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.**
Locations of care

Multileveled and varied

• Home
• School: therapist/facilitator, ASD specific school
• Clinics: screening, assessments, reviews, examination.
• Community: screening, support, care, acceptance, rehabilitation
Growth is never by mere chance. It is a result of forces working together.
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

- **STEP 1**
  - Signing an Autism Funding Agreement

- **STEP 2**
  - Learning About Autism Treatments

- **STEP 3**
  - Finding Professionals to Work with Your Family

- **STEP 4**
  - Hiring and Contracting with a Service Provider

- **STEP 5**
  - Building and Maintaining a Strong Team

- **STEP 6**
  - Continuing the Learning About Autism
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
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

- 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 in-country or funder vrs researcher
  Collaborator power imbalance
“THE WAY WE CHOOSE TO SEE THE WORLD CREATES THE WORLD WE SEE”

Barry Neil Kaufman

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.
- 5th year in collaboration
- Stakeholders involved...
- Wide outreach
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<th>Frequency</th>
<th>Valid Percent</th>
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<tr>
<td>Female</td>
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<th>Frequency</th>
<th>Valid Percent</th>
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<tr>
<td>1 - 5yrs</td>
<td>108</td>
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<td>6yrs - 10yrs</td>
<td>103</td>
<td>38.3</td>
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<td>11yrs - 15yrs</td>
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<td>16yrs and above</td>
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<tr>
<td>Total</td>
<td>269</td>
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<table>
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<th>Previous Attendance</th>
<th>Frequency</th>
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<tr>
<td>Yes</td>
<td>48</td>
<td>17.8</td>
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<td>221</td>
<td>81.9</td>
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<td>3.00</td>
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<td>.4</td>
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<tr>
<td>Total</td>
<td>270</td>
<td>100.0</td>
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4 year trend of consultation

<table>
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<tr>
<th>Year</th>
<th>Overview</th>
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<tr>
<td>2013</td>
<td><img src="image" alt="Bar Chart" /></td>
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<tr>
<td>2014</td>
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<tr>
<td>2015</td>
<td><img src="image" alt="Bar Chart" /></td>
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<tr>
<td>2016</td>
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**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

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<th>Challenges</th>
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<tr>
<td>Requires great coordination</td>
</tr>
<tr>
<td>Risk of over enthusiasm</td>
</tr>
<tr>
<td>Repeat attendees</td>
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<tr>
<td>Large number of Non ASD Participants</td>
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<tr>
<td>Merging interest areas of different sectors</td>
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### BENEFITS

<table>
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<th>Benefits</th>
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<tr>
<td>Multidisciplinary input</td>
</tr>
<tr>
<td>Wide variety of services on site</td>
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<tr>
<td>Manageable cost to each sector</td>
</tr>
<tr>
<td>Referrals made to support groups and ASD Clinical services</td>
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### FUTURE STRATEGIES

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<th>Strategies</th>
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<td>Improvement of pre-screening selection process</td>
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<tr>
<td>Regular Clarification of group goals and priorities better and ensuring fidelity.</td>
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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 practices 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 corporates 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 research and community roles.
- Amazing team commitment
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
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!
IT TAKES A VILLAGE TO RAISE A CHILD.
IT TAKES A CHILD WITH AUTISM TO RAISE THE CONSCIOUSNESS OF THE VILLAGE.

COACH BLAINE HALL