

# **NATIONAL COUNCIL FOR DISABILITY REPORT ON COMMUNITY DIALOGUE SESSIONS HELD IN KAMULI DISTRICT FROM 18TH – 22nd, JANUARY 2016**

## **PROMOTING RIGHTS AND ACCOUNTABILITIES IN AFRICAN COMMUNITIES (PRAAC) PROJECT COORDINATED BY PLAN UGANDA**

### **Compiled by**

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FACILITATORS  
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### **List and contacts of Facilitators from NCD who participated is provided as below:**

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| 1) Beatrice Guzu Executive secretary NCD                                  | 0772643084 |
| 2) Mari Samuel (Programme Officer- NCD)                                   | 0772660809 |
| 3) Tumwesigye Benson –Sign language interpreter                           | 0772315525 |
| 4) Adima Moses (Beatrice Guzu’s Guide as a Person with Visual Impairment) |            |

### **1.0 Introduction:**

The National Council for Disability (NCD) is a public institution established by Act of Parliament in 2003 and inaugurated in August 2004 as a National body charged with monitoring the extent to which Disabled Persons benefit from existing legislation, policies and programmes. Its establishment was jointly initiated and supported by Government and Uganda’s Disability fraternity as a means of monitoring and setting standards for Disability-related interventions in the country. The work of the NCD is conducted within the context of the international and national legal regime on human/disability rights, as well as the country’s Social Development Sector Investment Plan (SDSIP) that complements ongoing Government Poverty reduction initiatives elaborated in the National Development Plan (NDP). In its work, the NCD monitors Government institutions, civil society and the private sector. This is made possible through its structure that runs from the national to the sub-county level.

## **1.1 Functions**

The NCD operates on the basis of the National Council for Disability Act 14, 2003 with clearly stipulated functions, mandating it to:

Monitor and evaluate the extent to which Government, NGOs and the private sector include and meet the needs of PWDs in their work;

Act as a national body through which the concerns of PWDs can be communicated to Government and non-government actors for action;

Advocate for the promotion of activities undertaken by institutions, organizations and individuals for the promotion and development of programmes and projects designed to improve the situation of PWDs;

Carry out or commission surveys and investigations in matters or incidents relating to violation of PWDs' rights and take appropriate action;

Consider and recommend ways and means of controlling the unnecessary increase of disability in Uganda;

Assist the Electoral Commission in conducting free and fair elections for Parliamentary and Local Government Council Representatives of PWDs;

Identify and give guidelines on disability interventions and mainstreaming to organizations working for PWDs;

Hold representatives' annual general meetings for review and planning purposes;

Mobilize resources for use in the performance of the Council's work.

## **2.0 National Council For Disability Engagements with Plan Uganda and lessons learnt from the PRAAC Project Community Dialogue Meetings.**

In fulfillment of its mandate to mobilize resources, in the mid 2013, National Council for Disability officials approached Plan Uganda and held several consultations for closer working relationships. The discussions were fruitful and the two important output to note are:

(i) Plan Uganda supported National Council for Disability in terms of funding the development of NCD five year (20-15-2020 Strategic plan, and

ii) Plan Uganda engaged NCD officials in the community dialogue meetings under the PRAAC Project in districts where Plan already had its presence for purposes of capturing and documenting issues for follow up, policy development and advocacy to promote disability sensitivity and disability mainstreaming by duty bearers and other stakeholders.

The report provides a written account of the community dialogue meetings organized by Plan Uganda in the PRAAC project districts of Kamuli, Lira and Kampala Districts with National Council for Disability officials engaged to interface with the Persons with disability in order to capture concerns on violations of their rights, understand and document issues for follow up, and advocate for policy developments and disability mainstreaming.

The opportunity for Plan Uganda and National council for disability to engage together in community dialogue meetings under the PRAAC Project in three districts already highlighted above was kick-started when the Project officer in charge PRAAC Project, Jacqueline held some consultative meetings with the National Council for Disability senior officials at the NCD Secretariat (Ntinda) and agreed on carrying out joint community dialogue meetings in the three districts/areas of Kawempe division in Kampala, Kamuli district and Lira District in line with a drawn Terms of Reference (TOR). The original plan was to carry out the activities in the second quarter and the third quarter. However after one meeting was held in Kawempe in the second quarter, the rest of the programme was rescheduled for Third quarter to cover Kamuli district, Lira District and Kawempe division. The terms of reference (as attached) specified the detailed expected output, duties and roles of the different parties.

It is upon that background that National Council for disability staff conducted the Community dialogue meetings in the specified districts and areas stated in the body of this report for purposes of carrying out and engaging in dialogue with different communities including Persons with Disabilities, their parents, caregivers, leaders and community volunteers. The community dialogue meetings also enabled the Trainers/ facilitators from the National Council for Disability to identify and highlight advocacy issues, policy issues, and make recommendations for follow up by the PRAAC project managers, NCD as well as different Stakeholders- Including the Disabled persons organizations, the district organs and leadership.

### **3.0 The methodology:**

The methodology for conducting the community dialogues were more or less similar, as below:

**3.1** Opening key note Presentation by Resource persons –especially the police officers, on the positive and negative trends regarding the cases of protection and violations of rights of Persons-women, men, youth, the elderly and children with disabilities. Followed by complements, questions and clarifications by the members present.

**3.2** Specific questions and responses regarding challenges facing PWDs directed to Persons with disability, the care-givers , community leaders guided by the Facilitators from National council for disability facilitators.

**3.3** Experience/information sharing by Different resource persons/leaders/ PWDs/care-givers

**3.4** clarifications made on issues affecting PWDs and status of Service delivery to PWDs by Sub-county leaders, Project facilitators/ PWD Leaders and National Council for Disability facilitators

**3.5** Note –taking exercise by the NCD facilitators for purposes of documenting issues that need follow up by different stakeholders, recommendations for policy development, issues of advocacy, etc. to be submitted in a report to Plan Uganda.

#### **4.0 Recommendation For Follow Up By PRAAC Project Team, District Officials & Other Stakeholders For Purposes Of Policy Formulation, Follow Up On Identified Issues And Advocacy.**

##### **4.1 On Issues Of Programming & Advocacy**

4.1.1. National council for disability to include programming for capacity building for targeted District councils for disability committee members information Sharing on approaches of Community Based Rehabilitation – focusing on transfer of skills and knowledge to parents and care givers of Persons and children with disability from within their home /community settings, among others.

4.1.2. Community development officials need to work with the community leaders to arrange special programmes for sensitizing deaf youths in communities to understand issues of sexual and reproductive health, as well as legal implications associated with pre-marital sex.

4.1.3 PRAAC Project to contact existing FM Radio stations to popularize best practices in management of disability conditions & parenting.

4.1.4 PRAAC Project to advocate for formation of parental support groups for purposes of establishing peer counseling platforms & Village savings and lending Associations (VSLA) ,targeting PWDs and Parents of CWD, etc.

##### **5.0 On Issues On Immediate Follow Up ( details are captured in the matrix, below):**

5.1. For Children /Persons With Epilepsy Like Kintu Paul

Family counseled for other members to take the responsibilities of caring for the Person with epilepsy, cerebral palsy and cases of the terminally ill, to help the care-givers.

Referral support be availed for children with Epilepsy. Hospital management to be approached by the PRAAC Project to approach and advise for Epilepsy outreach clinics to be initiated and conducted in communities which are far from the Hospitals.

Family and community be made aware of how to provide first aid support to a person with Epilepsy who has fallen in a situation of feating by trained medical practitioners to be organized by PRAAC Project.

The mother and family members encouraged to continue supporting the Person with Epilepsy to take care when there are triggering signs

The Parents mother encouraged to join or form PWD groups of parent groups for children with disability to tap into the special grant/ Government programmes targeting support to PWD groups and other community groups

## **5.2 For Children /Persons With Celebral Palsy:**

Families –care-givers and parents be supported to the child stay clean

Family members to love and help train the Child to perform all the Activities of Daily living (ADL) independently

Family counseled for other members to take the responsibilities of caring for the child to help the mother.

The community development workers/ officials and parents and care-givers of Children with disabilities to be trained in Community based rehabilitation skills.( capacity to coordinate different relevant resource persons to transfer Knowledge, skills and professional information to the Parents, family members and care-givers of Children and Persons with Disabilities from within their home environment/settings)

Link the family/child with the Uganda Parents of People with Intellectual Disability (UPPID)

## **5.3 For Children /Persons who are deaf:**

Parents and care-takers of children who are deaf, or have any form of disability should love their children and give them educational opportunities.

The deaf /PWDs can marry like any other person as a human right issue

The deaf/ PWDs can engage in agricultural activities and participate in all economic / livelihood activities as a human right

The deaf/PWDs have the right to participate in all public / community affairs like any other people in community and should be provided with Signlanguage interpreters to facilitate their communication in all public meetings .

Employers of PWDs have the responsibility to pay them fairly because they have the same rights as any other, including the right to marry and take responsibility of their families.

Awareness raising programmes by both NGO and Government must give information concerning the rights of PWDs of all ages including Children with disabilities, so that the rights of PWDs are protected at all levels.

Seek more information from Uganda Association of the Deaf (UNAD)

## **5.4 For Children /Persons with severe physical disability :**

To be supported with appropriate mobility appliances ( crutches, wheel chairs / tricycles

5.5 Other Issues were captured in the matrix, below.

5.0 For purposes of clarity and ease of following the challenges identified and the recommendations proposed by the participants are highlighted in a tabular form:

REPORT ON KAMULI DISTRICT COMMUNITY DIALOGUE SESSIONS 18.01.2016-22.01.2016			
DAY ONE/ COMMUNITY DIALOGUE MEETING HELD AT VENUE NUMBER ONE: NABIRYE MADASANI PRIMARY SCHOOL ,BULONDO ZONE, BULUYA PARISH, MBULAMUTI SUBCOUNTY ON 18.01.2016			
SN	CHALLENGES IDENTIFIED	CASES FOR FOLLOW UP	RECOMMENDATIONS
1.	Two persons with severe physical disabilities shared their problem of difficulty with mobility since they did not have wheel chairs /not even tri-cycles.	A case of Nakizza Miria 23 –a female student who moves on four –crawling lacks a wheel chair and has sought for wheel chairs in vain for the last 10 years.	PRAAC project community volunteers to purchase the wheel chairs to those PWDs in the communities who need them
2.	A case of an abandoned/ rejected girl child with disability who is a total orphan and have no shelter- aged 16 years and the leaders	Betty indijanani (from Bulondo zone) Case of a girl child with disability who is a total orphan – with speech difficulty and physical disability – disowned / rejected by the clan/community on the false ground that the clan does not produce people disability like her, presently living in a house which is half way broken down-a shelter in a poor shape. Much as she was identified and being given school fees by some foreign well-wishers, her problem is lack of proper accommodation during	Local leaders ( LC1.) to take up the matter to the Kamuli District probation and welfare officer. The District Probation and wel-fare officer met by the NCD team the following day (day two) and requested to attend to the matter. He called the area subcounty community development

		<p>school Holidays.</p> <p><u>summary</u></p> <p>A girl child of 16 years with speech difficulty and physical disability</p> <p>A total orphan</p> <p>Living in a leaking house with a broken wall and leaking roof</p> <p>No treatment when she is sick/ she is told there are no drugs at nearest health unit she goes to</p> <p>No care from the clan and the community</p>	<p>officer to follow up and report to him the situation. Considered as a case of violation of rights of the child</p>
<p>3.</p>	<p>The challenge of lack of school fees for children with disabilities who are poor or orphans</p>	<p>Ojiambo Patrick-chairperson PWD Bulondo Zone reported a Case of a girl child with disability who is an orphan and has fees problems ( details captured by the community Volunteer ) and has dropped out of school because the heir to the family has denied her fees.</p>	<p>The child's details were captured by the Project community volunteer who is to forward the matter to the Mbulamuti sub county Community development officer and to follow up with the CAO and help with persuing bursary scheme for the child under the available opportunities for the scheme for the best performers.</p> <p>When the NCD facilitators visited the Office of the CAO Kamuli, the CAO informed the team that such opportunities of getting sponsors are rare</p>

			and whenever it comes it is normally referred to the office of the LC5 chairman to decide with the councilors on the children to benefit. Hence it is advisable to lobby the office of the LC5 and PWD Councillors female and male.
4	Lack of supportive attitudes for children with disability by other children in schools, and also in-accessible sanitation facilities and classrooms and environment for Children with disabilities in Schools makes most children with disabilities to drop out of school.	A number of school going aged children with disability were reported by parents having dropped out of school due to teasing and abusive language/insults meted against them by the non disabled children, lack of trained teachers, lack of accessibility provisions in the sanitation rooms, lack of special learning materials.	A team of 6 members/ including parents of children with disabilities that was earlier on constituted and supported under the inter-religious council to visit schools and advocate for accessible facilities for CWD revived and supported by the local councils.
5	Rampant negative attitudes in communities and families expressed towards PWDs / and their family members in form of discriminatory practices and abusive words.	Use of abusive language on CWDs by family members and parents	Parents and all to Avoid use of abusive language on PWDs/ CWDs
			General recommendation by NCD Facilitators:  Communities to be on the lookout and seek for information from community volunteers/community workers / local leaders to



			<p>support Families and persons with disability of all ages in terms of advocating for positive attitudes and providing relevant information.</p> <p>District and subcounty Councils for disability to be strengthened/ trained to carry out their mandate to support the disability mainstreaming Advocacy in schools, health centres, and all institutions, including Government and NGOs in line with the PWD Act 2006 and the Convention on the rights of PWD (CRPD)</p>
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<b>REPORT ON KAMULI DISTRICT COMMUNITY DIALOGUE SESSIONS 18.01.2016-22.01.2016</b>			
DAY TWO/ COMMUNITY DIALOGUE MEETING HELD AT BUTEGERE ZONE, NALUWOOLI PARISH, BUTANSI SUBCOUNTY ON 19.01.2016			
SN	CHALLENGES IDENTIFIED	CASES FOR FOLLOW UP	RECOMMENDATIONS
1.	Lack of awareness in communities and schools on the special needs of persons and children who are albinos.	A father of a child who is an albino (Details with community volunteer for Butegere Zone, Naluwooli Parish) raised the point that his child was getting difficulty in continuing with attending school due to visual impairment and difficulty seeing.	Project should help with medical referral and purchase of required corrective glasses and devices

2.	The problem of teasing using abusive or derogatory language towards children with disability in schools which discourages the CWD from attending school.	the issue raised by two children with disabilities and two parents of children with disabilities on the point of teasing using abusive or derogatory language towards children with disability in schools which discourages the CWD from attending school.	The PRAAC Project community volunteers , community leaders and other stakeholders to sensitise school communities to respect CWD and avoid abusive language towards PWDs.
3.	The schools facilities do not cater for the sanitation facilities for girls with or without disabilities	A mother of one of the girl child with disability noted that poor sanitation facilities in schools which discourage children with disability from attending school during their menstrual periods	PRAAC Project should support schools with free/affordable sanitary towels for girls with disability, and girl children generally.
4.	The difficulty of caused by long distance to the health centre for PWDs and the elderly	Many Parents and persons with disabilities raised this as a concern	Government to consider providing accessible/ with disability inclusive facilities' Health centres in the Parishes/ communities .

**REPORT ON KAMULI DISTRICT COMMUNITY DIALOGUE SESSIONS 18.01.2016-22.01.2016**

DAY THREE/ COMMUNITY DIALOGUE MEETING HELD AT VENUE NUMBER ONE: NABIRYE MADASANI PRIMARY SCHOOL ,BULONDO ZONE, BULUYA PARISH, MBULAMUTI SUBCOUNTY ON 20.01.2016

SN	CHALLENGES IDENTIFIED	CASES FOR FOLLOW UP	RECOMMENDATIONS
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1.	Lack of working capital for economically enterprising /Active PWDs. Lack of information for existing opportunities from Existing government programmes	<p>Testimony of One elderly participants who is a person with a physical disability making local trays (made out of some sticks and stems of crawling plants that grow in the forests, then smeared with cow-dung) used for winnowing grains in communities. He makes /weaves the trays and sells as a means of generating income.</p> <p>Voiced the challenge of working capital for purchasing raw materials and difficulty of transporting /peddling the products /winnowers made to markets.</p>	<p>PRAAC project community volunteers to explore means of supporting enterprising/economically active PWDs to be able to expand their businesses and to train other PWDs in similar trades. There is need to support PWDs to expand their craft businesses and to link them up with marketing centres that could be more profitable. (More information could be obtained from the PRAAC Community volunteer taking the area around St. Mulumba primary school , in Butesa Zone, Butansi Sub County).</p> <p>Enterprising PWDs to be mobilized to join existing PWDs or form PWD groups to benefit from the Government programmes e.g Special grant /CDD/ YLP, et.</p>
2.	Persons and children with severe mobility/physical disabilities lack access for wheel chairs/ and even tri-cycles and move crawling with the mobility devices (tri-cycles nor wheel-chairs). A few who once had wheel chairs, had them broken down beyond repair and are back to zero crawling.	Three persons with similar need showed up at the meeting . All the three were female and did not have wheel chairs /nor tricycles. All the three were within the age brackets of 15-17yrs. One of the three , said that she	The Community volunteer and family members were advised to document the details of the severely young girls with severe physical disabilities , including getting their photos to be filed with the community volunteer.

		<p>had a wheel chair which had broken down because she had no money to repair, not even to be able to replace the tyres.</p> <p>One of the three girls is doing some tailoring work without much skill; she is doing tailoring , but needs more training and a wheel chair.</p> <p>The youngest of the three aged 15 years was not able to continue going to school because of the long distance to school.</p>	
3.	<p>The challenge of means of transport for community facilitators , including local representatives of Persons with disability was a major set back to information access to PWDs who need information on Wheel chairs or tri-cycles</p>	<p>Mr. Siraj who is a sub county councilor representing PWDs in Butansi Sub County got an opportunity to talk and affirmed that the problem of lack of proper sources for wheel chairs for Persons with disability was outstanding. People with severe mobility problems requiring wheel-chairs/ tricycles were many in the area and there is great need for wheel-chairs to enable children with disabilities go to schools and adult PWDs to be able to visit health centres and marketing centres with their goods for sell.</p> <p>He also stated that he</p>	<p>Government and NGOs need to support Community facilitators , including Representatives of PWDs at Community level will means of transport for easy mobilization and dissemination of necessary information on how PWDs can access mobility appliances and other Rehabilitation devices.</p>

		could not share information with his constituents because of lack of easy means of transport like a bicycle or a motor-cycle.	
4	PWD Groups in Butansi subcounty seem to be lagging behind on information about existing government programmes like the Special Grant for PWDs, the CDD and so on, the councilors and most PWDs are not aware how they can form groups to be able to benefit from the existing programmes	<p>On the issue of how PWDs groups are benefitting from the Government programmes, like the Special Grant for PWDs, the CDD and so on, the councilor, mr Siraj expressed that he is not aware of any PWD groups in Butansi Sub county which have benefitted from the Special grant.</p> <p>There is generally poor mobilization of PWDs for economic empowerment in the community (ties).</p>	The PRAAC Project to partner with the office of the DCDO to sensintises the PWDs how to form groups and write proposals to benefit from the existing government programmes.
5	Common cases of visual impairments noted , requiring eye medical assessment and referrals , could be linked to the long distance to the nearest Health centre in Naluwooli. The most affected category of people reported are the PWDs , the women and the children.	There were four cases of visually impaired persons who expressed need for medical eye care, remedial eye-glasses for reading purposes , and corrective surgery.	Majority of the people recommended that another Health centre III be established in Butansi subcounty –in the area to provide accessible services to the community and serve many patients in the area who cannot move long distances to Naluwooli HCIII.
	Lack of disability friendly facilities for children with disabilities in all the	a deaf and dumb 14 year old Alice has dropped out of Maria care school	PRAAC Project to contact stakeholders to provide school fees support to Children with severe

	<p>schools.</p> <p>Lack of government aided inclusive and special needs schools in Kamuli which have resulted in many CWD dropping out of schools.</p>	<p>Kamuli- (which is a private school that provides specialized training for CWD) to come back home because in the entire district of Kamuli there is no school with facilities for teaching of such children.</p>	<p>disabilities.</p>
			<p>General recommendation by NCD Facilitators:</p> <p>Hence there is need for the Kamuli District local government to consider starting a Government aided school for Children with Special Needs (or for the deaf and dumb.) communities to be on the lookout and seek for information from community volunteers/community workers / local leaders to support Families and persons with disability of all ages</p>

<p>DAY FOUR/ COMMUNITY DIALOGUE MEETING HELD AT VENUE NUMBER ONE: COMMUNITY DIALOGUE MEETING HELD AT BUSAMO TRADING CENTRE, BUSAMO ZONE, BUGEYA PARISH, BUTANSI SUBCOUNTY ON 21.01.2016</p>			
SN	CHALLENGES IDENTIFIED	CASES FOR FOLLOW UP	RECOMMENDATIONS
1.	Lack of trained Community	Case of Malasa Richard (18 YRS)	PRAAC Project Community volunteers to

	Development workers in Community based rehabilitation (CBR) skills on home-based management of cases of children with cerebral palsy (delayed child development arising from brain damage at birth/infancy)	Richard child with a swelling on the hand that needs to be operated; the child is generally weak and cannot feed independently – depends on the mother to feed him.	link the CBR-trained Community Development workers and other professionals with parents/families of children with Cerebral palsy.
	Lack of tricycle for person with disability with severe mobility challenges	One elderly man with severe disability who struggled to get to the venue crawling; he requested for a wheel chair/a tricycle for easy mobility.	Advised to give his particulars and contacts to the community volunteer (Yeseri who would work with the sub county CDO and the community to lobby for support to purchase a tricycle /wheel chair from different sources both within and outside the district ).
	Parents /family members of children with Epilepsy have financial burden to buy drugs for their persons /children living with epilepsy	Katarina Warangal mother of a child living with epilepsy (13yrs). She requested for financial support to be able to buy the drugs from possible sources in Jinja and Kampala. Also finances to meet her transport to Hospital for attention on some days	
	Children with cerebral palsy were common and parents lacked skills and knowledge on their management within the home-setting. They also lacked easy transport for regular visit to hospitals /health units for medical review.	cases of children with cerebral palsy who have delayed growth and difficulty seating, standing and walking were about six reported by the 30 care-takers who attended the community dialogue session:  i) Babirye Prossy aged 2yrs, with cerebral palsy and cannot seat independently. Location Butatyama zone, Bugeyuwa	Most of them were given related advise; by the medical team from st. Benedictine Mission hospital and parents were advised to make corner seats to aid the children with seating. Also requested to take keen interest in keeping their children clean and given proper care to avoid inhygienic –related health problems. The PRAAC community

		<p>parish, Butansi s/c</p> <p>ii) Semuga Moses aged 3yrs, with cerebral palsy and cannot seat independently. Location Busamo zone, Bugeyuwa parish, Butansi s/c.</p>	<p>Volunteer and CDO to work together to link the families of the children and persons living with cerebral palsy to be able to make corner seats and relevant aids /tools to facilitate their growth/development.</p>
	<p>Long distances to school affecting children with disability in the area and making them to drop out of school. There were four cases reported by parents during the community dialogue.</p>	<p>Kamada Mulabe 15yrs with a physical disability (weak arms) and speech difficulty, in P7. Affected by distance because the nearest school is 3 km away. Information given by the mother; name-Yolyanaye Zabina</p> <p>ii) Kankwange Aseri 8yrs (female) with severe physical disability lacking a wheel chair/tricycle cannot go to school due to long distance to the nearest school which is three kilometers away</p> <p>iii) Nangobi Rita 11 years (female) also with severe physical disability from the same family with Kankwange Aseri, lacking a wheel chair/tricycle cannot go to school due to long distance to the nearest school which is three kilometers away</p> <p>iv) Wonaira Fatima 22yrs dropped out of school, also with severe physical disability from the same family with Kankwange Aseri, lacking a wheel chair/tricycle.</p> <p>v) Beatrice Namubiru 20 yrs, lacks wheel chair / the wheel chair needs repair and family can't afford; care -taker is Lovisa</p>	<p>The PRAAC Project to support the children with disability and other persons with disability to get mobility appliances NCD to lobby other organizations like Father's heart mobility Ministries and missionaries for the poor to provide free wheel chairs/ tri-cycles. The CDO and community volunteers to support the parents to join groups of PWDs or parents groups to benefit government programmes.</p>



		Basirika is in need of financial support to repair the wheel chair and support the family	
Most of the children with disabilities are faced with challenges of school fees. Their guardians and parents are faced with many constraints and lack knowledge of their potential. They need counsel from the different DPOs, like the Little People Association of Uganda (LPA-U), UNAPD-Uganda National Action on physical disability, etc	<p>i) Tibenkana Sylvia, a girl child with disability (with hunchback) age 25yrs. Completed senior four ; needs money for school fees. Her father is unable to support her for further education. location Busamo Zone, Bugeyuwa Parish, Butansi sub county.</p> <p>ii) Mivule Faruk- 12 years- a child with little stature and physical disability. Schooling at Nakyaka primary school. the mother is unable to meet his school fees and may drop out of school.</p> <p>Need to link him up with the Association of little people of Uganda (LPAU) and to seek for specialized Counsel for any possible financial support for his educational requirements.</p>	<p>Need to link the parents with Parents groups and Associations of Persons with Disabilities.</p> <p>Recommendation For Continuos Advocacy By The Community Facilitators/Community Volunteers :</p> <p>Advocacy: on establishing Income generating activities (IGA); then Forma/join groups for parents/ PWDs and seek for financial support as a group.</p> <p>The community volunteer and the CDO to lobby for their training and linkage with capacity building opportunities.</p>	
Lack of knowledge on the specialized facilities for persons and children living with Albinism.	Tukobere Janat aged one year and one month, female, Albino. With a skin rash. Mother's name is Nabirye Fauza; father's name is Mwase Tabliq. Contact: Butatyama zone, Bugeyuwa parish, Butansi Sub county.	<p>Need to link the parents with Parents groups and Associations of Persons Living with Albinism Disabilities (AA-U)</p> <p>Also parents to join parental groups for peer counseling and lobbying for resources.</p>	
Parents of children with critical conditions that require timely and quality medical assessments and referrals and the parents cannot afford the financial costs	Five cases of children/ Clients that need specialized treatment and referral services outside the district and yet the parents cannot	PRAAC Project to document the cases clearly and to lobby and fundraise other stakeholders, including,	

	<p>for transport and medical attention.</p>	<p>afford transport costs.</p> <p>i) Namugangu Rehema mother of child with complications in the throat requiring surgery at Entebbe (Naigaga Zaina 7 yrs). The mother cannot afford transport and medical costs required for the surgery to done at Entebbe.</p> <p>ii) Andrew Wabuke 66 yrs; weakness and pain on the back /spinal injury. Bukuluba Zone, bugeyuwa parish, Butansi s/c</p> <p>iii) Shafiq Lubale 6 Yrs. Developed hydro-cell (swelling in the testacles) after initial traatment were referred for further treatment from Namasagali. Fathers name is Lubaale Godfrey. Location Buyegu zone, Bunango parish</p> <p>iv) Mwase Sumani 10 yrs (name of mother who participated in the community dialogue is Nalubowa Zamu Nyago). The child is hard of hearing with purse in the ears. requires medical attention by the ENT Specialists. The mother requested for financial support to be able to take the child for treatment. She needs money for transport and treatment.</p> <p>v) Nyago Samuel ,6yrs, hard of hearing with purse in the ear and requiring necessary medical attention.( Mothers name is Nakizza Norah/ fathers name is Wamboga Geofrey. Location of contact: Bugaluka Zone Bugeyuwa</p>	<p>districts, DPOs and faithbased organizations to Provided Financial Support For Medical Referral Treatment</p>
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		parish ,Butansi s/c)	

DAY FIVE/ COMMUNITY DIALOGUE MEETING HELD AT KOKOTOKWA ZONE, BUGONDA PARISH, MBULAMUTI SUBCOUNTY ON 22.01.2016

SN	CHALLENGES IDENTIFIED	CASES FOR FOLLOW UP	RECOMMENDATIONS
	Common cases of PWDs Segregated/ discriminated- suffering long waiting in queues to be served in Health centres; even in community functions like parties they are served food last.	Case of Othieno Erenesti ; adult male with physical disability (one hand weak and paralysed ) with difficulty to do any hard work; Not allowed to participate in any role in community functions. Location of residence; kokotokwa zone; Bugonda Parish Centurio Mulegwe ; with physical disability and speech impairments, and also mental retardation; voiced his challenge as : being discriminated in government programmes and existing public opportunities like NAADS (Location of residence; kokotokwa zone; Bugonda Parish	PRAAC Project and Community volunteers and community development workers to create awareness on the provision of affirmative action (positive discrimination in favour of the marginalized/PWDs) in the constitution. PWDs be mobilized to join or form Groups to be able to tap government programmes like Special grant for PWDs, and create a bigger voice for stronger advocacy.
	Discrimination of the deaf in Employment and communication gap in community meetings on issues affecting the deaf.	Case of Samuel Musuwabwe; deaf , and married to a deaf wife, could not continue with employment as a slasher boy in Jinja because he was not being paid; cameback home and embarked on maize growing and to work with his wife (who is also deaf and knows signlanguage) to engage in Gardening .	PRAAC Project should train communities in sign language communication skills, beginning with project community volunteers, local leaders and community mobilizers.  Secondly the local government councils should enact policies and bye-laws that protect deaf persons at all levels.  Advocacy should be

			<p>directed towards Employers to recognize and respect the right of deaf persons/all PWDs to decent employment.</p> <p>Other Recommendations are noted below the matrix.</p>
<p>There is lack of awareness on the potential and positive lessons exhibited by PWDs living in different communities.</p> <p>Lack of signlanguage communication skills by community members and leaders makes Persons with deafness not to be effectively understood and their needs cannot be easily addressed.</p>	<p>Case of Muyanga Peace deaf - literate in sign language , wife of Samuel Musuwabwe(deaf - literate in sign language) , owns a saloon/ hair dressing business; with one boy-child. Her child fell and broke his leg and the child still needs treatment.</p> <p><u>Recommended</u></p> <p><u>Issue for immediate follo up</u></p> <p>PRAAC Project to follow up with the case of the child whose parents are both deaf and sustained broken legs as a result of falling from the tree as a request that was voiced through our sign language interpreter for the deaf Mother.</p>	<p>People with disability (the deaf) must be respected and accorded adequate space to participate in different community roles.</p> <p>People with disability (the deaf) have the potential to start and operate income generating activities and be economically productive and need the support of community facilitators to advocate for their affirmative action/positive discrimination.</p>	
<p>There is lack of awareness in the communities on what is disability &amp; the disability types and what is not disability most community members do not know and understand the difference between sickness/illness which requires treatment, and Disability which is a longtern/ permanent condition resulting in functional limitations of the person.</p>	<p>i) Cases of two ladies with Goitre, Mrs Watongola Elizabeth and another- adult lady with a goiter from KOKOTOKWA ZONE:</p> <p><u>Challenges voiced :</u></p> <p>both feel much pain around the neck and the chest because of the swelling both lack medical referral support and appropriate</p>	<p>The PRAAC project to partner with relevant disability borganisations in order to create awareness on what are the disability types and what are not disabilities; most community members do not know and understand the difference between sickness/ illness which requires treatment, and Disability which is a</p>	

		<p>medical treatment.</p> <p>Advised to seek medical treatment at the nearest hospital</p> <p>ii) case of Nakiyemba Tolofaina , single mother, with 4 children:</p> <p>Challenge voiced : with severe back pain; unable to support her 4 children with food and school fees.</p> <p>Nakiyemba Tolofaina has a back pain which requires a proper medical referral and treatment;</p> <p>Follow up by PRAAC Project be done ,to consider sponsoring the three ladies for proper medical referral for treatment.</p>	<p>longtern/ permanent condition resulting in functional limitations of the person</p>
	<p>Lack of Hospital medical outreach support/ Community based Rehabilitation care for cases of persons that need community/ home-based care (patients that need Hospital medical outreach palliative)</p> <p>Lack of community based rehabilitation training for the community members, parents and immediate family members for care of terminally ill and persons with celebral palsy.</p>	<p>Case of child with disability , name- Magambo Haruna – with celebral palsy, 20 yrs, does not talk, does not move, bed ridden too small for his age, (appearing 1 yr.old) Location (KOKOTOKWA zone)</p>	<p>PRAAC Project to lobby for hospital and other professional extension outreach services for families with Persons with celebral palsy and other cases of terminal illness.</p> <p>PRAAC Project to advocate for community development officers trained in CBR Skills to provide CBR training to the parents/care givers of Children with severe Disabilities</p> <p>The PRAAC project TO Partner with other stakeholders to advocate for a national multi-sectoral specalised outeach services to provide medical, physiotherapy, ENT, Epilepsy support kit, paedetric services and</p>

			orthopaedic services in communities. (refer below for more advocacy and follow up tips for children with Celebral Palsy)
Lack of awareness by the community on how to support persons with mental illness.	Case of person with disability , name- ABDUL ZIRA-EMBUZI – with Mental illness, 30 yrs, having been taken to Butabika National Psychiatric Hospital three times, but without much change. does not bathe, does not make sound decisions, depends on the parents for livelihood. Location (Kokotokwa zone)	Family/community members counseled for other members to take the responsibilities of caring for the person with mental illness to help the care-givers; also for the community to help protect the rights of the persons with mental illness-not to stone or harm them. Refer to Mental Health Uganda (MHU) and psychiatry experts for guidance.	
Lack of medical support/ medical outreach services for persons/children with epilepsy in communities.	Case of person with disability , name- Kintu Paul- 16years with Epilepsy, having been taken to Kamuli District Hospital a number of times, but without much change; does not bathe himself , with no control on Saliva –continuous flowing saliva, and depends on the parents for livelihood, does not make sound decisions.  Location (KOKOTOKWA zone)	PRAAC Project to advocate for the District Health services to provide free sufficient mix and quantity of drugs to support the persons with epilepsy in the district. The PRAAC project to lobby for the drugs to be delivered in regular days in community centres nearer the clients.	
Lack Of Government Aided Special School For The Deaf in the district Lack Of Learning Materials For The Deaf In Ordinary Schools in the district High drop out rate for CWD	Case of Bwiire Brian – Orphan Child with disability aged 16 years, who is deaf, and dropped out of a privately owned Maria care- school (Kamuli) with annex for the deaf.  <u>Challenge voiced by the mother of the deaf child- named Akobera Fida:</u>	Parents to form groups and lobby stakeholders for Educational support for their children with disabilities. Parents have the responsibility to educate their CWD in matters of sexuality and the consequences; issues of HIV/AIDS, Issues of morality and so on.	

		<p>She wondered how she could help the child on matters of sexual and reproductive health;</p> <p>In case the deaf son impregnated a girl would he be legally liable for the consequences and how does she handle this?</p> <p>Location ( from Kokotokwa zone) Mbulamuti Sub county</p>	<p>Recommended to get in touch with the CDO in charge Mbulamuti Sub county ( Nsooli Justine) to help coordinate with trained Health workers who understand sign language to arrange for counseling sessions for deaf youth with disability on sexual and reproductive health issues</p>
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**6.0 OTHER MEETINGS HELD DURING THE FIELD VISIT IN KAMULI.**

Meeting held with the Kamulli district CAO; the NCD Facilitators were able to pay a courtesy call to the CAO-KAMULI DISTRICT and sought to establish the status of the bursary schemes for brilliant poor students and how it works in Kamuli district. The CAO informed the NCD team that the bursaries still exist and some organizations offer funding opportunities to bright but poor students. The role of allocating such funds to the beneficiaries is with the LC5 Chairman and the Councilors.

**7.0 CONCLUSION:**

In all cases medical assessment for children/persons with disability is a must so that the rehabilitation /assistive devices can be acquired early enough to avoid secondary disabilities. There is need for reviews to be made every three months to establish whether the device is still fitting or not

The PRAAC project should support district Associations of PWDs and link them to the office of the District community development officer for sustainability of gains made by the project.

The PRAAC Project needs to target capacity building /training for government and community structures responsible for community mobilization and economic empowerment. The project needs to build media campaign strategies to disseminate information to the community beneficiaries, specifically focusing on persons and children with disabilities