

# 2022

## SUMMARY REPORT



TRANSFORMING THE LIVES OF  
PERSONS WITH SPINA BIFIDA  
AND HYDROCEPHALUS IN NIGERIA



## OUR VISION

A Nigeria where People with SBH and other forms of disabilities enjoy equal rights and live fulfilled and productive lives without any form of abuse, discrimination, and exclusion.

## OUR MISSION

- FFF is strongly committed to providing accurate strategic information on SBH and other types of disabilities for the purpose of raising public awareness and enlightenment.
- The Foundation commits to providing and/or linking persons with SBH and other types of disabilities to free or highly subsidized quality services across critical sectors such as health, education, rehabilitation, vocational, transport, assistive technologies, etc. and
- FFF shall maintain a strong and visible position as a major advocacy organization on the rights of persons with SBH and other types of disabilities; pushing for disability-inclusive legal, policy and institutional frameworks; disability-sensitive attitudes and behaviours, global best practices, standards, and systems as well as physical and all forms of accessibilities.

## OUR CORE VALUES

- CARE
- HIGH SELF ESTEEM
- EQUAL OPPORTUNITIES AND DIVERSITY
- TOTAL ACCESS AND INCLUSION
- KNOWLEDGE DEVELOPMENT
- PARTNERSHIP

## OUR GOAL

To improve the standard of living for all persons with SBH and other forms of disabilities by strengthening legal, policy and institutional frameworks, as well as promote positive public attitude.

# ANNUAL REPORT 2022

The year 2022 was an eventful year with records of life-changing projects implemented for disability community. Despite the blowback from the impact of COVID-19 pandemic, the Foundation has been able to position itself to continue to put smiles on the faces of its target beneficiaries. Remarkably, we expanded our activities to other geo-political zones of Nigeria (North Central and South south) apart from the Southwest zone we have operated since established. We are grateful to our partners, donors and friends who continued to share in our vision from inception till date. To our board, your continuous support and guide have put us on track while we see as a great opportunity working with our beneficiaries through whom we continue to learn each day of our work.

Here, we present the summary of our achievements for the year 2022 highlighting the impact of our various programs and activities. Also included here is audited income and expenditures as well as balance sheet for the year ended December 31, 2022.

**Afolabi Fajemilo**  
*Co-founder & Executive Director*

# SUPPORT Group

**S**pina bifida and hydrocephalus (SBH) is a disability with multifaceted challenges for both impacted person and as well their families. The burden of care and responsibilities saddled by their families often takes a toll on their mental wellbeing. In response to this, FFF has been running family support group since 2008 within the premises of Lagos State University Teaching Hospital (bi-monthly) and from 2017 at Obafemi Awolowo University Teaching Hospital Complex (quarterly) respectively. The meetings provide platforms for families to share experiences, coping strategies, and learning on supporting their children with SBH. Families are also empowered through health education, disability rights advocacy and counseling.

#### **Outputs/Outcomes: 8 In-Person meeting**

- 133 children and adults in attendance.
- 65 families had access to counselling, livelihood, and psychosocial support.

## SEXUAL AND REPRODUCTIVE HEALTH RIGHTS (SRHRs) ADVOCACY

**O**n 8th of September 2022, FFF scaled up its Breaking All Barriers (BAB) project, first implemented in 2017 and aims to raise public awareness of the Sexual and Reproductive Health Rights, (SRHRs) Advocacy of adolescents with disabilities in Agege education district of Lagos State towards reducing discrimination and stigmatization against them in the pursuit of their SRHRs. In an effort to expand the initiative into public schools, a training of trainers was organized among schools' guidance counsellors in Agege education district Lagos State.

#### **Outputs/Outcomes:**

- 94 guidance counsellors and 5 school administrators trained on SRHRs advocacy of adolescents with disabilities.
- Majority of the guidance counsellors who prior to training had misconceptions about disability issues and persons with disabilities expressed a change of perceptions while listening to live stories of accomplishments shared by adults with disabilities during the training.
- The training enhanced the capacity of guidance counsellors to take informed decision during assessment and enrolment of children with disabilities into public schools in Agege education district of Lagos State.

## INCLUSIVE EDUCATION

Aside from its other inclusive education projects, the “United for Inclusive Education (UIE) project” funded by Disability Rights Fund for which FFF has been an implementing partner in the coalition project ended in August 2022 with tangible outcomes. The project focused on advocacy for accountability and transparency in the implementation of inclusive education budget, promotion of participation of persons with disabilities in the implementation of the inclusive education policy and budget, and advocacy for improved delivery of education services for persons with disabilities. Below are key outcomes of the components of coalition project facilitated by FFF.

- Establishment of an innovative and technology-driven web-based Community of Practice on Inclusive Education (COMPIE) to sustain learning and experience sharing among inclusive education stakeholders.
- Facilitated inclusive schools monitoring by OPDs that led to increased engagements of OPDs with government and their participation in the implementation and monitoring of inclusive education policy in Lagos State.
- Documentation and report publication of inclusive schools monitoring by OPDs in Lagos State as a reference point in compliance with local and international legal and policy frameworks.


## CONTINENCE MANAGEMENT PROGRAM

Incontinence is inability to pass urine and/or feces in a socially acceptable and hygienic way. The negative effects of incontinence are profound for both children with spina bifida and hydrocephalus much as burden of care for their caregivers. Effects range from health complications, low self-esteem, social stigma, poor mental health. Affected children identify this program as the changing point in their lives, enabling their full integration and participation in society. Since 2017, FFF has been working with its UK partner – Shine Cymru to save lives and improve futures of children with spina bifida and hydrocephalus through access to comprehensive continence management and care. In 2022, FFF established more partnerships with six public teaching hospitals in Nigeria namely, Lagos University Teaching Hospital, University College Hospital Ibadan, Obafemi Awolowo University Teaching Hospital, University of Abuja Teaching Hospital, University of Benin Teaching Hospital, Rivers State University Teaching Hospital, thus reaching out to a wider public.


During the year under reporting, the Foundation

- Strengthened capacity of 60 healthcare professionals (nurses) on continence management and care through training and peer mentoring.
- Supplied vital continence equipment to 6 public health institutions for free use by children and young adults with spina bifida and hydrocephalus.
- Improved access of 155 babies, children, and young adults with spina bifida and hydrocephalus to comprehensive continence management and care, thus enhancing their healthy living.

## World Mental Health Day



On 10th of October 2022, FFF celebrated World Mental Health Day with a virtual focus group discussion among persons with psychosocial disabilities (PPDs) aimed to sensitize PPDs towards strengthening PPD cluster and become visible within the mainstream disability community in Lagos State.



### WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY (WSBHDAY)

In collaboration with Spina Bifida Hydrocephalus Association in Nigeria (SBHAN), FFF celebrated the annual WSBHDAY which holds every 25<sup>th</sup> of October. Both organizations used the day to pay advocacy visit to the authority of Lagos State University Teaching Hospital (LASUTH) to push for comprehensive continence management and care to enhance quality of life for patients with spina bifida who face medical and social challenges occasioned by their bladder and bowel incontinence. Other activities embarked upon by SBHAN and FFF were advocacy visit to Lagos State Office for Disability Affairs for the recognition of SBHAN as a disability cluster by the agency for the purpose of addressing and meeting the peculiar needs of persons with spina bifida and hydrocephalus within the mainstream disability community. FFF and SBHAN also engaged in media awareness both electronically and on social media to promote primary prevention of neural tube defects (NTDs) of which spina bifida is one of the commonest as well improved service delivery regarding treatment of SBH.

#### ADVOCACY ON DOMESTICATION OF DISABILITY BILL

Since 2021, FFF has engaged in policy advocacy project in Osun State. The organization has been supporting mobilization of OPDs to advocate for domestication of Nigeria Disability Act in the State through policy dialogues, public sensitization, and media engagements. In 2022, FFF intensified this effort to facilitate.

# PHOTO GALLERY



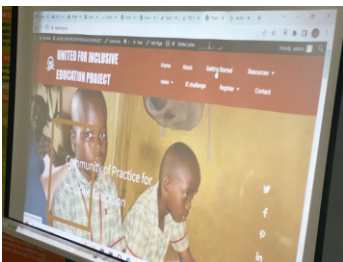
## Advocacy Visits To Osun State on Passage of Disability Bill

CBR Activities



# PHOTO GALLERY

## WORKSHOP ON DEVELOPING WEB-BASED COMMUNITY OF PRACTICE ON INCLUSIVE EDUCATION







## Support Group Activity



## Training on Sexual & Reproductive Health Rights



# PHOTO GALLERY



Continence Management Project Activities

- Five advocacy visits to relevant MDAs in the state.
- One press conference
- One peaceful protest to the state governor's office
- 5 stakeholder's meeting

## COMMUNITY BASED REHABILITATION (CBR)

**C**BR according to World Health Organization is community development strategy that focuses on the life areas that are crucially important for every person within a matrix: (health, education, work and income, a social life and self-empowerment). In partnership with The Leprosy Mission Nigeria and funding from Liliane Foundation, we

- Supported 34 children and youngsters with disabilities (CYWD) with school fees.
- Supported 5 CYWD with medication.
- Supported 12 CYWD with physiotherapy and medicals.

## SUMMARY OF RESULTS/OUTCOMES

- 133 CYWD of 65 families empowered to deal with the social and mental challenges of SBH and other types of disabilities.
- 98 education guidance counselors and school administrators had change of perceptions about persons with disabilities and disability issues through sexual & reproductive health rights advocacy training.
- Promotion of inclusive education learning and knowledge sharing through established innovative and technology-driven web-based Community of Practice on Inclusive Education (COMPIE).
- Facilitated increased participation of 8 organizations of persons with disabilities (PODs) in the implementation of inclusive education policy in Lagos State.
- Strengthened technical capacity of 60 healthcare professionals (nurses) in continence management and care across 6 public teaching hospitals.
- Donation of vital continence equipment and medication to 6 public health institutions in Southwest, North Central and South South.
- Improved health condition of 160 babies, children, and adults with spina bifida and hydrocephalus through access to comprehensive continence management and care.
- Facilitation visibility of Persons with Psychosocial disability group within mainstream disability community in Lagos State.

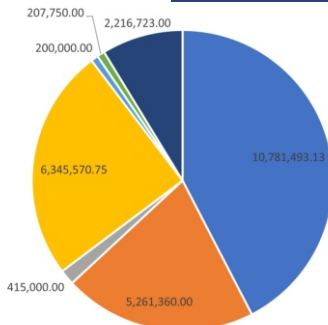
- 10 advocacy visits to relevant government ministries, departments and agencies on improved care and disability-inclusive services in critical sectors, including health and education.
- Policy advocacy and mobilization of OPDs to advocate for domestication of Nigeria Disability Act in Osun State.
- Educational support (school fees) for 34 CYWD
- Medical support (medication, surgeries & therapies) for 17 CYWD

## 2022 DONORS'

- **LILIANE FOUNDATION/THE LEPROSY MISSION NIGERIA**
- **WALES FOR AFRICA HUB/SHINE CYMRU**
- **DISABILITY RIGHTS FUND**
- **HYDROCEPHALUS ASSOCIATION**
- **PAN AFRICAN NETWORK OF PERSONS WITH PSYCHOSOCIAL DISABILITIES/IDA**
- **COMMITTEE FOR THE DISABLED- CHAPEL OF THE HEALING CROSS**
- **BT TECHNOLOGIES**
- **INDIVIDUALS**

# AUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31<sup>ST</sup> DECEMBER 2022

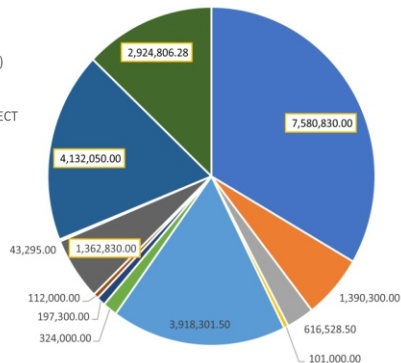
## SUMMARY OF INCOME FOR THE YEAR 2022 N25,427,896.88



- LILIANE FOUNDATION/THE LEPROSY MISSION NIGERIA
- HYDROCEPHALUS ASSOCIATION
- CODISA (CHAPEL OF THE HEALING CROSS)
- CORPORATE BODIED & INDIVIDUALS
- DISABILITY RIGHTS FUND
- WALES AFRICA HUB/SHINE CYMRU
- PANPPD/IDA

## SUMMARY OF EXPENDITURE FOR THE YEAR 2022 N22,703,241.28

- DISABILITY INCLUSION DRIVE & ADVOCACY (CHILD EMPOWERMENT PROGRAM)
- UNITED FOR INCLUSIVE EDUCATION PROJECT
- READDDRESS INCLUSION RIGHTS & EMPOWERMENT (MENTAL HEALTH) PROJECT
- EXPANDING DISABILITY INCLUSIVE SOCIAL PROTECTION PROJECT
- CONTINENCE MANAGEMENT PROJECT
- EDUCATIONAL SUPPORT
- MEDICAL & REHABILITATION
- LIVELIHOOD SUPPORT
- PROGRAMME DEVELOPMENT
- MEMBERSHIP SUBSCRIPTION
- SALARIES & WAGES
- ADMINISTRATIVE EXPENSES



# FESTUS FAJEMILO FOUNDATION

## FINANCIAL STATEMENTS FOR THE YEAR ENDED 31/12/2022

### STATEMENTS OF INCOME AND EXPENDITURE FOR THE YEAR ENDED

	31/12/2022 ₦	31/12/2022 ₦
<i>Total Donations Received</i>	25,427,896.88	25,609,060.38
<i>Less Total Expenses</i>	(22,703,241.28)	(30,893,206.00)
<i>Surplus Income</i>	<u>2,724,655.6</u>	<u>(4,284,145.62)</u>



**DONATION BY BT TECHNOLOGIES**

**Festus  
Fajemilo  
Foundation**

[fesfaj-foundation.org](http://fesfaj-foundation.org)

CAC/IT/No. 24051



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