



# MOVING TOGETHER

## Leaving no one Behind

A Publication of the LINC Africa Network

LILIANE FOUNDATION  
INCLUSION NETWORK



Rights

Response

Inclusive Societies



### Social Protection Policy review to include Persons with Disabilities (PWD) in Sierra Leone

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# EDITORIAL

We are honoured and pleased that you have in your hands the maiden edition of our bi-annual newsletter, "Moving Together," a production of the Liliane Foundation Inclusion Network (LINC) Africa. This newsletter is a tool for the LINC Secretariat to improve on national programmes outcomes by enabling members of the network share their experiences, communicate better unto program strengthening and response, thereby leading to inclusive societies.

To better meet the needs of its various audiences, the newsletter has been subdivided into specific columns: Perspectives, Trailblazers, Experiences, Success Stories, and Expert Voice. We trust you will find your heart beat in one of the columns.

This maiden edition displays LINC-Africa's member countries' efforts at informing, educating, coaching, training, advocating and partnering with relevant stakeholders to ascertain that rights of children with disabilities are protected and respected at all levels to ensure their full participation in society.

Our major engagement in the first quarter of 2019 was LINC-Africa face-to-face meeting held in Accra Ghana, with an exhibition to showcase works of Persons with Disabilities from participating countries. In attendance were international and national dignitaries.

In this edition, we shall take a tour of some member countries to get acquainted with their contributions in bettering the lives of children with disabilities. Thus, Cameroon shares

with us their efforts in bringing on board relevant Disability Stakeholders for successful interventions. Also, youngsters from Ethiopia and Cameroon will prove to us that indeed disability is not inability!

Also featuring in this edition, SWEB Foundation's redirection from an implementing partner to a network organization, Kenya's Social Innovation Lab Project (SILP), an outstanding approach to include Youth with Psychosocial and Intellectual Disabilities in mainstream Livelihood opportunities.

Nigeria on her part shares with us the results of a survey to determine the number of children living with cerebral palsy in selected communities of the Plateau State to benefit from assistive devices made from the Appropriate Paper-based Technology (APT). Meanwhile Sierra Leone takes us through the 2019 edition of the "We Ring the Bell Campaign which facilitated the South-South cooperation and a Social Protection Policy review to include Persons with Disabilities (PWD) in the country.

South Sudan efforts to promote Inclusive Education for Children with Disabilities (CWDs) are highlighted, while in Zimbabwe, girls and women with Disabilities who are victims of gender and sexual-based violence are assisted to access justice.

Congratulations to LINC Africa members for their efforts and support in putting this newsletter together.

**Enjoy reading!**



**Greaterman Chivandire**  
*Chairman LINC Africa*

# PERSPECTIVES

## Inclusion of Persons with Disabilities in Mainstream Educational Settings: A Human Rights Issue; The Case of Students with Disabilities in Ghana, Accessing the University Built Environment



### Accessible built environment is a **right for persons with disabilities**

In a world of technological advancement, education is an essential part of a person's development and growth process, which has become a necessity for every individual including persons with disabilities. Our communities and societies are mandated to ensure needed structures for accessibility. However, this is not the case of most university-built environment in Ghana. A research conducted by Eric P Tudzi, John T Bugri & Anthony K Danso of six

universities across Ghana brings us to the realisation of the huge gap in accessing education by Persons with Disabilities (PWDs). The social model of disability gives us a clear picture of the situation at hand. This model attributes the issue of disability to be a social construct not by individual impairments or differences, a collection of condition created by the social environment

chicks  
Disability rights have become a human

rights and developmental issue. Society creates barriers like those in the built environment and these ultimately create or engender disability. Research evidence from the world over gives credence to the idea that it is possible to remove debilitating barriers and build inclusive societies where Persons with Disabilities (PWDs') rights can be realised. Persons with Disabilities tend to be among the most stigmatised, vulnerable, poor and least educated people worldwide.



**Cont'd from Pg 3**

**Inclusion of Persons with Disabilities in Mainstream Educational Settings: A Human Rights Issue; The Case of Students with Disabilities in Ghana, Accessing the University Built Environment**

A study conducted by JKM Research Consulting in partnership with organisations in Ghana and Denmark showed that the poverty situation of persons with disabilities in Ghana was very severe. about 80% of the world's more than one billion persons with disabilities live in developing countries. In Ghana, only 1.4% of persons with disabilities have a tertiary level education. However, according to article 26 of the United Nations Universal Declaration on Human Rights, access to education is a fundamental human right. Moreover, the 2030 Agenda for Sustainable Development adopted by the UN identifies the need to ensure inclusive and equitable education for all, including PWDs.

Regarding human rights, accessibility opens the opportunity for PWDs on an equal basis with others to the physical environment, transportation, information and communication. However, the built environment is a debilitating factor in terms of accessibility for persons with disabilities education in Ghana despite the country being signatory to international protocols that protect the rights of PWDs.

A 2017 research to evaluate the accessibility of the built environment in the tertiary level of education for persons with disabilities as a reason of thier under representation at this level was carried out in six Universities of Ghana. The results of the research indicate that there is still a lot to be done for the higher education sector to be inclusive in many aspects.

**(I) Physical environment:**

The built environment was restrictive in varying degrees to students with

disabilities. This suggests that on a daily basis, students with disabilities have to struggle with the challenges posed by the nature of the built environment in order to pursue a degree in higher education.

**(ii) Transportation**

At the time of this study, the use of public vehicles adapted or modified to provide accessibility for persons with disabilities was generally not common in Ghana.

**Legal and regulatory framework**

Data collected from the Ministry of Education and the National Council for Tertiary Education (NCTE) on the political and legal context in which the universities operate, revealed that that no policy exists to specifically address the needs of students with disabilities at the tertiary education level.

The research confirmed the fact that even though persons with disabilities have a right to education and a right to accessible built environments at the university level, this was not the case. These rights will remain a mirage unless conscientious efforts are made to make them a reality.

This picture does not only obtain in Ghana, but across many sub-Saharan Africa nations. Inclusive educational settings will only become a reality as intentional efforts are made to enforce existing legal and regulatory frameworks at multiple levels.

In the case of Ghana precisely, the researchers recommended amongst others that the legislative instrument that

is to give effect to the Persons with Disability Act should be passed as a matter of urgency. Further, the Ministry of Education and the NCTE should develop a policy document on students with disabilities. They should ensure that every university has a policy document on persons with disabilities. Also, as a policy, universities should adopt universal (inclusive) designs for constructing buildings and facilities. Additionally, provision of reasonable accommodation for students with disabilities should be a major priority for the universities. Though the recommendations were limited to the scope of the study, they can serve as guides for other universities in bringing attention to the needs of students with disabilities and help address their right to an accessible university education in Ghana as well as other African countries, where there is a lack of multi-level preparedness to embrace inclusive education, as well as inclusive development at large. This research does not only expose gaps in the creation of an accessible environment for an inclusive education, but the scope of work that needs to be done to achieve this dream.

**Reference**

**Eric P Tudzi, John T Bugri & Anthony K Danso (2017) Human Rights of Students with Disabilities in Ghana: Accessibility of the University Built Environment, Nordic Journal of Human Rights, 35:3, 275-294, DOI: [10.1080/18918131.2017.1348678](https://doi.org/10.1080/18918131.2017.1348678)**

Osman Mensah, Jody Williams, Richmond Atta-Ankomah and Mboje Mjomba, Strengthening the Disability Movement in Ghana through Organizational Capacity and Advocacy: Contextual Analysis of the Disability Situation in Ghana, Accra (JKM Research Consulting 2008) <[www.gfdgh.org/Context%20analysis.pdf](http://www.gfdgh.org/Context%20analysis.pdf)> accessed 23 March 2016.



## We Ring the Bell 2019 and the South- South Cooperation (Sierra Leone)

Successes chalked from Girl Power Project, Her Choice and the Child Empowerment programmes with young people with disabilities prove our belief in their commitment and zeal in advocating for their rights and equal opportunities. Young people with disabilities empowered can educate and sensitize their communities to debunk myths and discriminatory practices that serve as a barrier to their development.

One Family People (OFP) in partnership with United Nations Educational, Scientific and Cultural Organization (UNESCO), African Young Voices Media Empire, Ministry of Social Welfare and Ministry of Basic and Senior Secondary Education of Sierra Leone organized #WeRingTheBell in 20 schools in Freetown, championed by 10 young leaders with visual, physical, speech and hearing impairment. This served as an avenue to highlight the benefit of Inclusive Education and also call on government to make schools accessible to all children including Children with Disabilities.

The campaign reached over 1 million people including pupils, parents, teachers, health workers, government officials and other Non- Governmental Organizations in the country. The

Ambassadors projected We Ring the Bell campaign to another level by also engaging in public education on the 10-action points of the manifesto campaign through radio and TV programmes.

Through this campaign, OFP reached notably milestone in advocating for Inclusive Education by a collaboration between the Government of Guinea and Sierra Leone in the promotion and protection of the rights of Persons with Disabilities under the South-South Cooperation. An MOU has been signed to bind both countries in the roll out and implementation of the activities therein. The United Nations Development Programme (UNDP), the Government of Guinea and the Government of Sierra Leone have committed to provide technical and financial support. Guinea and Sierra Leone also made a joint statement at the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) State Parties Conference 2019 in New York.

# TRAILBLAZERS

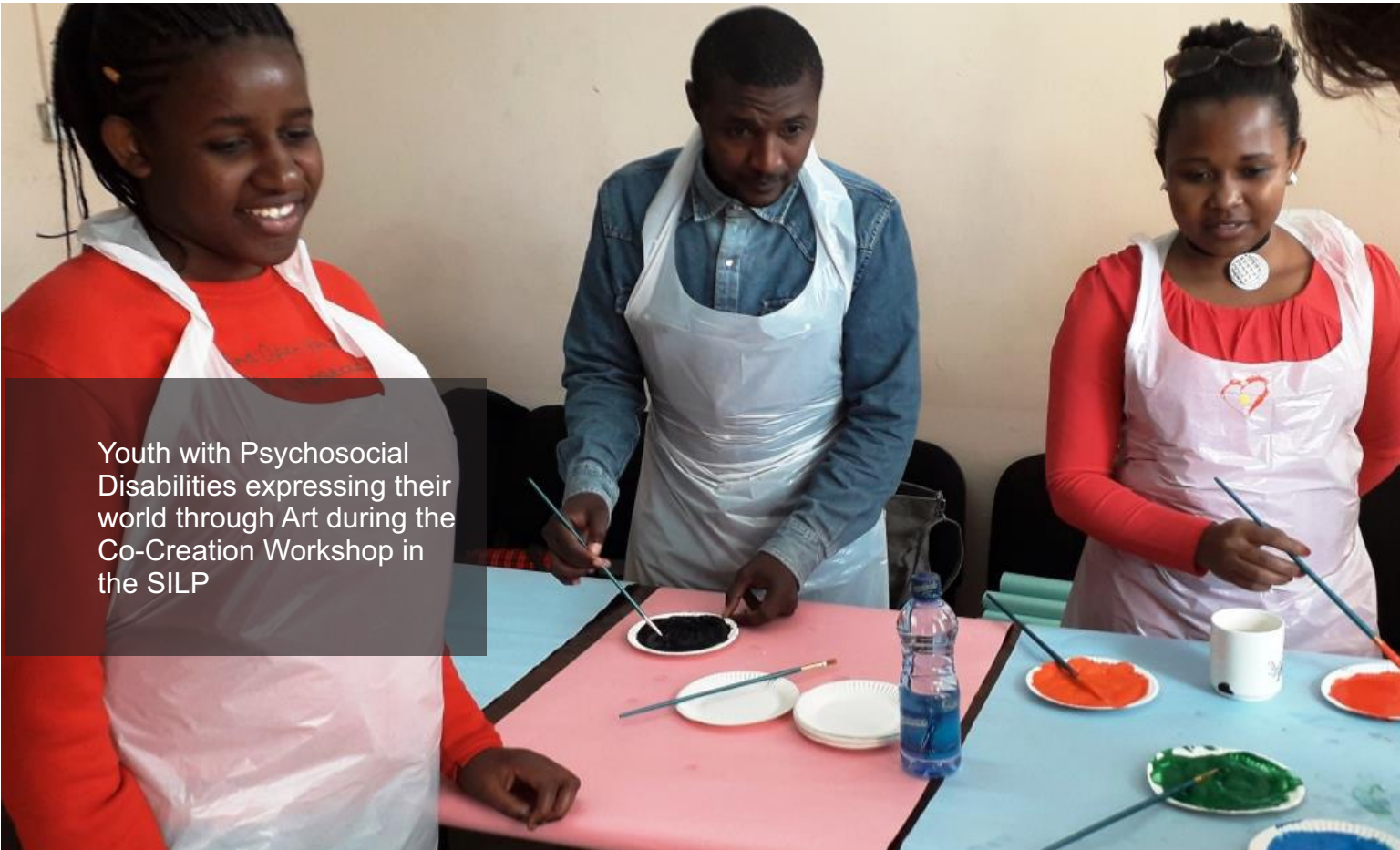
## Social Innovation Lab Project (SILP) on Youth with Psychosocial and Intellectual Disabilities for Inclusive Livelihood (Kenya)

**T**ransitioning to adulthood and employment opportunities are big challenges for youth with disabilities across the globe especially youth in Africa. This is propagated by stigma and discrimination owing to the negative social attitudes and beliefs by their communities and society at large. This impedes their access to education which translates to dependent lives at adulthood. In order to address this, Cheshire Disability Services Kenya (CDSK) and Agency for Disability and Development in Africa (ADDA), Ethiopia and Rwanda are currently implementing the EmployAble II Project. This project is funded by Liliane Foundation (LF) and Light For The World (LFTW) both from the Netherlands.

The Project focuses on equipping youth with disabilities with Soft and Competency-Based Skills in Inclusive Technical Vocation Education Training (TVET) Centres and Community Based Training Centres (CBTCs) with a deliberate linkage to inclusive work places for wage or self-employment. During the life of the Project more than 200 youth with various types of disabilities have been assisted to access inclusive TVETs and CBTCs.

They pursue various market driven courses such as Entrepreneurship, Print Technology, Carpentry, Food Production, Food & Beverage, Beadwork, Art, Fashion & Design, Hairdressing & Beauty, Motor Vehicle Mechanics, Dress Making, House Keeping, Masonry &

Plumbing, Pottery, Car Upholstery and Electrical Installation with components of soft skills such as decision making, self-esteem building and anger management. In order to match the skills and strength of the youth with disability to a particular competency-based market driven course, Career Counsellors are involved to offer career guidance. They are supported informally in an institution to enable them undergo training with the necessary facilities such as adapt/adjust infrastructure like the ramps, toilet / latrine and the training rooms to accommodate them. Beyond the infrastructure, skills and attitude of instructors are also impacted, to enable them support trainees in the learning process and ensure they participate actively.



Youth with Psychosocial Disabilities expressing their world through Art during the Co-Creation Workshop in the SILP

## Social Innovation Lab Project (SILP) on Youth with Psychosocial and Intellectual Disabilities for Inclusive Livelihood (Kenya) **Cont'd from Pg 5**



A Youth with Psychosocial Disability carrying out Self-Advocacy at Burns (A manufacturer of energy saving charcoal cooking stoves)

While youth with disabilities undergoing training, TVET Centres and CBTCs engage with employers on awareness creation for positive attitudinal change and reasonable accommodation to facilitate smooth transition from training to employment/internship. This Project has helped over 100 youth with disabilities transition from lacking employable skills and self-empowerment to meaningful employment (self or wage) and a strong belief in one's self.

From the assessment of EmployAble II Project, it was realized that youth with psychosocial and intellectual disabilities were not reached. This gave birth to the Social Laboratory component in the EmployAble Project. Which gave implementors the opportunity to try innovate approaches in training youth with psychosocial and intellectual disabilities in TVET and CBT and then transitioning to the work place (wage / self). It commenced early 2018 targeting 15 youth with psychosocial disabilities and 15 youth with intellectual disabilities. In September 2018, funds from Voice were secured for a period of 2 years (September 2018 - September 2020) to expand the Social Lab concept to reach 50 youth with psychosocial disabilities and 50

youth with intellectual disabilities. The Project was dubbed, "Social Innovation Lab Project (SILP) on Youth with Psychosocial and Intellectual Disabilities." The concept of social lab deviates from the ordinary project implementation as it is cyclical in nature. For CDSK, SILP identified the challenge of youth with psychosocial and intellectual disabilities not adequately reached through EmployAble II Project due the 'invisibility' and complexity of these 2 types of disabilities. The identification of challenge was followed with a workshop bringing together youth with psychosocial and intellectual disabilities, the stakeholders such as the trainers from the TVET Centres and CBTCs, the employers, parents / caregivers, Ministry of Education (MoE) Officials, business leaders and micro-finance institutions to analyse why youth with psychosocial and intellectual disabilities were not effectively included in vocational training and why they are not able to transition to inclusive work places. Deliberations at the workshop identified youth with psychosocial disabilities would prefer to engage in their own enterprises through self-employment due to the stigma and discrimination they suffer on disclosure of their situation at the place of work or during job placement.

### The 4 prototypes that were generated at the workshop were:

- Advocacy Toolkit to address the stigma and discrimination experienced by youth with psychosocial disabilities
- Business development skills for youth with psychosocial disabilities interested in being entrepreneurs
- Product development for youth with intellectual disabilities to make the products they produce competitive
- Awareness creation sessions at the community to enable inclusion of youth with intellectual disabilities

The above are the current prototypes being tested in the SILP Project with a possibility of adoption and scaling up as a promising practice to realise an inclusive society where everyone including persons with disabilities are recognized and given equal opportunities to work and live independent lives.

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# EXPERIENCES

## Access to Justice for Girls and Women with Disabilities in Zimbabwe

Leonard Cheshire Disability Zimbabwe (LCDZ) between September 2018 and April 2019 provided practical assistance to 201 girls and women with disabilities survivors particularly of sexual violence to access justice with less barriers. Globally, it has been noted that girls and women are vulnerable to sexual gender-based violence however girls and women with disabilities (GWwDs) are more vulnerable to this form of abuse.

Miriam Tshuma a 17-year-old girl with mental disability was raped by a male neighbor whilst herding cattle. The perpetrator threatened to kill her if she reported him. She kept it to herself for 4 months. The matter was only reported to

the police after her mother discovered that Miriam was pregnant. After reporting the matter to the police, her family was informed that she needed to be assessed by a psychiatric doctor before the case could be heard in court and this was only done in Harare the capital city of Zimbabwe yet they were far away from Harare. With her family facing serious economic challenges and struggling to even put food on the table, she then told herself the case had hit a brick wall. However, LCDZ came to her rescue to assist her and her caregiver throughout the investigation and legal process. The assistance she received from LCDZ in the form of transport and food whilst in transit ensured to access the justice she deserved. Finally, the

efforts made by LCDZ yielded positive results as the accused was sentenced to 15 years in jail. "I am forever grateful and happy for the support I received from LCDZ and I encourage all GWwDs who have been abused not to despair as they are organizations which can assist persons with disabilities."

GWwDs experience abuse as in Miriam's story and they face many challenges to access justice resulting in abandonment of cases. In response LCDZ offers the following services to GWwDs in contact with the law especially survivors of sexual gender-based violence, with funding from UN Trust Fund to End Violence against Women:

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- (i) Disability expert services: i.e. Sign Language Interpretation, disability technical advice and support persons.
- (ii) Logistical support: i.e. accommodation, transport and food costs in line with accessing justice.
- (iii) Psycho-social support i.e. counselling.
- (iv) Referral support

A survivor of sexual violence (center) during a counselling session with LCDZ's counsellor(left) and the caregiver (right)The above services have played a critical role since 2015, to expedite case completion and minimize delays and abandonment of cases by GWwDs survivors.



A survivor of sexual violence (center) during a counselling session with LCDZ's counsellor(left) and the caregiver (right)





## Social Protection Policy review to include Persons with Disabilities (PWD) in Sierra Leone

Effort made by OneFamilyPeople and POs through lobbying and advocacy, the Commission for Social Action has agreed to review the Social Protection Policy to holistically target persons with disabilities, their care givers and guides/aids and children of parents with disabilities. In light of this achievement, OneFamilyPeople organized a 3-day consultative workshop with POs, DPOs, government, local and international civil society to study the National Social Protection Policy, identify gaps and make recommendations. The United Nations Children's Fund (UNICEF) and the National Commission for Social Action appreciated the outcome of the consultation and committed to including the recommendations from the workshop in the policy.

## CBR: Ensuring Effective Management of Cerebral Palsy at Grassroots Level in Cameroon

Since the EDID program was created in 2014, the CBC Health Services as a Strategic Partner Organisation of the Dutch-based Liliane Foundation has worked with partner organizations in eight regions of the country to enable children and youths with disabilities from 0-25 years have access to education, health, social and livelihood opportunities. The program also makes sure that an enabling environment is provided for children with disability in their families, communities and the nation at large.

The EDID program has embraced a new strategy in the management of Cerebral Palsy called Support Tools Enabling Parents (STEP). This strategy developed by the

Liliane Foundation is also being piloted in Uganda, Kenya, and Tanzania.

Cerebral Palsy is a physical disability that affects movement and posture. It is usually due to damage to the developing brain either during pregnancy or shortly after birth. It affects children in different ways and can affect body movement, muscle control, muscle coordination, muscle tone, reflex, posture, and balance. Although Cerebral Palsy is a lifelong condition, some of its signs can improve or worsen over time. Children who have Cerebral Palsy may also have visual, learning, hearing, speech, and intellectual impairments and epilepsy.

**Cont'd from Pg 10**

**CBR: Ensuring Effective Management of Cerebral Palsy at Grassroots Level in Cameroon**



After 16 Weeks with CBR field workers, Raphael was able to sit on the chair by himself for long time

When the field worker met with Raphael's family, his mother wanted her son to sit normally, walk and talk. The field worker explained to her that they will have to set little goals at a time.

After fifteen weeks of work, Raphael's mother confesses, "I see improvements, they are not very big, but my son's life is visibly changing; he is now able to sit in a chair for long; I'm happy to be involved in his care and understand his condition more; this helps me to be patient and better appreciate any feat he attains."

Like Raphael, close to ten thousand children have benefitted from CBR interventions since 2015 in

communities across the eight implementation regions through the EDID Program.

Also, thousands of families of children with disabilities have been sensitized on the right attitudes towards disabilities, while more than 1200 children have had corrective surgeries for various mobility impairments and are reacting positively to rehabilitation.

This is clear proof that Cerebral Palsy, alongside other disabilities, is not a death sentence as opposed to the general perception in most communities. With appropriate assistance, children with this condition can live to fulfill their dreams like other children.

**Cont' on pg. 11**

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**Cont'd from Pg 9****CBR: Ensuring Effective Management of Cerebral Palsy at Grassroots Level in Cameroon**

With STEP, CBR field workers are trained not only to dispel the many myths that still surround disabilities in the communities, but also to help improve the functionality of children having Cerebral Palsy by coaching the parents through simple practical skills to manage this condition.

“Compared to taking children with Cerebral Palsy to rehabilitation facilities with little or no results, with STEP, CBR field workers are empowered to effectively simplify the understanding of the condition for parents who can, in turn, participate in managing and realizing improvements in the lives of their children,” explains Mrs. Agho.

“When parents go to rehab centres with their children who have Cerebral Palsy, most often their big one goal is only to see their child walk, and when this is not happening fast enough, they are disappointed. They don't understand that the child's ability to walk depends on the communication that goes on in the brain, and since children with Cerebral Palsy have some parts of their brain damaged, it may take a longer time for the brain to ever process the information to enable the child undertake all the activities that will eventually lead to walking. STEP ensures that the management of a child with CP is broken down into small steps. For a child to walk, that child has to learn to sit, then crawl, before standing and walking. Apart from these, the child also needs to eat & drink well, learn proper toileting and communication skills; be able to play and interact with other children etc.

These are all little things which children with CP find difficulty accomplishing and they need to be trained on how to do all these. When goals are set around these areas and parents are coached on how to accomplish them, the parents appreciate the progress being made,” expatiates EDID Program Manager.

The Supervisor of CBC Health Services' Physiotherapy Department, Mr. Fanfon Timothy, on his part, says the STEP Project, though at its early implementation stages in Cameroon, is proving to be an effective way of managing Cerebral Palsy.



**Raphael was not able to sit or raise his head by himself before his family met with the CBR field workers**

“We are now seeing more Cerebral Palsy children as we meet them in their homes and empower their families with basic skills to assist children. This has made providers more effective in managing the condition,” says Mr. Fanfon.

Families of children with Cerebral Palsy are finding hope and believing in a bright future for their children with the STEP interventions. Raphael Sonkeng is one of such children. He is four years old and is the first in a family of two children. Before the CBR field worker started seeing Raphael at home “he was not able to sit by himself, and when he tried, his forehead was touching the ground; he could neither talk nor walk, couldn't control nor raise his head up.”

Raphael's mother had a prolonged labour. Two days after his birth, he developed a high fever and was diagnosed with meningitis. At five months, Raphael could not do things infants of his age do. He was taken to the hospital where a C-T Scan was done. It was realized he had brain damage, probably due to lack of oxygen during prolonged labour and the effects of meningitis.

# Katalemwa Cheshire Home for Rehabilitation Uganda: Leaving no Stone Unturned to Ensure the Inclusion of Children with Disabilities in Mainstream Society



Stakeholders converged at the breakfast meeting to seek ways of ensuring the **inclusion of children with disabilities** in their communities

**K**atalemwa Cheshire Home for rehabilitation services (KCH) is a Strategic Partner Organisation (SPO) of the Liliane Foundation and one of the leading organizations in the rehabilitation of children with disabilities in Uganda and continues to register success in that area. Katalemwa's success is attributed to a number of factors; the partnership and support from key stakeholders and partner organizations, parental participation, continued funding from donors and commitment from staff and the Board.

Katalemwa Cheshire Home for rehabilitation services (KCH) role as an SPO in the rehabilitation of children with disabilities echoes the importance of collaboration and establishing cordial relationships with various governmental institutions. This explains the collaboration with the Ministry of Gender Labor and Social Development that resulted to organizing a breakfast meeting in March 2019.

The meeting witnessed the gathering of various high level Government Officials

from the various Line Ministries handling issues of children and youth with disabilities, with the aim of influencing the Inclusive Policy development programmes, push for policies on structural adjustments in schools and public places and to improve policies and programs that are responsive to Children with Disabilities (CWD) and Youth with Disabilities (YWD) concerns.

**Cont. on Pg 13**

## Katalemwa Cheshire Home for Rehabilitation Uganda: Leaving no Stone Unturned to Ensure the Inclusion of Children with Disabilities in Mainstream Society

Cont'd from Pg 12



In line with its inclusion agenda and better life outcomes for children with disability, KCH has been involved in piloting the STEP (Support Tools Enabling Parents) project, alongside other African countries since 2018. STEP is a pilot strategy supported by Liliane Foundation aimed at supporting and training parents/ caregivers of children with neurological disorder specifically Cerebral Palsy (CP) to be involved in the home care of their children.

After a year of implementation, a conference was organized in April 2019 to reflect on the achievements so far. Thus over the past year STEP has facilitated the development of guidelines to assist professionals and field workers in providing interventions for children with neurological disorders, provided practical tools and technology for field workers for assessment, goal setting and planning rehabilitation interventions. STEP is proving to be a context appropriate strategy to cater holistically for the needs of children with central neurological disorders, cerebral palsy in particular.

## Promoting Inclusive Education for Children with Disabilities (CWDs) in South Sudan

Children with disabilities have traditionally been excluded from education for reasons ranging from attitudinal, systemic and communicational. The situation however has been gradually changing thanks to global and national efforts. South Sudan has embarked on the train of inclusive education, to ensure that children with disabilities participate in education, which is the cornerstone of true development. Thus Episcopal Church of South Sudan (ECSS), an organisation with mandate to

promote inclusive education has been busy on the field, working to remove barriers that hinder children with disabilities to access education, thereby promoting their inclusion in mainstream educational settings. In this line, ECSS has been identifying children with disabilities in the communities, in schools to assess and better meet their needs. During this exercise, 18 children and youngsters with disabilities in early childhood, primary and secondary education that needed support were identified. These youngsters benefitted from educational materials

such as books, pens, school bags and mathematical sets. For equity purposes, teachers and Community Based Rehabilitation field workers carried out extra teaching at home during the weekend to help in content comprehension for children and youngsters with disabilities having learning difficulties. Slowly but surely, changes are being noted. With multisectoral collaboration, ECSS is confident that "No one will be left behind" in South Sudan's strides to development!

Bearing in mind that physical barriers can hinder children with disabilities to access education, CBR team members from ECSS collaborated with the State Ministry of Education and County Education Departments to assess accessibility for persons with disabilities in 67 schools (18 Early childhood, 39 primary and 10 secondary). Assessment findings showed that most of the institutions were not accessible for persons with disabilities. As such, persons with disabilities enrolled in these mainstream education facilities were being exposed to physical, communication and attitudinal barriers.

Based on the aforementioned, ECSS has embarked on advocacy, resource mobilisation and awareness raising to ensure that structural adaptations are carried out to enhance physical access, school curricular are adapted to the specific needs of children with disabilities and negative perceptions and attitudes are changed to enhance inclusion and improve educational outcomes for children with disabilities in mainstream settings.



# SWEB's NETWORK ORGANISATIONS (Ghana)

The SWEB Foundation began as a small community-based organization in Accra, providing home-based care to disabled children. In 2017 a capacity assessment of SWEB's activities with partner resulted in SWEB's Executive Council approving to adopt a formal national and international approach to working as a network organization a strategy to keep working in the absence of Liliane Foundation.

## SWEB and Partners

There are currently five distinct national level Networks:

### The SWEB Partners Network for Inclusive Development (SPAID):

This is a national network that promotes Community-Based Inclusive Development for advancing the rights and inclusive development of PW Ds in Ghana. The primary objective of SPAID is to develop programmes of coordination and mutual

action in designated policy issues affecting persons with disabilities (children and youth) in Ghana.

### The Civil Society Platform for Social Protection Ghana (CSPSP-Gh):

This is a platform that complements National social protection programme. The platform adopted has begun the process of reviewing its 2014 – 2019 strategic plan.

### Cerebral Palsy Network, Ghana (CP Network):

This network was formed as a result of the post conference review recommendations of CP Africa Conference in Ghana. Which transformed the local planning teams into the nucleus of CP Network in Ghana. Organizations working in the area of CP in Ghana such CP Ghana, CP Care Association and Special Mothers are members of the Network.

### Ghana Network for Evidence to Action in

### Disability (Gha-NEAD):

This is a disability research evidence open network that has been initiated by SWEB Foundation together with the University of Education, Winneba (Special Education Department) and Kwame Nkrumah University of Science and Technology (Public Health and Disability Department). Gha-NEAD was founded November 2018 as a network of various disability NGOs, local and national academics and researchers, CBR specialist providers and individuals.

### Association of Parents Support Groups in Ghana (APSG-Gh):

SWEB began the process of facilitating the formation of a National PSG since 2017



## Children with Cerebral Palsy assisted with Appropriate Paper-Based Technology (Nigeria)

A survey was conducted by Open Doors Special Education Centre, Jos funded by the Liliane Foundation, through the Daughters of Charity of St. Vincent De Paul to identify children with cerebral Palsy in rural areas in need of APT assistive devices to help in activities of daily living in Riyom, Bassa and Jos South Local Government Areas of Plateau State, Nigeria.

APT uses cartons, papers and cardboards to produce chairs, tables, gaiters and standing. A survey was conducted by Open Doors Special Education Centre, Jos funded by the Liliane Foundation, through the Daughters of Charity of St. Vincent De Paul to identify children with cerebral Palsy in rural areas in need of APT assistive devices to help in activities of daily living in Riyom, Bassa and Jos South Local Government Areas of Plateau State, Nigeria.

APT uses cartons, papers and cardboards to produce chairs, tables,

gaiters and standing frames for children with disabilities, with particular attention to children with cerebral palsy.

This technology was introduced in Nigeria in 2016 by the Liliane Foundation and Cerebral Palsy Africa, in collaboration with the Daughters of Charity and her implementing partner organizations. The APT resolved the lack of versatility of wooden products to support children with disabilities in activities of daily living and in school. A training programme was organized where participants were introduced to the various disabilities that affect humans with an emphasis on Cerebral Palsy.

In May 2019, the trained volunteers were assigned to 5 districts to access and identify children with disabilities. In June 3 staff from Open Doors visited the 5 districts in which the volunteers were assigned to, it was accessed that; The number of children identified in the districts were above the number

estimated thus an expansion of this research may provide more accurate data on the statistics of persons with disabilities in Plateau State.

· Most of the children with a disability identified were not enrolled in school.

· Families have not received any form of support from government or any government agency.

· Some children identified need immediate medical interventions. From the survey, it was realised there is a huge knowledge and resource gap for children with disabilities in rural areas. They face major challenges in accessing health care and education. Issues such as ignorance and poverty need to be addressed in community sensitization and education. 128 children with disabilities were found within months in 5 districts. Disabilities shows a lot of work need to be done in these areas to enable us achieve our vision of an inclusive society for all.

# SUCCESS STORIES



## From Residential to Home Based Care: a New Beginning for my Son (Cameroon)

"I received an urgent call that fateful morning informing me that my 9 year old son had collapsed in the course of playing with friends. Zantsa Bilios was rushed to the regional hospital of Bafoussam where several tests were run on him, yet, nothing was detected. They gave us some tablets and told us everything was normal but the pain increased by the day. Deep within me, I knew something wasn't right." Josephine recounted her son's ordeal.

Zantsa's growing malaise and excruciating pain took his mum from one hospital to another. His bladder didn't function properly and he could barely walk. His sight was getting weaker till one day when he woke up from bed and informed his mum he couldn't see any longer. He was later rushed to a paediatrician for check-up; a head scan was recommended. It was there that a brain specialist explained that he had a brain tumour.

"I am just being a normal child with desires to bond with love ones like other kids of my age. The only difference is that while they see what they want, I can only perceive my wants. I may have lost my sight, yet I a"

**Cont'd from Pg 15**

## From Residential to Home Based Care: a New Beginning for my Son

"I was confused; as a single parent who earns less than 90 Euros a month, I knew it won't be an easy ride. I can recall tears running down my cheeks and Zantsa touching my hand asking me what was wrong, if he was going to die. I had lied to him that all was fine. Though I felt lost, I knew I had to do the impossible to get him treated".

It is thanks to the support of some goodwill donors that Zantsa was operated upon. The next challenge that stepped in was his rehabilitation for his inclusion in society; to be independent afresh. Unable to stay back and help her son, Zantsa's mother was obliged to enrol him into a center for children with disabilities (CISPAM). This institution is a residential facility where children with visual

impairment live and learn mobility, orientation and Braille.

Though such skills were indispensable for the development of Zantsa, it was difficult to detach him from home into an unknown environment "Whenever I visited him, he will hold me tight in his arms as if to tell me not to let him go. My motherly instincts told me he felt abandoned and it traumatised me every time I visited him.

In line with the global move against institutionalization of children with disabilities, the CBC Health Services - EDID program facilitated Zantsa's transfer to his home after 2 years of institutionalization. "I loved CISPAM but I prefer living with my family. Their love makes me

stronger. I am just being a normal child with desires to bond with love ones like other kids of my age. The only difference is that while they see what they want, I can only perceive my wants. I may have lost my sight, yet I am just a normal kid." Zantsa beams as he explains.



## Community Based Training: Bringing to fruition the dreams of youths with disabilities By Cheshire Ethiopia



**A**lemu and his three friends live on the outskirts of Leku, a small town in the southern region of Ethiopia where there is social stigma and discrimination against persons with disability and no access for skill training and employment opportunities.

Three of the friends have physical disabilities while one has an intellectual disability.

They depended on their poor families, who could not even cater for their own basic needs and always dreamt of having a job, earn income for their living. They could only dream of this, being aware of the erroneous belief that people with disability cannot perform any activity.

**Cont. on Pg 17**



## Community Based Training: Bringing to fruition the dreams of youths with disabilities By Cheshire Ethiopia

Cont'd from Pg 14

As every dark cloud has a silver lining, these youths with disabilities were identified during assessment for the employable project and were selected for the community-based training (CBT).

They chose a local craftsman to train them in furniture making. They pursued the skill training with keen interest and their good performance is testimony to their passion

Currently they are running their self-employment activity in a shed they secured from the local government and with startup equipment, hand tools and materials from Cheshire Ethiopia.

The group obtained ETB 100,000 (One Hundred Thousand) loan from Omo microfinance of Leku district.

Their marketing skills and quality products have garnered them a client both from the community and local government institutions and they are happily making good business. This has helped them to start paying back their loan, save some amount and also use part of the income for their living.

Alemu is a good leader that led the team to achieve the objective of the group, generating a livelihood income through hard work.

They enjoy a good work relationship and ensure that their colleague with mental disability is treated with equity in every aspect as far as running their business is concerned.

Alemu and his friends are now role models for youths with disabilities that work in other self-employment schemes. They demonstrate to the community that persons with disabilities have the potential to do anything like their peers without if they get the opportunity. They beamed while explaining: "our future intention is to expand our business, support our families and also create employment opportunities for other youths with disabilities." CBT is a mode of skills development that could be applied in areas where other forms of skills training are not available. It will also be used to train those youth with disabilities who by virtue of their physical limitation cannot access the available skill training centers.

Who said disability was inability?





**Dr. Ndasi Henry**  
Orthopedic Surgeon CBC  
Health Services

# EXPERT'S VOICE

## Understanding the Clubfoot Deformity

The clubfoot deformity is one of those few disabilities that many people around the world, especially in developing countries, had come to accept as a condition to live with, either as a result of ignorance, cultural beliefs or inadequate healthcare systems. Though it does not have a high prevalence rate (1-2/1000 births), most cases go untreated, resulting in more cases of "neglected clubfoot" for a deformity that has a tested and proven effective method of correction.

We sought to know more about this preventable disability condition from Dr. Henry Ndasi, who is an orthopedic surgeon with the Cameroon Baptist Convention Health Services. Dr. Ndasi also doubles as the Clinical Supervisor of the Cameroon Clubfoot Care Project.

### What is Clubfoot ?

Clubfoot is a congenital condition (present at birth) that causes a baby's foot to turn inward and downward. It can be mild or severe and occur in one or both feet. In babies who have clubfoot, the tendons that connect their leg muscles to their heel are too short. These tight tendons cause the foot to twist out of shape.

### Causes of Clubfoot

The cause of clubfoot is unknown. However, there is strong evidence that there is a hereditary component as some affected children have a relative who was born with the condition. No one gene has been identified as being responsible for the condition, but a number of different genes and non-genetic factors are involved. Some theories postulating the cause of clubfoot include: The baby's foot stops growing at a certain point before birth or the position of the baby in the uterus (mother's womb) There is pressure on the baby's foot in the mother's womb and some of the bones or muscles in the foot do not form properly, causing the rest of the foot to grow in a crooked way.

### Diagnosis

Most commonly, a doctor, midwife or other health worker recognizes clubfoot soon after birth just from looking at the shape and positioning of the newborn's feet. But it is also possible to clearly see some cases of clubfoot before birth during a baby's intrauterine or antenatal ultrasound examination. Clubfoot can be mild or severe, but all cases require treatment. Clubfoot will not resolve without treatment and regardless of etiology or associated clinical problems, results in a severe handicap unless corrected.

### Treatment

Treatment of clubfoot should begin in the first week after birth. This is because the baby's bones are still soft, cartilage and joints are very flexible then. The goal of the treatment is to achieve a flat plantigrade, flexible and normal looking foot.

### The Ponsetti Method

In the 1950s, Dr. Ignacio Ponsetti developed the Ponsetti Method (also known as the Ponsetti Technique) of correcting clubfoot. It is a non-surgical technique that uses a series of casts, followed by an abduction brace (a special shoe with a bar between it) to correct congenital clubfoot.

This method is said to be the gold standard method of treatment as it is effective and least expensive. It involves:

Gentle manipulation and stretching of the deformed foot towards the normal position, Weekly serial casting over a few weeks to hold the correction in place till full correction is achieved

Lastly a minor surgical procedure (tenotomy) to correct the heel of the foot at the end of the correction process

The correction is then maintained by a foot brace for three months by wearing it 24 hours and then over the next three- four years by wearing the brace at bed time.

### Surgery

Surgery may be used if other methods do not work, but this is normally on a case-by-case basis.

Surgery aims to adjust the tendons, ligaments, and joints in the foot and ankle, for example, by releasing the Achilles tendon or by moving the tendon that goes from the front of the ankle to the inside of the foot.

More invasive surgery releases soft tissue structures in the foot. The surgeon then stabilizes the foot using pins and or a cast. Such invasive methods are no longer recommended due to poor outcomes and long term complications.

Surgery may lead to overcorrection, stiffness, and pain. It has also been associated with arthritis later in life.

Reason why clubfoot surgery is not opened to all surgeons but for those who have undergone training on doing clubfoot specific surgeries



## Regional LINC-Africa Meeting in Ghana

SWEB Foundation in collaboration with Liliane Foundation Inclusion Network (LINC-Africa) secretariat based in Harare, Zimbabwe, organized the 2nd annual three-days face –to-face meeting of LINC-Africa in Accra, Ghana from the 14th -16th May 2019 with the theme 'Sharing Experience in Disability and Resource Mobilization in Africa'.

The purpose of the meeting was to build technical capacity of LINC-Africa members in resource mobilization and share best practices in disability management. Eighteen (18) African countries, made up of eleven (11) English speaking and seven (7) French-speaking countries participated in the meeting. Officials from the head office of Liliane Foundation based in the Netherlands also attended

### Experience of Host Country.

LINC-Africa meeting gave the host nation an opportunity to meet other SPOs with Africa, share work experience and broaden our knowledge base on resource mobilization, best practices in disability management, and partnership development. Presentation at the conference was informative and LINC members attended fully and participated as well. We were supported and honoured when our partners in Ghana who work in the disability arena such as Ghana Federation of the Disabled (GFD), Sharecare Ghana, Salvation Army and National Council of Persons with Disability (NCPD).

The climax of the conference was an exhibition on the 3rd day with participants exhibiting items made by persons with Disabilities from their home countries, annual reports, brochures and pamphlets which further deepen our knowledge and experience sharing. All countries fully participated in the exhibition. We were honoured with the attendance of our special guests the Ambassador of the Royal Kingdom of Netherlands to Ghana, Mr. Ron Strikker, the Charge D'Affaires of Zimbabwe to Ghana and Deputy Minister of Gender, Children and Social Protection, Hon. Freda Prempah. The presence of these dignities has paved the way for SWEB to further engage in consultations/discussions in our

fight for the rights and social inclusion of persons with disabilities.

LINC-Africa regional meeting was a success; however, we will like to give a few recommendations to the next host of the meeting to better inform and improve the next meeting.

- a. Exhibition on the final day should be included in subsequent meeting.
- b. The conference should be made four days instead of three, to ensure all presentations and training take place. Fourth day should be dedicated to the exhibition and social outings to further cement bonds between participants.
- c. Accommodation, transport and feeding arrangement made by hosting SPO should be binding.

The SWEB team will like to take this opportunity to thank Liliane Foundation and all SPOs for the opportunity to host LINC-Africa meeting 2019. We will like to thank everyone for participating and hope we build on progress made at this meeting to realise the vision of LINC-Africa aspiring to an inclusive society where children, youngsters and adolescents with disabilities can enjoy their rights in equal conditions and in a dignified manner.





**Liliane  
Fonds**

open the world  
for a child  
with a disability

## MOVING TOGETHER Leaving no one Behind

A Publication of the LINC Africa Network

LILIANE FOUNDATION  
INCLUSION NETWORK



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