



2018-2019 REPORT

Transforming the lives of
persons living with Spina Bifida
and Hydrocephalus in Nigeria

FACTS ABOUT COVID-19



What is **COVID-19**? COVID-19 is a disease caused by a new strain of coronavirus. 'CO' stands for corona, 'VI' for virus, and 'D' for disease. Formerly, this disease was referred to as '2019 novel coronavirus' or 2019-nCov.' The COVID-19 virus is a new virus linked to the same family of viruses as severe Acute Respiratory Syndrome (SARS) and some types of common cold.

What are the symptoms of COVID-19? Symptoms can include fever, cough, and shortness of breath. In more severe cases, infection can cause pneumonia or breathing difficulties. More rarely, the disease can be fatal. These symptoms are similar to the flu (Influenza) or the common cold, which are a lot more common than COVID-19. This is why testing is required to confirm if someone has COVID-19.

How does COVID-19 spread? The virus is transmitted through direct contact with respiratory droplets of an infected person (generated through coughing and sneezing). Individuals can also be infected from and touching surfaces contaminated with the virus and touching their face (e.g., eyes, nose, mouth). The COVID-19 virus may survive on surfaces for several hours, but simple disinfectants can kill it.

Who is most at risk? We are learning more about how COVID-19 affects people every day. Older people, and people with chronic medical conditions, such as diabetes and heart disease, appear to be more at risk of developing severe symptoms. As this is a new virus, we are still learning about how it affects children. We know it is possible for people of any age to be infected with the virus, but so far there are relatively few cases of COVID-19 reported among children. This is a new virus and we need to learn more about how it affects children. The virus can be fatal in rare cases, so far mainly among older people with pre-existing medical conditions.

What is the treatment for COVID-19? There is no currently available vaccine for COVID-19. However, many of the symptoms can be treated and getting early care from a healthcare provider can make the disease less dangerous. There are several clinical trials that are being conducted to evaluate potential therapeutics for COVID-19.

How can the spread of COVID-19 be slowed down or prevented? As with other respiratory infections like the flu or the common cold, public health measures are critical to slow the spread of illnesses. Public health measures are everyday preventive active that includes:

- ✓ Stay home when sick.
- ✓ Covering mouth and nose with flexed elbow or tissue when coughing or sneezing. Dispose of used tissue immediately
- ✓ Washing hands often with soap and water
- ✓ Cleaning frequently touched surfaces and objects
- ✓ Observing social distancing.

(Written by Lisa Bender (Education UNICEF NYHQ), with technical support from the UNICEF COVID-19 Secretariat members)

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INTRODUCTION

The 2018-2019 report has been prepared by Festus Fajemilo Foundation (FFF). It consists of a background to FFF's year-long programmes and a description of the context within which the organization operated in 2018 and 2019. The report also presents the progress made towards expected outcomes and achievement of expected outputs. A summary of the accounts for the reporting periods is also provided.

Thanks to the team of committed staff, field workers and volunteers who put in so much effort towards the achievement of the set outputs and outcomes.

MESSAGE FROM THE BOARD CHAIRMAN

FFF has continued to blaze the trail in its area of competency. The last two years saw us setting new targets for service delivery by forging alliances with our international partners and associates. The coming year will see us continue to seek new frontiers within the NGO community and donor organisations.

Our dedicated management team led by Afolabi Fajemilo deserve special mention for their commitment to the cause. Without individuals like them, the quest in ensuring that the lives of those of us, physically challenged globally, would not have been brought to the fore.

Please continue to support our campaign and we thank you for being there for humanity.



• Olujimi Olusola III



from the Director's Desk



This report details some of our major successes and accomplishments from 2018 - 2019.

We thank the Almighty God for the grace, wisdom and strength He has bestowed on us from inception to date.

The years in focus have been busy for the Foundation with various activities/programmes and projects some of which we embarked upon in 2017. The Foundation made appreciable progress regarding funding, projects and programmes with remarkable impacts on our beneficiaries as children with spina bifida, hydrocephalus (SBH) and other forms of disabilities continue to experience improved health conditions and increased participation within/outside their families.

The two grants secured in the year 2017 for the No One Left Behind project funded by the International disability alliance (IDA) and International Federation for spina bifida and hydrocephalus and Breaking All Barriers project funded by Voice (OXFAM/HIVOS) made us to work across various disability groups. We also had the opportunity to work with diverse stakeholders and social actors among who are school teachers, secondary school students, government officials, health workers, media, NGOs and disability centers with lot of lessons learnt. The projects contributed in no small measure

towards the achievement of UNCRPD articles 7, 24 & 25 and SDGs 3, 4 & 17.

The Continence management project which was facilitated by Shine UK during the Commonwealth Fellowship of three FFF Staff members in the United Kingdom has brought a great relief to children living with Spina Bifida who face daily challenges of bladder and bowel incontinence.

The partnership with two health institutions namely Lagos University Teaching Hospital (LUTH) Lagos and Obafemi Awolowo University Teaching Hospital Complex (OAUTHC) Ile-Ife and establishment of FFF continence clinic have sustained access to continence care services for children with spina bifida. We appreciate Wales for Africa Hub for the funding support with matching fund from Shine U.K. and IFSBH.

I wish to specially appreciate the unflinching supports of our board and advisory council members. I salute the courage of parents of our dear children and youngsters with spina bifida and hydrocephalus especially those who gathered at the first support group in January 2008 and have remained committed to advancing the cause of the Foundation, to you I say "YOU ARE WARRIORS" This cooperation has kept FFF's flag flying. No wonder, FFF has been a reference point for non-profits focusing on spina bifida and hydrocephalus in Africa owing to the guidance role FFF has played in the formation of parents support group in some other African countries.

For us in the management team, we are committed to join hands with relevant stakeholders and organizations within and outside Nigeria to ensuring that people living with spina bifida and hydrocephalus in Nigeria are not left behind in the journey towards 2030 agenda of the Sustainable Development Goals (SDGs). FFF is therefore open to more collaborations and partnerships that will enhance the welfare of our members as well as promote primary prevention initiatives.



• Afolabi Fajemilo

*Thank you is such a simple word,
but it is said with my whole heart
- Lucinda Heavenridge*

OUR BOARD OF TRUSTEES

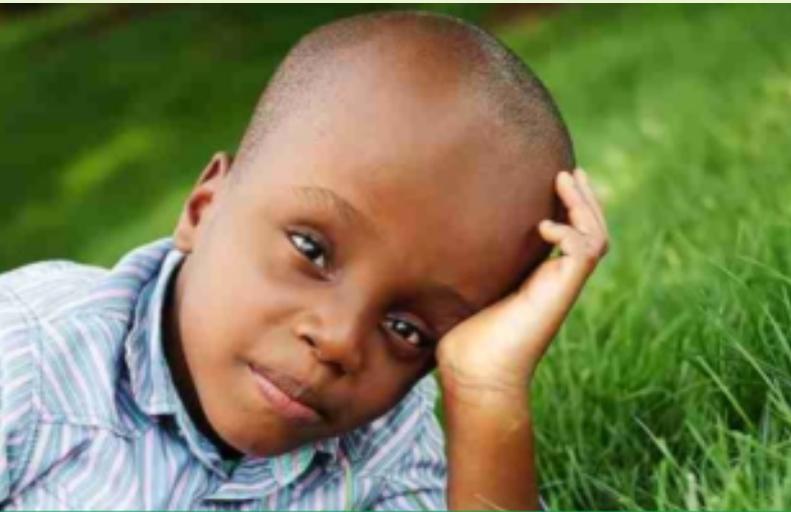
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ABOUT FESTUS FAJEMILO FOUNDATION

Festus Fajemilo Foundation (FFF) is a non-governmental and not-for-profit organization established in 2006 and registered under the Companies and Allied Matters Act 1, 1990 Part C of the Corporate Affairs Commission (CAC/IT/NO. 24051). FFF is the pioneer non-profit organization in Nigeria advocating for and promoting the rights of persons living with spina bifida & hydrocephalus and supporting initiatives targeted at primary prevention.

VISION

A Nigeria where everyone who has spina bifida or hydrocephalus can access quality healthcare, support with drastic reduction in the incident rate.

MISSION

To provide information, services and advocacy to ensure that people with spina bifida and hydrocephalus (SBH) have equal rights and access to good healthcare in Nigeria

HISTORY

The Festus Fajemilo Foundation began in 2006 and is named after a boy who developed hydrocephalus two months after he was born. Festus' parents found it hard to get any information and support, and his condition worsened, seriously limiting his development and requiring continuous and complex care. Appalled by the lack of affordable care, inadequate medical facilities and personnel, harmful taboos, and a pervasively negative attitude in the Nigerian society, Festus' parents decided that urgent action was needed, hence the birth of FFF.

CORE VALUE

Care:

We provide holistic support to our beneficiaries which includes health, education, livelihood, social and empowerment.

Equality:

We believe all human beings are created equally irrespective of age, gender, religion, race and socio-cultural background.

Self Esteem:

We crave for a society that allows persons affected by spina bifida and hydrocephalus to develop their potential without any hindrance. So, our various programmes are tailored towards building the confidence of our members to fully participate without any forms of discrimination.

What We Do

Spina Bifida – is a birth defect that occurs when the spine and spinal cord don't form properly. It's a type of neural tube defects. It occurs when a developing baby's spinal cord fails to develop or close properly while in the womb. It occurs during the first 25 days of development. At this stage, most women are not even aware that they are pregnant. This defect can result into hydrocephalus and the symptoms associated with it. It impairs nerve signals between the brain and the rest of the body. Treatment requires a multi-disciplinary approach starting with a surgical repair of the spine and follow up supportive therapies. Taking folic acid (400mcg) at least one month before conception until at least first three months of pregnancy, have been documented to reduce the risk of neural tube defects by up to 70%. Effects of spina bifida include latex allergy, pressure sores, paralysis and

loss of sensation, lack of bladder and bowel control (incontinence) and hydrocephalus.

Hydrocephalus – This occurs, when there is too much cerebro-spinal fluid or brain water within the cavities (ventricles) of the brain causing increased pressure within the brain. The prolonged pressure causes brain injury, which affects coordination, thinking, and development. The pressure can be regulated through surgical treatment using an endoscope or an inserted implant (shunt). A prompt intervention is required to prevent further long-term damage. Other effects of hydrocephalus include learning difficulty, poor coordination of muscles, eye problems, premature puberty, language & speech difficulties, seizures and spatial awareness.



Programmes & Activities

Child Development activities:

The child development activities are components of our child empowerment programme in partnership with Daughters of Charity of St. Vincent De Paul (DC) funded by Liliane Foundation (LF), Netherlands. These include facilitation of access to services (Health, Education, Livelihood, social empowerment), aimed to enable children and youngsters with disabilities (CYWDs) reach and maintain optimal physical, sensory, intellectual, psychological and social functioning. 61 children and youngsters with spina bifida and hydrocephalus have since received various supports in this regard.

Due to partnership expansion between 2009 and 2011, FFF had more responsibility and opportunity to engage with children with other forms of disabilities. To this extent, three centres namely - St. Sabina Catholic church Agege, St. Andrew Catholic Church, Badagry and Daughters of Charity of St. Vincent De Paul, Devine Mercy community, Bayeku, Ikorodu all in Lagos State were attached to the Foundation bringing to a total number of 103 children.

Through these activities, children and youngsters with disabilities continue to experience improved health condition, progress in education which in a great measure have boosted their self-esteem and confidence.

Outputs from the activities in the reporting periods:

INTERVENTION	2018	2019
Total number of children directly assisted	86 (55 males, 31 females)	103 (66 males, 37 females)
Education	67	75
Health (surgeries, physiotherapy, medications, Laboratory tests, assistive devices)	78	80
Livelihood (vocational training)	15	15
Home Visitation	86	103



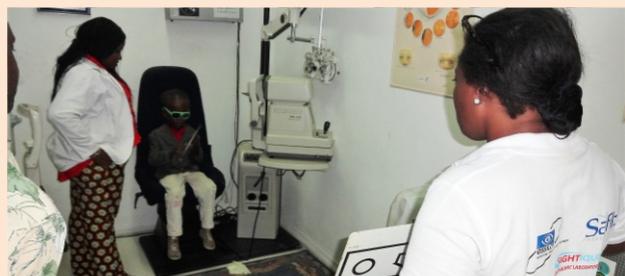
*Children during physiotherapy

Free Eye Examination & Glasses:

Since 2012, children registered with the Foundation have been receiving free eye examination and glasses from Pro-Optics Vision Specialists - a leading eye clinic in Nigeria located on Victoria Island and Lekki Lagos, Nigeria. Between 2018 and 2019, the eye clinic has supported:

- 16 children with free eye screening
- 4 children with new eyeglasses
- 4 children with replaced eyeglasses
- 2 children with replaced frame

We appreciate our advisory council member, Dr. (Mrs) Ogechi Nwokedi – the principal partner of Pro-Optics Ltd and her amiable team for this great support and the usual warm reception on every visit



@ Pro-Optics clinic

SUPPORT GROUP

For patient/parent dealing with challenges of life-long conditions such as spina bifida and/or hydrocephalus, life sometimes can be miserable. However, knowing that he/she is not alone brings a huge relief and increase coping skills. So, our support group activity which runs at two locations Lagos and Ile –Ife provides members with forum to share feelings, information, ideas and knowledge that could lead to common understanding, peer support, eliminating social isolation, reinforce

coping skills and gaining hope for a better life compared to others who are doing well. The Foundation partners with Hydrocephalus Association United States after becoming the first International community network member of the association in 2012. The association provides yearly grant as well as educational materials to support the Nigerian community. In the past years, FFF has used this platform to build the capacity of members on spina bifida and hydrocephalus and convention on the rights of persons with disabilities

(CRPD) – related topics such that members are able to advocate for the rights of persons living with these conditions. We equally appreciate the contributions of International Federation for spina bifida and hydrocephalus and Liliane Foundation towards the successes recorded during the reporting periods.



Members @ Lagos support group

Members at Ile Ife (OAUTHC) support group

ADVOCACY

We ring the bell:

We ring the bell is an annual advocacy/awareness programme held in collaboration with our partner, Daughters of Charity with funding from Liliane Foundation, Netherlands. The programme aims to advocate for the right of children with disabilities to quality and functional inclusive education. The concept enlists the support of school children, teachers, non-teaching personnel, political & community leaders, government

functionaries in ensuring education policy is structured in a way that meets the needs of learners with disability. Both 2018 & 2019 editions took place within Agege education district of Lagos state. Activities during the event include bell relay, signing of manifestos of a 10 point “urgent call for action”, media interview, media interview, sharing of information & educational materials and the 1-minute noise-making with various instruments such as bell, gongs, whistle, drums etc. signifying the climax of the event.

Outputs from the event in 2018 and 2019 are highlighted below:

Description of Target	Number Reached in 2018	Number Reached in 2019
No of Schools that participated in we ring the bell	2	3
No. of children who participated in we ring the bell	2535	4512
Number of Government Representatives	3	2
Number of publications	3	4
Television	2	1
Radio	1	1
Newspapers	1	1
Online	0	1
Number of Teachers who participated	15	25
Number of parents who participated	15	8
Number of NGO/CSOs	2	2



United for Inclusive Education



"We Ring the Bell"

9 OUT OF 10 CHILDREN WITH A DISABILITY ARE NOT WELCOME TO SCHOOL. Countries including Nigeria, have mutually agreed that it should be possible for all children to go to school no matter what. This includes children with a disability, but precisely this vulnerable group is commonly left behind at home. If we don't act, they will also be left behind in life. We are sounding the alarm bell and we say:

Support the Right to Inclusive Education for Children with Disabilities

10 URGENT ACTION POINTS NEEDED:

- 1 Provide children with disabilities (adapted) transport to school.
- 2 Make sure buildings, furniture and grounds accessible for children with disabilities.
- 3 Provide an adapted restroom at every school for children with disabilities.
- 4 Adapt lessons and rules for children with disabilities
- 5 Allow children with disabilities to participate in sports and games at school.
- 6 Teach children how they can be there for children with disabilities.
- 7 Stand up as parents for children with a disability.
- 8 Train teachers how they can better counsel children with disabilities.
- 9 Children with disabilities have the right to go to school.
- 10 Let children with disabilities advance and enjoy.



As stated in the UN Convention on the Right of Persons with Disabilities (CRPD), the UN Convention on the Rights of the Child (CRC) and the 2030 Agenda for Sustainable Development. www.welcometoschool.org





We Ring the Bell 2018

AWARENESS & PUBLIC EDUCATION

World Spina Bifida & Hydrocephalus Day:

WSBHD was established and designated by International Federation for spina bifida and hydrocephalus General Assembly in Guatemala in 2011. It aims to advocate and promote the rights of persons with these conditions. Since 2012, FFF

has been collaborating with the international body to celebrate persons living with spina bifida and hydrocephalus annually in Nigeria. Activities under the programme which the Foundation carried out in 2018 and 2019 include public lectures, advocacy visits to public offices and media houses as well as awareness roadshows.



● Public awareness on EKO FM in 2018 with over 3 million listeners reached



● Advocacy visit to former CMD LASUTH Prof. Wale Oke



● Awareness walk during 2019 World SBH day in Lagos, Nigeria.

SOCIAL ACTIVITIES

Annual End of Year Party:

Our annual end of year party is one of the ways of social integration for our children and youngsters as they are joined by families, friends and well-wishers every December to catch fun. This goes a long way to enhance their self-esteem and social interactions.



International Day of persons with disabilities (IDPD)

FFF held "One Day Talents Show" to commemorate international day of persons with disabilities on 3rd of December 2019 at Rita's Events & Suites in Ifako Ijaiye Local Government area of Lagos State. The event was well attended by government representatives from Lagos state office for disability affairs and ministry of Youth & Social Development, members of joint national association of persons with disabilities, NGOs, children with disabilities (CWDs), parents, school teachers, financial institution, religious leaders, people from entertainment industries and the media. The event was used to showcase the innate abilities of children with disabilities which demystify stigmatization and correct negative perceptions by members of the society. The event was supported by Liliane foundation. Additional support was received from Stanbic IBTC with physical presence of the bank representatives. More than 200 people graced the event.





Talents Show at International Day of Persons with Disabilities

IN-HOUSE SERVICES:

Continence Management Clinic:

The Health Hub of Festus Fajemilo Foundation is one of the objectives of the continence management project dated back to 2015, the clinic which runs twice monthly, provides a back up to our collaborating teaching hospitals (Lagos University Teaching Hospital & Obafemi Awolowo University Teaching Hospital Complex). Activities during clinic include training of children and parents on clean intermittent catheterization (CIC), bowel wash out (BWO), bladder pressure measurement (BPM) and oxybutynin instillation all done to manage bladder and bowel incontinence experienced by children and adults with spina bifida. Services are provided pro bono including materials and medications to achieve the goal of the project which is "Saving lives, improving futures".

The program has been made possible through funding from Wales for Africa Hub supported by IFSBH and Shine Cymru. Program has been further sustained by IFSBH & Shine Cymru through continuous donation of continence supplies and medications. We also appreciate the support of ICEMEDX LTD, for the continence nurse's stipend from July to December 2019.



Continence Nurse training parents at FFF's continence clinic

FFF Day Care Rehab:

The Foundation commenced in-house physiotherapy services in 2018 with the support of Liliane Foundation. The centre which only accommodates children and youngsters registered under the Foundation, operates periodically and helps to improve physical functionality of

the children with disabilities, enhance their mobility and independence. A survey conducted among parents of the children indicate satisfaction in the quality of services provided and response time compared to usual long waiting hours they experience at public facilities



Children during physiotherapy session at FFF's Day Care Rehab

Projects

No One Left Behind (NOLB):

NOLB is a 20-month project (July 2017 – February 2019) funded by the International Disability Alliance (IDA) & International Federation for Spina Bifida and Hydrocephalus (IF). The project seeks to ensure that children with spina bifida and hydrocephalus (SBH) and their families have the skills and knowledge necessary for fully participating in society, with emphasis on rights to health and education.

Expected results from the project aims to:

- I. schools in target communities are inclusive of learners with disabilities.
- ii. Festus Fajemilo Foundation and its members promote and support the inclusion of children with disabilities in education.
- iii. Persons with disabilities especially those with spina bifida and hydrocephalus in target communities enjoy improved health and living conditions through life skills, continence management.

The following activities were carried out towards realization of the above results:

- 3- day Skills training for mothers of children with Spina Bifida & Hydrocephalus for income generating to sustain school attendance of their children.
- 2-day inclusive education training for school teachers and mothers to support and promote inclusion in target communities.
- 1-day follow –up training for school

teachers and mothers to support and promote inclusion in target communities.

- Follow up visits to trained schools for on-job technical support and mentoring on implementation of learning from the training.
- 2-day continence management training for health care professionals of children with spina bifida.
- Life skills training for youths with spina bifida and hydrocephalus
- Parents training through support group activities
- 1–day continence management education for school teachers to provide support for reasonable accommodation of children with spina bifida in school as it concerns continence management.

Outputs/Outcomes from the project:

- 19 parents of children with spina bifida and hydrocephalus trained in soft skills, supported with seed grant are carrying out income generating activities and supporting their children education.
- 20 schools and 29 teachers trained and acquired knowledge in inclusive education, already applying new skills in their teaching and admitting children with disabilities.
- 15 youths with spina bifida and hydrocephalus have improved self-esteem through life skills training.
- More than 70 children with spina

PHOTO GALLERY



• Capacity building of health workers & parents on continence management



• Home visitations in Child Empowerment program



• Life Skills Training for Youths & Capacity Building for Teachers during No One Left Behind Project.

PHOTO GALLERY



• *Monitoring of our "Child Empowerment Program"*



• *Social Integration Activities*



• *We Ring The Bell campaign for Inclusive Education*



• *International Programs*



• *World Spina Bifida Hydrocephalus Day*

bifida are experiencing improved quality of life through continence care services.

- 9 nurses from four teaching hospitals and 1 private nurse trained and acquired knowledge on continence management
- 13 local parents have the skills and knowledge to advocate for and promote inclusive education in target communities
- About 150 parents were exposed to CRPD-related topics and more aware of the rights of their children especially those related to health and education through parent meeting activities.
- 10 school teachers received education on continence management to support and provide reasonable accommodation for children with spina bifida.
- 14 private schools and 1 public school received on – job mentoring and technical support on inclusive education



Various activities in the NOLB project

Breaking All Barriers (BAB) Project:

The BAB project focuses on sexual & reproductive health rights (SRHR) of young persons with disabilities (YPWDs). The 18- month project (Sept. 2017 – Feb. 2019) was funded by VOICE (OXFAM/HIVOS) under its influencing grants in the sum of €51,194.17. The project also received the financial support of Access Bank Plc in the sum of N2,342,850.00 to facilitate meetings of BAB clubs in all the participating schools and financial awards to some highly accomplished PWDs who are BAB ambassadors in the project.

The project is an initiative of Festus Fajemilo Foundation in collaboration

with Centre for Youth Studies (CYS) domiciled in Agege Education District of Lagos State.

It was designed to:

- Improve public understanding of sexual and reproductive health rights (SRHRs) of young persons with disabilities.
- Improve public understanding of available treaties/instruments on Sexual and Reproductive Health rights of young persons with disabilities
- Sustain societal awareness and acceptance of young persons with disabilities via organized forums,

publications and social media outreaches.

- Strengthen capacity of networks of advocates (especially young adults) to sustain social and policy advocacy on Sexual and Reproductive Health rights of young persons with disabilities.
- Increase capacity of young persons with disabilities to have improved self-esteem through life skills training.

Project Results:

- Trained 20 guidance counsellors from 20 private secondary schools in Agege Education District on SRHR advocacy.
- Trained 170 secondary school students (adolescent advocates) from 17 schools in Agege Education District through their schools' guidance counsellors on SRHR advocacy.
- Trained 12 YPWDs as peer educators of SRHR advocacy at three disability centres (Down syndrome Foundation, Hope Fountain School for the Deaf & Modupe Cole Memorial Childcare Treatment Home).
- Recruited 262 adolescent advocates (87 males; 175 females) of SRHR advocacy in the 17 secondary schools that participated in the project.
- Recruited 69 YPWD advocates (41

males, 28 females) through already trained YPWD peer educators.

- Influenced 9 of the 17 schools to offer admission to 10 children with disabilities plus 1 teacher with disability who got employment.
- Breaking all barriers club established in the 17 secondary schools involved in the project training students in life skills, sexual & reproductive health right advocacy.
- Members of BAB Club are seen as role models by other students.
- The project was seen, breaking barriers of negative perception of persons with disabilities.

The BAB project ended with award/graduation ceremony where the 17 guidance counselors, 170 adolescent advocates and 12 YPWD peer educators were presented with certificates of recognition for their roles in promoting SRHR of young persons with disabilities. The event also provided a platform for the 12 YPWD peer educators to demonstrate the impact the training has had on them. FFF & its collaborating partner - CYS remain grateful to VOICE/OXFAM, Access Bank Plc, Agege education district 1, the three disability centres and all the 17 schools who participated in the project.





Photos of activities during BAB project

Continence Management Project

Continence management programme is continuously celebrated as one of the most important ways of improving the inclusion of children with spina bifida in any society. The children identify this programme as a turning point in their lives, enabling them to have friends, enjoy education and becoming accepted in their community.

The Foundation commenced continence management project in Lagos in 2016 following a Commonwealth Fellowship programme in the UK by 3 FFF's staff hosted by our partner Shine, United Kingdom. Prior to this period, children with spina bifida experience infections, social isolation, rejection in school and sometimes untimely death as a result of complications from bladder and bowel incontinence.

Following two grants from Wales for Africa Hub (Hub Cymru Africa) initiated by Shine Cymru UK in 2015 and 2017, the continence management project kicked -off in 2016 with 2 visits of continence specialist nurses from Wales to Lagos, Nigeria. During the visits, scoping of available management options, training of younger children with spina bifida, parents and health care professionals, home visitations and interactions with management staff of Lagos state ministry of health and Lagos University Teaching Hospital were conducted.

Outputs/Outcomes from the project:

- 9 nurses from four teaching hospitals and 1 private nurse trained and acquired knowledge on continence management
- 2 teaching hospitals providing continence care for children with spina bifida
- FFF continence clinic established and providing backup for the collaborating public hospitals providing continence care especially during health workers strike
- About 75 children experiencing improved quality of life through continence care services
- Health workers (nurses) from 2 teaching hospitals receiving ongoing capacity through our quarterly continence working group.





Specialist Continence nurses from Wales & the project team members

CAPACITY STRENGTHENING

Training for Parents and Caregivers (Basic Physiotherapy Skills)

The 2-day workshop for mothers of children with developmental disabilities, funded by Liliane Foundation took place from 6th to 7th February 2018. The workshop provided mothers with skills to carry

out basic day-to-day physiotherapy exercises for their children at home to compliment what has been done by the professional physiotherapists. 30 mothers benefitted from the workshop.



Participants and demonstration by specialists at the workshop

Staff's Training

FFF sees capacity building of staff as key to overall organizational growth, ensuring quality service provision and sustainability of programmes. Between 2018 and 2019, the Foundation supported staff in both internal and external training.

Some of the training/workshops attended by staff include:

- Provision of specialized interventions for children/youngsters with

intellectual and/or multiple disabilities

- Practice of basic bookkeeping and financial accounting for NGOs
- Practice of monitoring and evaluation
- Procurement management
- Organization strategic planning
- Disability-inclusive disaster risk management for parents of children with developmental disabilities.
- Resource mobilization
- Planning & Reporting



Participants at some of the training attended by Foundation staff

Global Disability Summit

The first ever global disability summit took place in London from 23rd – 24th July 2018 and on the nomination of International Federation for Spina Bifida and Hydrocephalus (IFSBH), FFF Executive Director, Afolabi Fajemilo represented the global body at the summit. The summit was hosted by the UK's department for International development (DFID) alongside co-hosts, the Government of Kenya and International Disability Alliance (IDA).

The summit had the following objectives:

- Raise global attention and focus on neglected areas.
- Bring in new voices and approaches to broaden engagement.
- Mobilize new global and national commitments on disability and;
- Showcase best practice and evidence from across the world.

While it focused on four highlighted thematic issues which include:

- Tackling stigma and discrimination.
- Inclusive education.
- Routes to economic empowerment and;
- Technology and innovation.

The summit which was preceded by civil society forum on day one ended with a resolution that reads “We gather here in London and across the world to achieve a common aim: to ensure the rights, freedoms, dignity and inclusion for all persons with disabilities (PWDs)”. It was well attended by disabled people organizations (DPOs), their representatives, representatives of donor agencies, multinationals, the world bank, leaders of governments all of whom pledged their commitment towards the realization of 2030 agenda of leaving no one behind.



Scenes at the Summit

National Conference on Hydrocephalus (USA)

The biennial National conference on hydrocephalus hosted by Hydrocephalus Association and tagged "HA CONNECT -2018" held from June 28 – 30, 2018 in Orange County, California, United States. As one of the community network leaders of the

association, FFF director, Afolabi Fajemilo was present at the 3 –day conference.

The goal of the conference is to provide resources and tools for navigating the medical, educational and social challenges of living with hydrocephalus.



Sessions @ the conference in Orange County, California, United States

DONORS, NETWORK, PARTNERSHIP, COLLABORATION & MEMBERSHIP

The following organizations have contributed in no small measure to the success of our programs

DONORS



Hub Cymru Africa

NETWORK & PARTNERS

- Liliane Fonds, Netherlands
- Daughters of Charity of St. Vincent De Paul
- Hydrocephalus Association-HA (USA)
- International Federation for Spina Bifida & Hydrocephalus-IFSBH (Belgium)
- Nigeria Network of NGOs-(NNGOs)
- Spina Bifida Hydrocephalus Information Networking Equality-SHINE (U.K)

COLLABORATIONS

- Lagos University Teaching Hospital (LUTH)
- Obafemi Awolowo University Teaching Hospital Complex (OAUTHC)

MEMBERSHIP

Member, International Federation for Spina Bifida and Hydrocephalus

INTERNATIONAL COMMUNITY NETWORK

1st International Community Network Member,
Hydrocephalus Association, United States.

INTERESTING HUMAN STORY:

GABRIEL OYELEKE

Gabriel was born with spina bifida & hydrocephalus in 2005. While his father never wanted to see him, he was denied the much-expected love from the mother. However, the child was lucky to have a very loving grandma who faced all the challenges to give him the best to survive in life. At baby, neighbours labelled Gabriel as “lizard” because of his look. At about 3 years of age, the grandma came in contact with Festus Fajemilo Foundation and Gabriel was enlisted in a partnership programme between FFF and Liliane Foundation through which he has been receiving support for health and education. At first, he used to be pushed on wheelchair by the grandma to and from school daily but with continuous

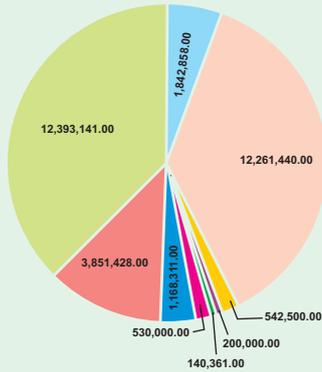
therapy and assistive devices, Gabriel achieved considerable improvements and able to move round on his own thus reducing the burden of care on his grandma. This has enhanced his self-esteem and participation in home and school activities. He was amazing during the life skills training held for youths with spina bifida & hydrocephalus by FFF in April 2018 where he displayed his talent in rapping. He on his own discovered a training centre for drumming on the street where he lives with his grandma and has since been acquiring skills in drumming. Thanks to his wonderful maternal grandma who came to his rescue and prevented him from the verge of untimely death. As he grows into a young man, Gabriel says “I thank grandma, FFF and Liliane Foundation for making me a happy boy”





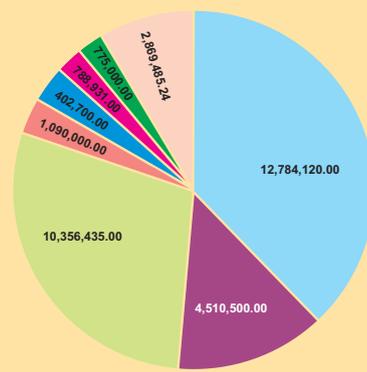
FINANCE

TOTAL INCOME FOR THE YEAR 2018 NGN 32,930,034.00



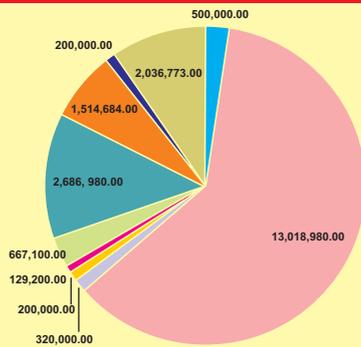
- Access Bank (5.6%)
- CODISA Chapel of Healing (0.61%)
- Individuals (3.55%)
- Lilian Foundation /Daughters of Charity (37.23%)
- Membership Due (0.43%)
- International Federation for Spina Bifida & Hydrocephalus (11.7%)
- Hydrocephalus Association (1.65%)
- Corporate Bodies (1.61%)
- Voice/OXFAM Nigeria (37.63%)

TOTAL EXPENDITURE FOR THE YEAR 2018 NGN 33,577,171.24



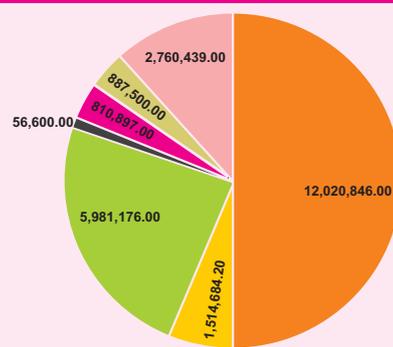
- Child Empowerment Programme (38.07%)
- Continece Management Project (1.2%)
- Training/Capacity Building (2.31%)
- No One Left Behild (NOLB) (13.43%)
- Medical & Rehabilitation (3.25%)
- Administrative Expenses (8.55%)
- Breaking All Barrier Project (30.84%)
- Programme Development (2.35%)

TOTAL INCOME FOR THE YEAR 2019 NGN 21,273,717.00



- Stanbic IBTC (2.35%)
- CODISA Chapel of Healing (0.94%)
- Individuals (12.63%)
- Lilian Foundation /Daughters of Charity (61.2%)
- Membership Due (0.61%)
- International Federation for Spina Bifida & Hydrocephalus (7.12%)
- Hydrocephalus Association (1.5%)
- Corporate Bodies (3.14%)
- Voice/OXFAM Nigeria (9.57%)
- Government (0.94%)

TOTAL EXPENDITURE FOR THE YEAR 2019 NGN 24,032,142.00



- Child Empowerment Programme (50.02%)
- Medical & Rehabilitation (3.69%)
- Training/Capacity Building (0.24%)
- No One Left Behild (NOLB) (6.30%)
- Programme Development (3.37%)
- Administrative Expenses (11.49%)
- Breaking All Barrier Project (24.89%)



Acknowledgment & Appreciation

FFF wishes to acknowledge and appreciate the support of individuals and organizations towards the successes and achievements recorded in 2018 and 2019. We also appreciate our Board of Trustees, Advisory Council members and management of FFF for working tirelessly in ensuring the sustenance and continuity of the Foundation.

Also, to the entire members and staff we say a big **THANK YOU.**

The contribution from every stakeholder has been instrumental to the successful completion and delivery of our project activities in 2018 & 2019.

We count on your continuous supports in subsequent years.

- ∴ Liliane Fonds, Netherlands ∴
- ∴ International Federation for Spina Bifida & Hydrocephalus ∴
- ∴ Spina . Bifida . Hydrocephalus . Information . Networking . Equality - United Kingdom ∴
- ∴ Hyrdocephalus Association, United States ∴
- ∴ International Disability Alliance ∴
- ∴ Voice (Oxfam/Hivos) ∴
- ∴ Stanbic IBTC ∴
- ∴ Access Bank ∴
- ∴ ICEMEDX LTD ∴
- ∴ BT Technologies ∴
- ∴ Committee for the disabled - Chapel of the Healing Cross ∴
- ∴ Liham Schools ∴

Sponsorship

Support our Vision.....



Donate to:

FESTUS FAJEMILO FOUNDATION

- **First Bank of Nigeria**
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- **Access Bank**
Account Number: 0046647380
- **Zenith Bank**
Account Number: 1012782883
- **Guaranty Trust Bank**
Account Number: 0108158482

Domiciliary Accounts:

Send through our Guaranty Trust Bank domiciliary accounts:

Account Name: Festus Fajemilo Foundation

SWIFT CODE: GTBINGLA

SORT CODE:058152382

GBP Account – 0173825502

Dollar Account – 0173825478

Euro Account – 0173825636

Thank you for your support in advance.





Pupils and students of Liham school in Lagos with their end of year gifts to FFF in 2019. Liham School Lagos has been a great friend of Festus Fajemilo Foundation.



Members of CODISA presenting office equipment in 2019



Our profound appreciation to the management & staff of BT Technologies for the company's yearly end of year support for more than 10 years.



...Support Group holds here



With our community, you are not alone

FFF support group provides localized support, education & empowerment

Join us today, and connect with other individuals & families

**...bimonthly @
Lagos State University Teaching Hospital, Ikeja.**

**.....quarterly @
Obafemi Awolowo University Teaching Hospital Complex, Ile-Ife**

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