



**COMMEMORATION OF WORLD INTERNATIONAL CEREBRAL PALSY (CP)-DAY  
REPORT HELD ON 12<sup>TH</sup>/10/2018 AT KYADONDO RUGBY GROUND KAMPALA.**



*Parents/caretakers of Persons with CP, Partners and other guests on the CP-Day*      *UNAC Executive Director gives Remark*

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## **1.0 Introduction:**

UNAC is non-government and an umbrella organization of persons with cerebral 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 mainstream NGOs programs.

**UNAC's Mission is** "Empowering persons with cerebral palsy to advocate for their rights through participation in sustainable development initiatives".

Cerebral palsy is a lifelong disability that affects movements and is often accompanied by speech, swallowing, cognitive, vision and hearing impairments. It is caused by an injury to the developing brain which occurs before, during or soon after birth. For most cases the cause is unknown.

Cerebral palsy is the most common physical disability in childhood and affects 17 million people globally and 350 million family members and caretakers.

As the umbrella organization of persons with cerebral palsy disability in Uganda, We joined the rest of the World and commemorated the international World cerebral palsy day on 12<sup>th</sup> October 2018 at Kyadondo Rugby ground Kampala under theme "**I AM Here.... We Are Here... Meaning "We move together, Inclusion now!"**"

## **1.1 Appreciation**

UNAC would like to appreciate the following Partners and stakeholders for the great contribution support towards our commemoration of world CP day. This include; Motivation Charitable trust, COMBRA, STEP-project, Coca cola Company, Spastiker and the media fraternity.

Over 250 people including; persons with cerebral palsy, parents/caretakers of persons with cerebral palsy, DPOs, Medical workers, Partners, CSOs, the Media fraternity and religious leader turned up for the Celebration of Cerebral palsy day for example persons with cerebral palsy were 80, 100 people were parents/caretakers of children with cerebral palsy and 70 people were other invited guests both from partners, media fraternity, CSOs and Government officials.

## **2.0 Purpose of the world CP-day celebration.**

The main aim of the event was to raise awareness on key concerns of persons living with cerebral palsy disability and show case their achievements and best

practices which will help to contribute to the creation of an environment that will allow them to enjoy productive lives.

## **2.1 Proceedings of the celebration.**

The commemoration started with registration of participants, Opening prayer, National Anthem followed with Buganda Anthem. Later hold a press conference with different journalist from Media house. Welcome remarks from Executive director of UNAC who later called the Chairperson with opening remarks as attached on this Report.

## **2.2 Special Remarks from invited guests.**

### **2.2.1 Commissioner for Elderly and Disability. (Mr. Musiga)**

The commissioner reorganised the presences of all protocols and parents of children with cerebral palsy. And told the gathering that people need to understand how to take care of children with cerebral palsy and know more about the truth information on cerebral palsy. For example it's us people with cerebral palsy to speak out ourselves because nobody else can speak for us. More so it's us people with cerebral palsy to talk about our issues as presented by UNAC chairperson. UNAC need to search for information for example chapter 4 in the constitution of Republic of Uganda talks about the existing framework of people's right. This is the legal instruments UNAC can use to lobby and advocate for the rights of people with cerebral palsy.

Furthermore on issue of poverty; the government of Uganda provides special grants for persons with disabilities. So are we members of sub county groups to inquire information on available grant opportunities such as Women Entrepreneurship Fund, livelihood fund, special grants for people with disabilities. And if we are not then lets join groups or form groups of persons with cerebral palsy and benefit from those grants.

The commissioner request the principal doctor from Ministry of Health and Disability (**Madam Barbra**) to take up the issue of assistive devise and ensure that assistive devises are tax free.

He encouraged parents of children with cerebral palsy groups to work together with sub county leaders to get funds for self-development. Parents of children with cerebral palsy should not separate themselves rather work together and mobilize other people with cerebral palsy to form groups and benefit from government funds. Also local sub county leaders need to be sensitized on different forms of disabilities like Cerebral palsy disability.

Finally the commission of elderly and gender is there in any matter and any support i.e some people with cerebral palsy like Stephen (Vice chairperson-

UNAC) are role models with respects to advocate for the need and rights of persons with cerebral palsy.

### **2.2.2 Equal opportunity Commission (EOC) presented by commissioner (Malole Hamidah)**

She recorganised the presence of UNAC Chairperson, members of UNAC staff and Development partners.

The commissioner shared a brief introduction about EOC as may include;

#### **Mandate of the EOC**

The EOC is a constitutional body established by the Equal opportunities Commission Act, No 2 of 2007 (EOC) “ to give effect to the state’s constitutional mandate to eliminate discrimination and inequalities against any individual or group of persons on ground of sex, age, race, colour, ethnic origin, tribe, birth, creed or region, health status, social or economic standing. Political opinion or disability, and take affirmation action in favour of groups marginalized on basis of gender, age, disability or any other reason created by history, tradition or custom for the purpose of redressing imbalances which exist against them; and to provide for other related matters”.

#### **Functions of the EOC**

The functions of the commission are spelt out under section 14 of the EOC Act, 2007. In brief there are: to monitor, evaluate and ensure that policies, laws, plans, programmes, activities, practices, traditions, cultures, usage and customs of organ of state at all levels, statutory bodies and agencies, public bodies and authorities, private businesses and enterprises, non-governmental organisations, and social and cultural communities, are compliant with equal opportunities for all and affirmative action taken in favour of groups marginalized on the basis of sex, age, age, race, colour, ethnic origin, tribe, birth, creed or religion, health status, social or economic standing, political opinion or disability, or any other reason created by history, tradition or custom. Therefore EOC is a government institution and act as Assessors of Planning and Budgeting of the government expenditure by government ministries and Departments.

Furthermore mentioned that the Government of Uganda put in place programs for Persons with disabilities, women, elderly, youth without jobs and this was passed in the parliaments. Therefore money to support Persons with disabilities is there. EOC ensure that every program provide accountability for persons with disabilities. Also she told the gathering that there is a quarter slot for persons with disabilities in each government development program. For example the Youth livelihood program provides a slot that each group must have persons with disabilities for it to qualify for the grant and therefore encourage persons with

cerebral palsy to join such group compositions in their communities or form groups at sub counties.



**Equal opportunity Commission (EOC) presented by commissioner (Malole Hamidah,** She emphasized that persons with cerebral palsy and their caretakers should not sit down and see things passing away to wrong beneficiaries. She called upon UNAC to work with EOC and bring out issues affecting persons with cerebral palsy because EOC have laws that support inclusion of persons with disabilities on financial budgeting and planning. And the government of Uganda has a good heart for changing lives of persons with disabilities.

Finally she has learnt a lot from persons with cerebral palsy disability and encouraged UNAC to keep increasing partnership with EOC and went ahead to appoint one of graduate person with cerebral palsy (**Mugisa Robert**) to be representative on executive committee of EOC for Planning and Budgeting.

### 3.0 methodology

1. Use of Banners, T-shirts, stickers and flyers printed with a theme messages of the celebration world CP day.
2. Assessment of Children with disabilities on the Cerebral palsy clinic by professional technical doctors and issuing wheel chairs.
3. Hold a press conference and Radio Talk about the demands for Persons with CP with different journalist from media house.
4. Mobilization and transporting persons with cerebral palsy and their parents/caretakers to commemorate their day.

### 4.0 Achievements of the celebration;



1. Good turn up of all invited people for the celebration of international world CP-day that is over 250 people.
2. Government representatives from different Ministries such as Health, Gender, labour and social Development and non-Government development actors such EOC are aware of issues affecting persons with cerebral palsy and their parents/caretakers including the best practices of breaking barriers for persons with CP to access services.
3. Recognition of international world CP-day by parents/caretakers and persons with cerebral palsy.
4. Increased partnership with different stakeholders to mainstream and support inclusion interventions for persons with CP in their programs.
5. Children with cerebral palsy received wheel chairs with support from Motivation Charitable trust.
6. Increased public awareness on the demand issue of person with cerebral palsy and visibility of UNAC activities.

## **5.0 Challenges**

Inadequate funds to mobilize UNAC members and support groups from all region of Uganda. For example Kasese groups, Mbale groups and Gulu group did not join the celebration of the world CP-day.

Some activities were not performed during the celebration like marching band in and surrounding communities of Kyadondo residences due to financial constraints.

## **6.0 Conclusion.**

Without different people UNAC can't achieve its objectives. Therefore UNAC acknowledge all its members, partners, representative from departmental government Ministries, different development actors and journalists from media houses with all your commitment to join us and celebrate world international CP-day. Therefore we encourage more of your contribution support in all kind of form to mainstream and support inclusion interventions for persons with Cerebral palsy.

## **Appendix**

### **1.0 Remark from UNAC Board chairperson**

#### **Ladies and Gentlemen.**

I greet you all on behalf of Uganda National Association of Cerebral Palsy (UNAC).

It is with great honor that I welcome the Chief Guest for honoring our function and all protocol observed. Thank you for coming and celebrate with us the world CP-day which is annually celebrated on 6<sup>th</sup>, October.

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.

UNAC is governed by the General Assembly, Board of Directors and Secretariat to ensure proper management and running of day to day organisation programs.

#### **Relevant achievements**

1. Due to the capacity building activities, members with cerebral palsy in the central, Eastern, western and Northern regions have been able to form support group structures and in total are ten (10). Leading to an increment in the number of people with cerebral palsy in the data base because of the regional mobilization and registration of new members which is done by the elected leaders in the regions and at the secretariat.
2. UNAC has been able to establish a better governance structure and relevant policies to ensure proper management of organisation.
3. Increased mobilization of persons with Cerebral palsy and their caretakers through sensitization programs on different Communities, Schools, TV and Radio talk shows.
4. Increased networking and partnership with different supportive agencies. This has enabled us to run activities of our organisation.
5. Increased Human Resource labour to run day to day programs of our organisation.

## **Challenges**

Despite the above achievements UNAC still faces a number of challenges of ensuring effective management of the organisation and ensuring the voices of persons with CP are effectively respected.

1. In Uganda the rights, responsibilities and potential needs of persons with cerebral palsy is still not recognised at national and local levels
2. In Uganda persons with cerebral palsy have found it hard to penetrate into employment opportunities due to severity of disability and negative attitudes by employers.
3. There is more demand on the issue of health improvement to children with cerebral palsy especially in areas of nutrition, Feeding the children, physiotherapy and psychosocial support.
4. There is increased number of children with Cerebral palsy school dropout due to lack of reasonable accommodation given to them. And most teachers need sensitization on the needs of children with cerebral palsy while at school.
5. Lack of supportive assistive devices like wheel chairs to support the mobility of persons with Cerebral palsy.
6. Most Medical personnel are not aware about handling and treatment of persons with cerebral palsy.



7. Expensive treatment services for persons with cerebral palsy that is physiotherapy and drugs in hospitals.
8. Person with cerebral palsy are among the people who live under the poverty line at grass root and isolated in economic development activities in Uganda.
9. Inadequate resource to strengthen the work of secretariat towards improving the livelihood of persons with cerebral palsy at national and regional levels.

UNAC humbly request;

1. Strengthen public awareness on cerebral palsy (CP) so as to end ignorance, stigma and discrimination among people with cerebral palsy
2. Ensure the government provide Rehabilitative support for children with cerebral palsy to have a meaningful life like any other citizen.
3. Ensuring that government officials at the local regional and national level move beyond passing proclamations and take concrete action to promote and protect our rights and opportunities.
4. Provide free and early diagnosis and prevention of early diseases that contribute to the severity of cerebral palsy.
5. Provide relevant information to parents/guardians of children with Cerebral palsy where to seek the subsidized or free medical services such as; physiotherapy, occupational therapy, drugs, and assistive devices.
6. Ensure all schools are inclusive for learners with cerebral palsy to access reasonable accommodation using appropriate policies that promote inclusive education at all levels.
7. Engage families, persons with Cerebral palsy in all poverty eradication programs as citizens of Uganda.
8. Recognition of the world Cerebral palsy day by the ministry of Gender labour and Social Development.
9. Invest in research on Cerebral Palsy so as to have sufficient data for appropriate planning and intervention.

We earnestly appreciate the following partners who have been of great support in running our organisation programs. These include DRF, Abilis, and Motivation Charitable trust, COMBRA, STEP-project, Coca cola and Spastiker for committed generous contribution towards the success of this celebration.



**Mr. Kalule Rashid**

## 2.0 Photo Gallery of Celebration





*Parents, children and persons with CP breaking dance on the CP-day.*





Parents, UNAC staff, Board and our Partner Motivation with some Children who got wheel chairs during CP-Day.



Parents and children with CP enjoying a prepared lunch on the CP-day.