

# Beyond an Autism Diagnosis: Strategies for care in the Nigerian Setting.

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# Outline

- Background
- Current
- Diagnosed?, so what next
- Future
- Models
- Conclusions

# Background

- Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development under one umbrella diagnosis of ASD.
- A chronic condition with lifelong challenges.
- Challenging in many ways: individual, family, community.

# ASD Burden

- Huge - public health significance.
- Centers for Disease Control and Prevention (CDC) released in **March 2014 – approx. 1 in 68 children USA** on the autism spectrum (x10 increase in prevalence in 40 years).
- Local figures suggest increasing prevalence (?higher suspicion and detection). Epidemiology - **X**.
- Out of pocket funding/ financial strain
- Disjointed/non existent services.
- Caregiver burden of care +++

# ASD Criteria

- DSM 5 (2013)
- A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome.
- These all now called **Autism Spectrum Disorder.**
- Severity - based on social communication impairments and restricted, repetitive patterns of behavior.



# ASD presentation

Under the current DSM-5, there are two domains where people with ASD must show persistent deficits.

Include:

1. persistent social communication and social interaction
  2. restricted and repetitive patterns of behavior.
- Stereotyped or repetitive motor movements
  - Insistence on sameness or inflexible adherence to routines
  - Highly restricted, fixated interests
  - Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment

# Diagnosis

- No single biomedical marker or simple laboratory test or procedure for ASD,
- Accurate identification of individuals with ASD is entirely dependent on clinical competencies.
- For the diagnosis of ASD, the knowledge base must include familiarity and experience with the research literature and with children with ASD.
- Is a **Process** – Not one off evaluation!
- Involves - **Screening, Clinical eval, Structured assessments.**

## ADOS-2

### Autism Diagnostic Observation Schedule, Second Edition

Get an accurate picture of current ASD symptoms based on real-time observation

Have more questions?

[VIEW FAQs](#)

# Locations of care

Multileveled and varied

- Home
- School: therapist/facilitator, ASD specific school
- Clinics : screening, assessments, reviews, examination.
- Community: screening, support, care , acceptance, rehabilitation



**CURRENT**

Growth is never  
by mere chance.  
It is a result of  
forces working  
together

AUTISM TREATMENT CENTER  
OF AMERICA

# Challenges in diagnosing

We are familiar with ..

- Inadequate Skilled manpower spread
- Culturally appropriate tools
- Disjointed and non comprehensive Services
- Uncertain course

# Current practises around diagnosis

- Home – Worried parent vrs Denial
- Clinics – Observant clinician vrs Overreassurance
- School – often in primary or secondary schools
- Community surveillance - Gtbs role\*\*\*

# Local experience of ASD diagnosis

- Denial
- Confusion and dilemma of “what next”
- Disjointed services
- Stigma
- Helplessness

# Consequences of this reality.....

- Missed Cases – Misdiagnosis, wrong diagnosis, late diagnosis.
- Limited educational options – cost, availability, access.
- Clinical effort – no comprehensive services, no funded programs.



**DIAGNOSED WITH ASD?,  
....SO WHAT NEXT?**

# A Diagnosis & what should follow?



## Next Steps Following An Autism Diagnosis in British Columbia



# If we suspect an ASD diagnosis?

- Identify at risk child
- Get evaluated clinically
- Structured assessment – areas of deficits.
- \*Inter agency collaboration.
- \*Educational services integration.
- \*Behavioural interventions
- \*Life span approach
- \*Learn more, advocate more



# IDEAL

- So, Post diagnostics interventions need to be :
- Multidisciplinary
- Evidence based interventions!
- Comprehensive nature
- Individualized
- Intensive
- (Not) Costly!!!

# Why do we struggle?

- Poor political will
- Different priorities – Govt versus the people
- NCDs Compete with infections and life threatening communicable disorders.
- Lack of understanding.
- Lack of Stakeholder cohesion

# Effects of our ongoing struggle

- More ASD patients suffer.
- Comorbidities persist and complicate course.
- Academic challenges persist in sufferers
- Inadequate culturally relevant data lacking
- Pathway to Independence unclear.
- Caregiver burden persists – emotional and physical.

# Ethics-ASD diagnosis/research in LAMICS

J Autism Dev Disord  
 DOI 10.1007/s10803-012-1750-2

ORIGINAL PAPER

## Ethical Considerations in Conducting Research on Autism Spectrum Disorders in Low and Middle Income Countries

Tamara C. Daley · Nidhi Singhal ·  
 Vibha Krishnamurthy

© Springer Science+Business Media New York 2012

**Abstract** Autism spectrum disorder (ASD) is being identified in an ever-increasing number of countries, including many that are low or middle income (LMIC). Research conducted in these countries requires awareness of unique ethical issues. Drawing on the experience of two organizations that have been involved in conducting and collaborating in ASD research in India, we describe specific considerations in conducting epidemiological, genetic and treatment studies as well as general principles from the

120 countries in which an ASD-specific organization has been established are low or middle income (see Fig. 1). In 2011 alone, studies were published from countries as diverse as Brazil (Paula et al. 2011); China (Chan et al. 2011; Wang et al. 2012); Colombia (Talero-Gutiérrez et al. 2011); Croatia (Benjak et al. 2011); Egypt (El-baz et al. 2011a, b); India (Kishore and Basu 2011; Srivastava and Mukhopadhyay 2011); Iran (Samadi and McConkey 2011; Samadi et al. 2011); Libya (Zeglam and Maouna 2011);

- Risk/fear of stigma.
- Description(epidemiology) versus solution (interventions).
- ASD Vrs other NDD
- Power play – Client/researcher
- Culturally sensitive tools.
- Expectations
- Consent and respect.
- International vrs incountry or funder vrs researcher
- Collaborator power imbalance

**FUTURE**



# Future & Way forward

Need to :

- Ask our own questions.
- Develop our uniquely sustainable solutions
- Be deliberate and plan....non adhoc!
- Stakeholders are key players

# Possible strategies

- Intersectoral collaboration
- Stakeholder involvement
- Parent led strategies.
- Local capacity development and training
- Utilize technology
- Corporates and ASD
- Centers of Excellence – comprehensive care and research.

# Intersectoral collaboration

- A key public health delivery strategy
- Inter agency collaboration to deliver otherwise non existent service.
- Example : Academia, banking, education, social development etc.
- Benefits for protection and balance in strategies.  
Minimizes risk of exploitation
- Well thought out research groups & planning meetings needed.
- E.g GTB- Blazing trails, Patricks, CMUL Collaboration



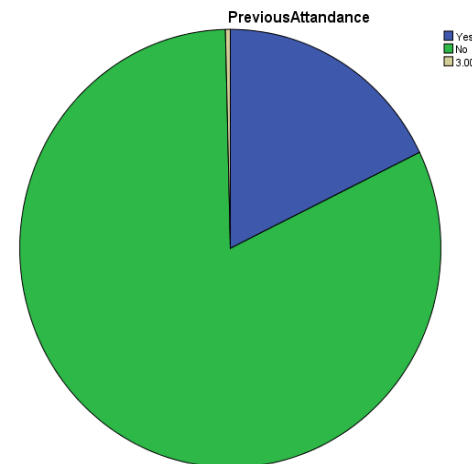
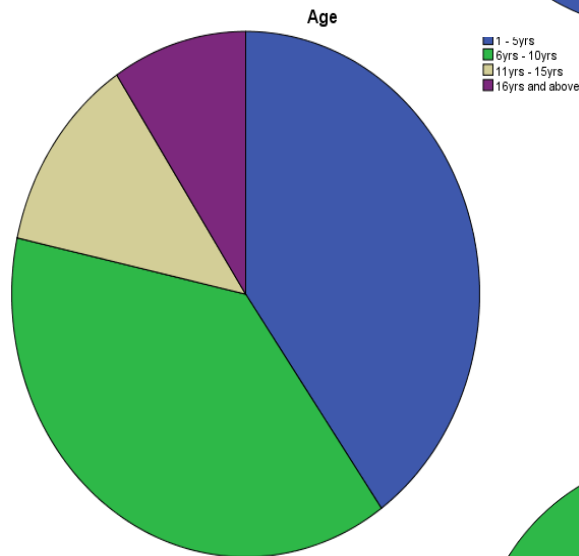
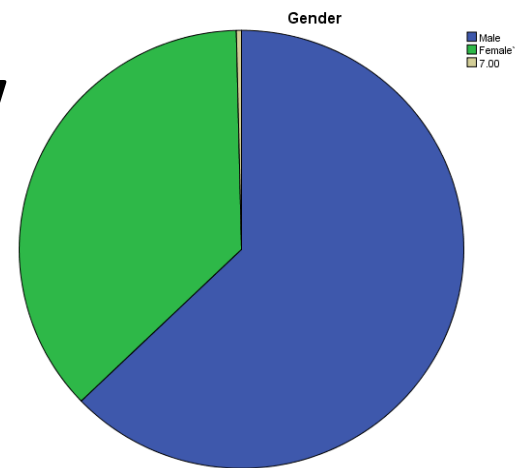
# Orange Ribbon - Consultation

- Annual.
- 5<sup>th</sup> year in collaboration
- Stakeholders involved...
- Wide outreach



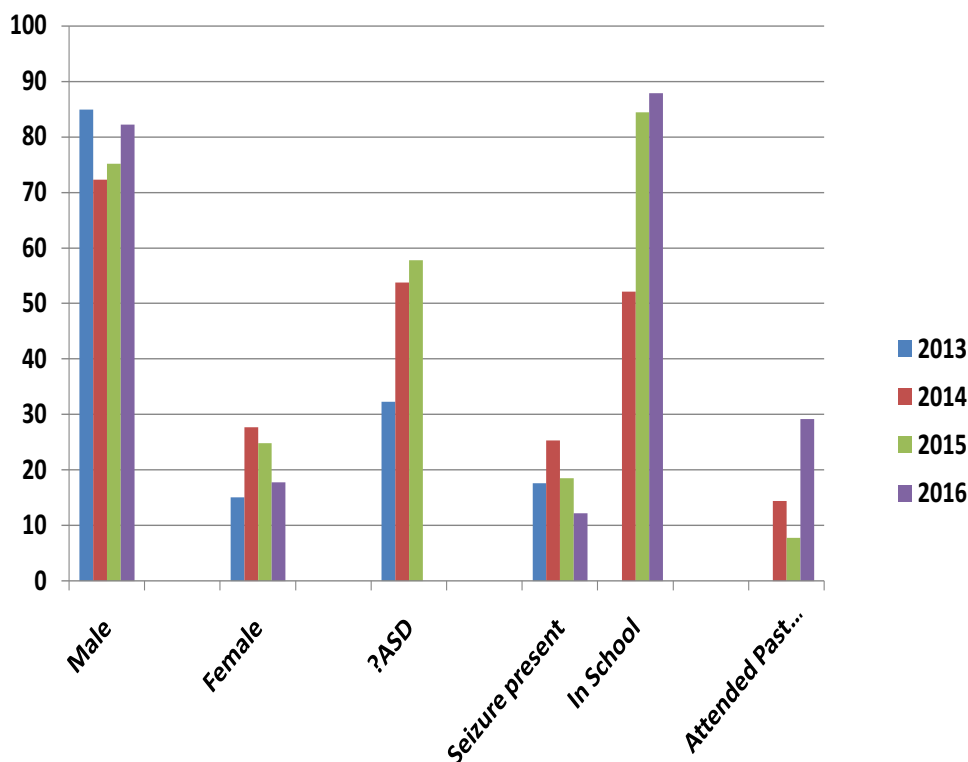
# 2016 overview

	Frequency	Valid Percent
<b>Male</b>	169	62.8
<b>Female`</b>	100	37.2
<b>Total</b>	269	100.0
<b>Age</b>		
1 - 5yrs	108	40.1
6yrs - 10yrs	103	38.3
11yrs - 15yrs	33	12.3
16yrs and above	25	9.3
<b>Total</b>	269	100.0
<b>Previous Attendance</b>		
Yes	48	17.8
No	221	81.9
3.00	1	.4
<b>Total</b>	270	100.0



# 4 year trend of consultation

## • Overview



## Utility

- First diagnosis
- Counseling
- Difficult challenges
- Referral to existing services.

## Downside

- Limited
- ?Continuity of care
- Therapeutic Misconceptions
- Need for more !

# LESSONS LEARNT FROM COLLABORATION

## CHALLENGES

Requires great coordination

Risk of over enthusiasm

Repeat attendees

Large number of Non ASD Participants

Merging interest areas of different sectors

## BENEFITS

Multidisciplinary input

Wide variety of services on site

Manageable cost to each sector

Referrals made to support groups and ASD Clinical services

## FUTURE STRATEGIES

Improvement of pre- screening selection process

Regular Clarification of group goals and priorities better and ensuring fidelity.



# Stakeholder involvement

- Who is a stakeholder?: Parent, professional, sufferer, interested agencies.
- Essentially from : Family , medical/educational fields, Academia, Corporate/ Private sector, NGO.
- Need for multifaceted involvement:  
As Donors &Volunteers  
Research Funders  
Service Innovators – best practises preserved

# Parent led strategies.

## Areas of Focus:

- Care - Global emphasis on parent led interventions e.g NDBI's
- Support – advocacy & support groups
- Participation in service & Policy development

# Local capacity development and training

- Affordability (client and trainee)
- Culturally sensitive
- Sustainable
- Verifiable credentials



# Utility of Technology

## Encourage and drive creation of Solutions to address:

- Mobile phone apps and other technologies.
- Awareness - knowledge
- Networking – other families and service providers
- Service access – Where to find care, remote regions, skill and training for caregivers

## Innovative technologies

- Autism speaks – robotics, apps, scans,





# Role of corporate/ private sector Stakeholders

- CSR support – Good so far but in reality not enough.
- ASD needs Investing the big money & govt not keen/ not able – Only way for coporates to stay in for the longterm take care of bottom line.
- Private equity can consider a huge long term bet on life Sciences development.
- Look for the business opportunity in research and science development.

# Corporate Questions

How large is the market?

What are the numerous opportunities?:

Sample bottles, consumables.

How can it impact on the bottom line?

How do corporate entities position to participate?:

Would funding venture capital industries to look into this help?

# Gown meets Town

- Needed to promote Investment in innovative solutions.
- **The Gown** must meet **The Town** & Vis versa.
- Leveraging on driving a well developed biotech industry.
- Ethics of ASD vrs other NDD as priority?
- Useful for variety of chronic disorders...scd, childhood cancers autism Inclusive...  
Invest in a research Laboratory.....eg a starting point with CANDo

# Centers of Excellence

- Tertiary care
- Research
- Capacity development/training.
- Examples - NARC (CAN-Do) CMUL



# CMUL : N-ARC / CAN-Do STORY

# CAN-Do CMUL

- About us
- Began in 2014 as **Neurodevelopmental and Autism Resource center(N-ARC)** of the College of Medicine University of Lagos ( CMUL). Following ASD Community consultation and a thinking of what next?
- Evolved to **Center for Autism and Neurodevelopmental Disorders (CANDo)**. One of the 5 research centers of excellence in the University of Lagos. is a multifaceted and focus driven Center positioned to address the research, learning and service needs of persons and caregivers of those living with autism and other neurodevelopmental disorders.
- The Centre engages in independent activities within the purview of its purpose.
- The centre is open to partnership with individuals and other organizations with similar interests.
- Services will be largely free or offer token charges to clients and trainees

# CAN-Do CMUL

So far

- Regular monthly Support groups.
- Biannual Seminars
- Biannual Workshops.
- Upcoming ; Training and professional master classes, town hall, therapy days, Research.





# CAN-Do CMUL

Our limitations:

Funding.

Funding

Funding



Our strengths

- collaboration amongst experts : local and international.
- Strategic positioning at interface of reseach and community roles.
- Amazing team committment



# CAN-Do CMUL

How can you help :

- Donate – toys, furniture, Computers, tablets,
- Help – renovation items,
- Sponsor – some one to a workshop, a training exercise,
- Volunteer – time, skill, knowledge.
- Partner – think tank, funder, resource developer.
- Participate – in research, in advocacy events, town hall open house meeting.
- For more details send email to [autismservice@cmul.edu.ng](mailto:autismservice@cmul.edu.ng)

# Existing and potential in-country

- CAN Do
- TLP
- PSLc
- GTBank
- Others.....

# Morale

- Successful collaborations can exist
- Lot of ground still to cover
- Knee jerk reactions not the way forward.
- Together we can do more

# **CONCLUSIONS**

# Take Home Facts

- FACT 1 – Early Diagnosis of ASD is a first important step.
- FACT 2 - We need to actively do more than diagnose
- FACT 3 – We can achieve more collaboratively...Not in Silos!
- FACT 4 – Each person here CAN Do Something...

# Recommendations

- Stakeholder increased Participation in existing services as: **funder, volunteer, advocate.**
- Corporates to explore investments in research and service development.
- Institutional and individual contributions to fund /participate in **research**, thus, generating our own culturally relevant data.
- Time to embrace and harness technology!

# Quote

IT TAKES A VILLAGE  
TO RAISE A CHILD.  
IT TAKES A CHILD  
WITH AUTISM TO  
RAISE THE  
CONSCIOUSNESS OF  
THE VILLAGE.

COACH BLAINE HALL

