

UGANDA NATIONAL ASSOCIATION OF CEREBRAL PALSY



Some of Children with disabilities at the Day-Care and Rebilitation Centre Cutting Chrismas Party Cake with UNAC members, local government leaders, Parents, Leaders of Persons with disabilities and Partners at St. Charles Lwanga Primary school Bukerere in Mukono District.

"Paving Way to Our Destiny"

ANNUAL REPORT 2021

Kiwanga Mukono

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FOREWORD

Greetings to you all



It is with great honor that I present to you UNAC's Annual Report for 2021 with highlights of key achievements and challenges amidst of hardship periods of COVID-19 Pandemic.

The year 2021 was the fifth year into out of end of our strategic plan (2016 to 2021). It was full of challenges instigated by the 2nd wave outbreak of Covid-19 pandemic. The outbreak of 2nd wave Covid-19 doubled negative impact on our communities' economic activities especially the livelihood of families of persons with cerebral Palsy and social emotional challenges to children with cerebral palsy out of school for this long periods. In general, the lockdown periods practically negatively affected the economic activities and could

hardly survive including one of our own poultry business project. Many families of persons with cerebral palsy were enormously affected and could hardly afford 2-meals a day or able to meet the basic needs such as health needs for children with Cerebral Palsy. Visit; www.unacp.org,

Even after the relaxation of the 42 –days total lockdown by the government restrictions that were put in place in an attempt to contain the effects of Covid-19 pandemic, the cost of living shot up with the cost basic services doubling and others tripled. Accessibility to services was limited due to restriction on public transport, few families of persons with cerebral palsy were able to attend referral rehabilitation services to Katelemwa Cheshire Home and this left many in far districts not accessing theses services.

Special recognition go to our development partners such as DRF, Spastiker, Lilian Fonds through Katalemwa Cheshire Home and DHF, who amidst of Covid-19 impact in our own country continued to support our programs.

The Board members appreciates the staff of UNAC for the exceptional commitment to uphold the organization's mission by proving usual quality work and responding to the needs of persons with cerebral palsy into the mainstream development programs.

We look forward to attain greater accomplishment in the year to come as well as implementing the new five year strategic plan (2021 to 2026).

Mr. Kalule Rashid

Chairperson Board Directors.

UNAC.

Acknowledgement



We bring you once again warm greetings from UNAC!

The year 2021 was characterized by the greater fear of unknown and the future especially after the outbreak of 2nd wave of Covid-19

pandemic which negatively impacted the families of persons with Cerebral Palsy. Few families of persons with cerebral palsy were able to attend medical reviews and referrals living the many families outside of Mukono and surrounding districts. This was due to hiked transport costs and great fear associated with the 2nd wave Covid-19 spread. This in the long run negatively affected the health of children with cerebral palsy both mentally and social emotional challenges especially to children out of school and Day Care centre.

Nevertheless, the organisation was able to register a few achievements in program activities as these are highlighted as you take a read of our report. I extend my gratitude appreciation to our donors and partners like DHF, Spastiker, DRF and Lilian Fonds through Katalemwa Cheshire Home for having supported our programs amidst

of Covid-19 pandemic. For example some partners provided us with Internet installation equipements, internet data, desktop Computer to run office activities and meetings online.

My immense gratitude also go to all our Board members, parents/caretakers of children with cerebral palsy, your commitments, persistent efforts and support has made UNAC secretariat sprout to greater heights.

In the same way, I recorganise the immense contribution of UNAC staff for good cooperation, team work and persistence to volunteer amidst of Covid-19 Pandemic and inadequate finance within our reach. Their outstanding expertize in various field are the pillar of the organization's efficiency and effectiveness.

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



Kirungi Christine

Executive Director-UNAC

INTRODUCTION

EXECUTIVE SUMMARY

Uganda National Association of Cerebral Palsy (UNAC) is a non-governmental organization established in 2013 and legally registered with National Bureau for Non-Governmental organisations (NGO) with registered number MIA/NB/2013/08/1724 to advocate for the rights of people with cerebral palsy.

The organization was established by a group of persons 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 and her structures to mobilize and manage resources.
- Advocacy and lobbying for inclusive participation of persons with cerebral palsy in mainstream development initiatives in Uganda.
- Awareness raising on the concept of cerebral palsy and addressing the needs of persons with cerebral palsy through community engagement meetings, Radios and TV talk shows and brochures supplements.
- Promoting inclusive education and better access for health of children with cerebral palsy through training parents/caretakers in occupational therapy home basic skill, Nutrition for children with Cerebral palsy and provide referrals to rehabilitation centres.
- Establishment of membership association group of persons with Cerebral Palsy and build their capacities in leaderships and resource mobilization for their sustainability.
- Participation in the national and international events to promote the rights, responsibilities and potential needs of persons with cerebral palsy.
- Economic empowerment of persons with cerebral palsy in income generating activities skills so as to meet their basic needs.

This report therefore, presents a summary of programs, activities and interventions implemented by UNAC between 1st, January to December of 2021 in the 12 structure association members across the 4 region operation districts in the country. It a highlights of registered achievements, lessons learnt and challenges encountered during the implementation of activities.

UNAC currently stands at a total number 1023 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.

OUR VISION, MISSION AND CORE VALUES

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

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

Status of Program progress amidst of Covid-19 Pandemic 2021.

Activity/Projects	Key major Progress	Partner
Supporting	4 support groups are fully registered in their respective sub-counties	SPASTIKER
Persons with	and have interim committee leaders who are preforming their roles	
Cerebral Palsy in	in communities.	
Uganda.	Group leaders are well equipped with leadership skills, advocacy	
	skills and lobbying skills to sustain group members.	
	All 4 group members are engaged in livelihood activities and Saving	
	scheme. However the saving culture is small due to external factors	
	like COVID-19, landslide and Floods which has increased poverty.	
	3 out 4 Support groups have been able to benefit from DHF trust	
	fund. And 2 groups from special grants in their respective sub-	
	county like Munkunyu and Nama-sub-county.	
	UNAC has been able to work with local and international partners	
	like lilian fond through Katalemwa Cheshire home, Light for the	
	world and other DPOs. This has increased support in form of funds	
	and Materials	
	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 CEREBRAL PALSY and	
	parents/caretakers, Village health team, CDOs, community	
	members in training workshops at grassroots and national levels.	
	And media fraternities.	
	UNAC has a financial control systems in place. These include	
	Financial policy, QuickBooks software that is functional, and	
	financial record books. Others are Audited reports, Asset record	
	book and policies	
	UNAC established poultry income model with 240 chicken which	
	has relatively generated two phases of sales returns amidst of Covid-	
	19. However access to reliable market and buying habit of customers	
	is still low because people are still low.	
	Held 6 Community engagement meetings together with grass-root	
	structured leaders of persons with cerebral palsy addressing key	
	community personnel about the concept of cerebral palsy disability,	
	their rights and potential needs for them to actively participate in	
	community. In total 70 people (36 Female, 34 Male) and these	
	include; Nurses, Mid-wife, Police, Cultural leader, Religious	
	leaders, Community Development Officer (CDO), Councilors for	
	Persons with disabilities, Teachers, COVID-19 task force leader,	

Capacity Building Program	Local leaders, Media Journalist, Parents of children with CEREBRAL PALSY, and Village Health Team(VHTs). UNAC has developed a strategic plan 2021 to 2025 to strengthen her capacity of resource mobilization. Trained 10 UNAC staff and Board members (4 Male 6 Female) in Safeguard policy and its implementation. A policy has been developed and in operation.	Disability Right Fund in Uganda. (DRF)
Child Empowerment.	1 Children with cerebral palsy in candidate classes was supported with school fees. (Kajungu Goerge of St. Mary's High school Migade) There are 25 children with disabilities in the day care centre getting daily occupation therapy, nutritional and physical daily-life activities and their wellbeing have been improved. Modification of some school facilities at St. Charles Lwanga primary school. Such walkways, Incinerator, toilets. 45 Parents/caretakers of children with Cerebral palsy were trained in occupational and nutritional home Basic skill which has improved quality of health lives of children. 20 Children (9 boys and 11 girls) received medical treatments and medical review follow up. This improved health and life-long support amidst of Covid-19 pandemic. Provided 55 assistive devices to children which has improved their mobility, and their active participation in daily life activities.	Liliane Fonds through Katalemwa Cheshire Home.
Organisation Development	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 CEREBRAL PALSY and parents/caretakers, Village health team, CDOs, community members in training workshops at grassroots and national levels. And media fraternities.	Danish Association of the Disabled (DHF)

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UGANDA NATIONAL ASSOCIATION (A Company Limited by Guaran	TION OF CER	REBRAL PALSY aving a Share Capit	(UNAC)
Statement of Co for the year ende	mprehensive	Income	
		2020 Ushs.	2019 Ushs.
INCOME	Note		
Grants and Donations			
Other Income	3	299,164,328	279,213,250
	4	6,737,742	209,137
Total Income		305,902,070	270 422 201
723070		303,702,070	279,422,387
EXPENDITURE			
Programme cost	5	185,638,783	194,012,750
Governance cost	6	2,785,000	16,438,000
Personnel cost	7	63,431,450	78,051,725
Office costs	8	12,446,000	
Equipment cost	9	76,200,000	12,420,700
Transport costs	10	2,805,500	140,000
Finance cost	11		4,920,200
		3,592,662	3,609,541
Total Expenditure		346,899,395	309,592,916
Surplus /(Deficit) for the year		(40,997,325)	(20 170 520)
Balance as at 1 January		41,023,490	(30,170,529) 71,194,019
		11000000000	71,194,019
Balance as at 31 December		26,165	
		20,103	41,023,490
BALANCE IS REPRESENTED BY:			
Cash and bank balances	15	35,532,806	78 030 653
Receivables	14	21,932,636	78,039,653
Deferred income	17	(27,488,701)	433,900
Payables and accruals	18	(29,950,576)	(27,451,600)
		(4717-99)370)	(9,998,463)
		26,165	41,023,490

UGANDA NATIONAL ASSOCIATION OF CEREBRAL PALSY (UNAC) (A Company Limited by Guarantee and not having a Share Capital) Statement of Financial Position for the year ended 31 December 2020 2019 2020 Ushs. Ushs. Note 4,330,856 60,281,354 ASSETS 13 PROPERTY AND EQUIPMENT 433,900 CURRENT ASSETS 21,932,636 14 78,039,653 Receivables 35,532,806 15 Cash and bank balances 78,473,553 57,465,442 82,804,409 117,746,796 TOTAL ASSETS **FUNDS AND LIABILITIES** 4,330,856 **FUNDS** 60,281,354 41,023,490 Capital Fund 7,656,608 16 Donor Funds (7,630,443)General Fund 45,354,346 60,307,519 27,451,600 CURRENT LIABILITIES 27,488,701 17 9,998,463 Deferred income 29,950,576 18 37,450,063 Payables and accruals 57,439,277 82,804,409 117,746,796 TOTAL FUNDS AND LIABILITIES The accounting policies and notes set out on pages 32 to 43 form an integral part of these financial statements These financial statements were approved by the Board of Directors on 21/62 2022 and were signed on its behalf by: CHAIRPERSON BOARD OF DIRECTORS **EXECUTIVE DIRECTOR**

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UGANDA NATIONAL ASSOCIATION OF CEREBRAL PALSY (UNAC)

(A Company Limited by Guarantee and not having a Share Capital)

Notes to the Financial Statements
for the year ended 31 December 2020 (Continued)

16. DONOR FUNDS

The amount on this account is made up of the following:

	Balance at I January 2020 Ushs.	Grants Received	Other Income	Grants Utilised During the Year	Transfer to General Fund Ushs.	Funds at 31 December 2020 Ushs.
		Ushs.		Ushs.		
Katalemwa	44,208,672	147,574,389	2,000,000	(186,496,620)		7,286,441
	(6,427,055)	68,596,386	1,705,000	(45,578,092)	(200,000)	18,296,239
SPASTIKER	1,696,945			(930,000)		766,945
OSIEA	The second secon		-		(878,127)	-
Xavier	878,127 (40,657)	54,793,553		(69,694,883)		(14,941,987)
DRF	311,532	21,010,000				311,532
Abilis	395,926	18,000,000		(21,438,488)		(3,042,562)
UNAPD	312,720		- 3	(1,020,000)		(1.020,000)
CIV Source	- 1	-	- 4			
Light for the World		10,000,000	510,000		(10,510,000)	*
TOTAL	41,023,490	299,164,328	4,215,000	(325,158,083)	(11,588,127)	7,656,608

Community Awareness Engagement Meetings



"I would like to thank our dear families, friends, organizations, and my fellow colleagues living with Cerebral Palsy for the support towards ensuring that this important world-Cerebral Palsy day is celebrated today in Uganda. Cerebral Palsy is a condition that can be stressful for some and a lifetime of daily challenges for others. Sadly, there is very little public awareness regarding Cerebral Palsy hence need for joint effort to raise public awareness and putting an end to stigma, discrimination and stereotype faced by persons with Cerebral Palsy, and their families in society. Quality of life beyond mere survival, medical and other therapies, the overall well-being of persons with cerebral palsy is of paramount concern, Therefore, this day is very important in the lives of persons with Cerebral Palsy and their families, to raise awareness and to commemorate our achievements together and to make our voices heard". Remark by Mr. Godfrey Nsamba General Secretary Board member-UNAC.

On 6th, October 2021 UNAC in Partnership with Capital Center Medical Clinic marked the world Cerebral palsy day at Blends Garden in Bwaise Community Kampala Suburb. The event attracted 200 people around and outside the community to come together to celebrate and support persons living with Cerebral palsy, embrace diversity and to help create more accessible future for everyone without discrimination. UNAC and Capital Centre medical clinic joined the rest of 17 million people worldwide to ensure that voices of persons with Cerebral palsy are heard because every person living with cerebral palsy is a reason to strive for change.

Establishment of A Day-care centre for children with severe disabilities at St. Charles Lwanga primary school.



Head teacher Madam Namakula of St. Charles Lwanga Primary School addressing the community members and district leaders on the concern needs of children with disabilities in school, she requested more support for the development of the Day Care centre and encouraged Parents/caretakers to bring children with severe disabilities in the Day Care and Rehabilitation Centre. The gathering involved a fundraising opportunity to complete the Day- Care centre facility.

"I request fellow community members, local leaders to take action on sensitizing fathers of Children with disabilities that it's their roles and responsibilities to provide all necessary support needed by their children and should stop neglecting their families. I also encourage teachers and head teacher to admit children with disabilities, provide necessary support for all learners without discrimination. St. Charles Lwanga should be role model to all schools stakeholders in Mukono district". Says Annet Nakanwagye- Woman councilor persons with disabilities.

Case study: Sustainability of UNAC structure Associations.



UNAC handing her annual report 2020 and strengthening the collaboration of Munkunyu local leaders in Kasese district to provide adequate support to Munkunyu Association of persons with Cerebral palsy so that they can benefit from mainstream government program. (in the picture includes UNAC staff, CDO, Chairperson LCIII, Probation Officer, PWD woman Councilor and Parish Chief)

Commemoration of world Cerebral palsy awareness week and Cerebral palsy day.



Children with Cerebral palsy and their Parents/Caretakers in a group photo after having fun on the CEREBRAL PALSY day cerebration in Masaka district

Resource Mobilization for the completion of Day Care and Rehabilitation Centre for Children with Severe Disabilities at St. Charles Lwanga.



Clare Ainomugisha from Rose Academies speaking to the Congregation during the Christmas Party for Children with severe disabilities and fundraising function for the completion of the Day-Care and Rehabilitation Centre at St. Charles Lwanga Primary school Goma Sub-county Mukono district. And contributed 13 Bags of Cements.

Training the Parents/caretakers of children with cerebral palsy on Occupational Home Basics skills and Nutrition to improve well-being to their Children.



A parents is practicing the best feeding positioning during the training workshop as instructed by the trainer.

Improving the well-being of children with cerebral palsy

Natembo Brenda: Story.



Amidst of living with cerebral palsy, Brenda's life represents determination and brings lots of hope to her Mother (Kaitesi). Brenda is 6 years old who at one time had difficulties in communication, eating and drinking. She underwent several home basic occupational therapy exercises these includes communication skills (Speech therapy), eating and positioning exercises with support of UNAC field worker staff. And also her mother was trained same skills so that she can keep on practicing in order to improve the life of Brenda. "I can now easily communicate to Brenda, she can now try to feed and drink by herself. More so stretch her legs due to physio-exercise, she easily interact with her siblings and fellow community children. All these changes and life improvement both mentally and physically day-by-day continue to bring me lots of hope and happiness on Brenda. However Brenda still have difficulties in toileting". Says Kaitesi Lyn (Brenda's Mum, a resident of Goma zone in

Goma Division Mukono district.

How COVID-19 pandemic impacted her household income. In a shared conversion this is all she had to say, "Before COVID-19, I had a relatively income generated from tailoring and my Grocery with good number of customers to meet house needs like medical bills. However the outbreak of COVID-19 and Lockdown, the capital reduced with limited number of customers and much is spent on buying foods for the family. All in I need is some additional capital to boost in my Grocery business (Mudala) because it's only source of income with relative customers".

Case study: Kazungu George William Story (a beneficiary on Education support fund);



Kazungu's life represents determination even with education challenges. Living with cerebral palsy, George Kazungu is 18 years old and a student at Mary's High school Migadde a long Bombo Road in Wakiso district. He faced a number of challenges that many student with cerebral palsy under go through to achieve their education career dream and become productive members like any other Citizen in the Country, some of these includes; being beaten by teachers because of poor hand writing, no additional extra time given to them during examination periods accompanied by negative attitude by their teachers that persons with cerebral palsy they can't make it to be productive people in the society. All these violates their rights to education and a human right dignity. "I have been always beaten by teachers forcing me to write well and very fast like others during learning, to make matter worse during examination period our teachers do not provide me enough extra time. However I accepted all the challenges till to date and I would like to thank

Uganda National Association of cerebral palsy (UNAC) who had my outcry and came to meet school administration and lobbied me for a reasonable accommodation a head of my final senior four (S.4) examination on March 2021. Also not forgetting the tuition fees they are providing me through Katalemwa Cheshire Home. I hope to go for further studies after s.4." Says Kazungu very bright student and prepared to seat his final papers in March 2021 with resolving adding, "I am still health, and have nothing wrong in my brain."

Key gaps for future improvements in next programs

- ➤ Increase the capacities of resource mobilization and lobbying to obtain land for UNAC secretariat and its sustainability.
- Improve the well-being of children with severe disabilities in more practical daily life like engaging them in home basic occupational and nutritional therapy.
- ➤ The outbreak of Covid-19 Pandemic negatively affected the income status of most Parents/caregivers. For some sold their livelihood projects like pigs, poultry to meet hold needs (health, and food). There is need to lobby and resource mobilization to provide livelihood support to parents/caregivers of children with cerebral palsy.
- There is a need to build capacities of parents/caretakers in Child protection so that their rights are not abused in their respective communities and strengthen their capacities to access Sexual Reproductive Health and Rights as the away to reduce sexual abuse and sexual harassment.
- ➤ Involving fathers of children with disabilities in project activities. This will enable both parents to provide needed support and care.
- > Developing strategies for local fundraising and working with other networks in disability movement.
- ➤ Influencing the implementation of policies that promote participation of persons with cerebral palsy like in health, livelihoods and education services.
- > Organisation refresher trainings for staff in different courses to deliver quality work.
- ➤ Encouraging parents/caregivers contributes towards different projects like Day-care centre activities.
- > Strengthening sensitization and awareness raising about the concept of cerebral palsy both at national and local levels using different platforms.

Key major challenges faced by UNAC to meet the needs of her members.

- 1. UNAC has limited income support project for its sustainability due to the fact that it does not own land and premises for investments or to put in place income generating activities.
- Children did not access scholastic materials during the COVID-19 restrictions such as Partial and total lockdown and e-learning was not disability friendly. For example learning from Tv and Radio station
- 3. Parents/Caregivers are worried about Children missing medication and access to Rehabilitation services are expensive, and limited to Health centres IVs due to their reduced income status as the result of Covid-19 pandemic and being excluded in mainstream economic recovery programs.
- 4. Inadequate access to sexual reproductive health and Sexual rights. Youth with disability are at high risk of sexually abused and school dropout. And have limited access to sexual reproductive health and Sexual rights.
- 5. High expectation from parents/caretakers of persons Cerebral palsy 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.

Supporters and Partners

A big thank to our donors, supporters and Partners, who has always stood with UNAC, providing resources both in finance and any kind encouraging our initiatives, strengthening our objectives and helping us expand our reach. We are grateful for your generosity. This enabled us transform the lives of persons with cerebral palsy. These include; Spastiker, DHF, Disability Right fund (DRF), Lilian Fonds through Katalemwa Cheshire Home, UNAPD, Capital Medical Centre, St. Charles Lwanga Primary schools, Mukono District local leaders, Munkunyu Sub-county leaders, Community development Officers (CDOs) in our districts of operation, MADIPHA-in Masaka,

Future plans

- ➤ Completion of the Day-Care and Rehabilitation facility at St.Charles Lwanga primary school Goma division in Mukono districts.
- > Obtain the organisation land property
- ➤ Extend our services to other parts like Mubende, Gulu, Lira and Hoima depending on the availability of resources.
- > Strengthening the capacities of existing structure association in resource mobilization and self-advocacy in their respective communities.
- ➤ We hope to continue soliciting support through institutional fundraising, Building partnership and ascertain the effective implementation of programs.

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 Cerebral Palsy in the country.