

Caregiver support group: gains and challenges

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College of Medicine Autism and Neurodevelopmental Resource Centre (ANRC)

- The Autism and Neurodevelopmental Resource Centre is one developed and designed to provide wholesome, affordable, accessible and culturally-relevant but globally-acceptable resources and services to families and children with Neurodevelopmental disorders.
- This centre will run 5 cardinal services and these include:
 1. Support Group for family caregivers of affected children
 2. Clinical Evaluation services
 3. Educational services
 4. Advocacy
 5. Research

Services

- A. Support Group
To provide an avenue for the family caregivers to meet regularly for mutual and practical support for one another.
- B. Clinical evaluation services
Medical and allied professionals shall offer services such as evaluation/assessment of children with these disorders, diagnosis, and management of cases. Services to be provided include clinical consultations, psychometric evaluation, occupational therapy, speech therapy and behavioural therapy.
- C. Educational services
Information about existing resources in Lagos and other parts of the country shall be made available. Parental training and training of different cadres of personnel involved in caring for the children will be carried out regularly.

Services

- D. Advocacy

The centre shall also be involved in advocating for neurodevelopmental disorders by interfacing with the general public and with government. This shall be done via public speaking, distribution of enlightenment materials and engagement with the government in the promotion of the rights of affected people and their families.

- E. Research

The centre shall also be involved in designing research topics, collection, collation, analysis and publication of data. This will help to understand the needs of the service users and thus help to drive and implement change and audit of the activities of the centre.

What has the resource centre been up to?

- Two of the three rooms have been renovated by contributions from some members of the Autism Research Committee (comprising faculty members of the college)
- Some furniture have been provided by the College of Medicine
- GTBank has supplied photocopier, stationeries
- The centre had its First Biannual Seminar in January

Biannual Seminar

- Seminars shall be held twice a year
- Aim is to focus on topical issues in the area of neurodevelopmental disorders
- First one took place on the 13th of January 2016
- Sponsored by Dr. Oshodi
- Topic was on Diet and Nutrition in Autism- myths, diet fads and evidence-based facts were discussed
- Facilitators were Dr. Yewande Oshodi and Dr. Motunrayo Oyelohunnu
- Quite topical as envisaged and enjoyed a good participation

First Biannual Seminar



First Biannual Seminar



First Biannual Seminar



First Biannual Seminar



First Biannual Seminar



Support Group

Where are we?

- The group has continued to meet regularly
- Participants have increased
- Participation has improved
- Several activities have taken place
- We had regular monthly meetings and two weekend seminars

Monthly meetings

- We have discussed various topics:
 - Caregiver stress and how to manage it
 - Identifying and celebrating the talents/gifts of people with special needs

Support Group Meeting



Support Group Meeting



Support Group Meeting



Support Group Meeting



Support Group Meeting



Programmmes

- We had 2 stand-alone programmes:
 1. The Couples' Breakfast Meeting
 2. A one-day workshop

Couples' Breakfast Meeting

- Held on the 14th of November, 2016
- First programme that took place at the refurbished resource centre
- Organized for parents (couples)
- Objective was really to improve male spousal participation in the care of the children
- This meeting was funded by contributions from some members of the faculty of the College of Medicine
- The Provost of the college was represented by the Deputy Provost, Professor Okanlawon
- A couple (Mr & Mrs. Sesan Olajide) who is known to be supportive was invited

Couples' Breakfast Meeting

- We had a joint session and then a break-out session where the men met alone and the women alone; sessions were facilitated by the respective gender and group coordinators
- Both speakers encouraged support by sharing their own experiences: how they coped
- They particularly shared plans they have put in place for their child with autism when they are no more
- This opened up discussions about how parents can plan for their children with special needs, especially considering setting up **trust fund**
- We would like the management of GTBank to consider if a package can be set up in this wise

Workshop

- One-Day workshop tagged “Understanding Neurodevelopmental Disorders”
- Took place on March 19th, 2016
- Objective was to give lectures in simple terms on 4 conditions- Autism Spectrum Disorders, Down Syndrome, Attention Deficit Hyperactivity disorder, and Cerebral Palsy
- A general overview of what neurodevelopmental disorders are was given
- Facilitators were- Dr. Campbell, Dr. Ayomide Adebayo, Dr. Ogunleye, and Dr. Oyelohunnu
- Workshop was supported by the GTBank with writing materials, lunch and drinks

Workshop

- Dr. Adebayo facilitated on advocacy
- This was done in a bid to teach parents on how to be advocates for their children
- Summary – 5 steps
 - Step 1- Discover your cause
 - Step 2- Define your message
 - Step 3- Decide your audience
 - Step 4- Choose your medium
 - Step 5- Find your tribe

International Meeting for Autism Research (IMFAR)

- Took place May 11-14th 2016 at the Baltimore Convention Centre, Baltimore, USA
- It was interesting to note that several of our activities are similar to what are being done in other places but there is still room for improvement

Gains

- We have been identified
- In June 2016, we received an invitation to present 2 participants to attend a caregiver/service user group training in Ibadan.
- The programme was a 3-day Capacity Building Workshop for Service Users/Caregivers in Mental Health sponsored by the EMERALD group, Nigeria chapter (Emerald group is a consortium of 12 participating institutions based in five EU member states, as well as six partners in Ethiopia, India, Nepal, Nigeria, South Africa and Uganda)

Gains

- It was a sponsored programme which covered accommodation, feeding and transportation
- It was highly impactful and the 2 representatives gave both a verbal and written feedback/report
- There, a national association was formed and one of our members, Alhaja Ramota Abbass, was nominated as the National Treasurer

Gains

- We receive verbal reports from members on how the group has improved their knowledge base about caring for their children
- One of our members is enrolled to study special education
- Some members have developed interest in advocacy and setting up programmes for children with special needs

Challenges

- Meeting the “real” needs of families in terms of provision of intervention
- Availability of Allied Professionals in the provision of affordable and effective, accessible services
- Financial handicap to meet all our goals and target
- Support for families- vocational trainings for parents
- Government support

Acknowledgements

- All members/participants
- Provost College of Medicine, University of Lagos
- Members of the Autism Research Committee, CMUL
- GTBank; Mrs Tolu Onipede & Miss Chichi Ikonta
- Staff, Department of Psychiatry, LUTH
- Mr & Mrs. Sesan Olajide
- Dr. Ayomide Adebayo
- Mrs Thelma Animashaun
- Mrs Stella Echebina

Thank you for listening

