



**UGANDA NATIONAL ASSOCIATION OF CEREBRAL PALSY**



**“Paving Way to Our Destiny”**

**ANNUAL REPORT 2019**

## FOREWORD



It is with great honor that I present to you UNAC's Annual Report for 2019 with highlights of projected activities, results and achievements realized in the course of our implementation.

UNAC was privilege to have hosted a number of partners during the course of the year including guest from Spastiker and partner DHF (Thomas Arpel, Rasmus and Sven). The Country Coordinator Abilis (Beatrice), DRF headed by Esther Kyoziira and Jackson Atria. Mr. Katende Godfrey and team from SIEA and lastly Lilian Fonds members ushered in by Nangai Kenneth and Namatovu Samali, the Executive director, Katalemwa Chiesheir Home.

We are also glad to inform you that in the same year, UNAC was able to organize its first Annual General Meeting (AGM). Two new Board members were coopted to fill in the position of General Secretary and Treasure to the board with funding from Disability Rights Fund.

Our sincere appreciation to Sparstiker, DRF, and Lilian Fonde through Katalemwa Cherisher Home, OSIEA, Abilis, DHF and Motivation Charitable Trust. The National Union of Disabled Persons of Uganda (NUDIPU), Uganda National Action on Physical Disabilities (UNAPD) and COMBRA for the timely support towards UNAC's projected programmes.

It is candid to note that, all the achievement highlighted in this report would not have been possible without your financial and technical support as donors or partners.

I extend my heartfelt gratitude to the committed Board members and UNAC secretariat with whom we ensure there is continued progress and services for the benefit of persons with cerebral palsy.

Mr. Kalule Rashid

**Chairperson Board Directors.**

**UNAC.**

## *Acknowledgement*



Hullo our readers, we bring you warm greetings from the team at UNAC!

As we wrap up the year 2019, we bring you volume of information to help widen you're understand on our range of activities and interventions. A representation of summaries, insight and stories behind our achievements during the projects implementation phase.

I am profoundly delighted to be presenting specific program achievements and outcomes of our project activities in this annual report.

We acknowledge the support given to us by all our development partners namely, DRF, Abilis Foundation, Spastiker, DHF, Lilian Fonds through Katalemwa Cheishere Home and OSIEA. We want to thank Dream TV and Mama FM among other media outlets for their consistent and accurate representation of persons with cerebral palsy, their parents and caretakers in their programming. Keep it up

My immense gratitude also to all our Board members, your commitments, persistent efforts and support has made UNAC secretariat sprout to greater heights.

Thanks to the team back at office (staff) for the work well done in ensuring that UNAC's vision and mission is achieved in spite of the limited resources and glaring challenges. Never the less, your knowledge, skills and expertize combined helped inspire the numerous changes we see today in the lives of persons with cerebral palsy.

Not forgetting all parents and caretakers of children with cerebral palsy who found solace and made meaning out of our work through effective collaboration in their support groups.

We are committed to making sure that persons with disabilities live better quality life and in a decent world for all. A world where persons with cerebral palsy are able to realize their full potential, rights, responsibilities and potential like any other citizens in the country.

Sincerely yours

A handwritten signature in purple ink, which appears to read "Kirungi Christine". The signature is somewhat stylized and is placed directly above the printed name.

Kirungi Christine

**Executive Director-UNAC**

## **INTRODUCTION**

### **EXECUTIVE SUMMARY**

Uganda National Association of Cerebral Palsy (UNAC) is a non-governmental organization established in 2013 to advocate for the rights of people with cerebral palsy.

The organization was established by a group of people with cerebral palsy after realizing that their rights were being violated and were not benefiting from government and NGOs programs.

#### **Strategic areas of focus for UNAC**

- Strengthen persons with cerebral palsy and enhance their capacities to lobby and advocate for their rights.
- Build and strengthen the capacity of UNAC management to mobilize and manage its resources.
- Mobilisation and registration of persons with cerebral palsy in Uganda.
- Awareness raising on the concept of cerebral palsy through community engagement meetings, Radios and TV talk shows and brochures supplements.
- Establishment of membership association group of persons with CP and build their capacities in leaderships and organisation management in regional structures.
- Participation in the national and international events to promote the rights, responsibilities and potential needs of persons with CP.
- Mobilization and sensitization of parents/caretakers on the CP concept such as home basic skills in physiotherapy, nutrition and feeding methods to children with cerebral palsy.
- Advocacy and lobbying for inclusive participation of persons with cerebral palsy in mainstream development initiatives in Uganda.
- Supporting people with CP in income generating activities so as to meet their basic needs.
- Promoting inclusive education and better access for health of children with cerebral palsy.

This report therefore, presents a summary of programs, activities and interventions implemented by UNAC between January...to..December... of 2019 in the existing regional structure spread across the country. It a highlights of registered achievements, lessons learnt and challenges encountered during the implementation of activities.

UNAC currently has a total number 850 members in 4 regions and 10 Districts of Uganda. UNACs has since inception partnered with a number of local and international organization who have been a benchmark for providing support towards UNAC to implement its mandate as illustrated in its 2016-2020 strategic work plan.

## OUR VISION, MISSION AND CORE VALUES

**Vision:** A world where persons with disabilities live a better quality life.

**Mission statement:** Empowering persons with CP to advocate for their rights through participating in sustainable development initiatives.

**Slogan:** *“Paving Way to Our Destiny”*

### UNAC’s Planned Programmes and Strategic Objectives - 2016-2020.

No	Program Areas	Strategic objectives
1	Institutional Capacity Strengthening	<p>Build capacity of UNAC to be able to deliver high quality services to persons with Cerebral Palsy. Strengthened.</p> <p>Increase UNAC’s source of funding so as to implement its planned programs.</p>
2	Access to social services (Education, Health and Sports)	<p>Increased access to quality education for Children and Youth with cerebral palsy in UNAC operation districts.</p> <p>Improved health and life-long support for persons with Cerebral Palsy in UNAC operation districts</p>
3	Economic Empowerment	<p>Enhance Persons with cerebral palsy capacity to engage in income generating activities.</p> <p>Enhance Persons with Cerebral palsy in entrepreneurship and employment skills in UNAC operation districts.</p>
4	Human Rights Promotion	<p>Increase public awareness about the concept of Cerebral Palsy, promote their rights and potential of persons with cerebral palsy for purpose of inclusion in UNAC district of operation.</p> <p>Reduced violation of rights and abuse of persons with CP in UNAC operational areas.</p>

## Status of Program Implementation & Areas of Coverage.

Capacity Building programme (DRF - Livelihood support project, Child Empowerment, Institutional and member's structural development, DHF, Health and CBR Development).

### Progress of Activity implementation

Activity/Projects	Key major Progress	Partner
Supporting Persons with Cerebral Palsy in Uganda.	<p>Improved health and life-long support for children with Cerebral Palsy through CBR Trainer of trainees in physiotherapy home basic skills in Kyarumba, Munkunyu sub-counties Kasese district and Nama sub-county in Mukono district. 45 Parents/caretakers of children with Cerebral Palsy were trained in physiotherapy home Basic skill for improved quality of both their lives and that of their children.</p> <p>Improved capacities of UNAC's staff and Board members in project management Cycle, planning, formulation / development and implementation. 12 staff members and Board members were trained in Project Management cycle. This helped increased resource base for the organization due to mobilization and fundraising skills attained.</p> <p>UNAC development an Excel database system for its members. This has enabled them tracks the records of their cluster member's annual contribution and subscription cost.</p> <p>Improved family bound with fathers starting to accept and take responsibility of their children born with Cerebral Palsy. Besides reducing stigma and negative attitude posed towards them in their families and in communities.</p> <p>Increased membership on the side of UNAC from 800 to 850 members all of persons with Cerebral Palsy, their parents and caregivers in UNACs' areas operation.</p>	SPASTIKER
Capacity Building Program	<p>Developed additional Organization polices including Child protection policy and Reviewed UNAC's Financial policy among others.</p> <p>UNAC has assertive group leaders of association groups/cluster in its area of operation and they are able to make decisions and implements their own.</p>	Disability Right Fund in Uganda. (DRF)

	<p>On 28<sup>th</sup>, October 2019, UNAC held its First Annual General meeting. The event was presided over by Mrs. Kyozi Esther from Disability Rights Fund (DRF) serving as the guest of honour.</p> <p>Other guest that graced the event included, Mrs. Samali Namatoovu the Executive Director, Katalemwa Cheshire Home and Ms. Nankya Elizabeth from DHF. Two Board members were co-opted by the general assembly, Miss. Namuga Asuma acting as the Treasurer while Mr. Nsamba Godfrey came in as General Secretary.</p> <p>More 3 groups of persons with cerebral palsy have been formed in Central region, these included Lugazi group in Buikwe district, Mpigi group in Kintuntu sub-county Mpigi district and Greater Masaka association Masaka district.</p>	
Inclusive Education for Children with Disabilities.	<p>Conducted a Baseline Survey on inclusive education in Goma and Central Division of Mukono Municipality aimed at identifying gaps affecting access to inclusive education for children with disabilities besides analyzing best practices and existing opportunities.</p> <p>Improved acceptance of teachers and school administrator to enroll children with disabilities. For example, at St. Charles Lwanga Primary Schools, Froebel Primary Schools and Seeta Church of Uganda. This has helped reduced the negative attitude of teachers towards learners with disabilities.</p> <p>The activity has strengthened the work relation between teachers, school administrators, local leaders and parents. 4 Parent Peer support groups have been formed in Goma and Mukono central respectively all working towards the implementation, and promotion of inclusive education. At St. Charles Lwanga at least 16 children with disabilities has been enrolled and the school pledged establish a conducive environment for these learners with disabilities.</p>	Open Society Initiative for East Africa (OSIEA)
Improving Livelihood of Persons with Cerebral palsy.	<p>Improved livelihood and income households of persons with Cerebral Palsy, their parents and caretakers. For example 34 persons with Cerebral Palsy and their parents/caretakers in Lulemu and Nama in Mukono districts received income generating materials to boost the household income and meet their needs including access to education, shelter and health bills.</p>	Abilis Foundation
Support tool Enabling Parents and Child Empowerment.		Liliane Fonds through Katalemwa

	<p>Establishment two Day Care Centre for children with severe disability (one at St. Charles Lwanga Primary School in Mukono district and the second at Mityana Hospital IV in Mityana district.</p> <p>Increased support for Children with severe disabilities in accessing education, CBR physiotherapy home basics services through reaching children with cerebral palsy at their homes by UNAC field workers. And also passing on the skills to parents/caretakers of children. For example, 15 parents/ caretakers of children with CP have been trained on how to offer home based basic physiotherapy services. And 20 children are being supported with school fees. In Mukono, Kampala and Wakiso districts.</p>	Cheshire Home.
Supporting several inclusion of children with cerebral palsy in Mobility.	Improved mobility of children with cerebral palsy. Many children cerebral palsy were supported with wheel chairs. This enabled them participate equally and interact with their peers in homes and at school environments. For example, 15 children with Cerebral Palsy were supported with wheel chairs in Mukono District.	Motivation Charitable Trust Uganda.
Organisation Development	<p>Active participation of UNAC members in creating awareness raising and sensitization about the concept of cerebral palsy, rights and potential need of persons with cerebral palsy. This has been done through involving local sub-county leaders, support group association of persons with CP and parents/caretakers, Village health team, CDOs, community members in training workshops at grassroots and national levels. And media fraternities.</p> <p>Two UNAC clusters members of persons with cerebral palsy and their parents/caregivers in Mukono and Masaka districts were supported in proposal formulation and also received DHF trust fund to implement their independent activities on their own.</p>	Danish Association of the Disabled (DHF)
Improving household income for persons with cerebral palsy and their parents/caretakers	25 Parents of person with cerebral palsy in Lugazi Buikwe district were supported with additional income generating activities with support from Trust fund. And these parents are actively engaged in livelihood income activities like piggery, Charcoal selling, Grocery business (Mudala).	Trust fund UNAPD.



## Finance and Administration Department

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**UGANDA NATIONAL ASSOCIATION OF CEREBRAL PALSY  
(UNAC)**

**Consolidated Statement of Comprehensive Income**  
**for the year ended 31 December 2018**

	Note / Page	Actual 2018 Ushs.
<b>INCOME</b>		
Spastikerforeningen - DPOD		68,803,951
Disability Rights Fund - DRF		25,034,940
Abilis Foundation		18,152,400
Katalemwa Cheshire Home		12,400,000
OSIEA		35,150,000
CIV Source		2,300,000
<b>Total Income</b>	9	<b>161,841,291</b>
<b>EXPENDITURE</b>		
Spastikerforeningen - DPOD	21	72,208,521
Disability Rights Fund - DRF	22	23,658,550
Abilis Foundation	23	15,445,600
Katalemwa Cheshire Home	24	13,239,000
OSIEA	25	6,425,000
CIV Source		2,280,000
<b>Total Expenditure</b>		<b>130,976,671</b>
Surplus for the year		30,919,620
Funds from the previous year *		40,274,399
<b>FUNDS BALANCE AS AT 31 DECEMBER 2018</b>		<b>71,194,019</b>
<b>Represented by:</b>		
Bank Balances	4	78,620,119
Receivables	5	603,100
Payables	8	(8,029,200)
<b>TOTAL:</b>		<b>71,194,019</b>

\* Funds from previous year relate to unspent donor funds transferred to 2018 activities.

**UGANDA NATIONAL ASSOCIATION OF CEREBRAL PALSY  
(UNAC)**

Consolidated Statement of Financial Position  
for the year ended 31 December 2018

	Note	2018 Ushs.
<b>ASSETS</b>		
<b>NON-CURRENT ASSETS</b>		
Property and Equipment	3	5,590,875
<b>CURRENT ASSETS</b>		
Cash and Bank balances	4	78,620,119
Receivables and Prepayments	5	603,100
		<u>79,223,219</u>
<b>TOTAL ASSETS</b>		<b>85,814,094</b>
<b>FUNDS AND LIABILITIES</b>		
<b>FUNDS</b>		
CAPITAL FUND	6	5,590,875
RESTRICTED FUNDS	7	71,194,019
		<u>76,784,894</u>
<b>CURRENT LIABILITIES</b>		
Payables and Accruals	8	8,029,200
<b>TOTAL FUNDS AND LIABILITIES</b>		<b>85,814,094</b>

These financial statements were approved by the Board of Directors on 26-10.....2019 and were signed on its behalf by:

  
MR. RASHID KALULE

CHAIRPERSON  
BOARD OF DIRECTORS

  
MS. CHRISTINE KIRUNGI

GENERAL SECRETARY  
EXECUTIVE DIRECTOR

## Analysis of Key Achievements Of 2019

Awareness raising on the Key concept of Cerebral Palsy, rights and potential needs for inclusion during the commemoration of world Cerebral palsy 5<sup>th</sup>, October 2019 at Bukerere play ground in Goma Division.



**Children with Cerebral palsy having fun on the CP day celebration in a Picture at Bukerere play ground**





*UNAC Partners from Katalemwa Cheshire Home giving Remarks. Promised to build stronger partnership and provide more support on child empowerment program with UNAC.*



*The Media moments with Mutabazi Ali (Youth leader with Cerebral palsy)*



*Executive Director delivering her speech on the world Cerebral palsy, Argues Parents not to give up “You are our Heros”*



*Namuga Ashman(Youth with CP): Advices parents to give hand support to children with Cerebral palsy “Please stop keeping child with Cerebral palsy inside house”*



Muhumuza Stephen, UNAC's Executive Director during a Radio talk show at Mama FM raising awareness & sensitizing the Public on the rights and needs of persons with cerebral palsy for inclusion

**Strengthening the membership of UNAC's structures and building the organization ownership among Persons with Cerebral Palsy in Uganda through Annual General Meeting.**



From the left is Ms. Namatovu Samali, Executive Director Katalemwa Cheshire Home & Mr. Luyima Ronald (Technical Board) attend UNAC First Annual General Assembly 2019).





Massive turn up of the delegates of persons with cerebral palsy in the Annual General Meeting 2019 as Mr. Odongi Simon is taking them through UNAC's constitutions reviews for amendments.

**Training the Support Groups to Provide Home Basics in TOT on Physiotherapy Support to Children with Cerebral Palsy.**



*The trainer demonstrate practical hands-on training on Physiotherapy home basic knowledge skill of positioning a child with Cerebral Palsy during the trainer of trainees (Parents/caretakers of children with cerebral palsy) at Kagando in Kasese.*



*The trainee demonstrate the lesson learnt during the TOT training workshop in Physiotherapy home basic knowledge skills at Kagando Save the Disabled Child Home(SADICH), in Kasese district.*





*The CDO in Munkunyu sub-county giving remarks to Munkunyu Association of persons with Cerebral palsy on the requirements to access the CDD grant funds at the sub-county*



*Mr. Thomas Arpel and UNAC staff meeting the Kasese leaders of persons with cerebral palsy and their parents/caretakers during monitoring visit.*





**Dr. Florence Odette** lecturer from special needs Kyambogo University explaining to the teachers from Goma Division and Mukono Central on the best teaching practices, safe and accessible environment for learners with disabilities during the training workshop on inclusive education held at COMBRA Hall



Staffs of UNAC and Board Members participate in a capacity build training workshop organised by for CBED and Partners on Introduction to the constitution formulation, its importance and best practices on how to use it. The demarcation of the various Board roles and functions of distinct positions, their work relationship and Secretariat. Project Cycle process, Budget development process and accountabilities. Development of project proposal ideas and its implementation. This was organised by the DHF Kampala and held at **MURS Country Resort Hotel in Mukono,**

## Challenges.

1. There is a huge numbers of Persons with Cerebral Palsy, their parents and caregivers who need to be support with self-help skill development and income generating activities.
2. Children with Cerebral Palsy continued to be pushout of schools due to negative attitude by school authorities including teachers besides incurring extra cost related to enforcing reasonable accommodation, poor hygiene and sanitation and inaccessible school building structure.
3. Poverty among families of Persons with Cerebral Palsy, their parents and caregivers due to discrimination and isolation posed by their own families and the community at large.
4. Cerebral Palsy as a disability has not yet been enlisted and recognized as a disability by disability movement. They have been simply lumped up among the other marginalized groups like those with intellectual disability. Implication, they are left out in virtual community development initiative at both government and mainstream NGOs work.
5. High expectation from parents/caretakers of persons CP and structure group leaders. For example, they expect more support from the mother organization to fundraise for their project.
6. Financial constraint to support and reach the demands of persons of cerebral palsy in areas of inclusive education, Home basics rehabilitative skill in physiotherapy services, awareness raising and community sensitization about the concept of cerebral palsy, rights and potential needs of persons with cerebral palsy in other areas where UNAC has not reached.

## Lesson learnt

1. Families of low socioeconomic status often cannot afford the cost of long term rehabilitation services like physiotherapy home basic skills and speech therapy. Therefore, training Parents support groups of Children with CP in Physiotherapy home basic skills is the best practices. This way, irrespective of socioeconomic status every child with CP has an opportunity to physical empowerment. UNAC feels there is great need to expand this program to other areas so the category in question are supported.
2. UNAC is steadily growing as an organisation. Additional support in terms of communication (airtime, data for internet and strong online presence with a website) is needed to aid the visibility of UNAC and its core activities. Our projection is to increase our budget to meet all these and additional administrative cost.
3. There is need to start awareness raising programs right from the community where these children are hosted. UNAC has proven that, grassroots awareness campaigns are critical in helping people with CP and the society develop empathy for one another. It also helps in subsiding the stereotypical mind-set of the society, hence providing vast opportunities for everyone to get involved in creating a positive and inclusive society for all.
4. Events broadcasted on TV and aired on radio stations created more awareness on the condition, need and support services for Persons with CP in the community. From the presentation and

engagement, UNAC has realised an increase in the numbers parents/caregivers of Children with CP approaching the organisation for support.

5. Provision of assistive devices to Persons with CP like wheelchairs have supported them to socially and actively engage in social activities within the confines of their home and community.
6. Active involvement of local government leaders/authorities, and community members in organization programs is the best practice to reduce stigma and isolation of persons with cerebral palsy and their parents/caretakers in community development activities in Uganda.

### **Case Theories of Change.**

*Richard is a youth with CP who has been living and an independent life and surviving on fetching water for cash. Before the Abilis project, Richard used to walk around all day long looking for people interested in his service. However, the struggle is no more after he was given support under the improving livelihood of Persons with CP from UNAC. Whereas, he is still engaged in fetching water for his clients, Richard sceptical of his time and no longer loiters in the community since he has to be at home to attend to his pigs given to him under Abilis project. “Now I know how to plan for my time and am always busy looking for food for my pigs” Richard said.*



### **Cerebral Palsy and Leadership...!**

Mr. Muhumuza Stephen did not let Cerebral Palsy (CP) prevent him from doing things “**normally**”.

Stephen formerly served as the Chairperson and also Vice chairperson of UNAC. He is also the Acting Executive Director, COMBRA position he has held since 2016 besides coordinating projects.

At 41years old, Stephen is a proud father of five daughters. He acquired CP from childhood.

He’s motivated to be a leader so as to express his ability and change attitudes of communities towards people with CP. “More often than never, people with Cerebral Palsy are misunderstood, shunned and kept indoors by the society. Majority are seen and declared medically and physical unfit by Physiotherapist and discharged from Rehabilitation centres. This means they have to rely on the mercies of well-wishers and the community to survive. They have always opted to looked at local charities like UNAC for temporary support including housing, skill trainings and being rehabilitated back with their families or into communities.” Stephen said.

Adding that his continued efforts in speaking out on the rights of people with CP is deliberate and aimed at changing the status quo.

“I will continue to advocate for the needs and inclusion of People inclusion in communities at whatever cost. I am still healthy and I don’t see any harm in helping change negative attitude of the society.”

***Written by Bychance Emmanuel -UNAC***

*“We don’t discriminate children with disabilities, we learn together, play together. We compete with them and they (learners with disabilities) even perform better than us.” FGD Froebel learners without disabilities.*

### **Conclusion.**

Without the support from different people, organizations and partners, UNAC would not have achieved any of its set strategic plan, objectives and programs. As UNAC we want to acknowledge the efforts and contribution of our all our members, partners, local government leaders, different development actors and media houses that have been a part of UNAC.

All your commitment and contribution in support and improving the lives of persons with cerebral palsy and their parents/caretakers is commendable.

We implore you to continue supporting the work of UNAC for sustained and improved quality of lives of all persons with CP in the country.