




ONE-ON-ONE AUTISM CONSULTATION: EXPERIENCE FROM ANOTHER COMMUNITY

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Autism is referred to as a spectrum disorder to signify similarities among a group of individuals who share a common diagnosis, but who differ in how core characteristics are manifested, and in the number and severity of specific characteristics.



BACKGROUND

- Children with Autism Spectrum Disorders (ASDs) and their parents carry a huge burden in the absence of a comprehensive in-country platform for timely diagnosis, management and support
 - In Nigeria, the areas of **unmet needs** among Children with ASDs are **huge** (Such needs include having diagnosis, training, caregiving, education etc).
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SCOPE OF ORANGE RIBBON

- This initiative is operationalized in two broad approaches:
 - organizing seminars with broad stakeholder participation to, not only create awareness, but attempt to define the way forward on how parents could cope with and manage the challenges of ASDs and
 - conducting consultative sessions with clients with ASDs.



AUTISM IN NIGERIA

- These clients are seen in the hospital.
- Few are followed up and most if not all are referred for services in the community
- Minority of the cases seen are published to add to literature.
- Publication from this part of the world are few and limited in scope.
- Most report few sample size and mainly clinical.



DIAGNOSIS

- Diagnosis is usually done by medical personnel
- Most of these health facilities are in big cities and are not
 - Affordable
 - Accessible
 - Available or
 - Acceptable



PROBLEMS PREVENTING EARLY DIAGNOSIS AND INTERVENTION

- These personnel are few and scattered all over the country
 - > 300,000 doctors vs >500 paediatricians
 - About 250 psychiatrists vs >20 child & adolescent psychiatrists
 - >50 speech therapists
- Non availability of resources and lack of awareness
- Social exclusion and social distance hampering access to care



COMMUNITY INTERVENTION

- For all health related issues that are stigmatizing especially chronic medical disorders, community approach is advocated by the World Health Organization. This is said to reduce neglect and violation of human right.



WHAT IS A COMMUNITY

- A locality or space, people or members, shared institution and values, interaction, distribution of power and a social system.
- The concept within a system of care includes issues of locality, connection, and services as well as a social bond characterized by a sense of mutuality, **identity, care, awareness** and **obligation to others.**







CONSULTATION

- Began 3years ago.
- Total of 350 (70+95+185) individuals with **neurodevelopmental disorders** were seen
- A significant number of the subjects seen had **ASD** (32.0%)
- Invitation was by e-mail, letters to special schools, verbal invitation, print media and radio jingles.





SAME METHOD DIFFERENT RESULT

- First consultation in Abeokuta
- Means of invitation basically same but another stake holder was involved.
- More of a community approach, call it political will (Oba ran e nise).
- Information were disseminated in local content regarding available services



RESULT

- A massive turn out, a total number of 360 individuals with **neurodevelopmental disorders** over a period of 5 days but less of **ASD**.
- People organized themselves, came early in large number irrespective of distance.
- They showed interest and eagerness to be seen



FACTS FROM BOTH COMMUNITIES

- Neurodevelopmental disorders/autism are common in our environment
- Distribution cuts across social classes
- Diagnoses are still late (about a tenth in their 20s)
- Many have not received any intervention
- Interventions are not sort because of cost and availability
- Many do not have an idea of where to go



FACTS CONT'D

- There is no support for caregivers of these patients.
- Many family members and friends refused to help. A few husband abandoned their wives
- Most of these clients are first born child
- Poor obstetric history accounted for about a third
- A little over a third have sought some help and have a diagnosis of different comorbidities



WHY THE DIFFERENCE

- Community involvement
 - Limited to Ogun state and a few surrounding cities- Lagos, Ibadan. Lagos was a mixed multitude
 - Inter-sectoral collaboration
- People saw it as their own no wonder the glamour at the opening ceremony.
- A few came who had no disability whatsoever. National cake???



PROBLEMS FACED

- No appropriate 'local/native' word to describe neurodevelopment disorder talk less of autism
- Lack of information to caregivers
- Inadequate skilled manpower
- Lack of adequate training and regulation of resource persons
- Inadequate (relatively costly) services in the community
- Lack of legislature
 - No/ineffective laws
 - No registry



LANDMARK ACHIEVEMENTS

- First large scale surveillance
- Identification by a financial institution to people that the society stigmatize
- Continuity and expansion in scope
- Intersectoral collaboration. No longer is a sector seeing it as their sole territory
- Inclusion in published data
- Nigeria is now represented among those researching into autism





Pattern of Behavioral Deficits among Nigerian Children with Autism

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The Orange Ribbon Initiative
is a NACF for children with special needs



Guaranty Trust Bank

Background:

Beyond diagnosis of autism spectrum disorder (ASD), interventions are most effective if need-tailored and predicated on what is known about specific behavioral deficits. This study is set to profile behavioral and emotional problems among children with ASD in a resource restricted setting.



Methodology:

The study participants were made up of 100 children with ASD and their caregivers recruited during the annual autism project done in 2014 and 2015. This autism program is anchored through the collaborative partnership among College of Medicine, University of Lagos; Guaranty Trust Bank and Blazing Trail International, USA. A designed

questionnaire was used to collect socio-demographic, clinical and psychosocial characteristics of the participants. Following screening with the Modified Checklist for Autism in Toddlers (M-CHAT) and Childhood Autism Spectrum Test (CAST), clinical diagnosis of ASD was done based on DSM-V criteria. Subsequently, the Strengths and Difficulties Questionnaire (SDQ) was used to profile behavioral deficits across multiple dimensions among the participants.

Results:

- Mean age of the children, their mothers and fathers was 7.7(±5.7), 38.9(±6.7) and 43.7(±7.2) years respectively
- Majority of the children (74%) were males
- More than four-fifths of their mothers (87%) and fathers (81%) had tertiary education
- Close to two-thirds (63%) of the children with ASD reported various degrees of difficulties as shown by overall SDQ score that ranged from high (39%) to raised (24%) deficits
- The domain score on peer problems showed the worse level of deficits, with up to 80% reporting more than average difficulties
- 67%, 36% and 17% of participants reported considerable challenges with respect to hyperactivity, prosocial behavior and emotional symptoms respectively
- All participants indicated this encounter to be their index evaluation despite 80.5% of them having had problems for more than one year

Conclusions:

Our study observed varying degrees of difficulties across the dimensions of SDQ among children with ASD, with worse deficits reported on domains capturing "externalized symptoms". Given the array of "unattended" behavioral and emotional problems profiled among children with ASD, there is need for sustained resources including research, training and intervention to address these behavioral challenges.

Keywords: Autism Spectrum Disorders; Behavioral analyses; Emotional problems; Nigeria



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QUESTIONS TO ALL

- Do we move quickly to another community till we cover the 36 states and the FCT?
- Are we mature to limit ourselves to only autism? May be for this conference but in reality, other conditions look too similar.
- Do we just bring awareness to their door steps, diagnose them?
- Do we have the resources?
 - Financial
 - Manpower



WAY FORWARD

- We cannot not move too fast less we loose the local content
- Need to conserve resources and build manpower.
- Set up a platform for training, research, service and standardization.
- It cannot be overemphasized that a resource centre will answer all these



CONCLUSION

- This project is addressing a core need in our society
- The concept of community ownership is in the right direction
- Caregivers burden are huge and a lot of burden needs to be alleviated
- With organized and sustained support, we will be able to provide quality care for these marginalized group



THANK YOU

