

UPDATE

UNAPD

A bi-monthly newsletter for Uganda National Action on Physical Disability

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Mary Nabifo, a former employee of UNAPD at her wedding with Dickens Miramago. They tied the knot at the Appointed Harvester's Church (Rubaga Road) and hosted their guests at a reception at St. Matia Mulumba, on October 11, 2009. Another UNAPD staff, Apollo Mukasa, was also introduced by his fiancée, Beatrice, on October 4. See photos on pg5.

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**ED Meldah
Tumukunde**

We have almost come to the end of the year 2009. Thanks to the partners, members and stakeholders whom we have worked with. It has been a challenging year but we have been able to go through it because of your support and commitment.

The year has also had a lot of opportunities that we have endeavoured to exploit for the benefit of our organisation and membership. I hope we shall continue with this cooperation even in the New Year.

I thank members who have answered our call of registering with UNAPD in your respective district associations as individual members. Particular thanks go to the district associations that have registered more than the required minimum number of 50 members. I once again remind you that membership registration is a continuous exercise and you should not stop after registering the required minimum number. The more members you register the bigger and stronger your district association and UNAPD will be.

Registration of individual members is a condition for any district association to qualify to be a full member and be able to benefit from UNAPD programmes.

In the month of November, UNAPD hosted Ole Ansbjerg and Lene Van der Keur from the Danish Sports Organisation for the Disabled who visited Uganda/UNAPD to learn about the involvement of persons with physical disabilities in sports activities. Sports is one of the areas where persons with disabilities have not actively been participating, yet they equally enjoy the games and can play like the able-bodied. A few people even in the sports field are aware that PWDs can participate in most of the sports activities and greatly contribute to the development of the game.

During their two days stay, several issues were discussed including the possibility of a partnership project on sports. They were very impressed with the discussions and promised to consider partnering with UNAPD. Ole and Lene were also excited when they watched two teams (for males and females) of sitting volleyball playing at UNAPD headquarters.

Last but not least, the disability fraternity will converge in Luwero on December 3, 2009, to celebrate the International Day of Persons with Disabilities (PWDs). UNAPD has been preparing for this day and will actively participate in the celebrations. I wish all our members good celebrations.

I wish you a Merry Christmas and Happy New Year.

EDITORIAL

IDD; time to reflect on disability concerns

On December 3, the disability fraternity will flock to Luwero District, to celebrate the International Day for Persons with Disabilities (IDD). The annual observance of IDD, aims to promote an understanding of disability issues, the rights of persons with disabilities and gains to be derived from the integration of persons with disabilities in every aspect of the political, social, economic and cultural life of their communities.

The day provides an opportunity to all persons with disabilities in Uganda, to mobilize action to achieve the common goal of full and equal enjoyment of human rights and participation in society by persons with disabilities.

The day's theme; "Making the MDGs Inclusive: Empowerment of persons with disabilities and their communities around the world", blends well with the international PWDs quest to fully and equally enjoy human rights. All efforts of Disabled Peoples Organisations should be geared at making sure that relevant players in Uganda's development appreciate that without mainstreaming of PWDs in all society's activities, no single Millennium Development Goal (MDG) may be achieved.

The MDGs are goals to be achieved by 2015 that respond to the world's main development challenges. They were drawn from the actions and targets contained in the Millennium Declaration that was adopted by 189 nations during the UN Millennium Summit in September 2000.

The eight MDGs are: eradicate extreme poverty and hunger; achieve universal primary education; promote gender equality and empower women; reduce child mortality; improve maternal health; combat HIV/AIDS, malaria and other diseases; ensure environmental sustainability; and develop a Global Partnership for Development.

80% of PWDs (400million people out of 650) live in poor countries like Uganda where there is a strong link between disability and poverty. Today for instance, statistics on PWDs employment are really appalling. In developing countries, 80-90% of PWDs of working age are not employed. PWDs rights to education and health are also routinely denied. 90% of children with disabilities in developing countries do not attend school, says UNESCO. Approximately 20 million women acquire disabilities as a result of complications during or at birth.

These statistics highlight the need for all states to design special interventions to combat extreme poverty, HIV/AIDS, illiteracy, death (some parents still kill children born with disabilities), gender equality, among PWDs. If this is not done the respective MDGs will never be achieved. This will be a huge shame to Uganda.

UNAPD wishes you good IDD celebrations, a good festive season and a prosperous New Year 2010. We hope that we shall continue to enjoy the good relationship like we had in the year 2009.

Best wishes for happy IDD celebrations



Hon. James Mwandha
Chairman UNAPD

This issue of Update is coming out close to the International Day of Persons with Disabilities, December 3, 2009, which aims to promote an understanding of disability

issues, the rights of persons with disabilities and gains to be derived from the integration of persons with disabilities in every aspect of the political, social, economic and cultural life of their communities. The day provides an opportunity to mobilize action to achieve the goal of full and equal enjoyment of human rights and participation in society by persons with disabilities.

In Uganda, the disability fraternity has used the whole month of November to December 3, to raise awareness of the public about disability issues and the need to mobilize action to achieve full inclusion in the Millennium Development Goals (MDGs) in line with this year's theme.

The coordinators of the activities for the disability month have done a commendable job, and should be appreciated. UNAPD has played an active part in the programme as it has always done in the past. Member associations of UNAPD are called upon to turn up in big numbers

at the national celebration venue in Luwero.

Our Accessibility Project is progressing quite well and we would like, all being well, to launch the Accessibility Standards before the end of the year. We are also working very hard with support of the Department for Disability of the Ministry of Gender to popularise the standards within government and we may be able to get them adopted in the Building Control Bill.

The exercise for registering members is their respective associations is progressing very well. So far 17 districts have registered the minimum number of 50 members and in many cases beyond that number. Thirteen district associations have not yet reached the minimum number of 50 and there are others who are registering but have not yet informed us of the progress they are making. We, in any case,

would like to hold a General Assembly when we have at least 20 registered member district associations.

The Labour Market Project has finally taken off. A Project Officer and an Assistant have been appointed. They have approached some employers and sensitised them about employment of disabled persons. They have also advertised calling unemployed disabled persons with qualifications to register with them to enable them to build a databank which they will use to negotiate with employers. I call upon disabled persons with qualifications to take advantage of this project and register.

I wish to take this opportunity to thank our partners for the support we are getting in serving our members. All these achievements would not have been realised without their support.



Some of UNAPD members, staff and Board, in front of UNAPD's stall at last year's IDD celebrations in Mbarara District. UNAPD members are urged to come to Luwero in big numbers for this year's celebrations as they have always done.

READERS' PLATFORM

Send your views, letters or comments to the Editor, UNAPD Update, P.O Box 959, Kampala, Email: unapd@utlonline.co.ug

Improving living conditions of Person with Disabilities

BY IRENE NABALAMBA

If a person gave birth to a Child with Disability (CWD) in Uganda, they live to regret because the parent/parents will have to single-handedly meet all the child's needs. First, in many cases, the father may abandon or disown the child in the pretext of 'we don't produce disabled children in our family'. The Government that is supposed to take care of all its citizens, in most cases, doesn't have special interventions for CWDs.

Many parents of children born or living with disabilities struggle to bring them up. They incur the cost of their education (special needs education), health (surgery, physiotherapy, rehabilitation, routine medical checkups, disease treatment, mobility appliance/aids their repair and maintenance), and transportation by public means as many do not own cars. In public transport, a CWD may pay three times as much as the able-bodied child. That is for him/herself, helper and for the movement aids like a wheel chair.

Parents become helpers/personal assistants to their CWDs because they cannot afford to hire paid labour. This means that the economic productivity of the family is limited as most time is spent taking care of this child mostly by the mothers. If they were working, they may have to resign from their jobs to take care of the child's numerous and peculiar needs.

The Government does not help out with most of the above costs. Non-Government Organizations (NGOs) have done a great job to help people, children and parents of children with disabilities but there are still many of those who are not reached. No wonder the stigma attached to giving birth to a child with a disability, or living with a disability is high. This is because of the immense challenges associated with it.

When you look at other countries, for example Denmark, the situation is different. A Person with Disability (PWDs) is provided with helpers/personal assistants up to four or more, depending on

the kind of disability. Their costs are met by the Government. PWDs are given free mobility aids and assistive devices like electric wheel chairs, salary/pension every month in case they are not working, and helped to secure cars and houses modified to suit their disability. Education and health costs are also paid by the Government. This is more or less the same case in a couple of other countries.

One can rightly say that you cannot compare Uganda to Denmark. Yes, I agree! However, given the kind of support other governments give to their PWDs, the Ugandan Government with its meager resources, could also do what it can in its own context. For now, Uganda can start small by providing a wheel chair, walking stick, calipers or crutches to every child with disability who needs them. Government can also afford to extend free health care and rehabilitation services to every PWD. Cars, houses, salaries, etc, may be beyond our Government's reach right now. It's the duty of Government to take care of its vulnerable people and to protect them and their property, but the Government has apparently 'delegated' this role to NGOs. Reversals of duties, isn't it?!

It is very common to find PWDs crawling on the streets of Kampala and other districts because they cannot afford to have a wheel chair. Crawling - for example crawling into toilets - has many challenges and health implications. This makes one really wonder if the vulnerable members of society are cared for in Uganda. At a minimum cost of 200,000/= - depending on the type - the cost of a

wheel chair is so high that most PWDs cannot afford. Other assistive devices are also quite expensive. If many able-bodied men cannot afford to buy a second-hand bicycle of 50,000/= in their life time, what about a PWD managing to buy a wheel chair.

Government has to be active in taking care of people with disabilities. The proposed monthly pension/allowance to PWDs is a good start in the right direction, which should be implemented very soon, because it has been long over due. Parents of children with disabilities should be helped to raise them with dignity. In the past, assistive devices were free in Mulago Hospital, but it is no longer the case now.

At the start, Government, through its departments and ministries, should establish the exact number of PWDs including CWDs and their respective needs. These statistics can help to plan service delivery and on how best PWDs can be helped individually. Furthermore, Government should intensify measures to prevent new cases of disabilities because the number of PWDs now is already overwhelming.

The writer is a PR and Program Development Officer at CoRSU Rehabilitation Hospital, Kisubi



UNAPD occasionally gives out mobility devices to her members. Government has abandoned some of its duties like helping the vulnerable people to NGOs.



Apollo Mukasa, Programme Officer Accessibility Project was introduced by Beatrice Nassali on October 4. Rights are some of Mukasa's friends and fellow UNAPD staff, who accompanied him to Beatrice parent's home in Bukuya, Mityana.



UNAPD's former staff Mary Nabifo and husband Dickens Miramago. Also see another photo on Pg 1.



Polio survivors pose for a group photo after a training on Post-Polio Syndrome (PPS) and its management.

Happy New Year 2010

UNAPD wishes all her members, partners and stakeholders a Merry Christmas and a prosperous New Year. We are very grateful for all the support and cooperation you have given to us this year and wish for the same in the year 2010.

We also wish to inform you that we shall break-off for the festive season on Friday, December 18, 2009 and re-open on Monday, January 11, 2010. Have a blessed festive season.

In the last four editions, we looked at Polio, Cerebral Palsy, Club Foot, Birth Defects, Hip Problems, Dwarfism, Spinal Cord Injury, types of common physical disabilities. We also looked at Spinal Bifida, Elephantiasis, Muscular Dystrophy and Muscular Sclerosis, a slow disabling condition.

Rheumatic Arthritis; a peculiar

WHAT IS RHEUMATIC ARTHRITIS?

This is a serious disease marked with fever and pain in muscles and joints that usually results into disfiguring or deformities of the hands. Rheumatic Arthritis is an inflammation in the body that primarily affects joints. It is sometimes called the disease of the joints. When it is so severe, Rheumatic Arthritis can deform every joint in the body, damage muscles, skin and other organs like the heart, liver and kidney.

The condition affects women more than men. Normally, it begins in early middle age, although sometimes it occurs earlier, like during childhood. Rheumatic Arthritis affects everyone differently. The nature and magnitude of pain may vary each day. Rheumatic Arthritis is not easy to diagnose; it is more often confused with sickle cell disease especially when it starts during childhood.

CAUSES

Although Rheumatic Arthritis attacks and destroys the joints leading to deformities, its causes are not known. It's thought that Rheumatic Arthritis is preceded by a viral infection mainly Parvovirus B. though some times it can be in the family. That is, genetic

PREVALENCE

Rheumatic Arthritis is one of the greatest causes of disability. The pain and disability caused by this disease leads to great suffering. According to international statistics, one out of every 100 people has Rheumatic Arthritis. Out of Uganda's population of about 30 million people, 300,000 are believed to be affected by this condition. 40 people living with Rheumatic Arthritis including 10 new and 30 continuing ones visit the Rheumatology Clinic in Mulago Hospital every Friday.

SIGNS AND SYMPTOMS

- Affects joints symmetrically. That is both the right and left side of the body. The condition can affect different joints most often joints in fingers, hands and knees.
- Pain in the joints or a visible swelling

which makes the joint feel sensitive and painful to touch. If not treated, this may result into deformed joints or disfiguring of the body.

- Stiffness of the joints (fingers, elbows and knees) when the person affected spends a long period of time without stretching or moving the joints. It normally occurs upon waking up in the morning, making joints unable to perform some of the activities of daily living like brushing, dressing etc.
- The inflammation of the body can cause excessive fatigue and other generalized symptoms such as fever or loss of weight.
- Though it affects people differently, some people living with Rheumatic Arthritis notice a gradual onset of symptoms with problems beginning in the fingers, wrists, feet or other small joints. Over the years, the condition can progress to larger joints such as the hips, elbows or shoulders. In other people, however, the condition can worsen more quickly.
- Symptoms can ease or go during which pain and swelling lessens or even disappear. This can be as a result of successful medication or simply for no reason whatsoever.
- It can also affect the entire body causing problems that go beyond joint pain. For example, inflammation can affect: the mouth or throat, causing difficulty in speaking; the lungs, causing difficulty in breathing; or the heart tissue, causing pain in the chest or heart failure.

NOTE: Every person living with Rheumatic Arthritis may not experience all these signs, and the severity may vary from one persons to another.

TREATMENT

There is no cure for Rheumatic Arthritis and the current treatment is intended to keep the disease under control. Treatment is designed to reduce pain and inflammation, maintain the motion and strengthen the joints, and halt the damage to the bones and cartilage. This is important because the longer the disease exists, the greater the



Some of the members of UNAPD Rheumatism Club. L-R Arthur Jjunju, Immaculate Ssemwogerere

joints become more damaged.

- Use of common pain killers, helps to reduce the pain and swelling. They include panadol, ibuprofen, diclofenac, indocid. These are available but they are not enough to manage the disease.
- Other drugs include use of steroids such as prednisone (has many side effects), antimalarials like hydroxyl chloroquine, gold salts, methotrexate, sulphasalazine.
- Regular participation in exercise and sports is becoming ever more popular to reduce pain, relaxation, enjoyment, fitness and general health benefits. This is true for everyone in the community whether or not they have rheumatic arthritis. In general, exercise like stretching helps to increase mobility of joints and muscles, and keep them healthy and in good working order. Heat or warm baths can offer short-term, temporary relief of pain and stiffness. Heat also helps relax aching muscles. Wrap a piece of cloth soaked in warm water around the affected joints to relieve pain and joint stiffness. However,

Cord Injury, Spinal Curve and other Back Deformities, Amputees, Leprosy, Burns and Burn Deformities among other Ar Atrophy, Juvenile Arthritis and Born Infection. In this edition, we look at the last physical disability: Rheumatic Arthri-

Ar type of physical disability



ism Wing Steering Committee: Nere, Irene Nabifuge and Godfrey Agono.

- Keep away from cold conditions to avoid stiffness of joints. You should also keep wearing warm clothes. Cover the legs and hands in a warm cloth.
- Stop smoking. Smoking increases the risk of arthritis. It is, therefore, advisable for people to keep away from the deadly habit.
- Take all medications prescribed by your doctor.
- Give your doctor a complete medical history including all recent illnesses and medical forms. This enables your doctor to choose a treatment plan which works best for you.
- Find a support group of other people living with Rheumatic Arthritis. By doing so, you receive emotional support from others in a similar situation and can share and increase your own knowledge-base about coping with Rheumatic Arthritis.
- Absence of medical facilities and trained medical workers to handle the disease. There is only one Rheumatology Clinic in the country at Mulago Hospital. The clinic operates once a week on Fridays. The clinic and Uganda has only one trained doctor (Rheumatologist).
- Very little is known about Rheumatic Arthritis by health practitioners and people living with it themselves.
- Drugs to relieve pain are not recognised by Government as essential drugs, and therefore, are neither subsidised nor available in district hospitals.
- Limited opportunities for people living with Rheumatic Arthritis to participate in income-generating activities, yet they require a lot of money for medication.
- Misconceptions. Since the disease presents with different signs, it is often confused with many other complications. Sometimes people living with Rheumatic Arthritis present with acute chest complications, fever, and chest pain, difficult breathing, just like persons living with sickle cell. Some people think people living with Rheumatic Arthritis are bewitched and therefore go to traditional healers.

HOW RHEUMATIC ARTHRITIS BECOMES A PHYSICAL DISABILITY

Once the disease sets in, a patient stays in continuous pain and keeps on drugs in order to reduce pain. Nevertheless, the disease can cause joint stiffness (unable to fold) in the fingers, legs and hands, hence deforming the patient. This makes activities of daily living difficult or impossible. This leads to physical disability as it affects the patient's posture and limits their movement. Many people living with Rheumatic Arthritis use walking sticks, clutches or are confined into wheel chairs.

MAJOR CHALLENGES IN UGANDA

- The drugs dilemma. At about \$200 (400,000/=) per dose for one month, most of the effective drugs are so expensive. There are drugs such as hydroxychloroquine, sulphasalazine, leflunomide and others which cost about 35,000/= per dose, per month, but they are not very effective when used alone.
- Dependence on medicine comes with side effect such as ulcers, dizziness, low blood hemoglobin among other complications. Consult the doctor in case you get complications.

WHERE TO SEEK MEDICAL HELP

In Uganda, Rheumatic Arthritis is managed under National Referral and Teaching Hospital, Mulago, where there is a Rheumatology Clinic and a specialized doctor. On the 2nd week of every month, people living with Rheumatic Arthritis are counseled and trained in management of the condition. About 40 people living with Rheumatic Arthritis visit the clinic every Friday.

The clinic is located on 4th floor, Medical Out Patient Department, Mulago. Although there is no cure, great progress has been made in treating the disease. People who would have been bedridden are able to live a more active and fulfilling life if they use the available modern, drugs and attend counseling sessions. With early diagnosis and proper treatment, Rheumatic Arthritis can be kept under control.

don't use heat for longer than 15-20 minutes each time. Let your skin return to normal temperature before using it again.

- Surgery is the final option where a joint is badly damaged and very painful. See medical doctor for proper diagnosis, care and treatment.

CHANGE LIFE STYLE

- Counseling. Since the disease is for a lifetime, people living with Rheumatic Arthritis should be constantly counseled about dealing and living with it without resentment. Always have a positive attitude. Try to live a normal life and participate in social activities and relationships. Psychological counseling helps people living with Rheumatic Arthritis and their families to cope with the disease.
- Eat a balanced diet and take a lot of water, fruits and vegetables. Eat white meat such as chicken and fish. Malnutrition complicates Rheumatic Arthritis symptoms. Omega 3(fish oil) and egg shell supplements are highly recommended.

UNAPD MISSION: To remove barriers in society that prevent people with physical disabilities from enjoying full rights on an equal basis with other citizens.

UNAPD members start to realise benefits of trust

BY APOLLO MUKASA

Through the Capacity Building and Accessibility Project, UNAPD members in eight project districts have received funds to strengthen their leadership and carry out activities aimed at improving accessibility in their areas. The project districts include; Wakiso, Kampala, Hoima, Masindi, Nebbi, Yumbe, Kapchorwa and Soroti. Each district has an established UNAPD district association and five sub-county associations through which the project is implemented.

The Trust Fund has two main objectives: to support the associations to get established based on democratic procedures; and to facilitate the associations to carry out advocacy activities to improve accessibility in the districts.

The associations started receiving the trust fund in January 2008 to implement various activities that have resulted into several achievements as of October, 2009. Below we look at the achievements categorised under: physical accessibility, democratic governance, membership registration, and external support received by the associations from January 2008.

1. WAKISO DISTRICT

Wakiso Action on Physical Disability (WAPD) is the name of the district association. The sub-county associations are: Wakiso Town Council Action on Physical Disability, Wakiso Sub-County Action on Physical Disability, Nansana Kansimbe Akaggo Persons with Physical Disability Society, Masulita Sub-County Action on Physical Disability and Kakiri Sub-County Action on Physical Disability.

Physical accessibility

Advocacy by the respective associations in Wakiso District has resulted into 23 newly constructed ramps and 1 PWDs latrine: 7 ramps in Wakiso Town Council; 4 ramps in Wakiso Sub-County; 2 ramps in Nansana Town Council; 9 ramps in Masulita Sub-County; 1 ramp and 1 PWDs latrine in Kakiri Sub-County.

Democratic governance

The district association and all the five sub-county associations have held their General Assemblies and democratically elected their respective executives.

Membership registration

170 individual members have been registered from the five sub-counties.

PWD councilors

Wakiso District and sub-county associations have 9 members who are PWD Councilors at various levels in the project area.

External Support towards

The associations have so far received 650,000/= and 38 wheelchairs from various partners in Wakiso District since January, 2008.

2. HOIMA DISTRICT

Hoima Persons with Physical Disability Association (HOPDA) is the district association, with five sub-county associations in Hoima Town Council, Kitoba, Bugambe, Kigorobya, and Buhimba sub-counties.

Physical accessibility

Eighteen ramps have been constructed in the district out of the members' advocacy since January, 2008: 2 ramps at district level, 1 in Bugambe Sub-County, 2 in Kigorobya Town Council, 3 in Kitoba Sub-County, 5 in Buhimba Sub-County, and 5 in Hoima Town Council.

Democratic governance

The district association and three sub-county associations (Hoima Town Council, Kitoba and Kigorobya Sub-Counties) out of five have held their General Assemblies.

Membership registration

53 members have been registered from the five sub-counties.

PWD councilors

Hoima has a total of 5 members who are PWD councilors at district level and in the five sub-counties.

External support

The district has so far received 16 wheelchairs, 6 tricycles and 1 pair of crutches since January, 2008.

3. NEBBI DISTRICT

Nebbi Association for Physical Disabled (NAPD) is the name of the district association with five sub-county associations namely; Nebbi, Paidha and Packwach town councils, and Panyimur and Parombo sub-counties.

Physical Accessibility

Nebbi District has record 72 ramps widely spread in different public places. This great achievement is attributed to a declaration made by the Mayor of Nebbi Town Council in 2007, to close all public places which were not accessible to PWDs. This followed an Accessibility Auditing exercise in Nebbi done in November, 2007 by UNAPD, supported by the project. The activity was carried out in conjunction with Nebbi District Union in preparation for the International Day of Persons with Disability celebrations. Service providers hurried to make their places accessible to avoid closing of their premises.

44 ramps are in Nebbi Town Council alone, 14 in Packwach Town Council, 2 in Panyimur Sub-County, 4 in Parombo Sub-County, 8 in Paidha Town Council.

Democratic Governance

The district and 3 sub-county associations (Paidha, Panyimur and Parombo) have received funds to hold their General Assembly before the end of November, 2009.

Membership registration

50 members have been registered in the project area.

PWDs councilors

Nine members of the executives from the project area are PWD councilors since January, 2008.

External support

The district and sub-county associations have received 720,000/=, 6 tri-cycles and 9 wheelchairs from different partners since January, 2008.

Trust fund through intensified advocacy activities

4. MASINDI DISTRICT

Masindi District Association of Physical Disability is the district association, under which are five sub-county associations, including Masindi Town Council, Karujubu, Nyangahya, Kimengo and Bwijanga sub-counties.

Physical Accessibility

Six ramps, 2 toilets and 1 latrine for PWDs have been constructed. However, the latrine and toilet were not constructed according to the required standard.

3 ramps at the district level, 3 in Masindi Town Council, 1 toilet at the district headquarters, 1 toilet in Masindi Town Council, and 1 latrine in Nyangahya Sub-County.

Democratic governance

The district association and three sub-county associations (Masindi Town Council, Karujubu and Nyangahya sub-counties) have held their General Assemblies.

Membership registration

72 members have been registered from the five sub-counties.

PWDs councilors

Masindi has 3 members who are PWD councilors at district and in the five project sub-counties.

External support

Masindi associations have received 300,000/= and 9 wheelchairs from external sources since January, 2008.

7. KAMPALA DISTRICT

Kampala District Association of Physically Disabled Persons is the umbrella association, with associations in all five divisions, namely; Kampala Central, Nakawa, Kawempe, Rubaga and Makindye. The associations have all held their general assemblies, and therefore, are run by democratically elected executives.

The district has registered 132 members. However, it has not yet carried out advocacy activities on accessibility, because none of the associations has received trust funds for this activity.

5. KAPCHORWA DISTRICT

Kapchorwa District Association of Physical Disability (KADAPD) is at district level, with five sub-county associations. Their efforts have resulted into construction of 9 new ramps since January, 2008. The project is implemented in Kapchorwa Town Council, Tegeres Sub-County, Kaserem Sub-County, Kaproron Sub-County, and Cheema Sub-County.

Physical accessibility

2 ramps in Kapchorwa Town Council, 3 ramps in Tegeres Sub-County, 1 ramp in Kaserem Sub-County, and 3 ramps in Kaproron Sub-County.

Democratic governance

The district and all the five sub-

county associations have held their General Assemblies and currently run on democratic principles.

Membership registration

The district association has submitted 50 fully registered members from the five project sub-counties to UNAPD Headquarters.

PWD councilors

There are 9 members who are PWD councilors at the district and in the five sub-counties.

External support

The district and sub-county associations have so far received 14 wheelchairs, 15 pairs of crutches and 6 walking sticks in form of donations from various partners since January, 2008.

8. SOROTI DISTRICT

Soroti District Action on Physical Disability (SODAPD) is at district level in Eastern Uganda and an umbrella of five sub-county associations. That is, Soroti Sub-County, Attira Sub-County, Asuret Sub-County, Kamuda Sub-County and Western Division Sub-County.

Physical accessibility. 6 ramps have been constructed out of advocacy activities by members since January, 2008. 1 ramp at the District Headquarters (CAO's Office), 2 ramps in Soroti Sub-County, 1 ramp in Attira Sub-County, and 2 ramps in Asuret Sub-County.

Democratic governance

The umbrella district association and two sub-county associations (Soroti Sub-County Action on Physical Disability and Attira Sub-County Association of Physical Disability) have held their General Assemblies.

Membership registration

72 members have been registered from the five sub-counties.

PWD councilors

There are 3 members who are PWD councilors in the five sub-counties and at the district.

External support

The district and sub-county associations have so far received 157 wheelchairs from different partners as donations since January, 2008.

6. YUMBE

Yumbe District Association of Physically Handicapped (YUDAPH) is the umbrella association in the district, with Yumbe Town Council, APO, Odravu, Kuru and Midigo sub-county associations under it.

Physical Accessibility

10 new ramps have been constructed in Yumbe in the various project sub-counties. 5 in Yumbe Town Council, 2 in Midigo, 1 in Kuru, 1 in APO and 1 ramp in Odravu sub-counties.

Democratic governance

The district and four sub-county associations have held their General Assemblies, except Kuru sub-county.

Membership registration

84 members from the project area have been registered.

PWD councilors

Yumbe District has 5 UNAPD members, who are PWD Councilors since January, 2008.

External support

The district has received 4 wheelchairs from different partners since January, 2008.

How UNAPD is implementing the Convention

On October 29, 2009, the National Council for Disability organised a stakeholders' meeting, where representatives of Government ministries and Disabled People's Organisations (DPOs) attended, and shared information about how each is implementing the UN Convention on the Rights of Persons with Disabilities. Below is an excerpt of what Hamad Lubwama presented on behalf of UNAPD, highlighting what UNAPD is doing in regard to specific key articles in the Convention.

Article 6: Women with disabilities

UNAPD has supported the development of a Youth Wing (comprising of youth with physical disabilities) and Women's Wing (comprising of women with physical disabilities) within the organization. The Wings' members have been trained into leadership, peer counseling, HIV/AIDS, communication skills, advocacy skills, etc. This is aimed at building their capacity in self-governance, advocating for their concerns, actively participate in UNAPD activities, and to take on leadership positions within UNAPD and in their localities.

Article 7: Children with disabilities

Early this year, UNAPD carried out an accessibility survey in nine schools in Wakiso District, to assess how far CWDs can access school facilities. One out of the nine schools was found to be fairly accessible. The findings of the survey were shared with the district leadership that committed itself to implement the recommendations of the study. UNAPD strives to make sure that Children with Physical Disabilities access all services like other children.

Article 8: Awareness-raising

UNAPD is raising awareness about disability and the Convention. Through the Disability Rights Awareness Project, UN-

APD has sensitized local government and services providers in Rakai and Ntungamo districts about the Convention. UNAPD members are being supported with a trust fund to independently implement advocacy activities.

Article 9: Accessibility

UNAPD took the lead in the development of Accessibility Standards that guide stakeholders in the construction industry, to construct accessible facilities. The document, developed together with line ministries, stakeholders and partners, will be launched this year. UNAPD is working with relevant Government bodies to make sure that the Accessibility Standards are annexed to the Building Control Bill. UNAPD is also implementing a project aimed at promoting accessibility in eight districts of Uganda; namely Kampala, Wakiso, Hoima, Masindi, Soroti, Kapchorwa, Nebbi and Yumbe.

Article 19: Living independently and being included in the community

Article 19, Article 20 (personal mobility), Article 26 (habilitation and rehabilitation) and Article 9 (Accessibility) are implemented in unison by UNAPD. The organization advocates for provision of community-based services and provision of quality mobility devices at an affordable cost to PWDs. We also advocate for an environment that allows persons with physical disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. With the availability of assistive devices, an accessible physical environment, accessible services, and rehabilitation services, persons with physical disabilities are able to live independently and participate in all society's activities. UNAPD secures from some partners, assistive devices for some

members.

Article 25: Health

UNAPD has participated in many activities to promote immunization against polio to prevent new polio infections. We also help Persons with Cerebral Palsy and Acquired Brain Injury to live a better life through counseling, physiotherapy services, provision of medicine (in conjunction with Butabika Hospital) and linking people with these conditions to other hospitals and rehabilitation centers. UNAPD has also led to the revival of the Rheumatology Clinic in Mulago Hospital, where Persons with Rheumatic Arthritis are attended to. Concept papers to Parliament and Ministry of Health have been written, petitioning for availability of medicines to help in the management of these conditions in Health Center Ills and IVs.

Article 27: Work and employment

Through the Labour Market Project (has just started) UNAPD seeks to increase the employability of persons with disabilities and to make sure that they are gainfully employed. A Labour Market Desk has been established, where PWDs seeking employment register, and where employers will come for potential workers.

Conclusion:

One of the main challenge faced so far during the implementation of the Convention is that service providers and local governments always complain of not having funds to put in place the need of PWDs. Efforts have to be made to draw their attention to the CRPD's notion of Reasonable Accommodation, Progressive Realisation and the strategies for effective use of limited resources (target low-cost programmes, and to target people in most marginalized situations.



Uganda National Action on Physical Disability (UNAPD)

Employment of Persons with Disability

Are you a qualified and committed Persons with Disability (PWD) seeking employment?

UNAPD is implementing a Labour Market Project, through which PWDs with various qualifications are linked to potential employers. On every Thursday of the week (9am-3pm), project officers are available to provide information on employment opportunities and provide newspapers for employment news. They also provide PWDs with job-searching skills, to facilitate entry of PWDs into the labour force. Please bring your CV to UNAPD, Kanyanya, Gayaza Road, P.O Box 959, Kampala. PWDs have the ability to work like any other person.

Contact UNAPD Tel: 041 456 7541, Email: unapd@utlonline, or Project Officer Tel. 0779184472, peacequinnlaura@yahoo.co.uk

UNAPD VISION: A society where people with physical disabilities are accorded rights enjoyed by all citizens

BY ALICE KUTYAMUKAMA



Alice K.
Ass. P.O. UBISP

I am on my routine visits of children with Cerebral Palsy and Acquired Brain Injury, to offer counseling and guidance to parents of children suffering from these conditions. I also perform exercises to the children and on-spot training

of parents about how to take good care of these children for them to grow into productive citizens. I am in company of Faizo Njuki, a community volunteer in Wabigalo Parish, Church Zone, Makindye Division, and Godfrey Basoita, Programme Officer, Uganda Brain Injury Support Project (UBISP).

There is total silence at Joshua Wamono's place. His parents' house is closed. We call out at the neighbours, to ask for the whereabouts of the family. "The wife went for a funeral and the husband is nearby," a lady responds. "Where is Wamono," we ask, before she opens his parents' house. I start panting at the sight of Wamono. "I am I dreaming, or I have become visually impaired?" I ask my self in a wild rush of questions, at seeing a very handsome boy tied on a rope like a goat. I turn to my colleague and we stare at each other in disbelief. A moment of silence follows, as if in memory of a friend who has passed on.

The six-year child is severely malnourished and looks like a one-year old. He can not talk. He can not stand. He can

The misery of a disabled child who is tied on rope

hardly sit, and on seeing us, he struggles to pull himself over for help.

The neighbor lifts him up and we go outside the house. Wamono sees a different world, with a sun and the feel of the warmth it generates that he has apparently not experienced for a long time. Out of excitement, he struggles to speak but he can not. He tries to stand up, but he cannot. However, the first born of the family can't afford to keep off the smile!

We send a little girl to call us Wamono Senior for a talk, but she quickly returns with a message: "He has told me to tell you that he is not there?" He was at a certain 'Malwa' (a local brew) joint taking alcohol at 10am.

Wamono (father) separated with his wife three months back when she was going to the village for a funeral. "He (father) told his wife to take both children but she refused. He instructed her not to come back if she didn't go with the two children and she refused," the neighbor says. By the time we visited Wamono, her mother had not returned more than three months after she went. Wamono's follower is three years old but she can do activities like walking, talking, among others, that Wamono cannot do.

Wamono suffers

from Cerebral Palsy (CP), a disabling condition that is acquired before or during birth. Children suffering from CP are normally unable to control their neck, with weak arms and legs. They can't do things like sitting or crawling like their fellow children of the same age (they 'take long' to grow). They also normally suffer from epileptic fits (ensimbu).

The most common causes of CP are: pregnant mothers suffering from diseases like malaria; poor feeding during pregnancy; domestic violence; poor feeding and poor antenatal care, poor use of medicines during pregnancy; delay in labour, among others.

In Uganda, there are many children suffering from CP. However, when they are taken good care of, they can grow very well, get educated and become productive citizens who can live an independent life.

These children too need love, care, respect, understanding, good shelter; they need all the essential human needs just like any other person. They should be left to play with other children.

Life is so sweet! Therefore, if saved, it must be lived.

Update about UBISP activities

- Community-Based Rehabilitation and field activities have been going on in the entire project area. Home visits give us an opportunity to interact with the family members.
- Psychiatric outreach clinics have also been on going where clients receive drugs.
- Follow up on the registration of the six Self-Help Groups as Community-Based Organisations in their respective divisions of Kampala.
- We are organising to present a concept paper to Parliament, Ministry of Health and the Ministry of Education and Sports, highlighting the special needs of people with Cerebral Palsy and Acquired Brain Injury.
- Preparing to participate in the celebrations to mark the International Day of Persons with Disabilities.
- Planning to have a meeting to share information that was obtained from our CBR visits in Kayunga, Busia and Tororo Districts.
- Planning to have a radio talk show to sensitize the general public about People with Cerebral Palsy and Acquired Brain Injury.



Children who suffered from CP but are happily living

UNAPD women steer national volleyball

BY OPOT SCHOLAR

In one of the editions of UNAPD Update this year, Irene Nabalamba, castigated government and sports organisations for not considering participation of PWDs in sports. She said PWDs love sports and can actively participate in it, and therefore, thrill spectators on seeing the same sport played in a different way.

Nabalamba's article apparently caught the attention of the National Council for Disability, who through the Uganda Disability Sport Association, invited UNAPD to start participating in sports activities.

As I write, about 20 women from UNAPD, including me formed the national women sitting volleyball team for PWDs, now undergoing training in Lugogo, or sometimes at UNAPD headquarters in Kanyanya.

In August this year, Uganda Disabled Sitting Volleyball Association, had approached me to join the organization, that for long lacked women with disabilities. Their aim was to start the women team. I welcomed the idea that was long over due.

One of UNAPD's staff, Irene Namigayo, was selected and trained into coaching children with disabilities in sports. She is now a qualified trainer, doing her stint at Agakhan play ground, with a good number of children.

The PWDs quest for participation in sports has also received a boost from Ole and Lene from the Danish Sports Organisation for the Disabled, who visited UNAPD this month, to discuss involvement of PWDs in sports activities. They also discussed the possibility of starting a sports project in Uganda in partnership with UNAPD.

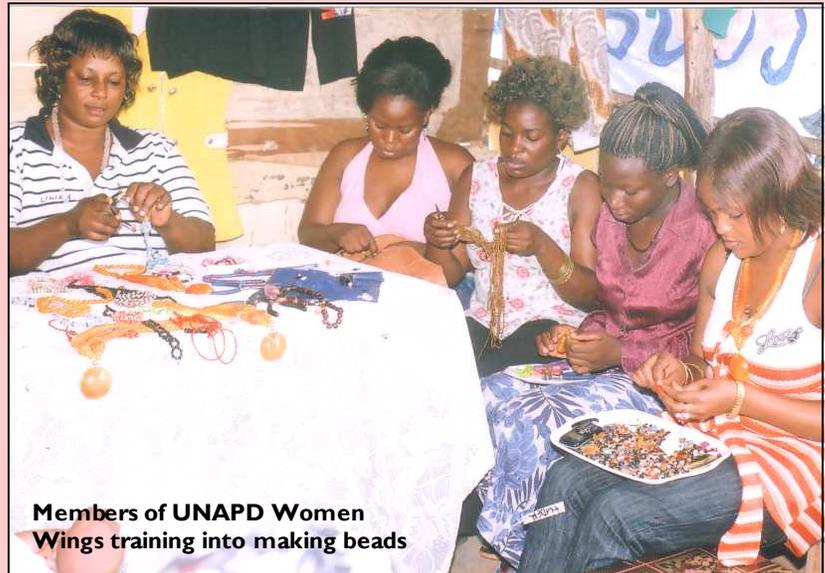
The visitors were convinced that the women and youth wings of UNAPD are determined to make Uganda a country in which PWDs are seen as great sport ladies and gents.

Ole Ansbjerg and Lene Van der Keur were impressed when they watched the women and men sitting volleyball team playing at UNAPD.

The men's team that has been in the game for the last five years have participated in various competitions with neighbouring countries of Rwanda, Congo and Kenya, among others.

We are also actively participating in games like table tennis and cricket, as we look out to other games that we can participate in.

UNAPD Women trained in making sweaters and beads



Members of UNAPD Women Wings training into making beads

BY HARRIET ZANSANZE

UNAPD Women Wing have been trained in making sweaters and beads, using the Wings Project Trust Fund. Ten participants from five divisions of Kampala district attended the training on 26 October—November 1, 2009. Five women trained in making sweaters and other five trained in making beads. The trainers were Lilian Walugembe, a member of the Steering Committee of the Women Wing, and Aidah Zawedde, a member of the Polio Survivors' Working Group. The women appreciated the training and pledged to start earning money by making and selling sweaters and the beads. However, the trainees in sweater making said they needed more time to learn how to make sweaters for babies. Vincent Naliima, a Board Member of UNAPD closed the training.

POLIO SURVIVORS FORM GROUPS

The polio survivors have formed groups in each of the five divisions of Kampala through which they will create awareness about Post-Polio Syndrome and advocate for their rights and needs. Each group's executive comprises five committee members. The groups were formed following the training of the members into leadership and advocacy skills on 23 October, 2009. They were also trained in managing Post-Polio Syndrome (PPS), a condition that manifests itself in renewed weakness of muscles several years after suffering from polio.

PLANNED ACTIVITIES

- The Rheumatism Wing is planning to raise awareness about Rheumatic Arthritis, (a serious disease of joints and muscles), in various churches in November and December 2009. A general meeting for the Wing is also planned for December 2009, to share experience and progress.
- The Women Wing are planning to carry out advocacy meetings in schools to sensitise authorities and students about the rights of children with disabilities.
- The Youth with Physical Disability in Iganga are planning to carry out HIV/AIDS sensitisation among the youth to create awareness about the scourge.