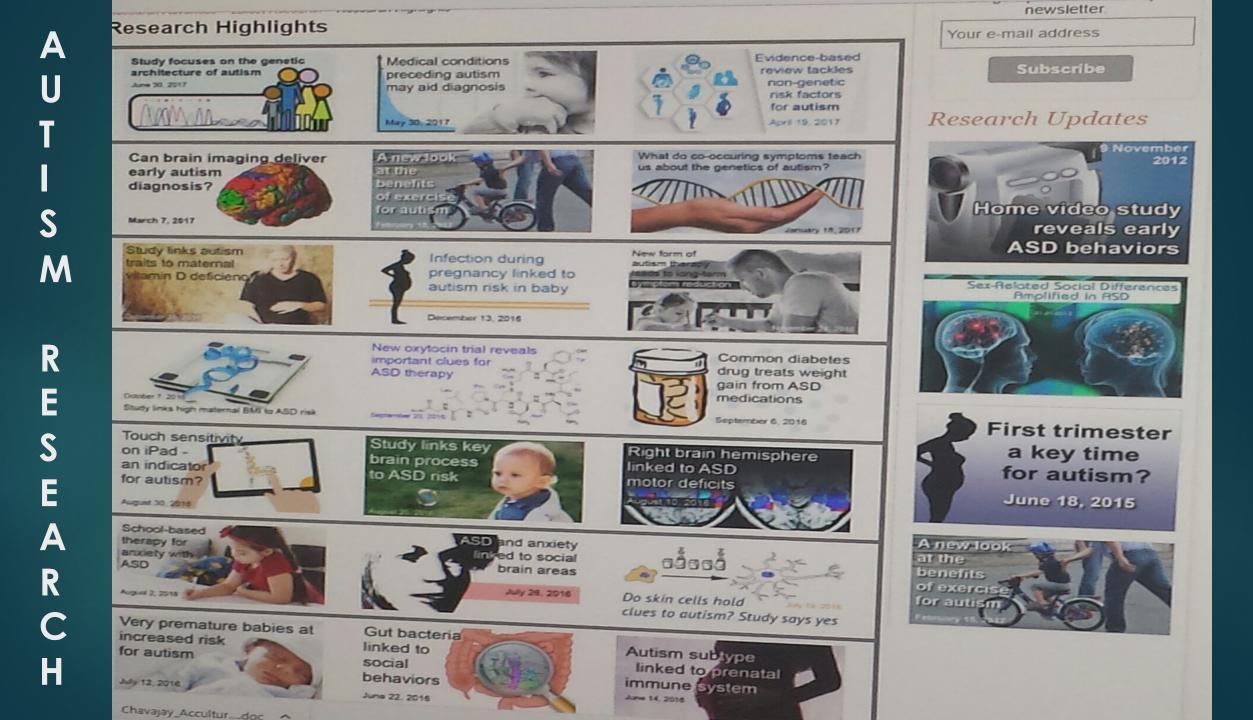
Importance of Collaboration

AUTISM Research in AFRICA (Nigeria)

Way Forward to Becoming Active Players



Source: Autism Reading Room: GrRoss Senter, Karthik Kumar, and Sharmila Banerjee-Basu, Ph.D. http://readingroom.mindspec.org/?page_id=572



Recent Findings 2015-2017

Large study on parental age and autism finds increased risk among children of teen moms

ADHD symptoms can delay autism diagnosis for years

Study links autism to epigenetic changes in dads' sperm

Discovery of brain-immune system link could advance understanding of autism

Can brain imaging deliver early autism diagnosis? March 7, 2017

Recent Findings 2015-2017

- Research on females with ASD is leading us to question whether we need new or adapted screening or diagnostic tools to ensure that girls aren't put at a disadvantage
- Neuroimaging technique may help predict autism among high-risk infants
- Future Autism Diagnosis linked to Early medical condition
- The 'robot therapist'

Þ



Recent Findings: 2015-2017

- Autism risk linked to fever during pregnancy Prenatal exposure to maternal fever during the second trimester raised odds of autism spectrum disorder by 40 percent
- Possible early diagnosis of autism spectrum disorder through proteins in the blood
- System detects, translates sarcasm, humor on social media
- Brain Circuit Tweak Wins Her Affection (if she's a vole) -Previously unknown mechanism underlying pair bonding behavior discovered



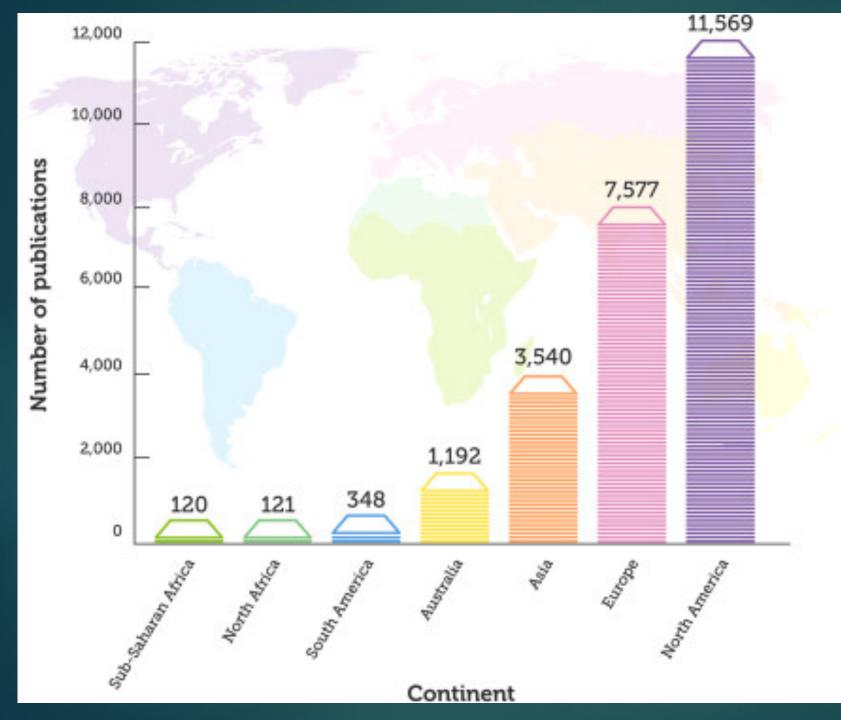
Commonalities

- Multisector collaboration
- Information sharing
- Data Collection
- Small and large population studies
- Unrelenting thirst for more information
- Backed by governmental and non-governmental entities
- Public-Private Partnerships
- Institutional Research
- Samples and target population limited to the Western Hemisphere
- Race for more effective intervention and therapies
- A desire for continuous improvement and progress

AUTISM RESEARCH IN AFRICA

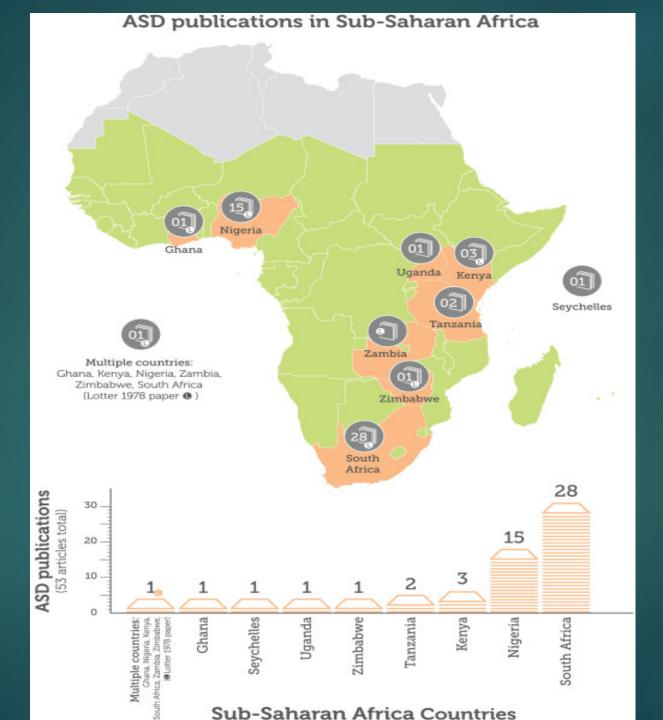
- The "90-10" divide—although 90% of the world's children and adolescents live in low- and middle-income countries, only 10% of research is performed there [Kieling et al., 2011].
- One of our Greatest Knowledge Gaps is about Autism in Developing Countries
- Children and adolescents in Africa are under-treated and underresearched. The treatment gap for child and adolescent mental health and neurodevelopmental disorders is estimated to be 90% and very little research is performed in Africa. A lack of awareness and knowledge...exists in all levels of African Society...yet the need is great. The UN predicts that by 20150, 40% of the worlds children and adolescents will live in Africa. "

Geraldine Dawson, President, International Society for Autism Research New, April 13, 2017



Publications about ASD around the Globe.

The figure shows the number of publications ever published on ASD by continent.



Publications about ASD in sub-Saharan Africa.

The figure shows the number of peer-reviewed, data-containing publications ever published on ASD by country.

(a) phenotype (n = 13), (b) genetics (n = 2), (c) risk factors (n = 3), (d) screening and diagnosis (n = 2), (e) professional knowledge (n = 9), (f) interventions (n = 11), (g) family perspectives (n = 8), and (h) social-cognitive neuroscience (n = 5).

Epidemiology of ASD

- Early interventions, including naturalistic, developmental behavioral interventions (NDBIs)
- Education and education systems
- Transitional care from childhood to adult services
- Treatment of ASD with medications in Africa.
- Access and efficacy of to behavioral intervention.
- Adults with ASD
- Use of technology for screening, diagnosis, training and monitoring

- **Screening Diagnosis**
- Need for people who speak the language
- Need to use developmental history and screening tools
- Challenges of translation, validation, cost of training on existing tools, need for open access, culturally
- Fair and globally relevant screening and diagnostic tools for ASD
- Low technology techniques
- Therapies
- Needs intensive therapy with frequent sessions. specifically trained therapists and one-on-one basis

Phenotype

No large scale or population based studies No use of standardized diagnostic instruments Mainly categorical descriptions

Genetics Need to integrate genomic/ phenotype data from SA Understanding of etiology of and Examine the interplay between genetic and environmental factors

Mixed Races

Genetics

-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

-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.)

Risk Factors

High rate of communicable diseases, malaria, tuberculosis Role of risk factors

Interplay between communicable and non communicable diseases

Need for single case control study aimed at examining a comprehensive set of potential risk factors

- **Training & Development**
- Need for training of parents caregivers and families
- Need more parent support groups and parent based interventions taking into account contextual factors
- Need Psychoeducation of parents ...what to expect
- **Other Themes**
- What about ASD among Africans outside African Continent ASD among Africans among Africans
- What about etiology and explanations based on opinion?
- What about train the trainer models?
- What about aging in autism?

Other Themes

Why is there a wide gap between age of onset of symptoms and diagnosis of ASD? Is there any plan for a large scale epidemiological study on ASD to determine difference in prevalence of ASD between rural and urban areas? Why is a diagnosis of ASD rarely made exclusive of intellectual disability in Africa?

Other areas 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.

Africa's Possible Contribution....

Source of new knowledge **Comparative genomic science Mutually beneficial gains Consistent** with missions **Identify** peculiarities **Incorporates cultural differences** Offer low resource techniques that work **Migrations worldwide Community based autism detection program** Use of traditional treatments or therapeutic approaches

Moving Forward...

DIASPORA-Hometown Associations

DUAL CITIZENS

INTERNATIONAL STUDENTS - (Global Student Council)

INTERNATIONAL ALUMNI OF NIGERIAN UNIVERSITIES

Moving Forward...

CHILDREN OF "BRAIN DRAINERS"

GRANTS TARGETING INTERNATIONAL/GLOBAL REACH

CHARITIES WORLD WIDE

BRAIN DRAINER" FACULTY

Moving Forward...

- **UNIVERSITY STUDY ABROAD**
- **FACULTY DEVELOPMENT AREAS**
- OUTREACH GRANTS AFRICA-US Higher Education INITIATIVE
- University partnerships- "Africa Initiatives"
- Worldwide Charities
- Outreach Projects, non profits, endorsements, social media, webinars (free), webchats, Twitter, etc.



Moving Forward

- International Associations
- CODESRIA www.codesria.org
- Partner with grant awardees
- Autism international foundation
- International Society for Autism research
- Global Development Network
- NATIONAL ENGAGEMENT SCHOLARSHIP CONFERENCE SEPTEMBER 26-27
- International Community Engagement Awards

ADVANCES IN SPECIAL EDUCATION VOLUME 18

AUTISM AND DEVELOPMENTAL DISABILITIES: CURRENT PRACTICES AND ISSUES

EDITED BY

ANTHONY F. ROTATORI Saint Xavier University, USA

FESTUS E. OBIAKOR University of Wisconsin-Milwaukee, USA

SANDRA BURKHARDT Saint Xavier University, USA



United Kingdom - North America - Japan