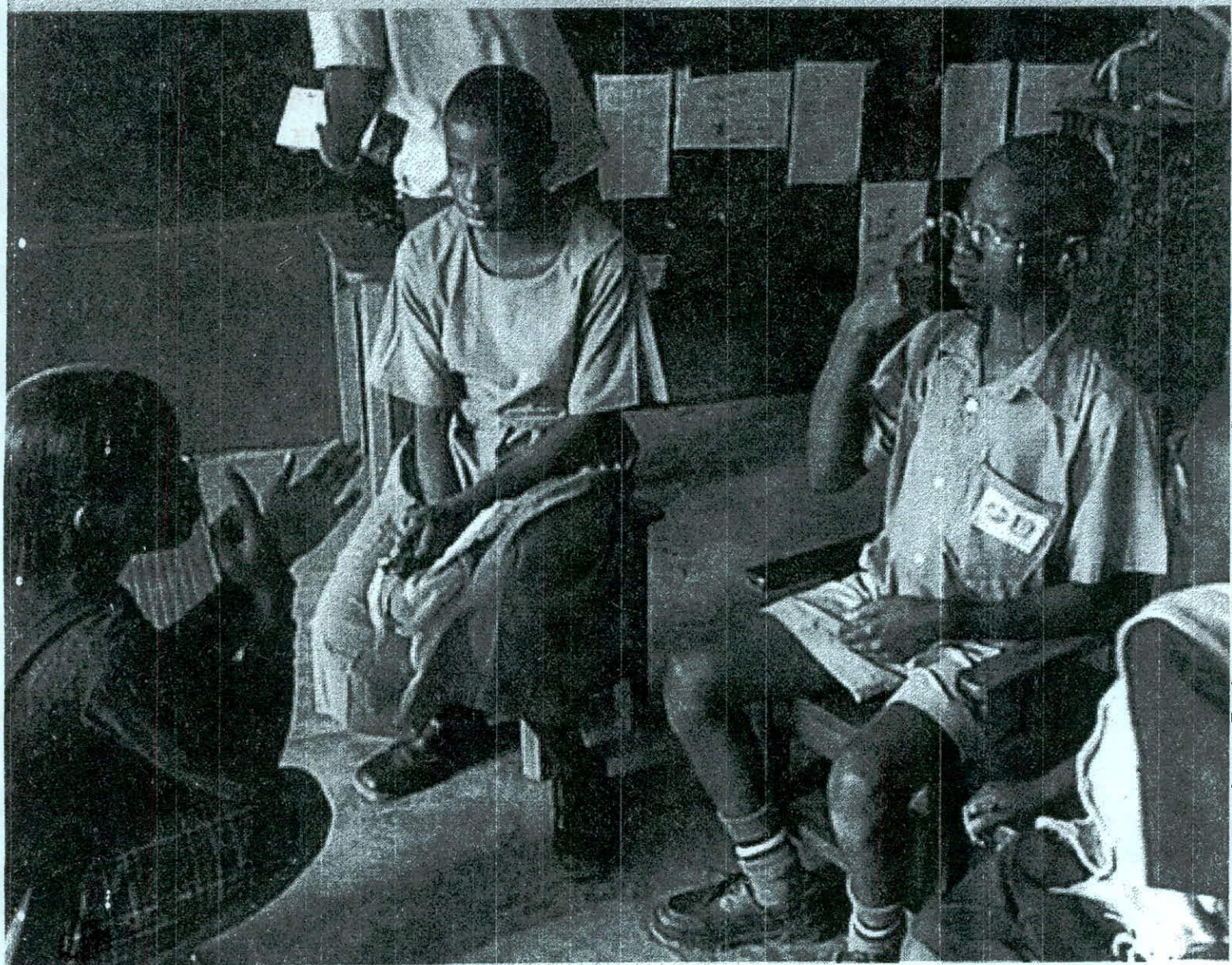


LET'S FACE IT:

Telling it as it is



An on-the ground perspective on children with disability
in education policy & practice in Uganda

By The Uganda Child Rights NGO Network

Lets face it: telling it as it is

**An on-the ground perspective on children with disability in education policy
and practise in Uganda**

Recommendations for CSO advocacy and key actors' action

Data collected & synthesised by the **UCRNN** working group on children with disabilities:

USDC, ADD, NUDIPU, CAWODISA

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1 Introduction

In the Annual General Meeting of UCRNN held early this year, it was agreed that UCRNN carries out joint advocacy for the revision of education policies and practise to facilitate the integration of children with disabilities into the education system.

To inform this advocacy, it was found necessary to carry out an analysis of the situation on the ground to identify key issues that hindered their access of children with disabilities to education – primary education in particular. The study was carried out in the districts of Arua, Yumbe, Kisoro, Kasese, Mubende, Kiboga, Tororo and Iganga. The findings captured here were solicited from central government ministries, district officials, NUDIPU, children with disabilities, their care takers, teachers, headmasters, children of parents with disabilities, civil society organisations, donors, bi-lateral agencies and policy makers among others. UCRNN draws its own recommendations for action based on the discussions with these stakeholders.

2 “Who are we; how many are we; and where are we?”

The biggest challenge that policy makers have in addressing the needs of children with disability in relation to education is that they do not know how many they are; who they are and where they are. Making a case for budgetary allocation, more teacher training, acquisition of assertive and teaching devices etc is all defeated by the lack of knowledge of the number, nature and location of children with disabilities.

Recommendations for action

There is no reason why Uganda cannot establish the number of children with disabilities and where they are. In the recently concluded census it was established that the prevalence of disability amongst children aged below 18 years was 2 percent. Information on disability is otherwise not categorised by age or district. The Children Act Cap59 charges LCs with the responsibility of registering children with disabilities in their localities. The Act came into force in 1997 and 7 years down the line, districts still do not know how many CWD they have. There are several considerations that can be made:

- ◆ The Ministry of Local Government should send a directive to all Local Governments to enforce this section of the law. District authorities should in turn compel SCA's /Local Councils LC's to submit information of the numbers of children with disability on a quarterly or biannual basis. NUDIPU structures can support the LCs in this function while Kyambogo provides guidance.
- ◆ The national and Community birth and registration that is being promoted by UNICEF and the Ministry of Justice should capture this information alongside the birth details.
- ◆ Donors and all stakeholders should support the newly created National Registration Bureau to streamline this process into national processes.
- ◆ SNECOs in conjunction with the district health officials (through the village health teams) should work with LCs in identifying and assessing CWD. For purposes of education (and even otherwise) the school structures can be used to achieve this. All it takes is a little coordination and leadership.

The future of CWD should not be jeopardised just because we do not know how many they are and where they are located.

3 *“The school we want”*

The school environment is key in determining whether or not CWD access education. The study showed that a school for CWD should:

- ◆ Make the CWD appreciate themselves and be appreciated by others;
- ◆ Be a place where teachers and their fellow pupils others treat them with respect;
- ◆ Be where CWD should be supported to have and strive to attain their aspirations;
- ◆ Help them and others see and acknowledge their worth;
- ◆ Enable them to fit in family and society.

The school environment should however not be:

- √ Exhausting –physically, mentally etc because CWD already put in extra effort to be at school
- √ Inconvenient and therefore uncomfortable
- √ Discriminatory; not having what others have
- √ Non-accommodative; characterised by teasing, abuse etc

Teachers are key determinants for CWD access to and willingness to learn. If a teacher does not know how to deal with a CWD and is insensitive to disability issues, the child and parent cease to make the effort to access education. The biggest draw back in school for CWD is the constant teasing and nick naming from their fellow pupils that they have to deal with. It slowly and surely erodes any sense of self-confidence.

4 *“Do we really want to go to regular schools?”*

Inclusive education for children with disabilities is desirable especially by officials and proponents of human rights because it helps integrate children into their communities and teaches other children how to relate with these children without stigmatisation. In some districts where NGOs or specific CBR programmes are run, there are successful models of inclusive education but these are achieved with high cost in terms of human, financial and logistical resources. These are not available to schools countrywide. In Uganda today, inclusive education is largely not feasible. There aren't enough teachers, facilities and support systems to make this policy feasible. This is further complicated by the negative community attitudes towards CWD and the expenses involved in enabling children to get education. As one respondent noted, inclusion in Uganda only promotes socialisation but all other educational objectives are hardly met e.g. learning.

Children with disabilities who do attend regular school are those who are not severely disabled. For the CWD who can see, hear and have some degree of mobility and are in a disability sensitive school, they have no problem with inclusion.

However, all other children with disabilities do not like attending inclusive schools. This is mainly because other children tease them. Many of the adults with disabilities who have been to regular schools did not savour the experience. Parents of children with disabilities vouch for special schools as opposed to inclusion to protect their children from the torture of teasing and the fact that they are unable to fit in due to the limitations cited above.

Recommendations for action

- ◆ Inclusive education for CWD is largely speaking not feasible and should not be promoted in the current state in which it is, as it negatively impacts on CWD access to education. It should be acknowledged and accepted that CWD cannot fit in the regular schools and need special attention if they are to access education. Lumping them under UPE and the general provisions for primary education simply does not meet the objectives of education.
- ◆ Uganda's policy contrary to that promoted internationally should be setting up special schools for CWD – especially for those with severe and multiple disabilities. This should continue to be the policy until all attendant factors for meaningful inclusive education are achieved. Before Uganda chooses to promote inclusive education it should ensure that it has the instructional materials, a suitably flexible curriculum, facilities, teachers, structures and that a correct attitude prevails especially in the school environment. Short of this, CWD are further prone to suffering abuse and stigmatisation in their bid to access education.
- ◆ UCRNN commends all the non-state actors that are engaging with CWD in education. However, UCRNN is also aware that this cannot go on forever. The government has to face up to its responsibility of providing accessible and quality education for CWD. NGOs can continue to lend a hand, but as a country we need to have a sustainability plan that will support the model initiatives and afford the replication of good practice countrywide.
- ◆ Sensitisation to change attitudes and perceptions about children with disabilities should start to focus more on parents of children without disabilities and on the children of school going age, first in already integrated schools, in order to remove the stigma they cause CWD, to feel and discrimination they practice. Punitive measures should be employed against children who tease and bully CWD (e.g. write them out in a book of shame) and the parents of these children should be involved in correcting the child's behaviour and attitude.

5 “Put us in boarding schools?”

One of the biggest challenges that parents of children with disability continuously face is transport to school. This applies to whatever nature of disability; physical, visual, hearing, mental and multiple. The challenge in getting children to school and back home every day, worse so during the rainy season, has led to dropping out of school. Punishment for late coming is common in most schools – and whether punished or not there is stigma related to reaching school late.

Advocates against boarding schools for CWD argue that it isolates them rather than helping them and the community come to terms with their disability. It does not enhance parent-child relationship. Parents will not quickly learn how to support their own children and some even forget about them when they are in school. The standard of care and communication at home and school style vary and this does not help the children progress evenly.

Advocates for boarding school site the very practical impediment of reaching school daily and the stigma this causes. Besides they are sure that in boarding school, children are assured of professional care 24 hours a day. Children themselves have voiced the desire not to go to inclusive schools but would prefer an environment where they are properly cared for, fit in and have an environment that understands them and prepares them for the outside world.

How do we then synchronise parent's right to choose the style of education for their children, the policy position of being against institutionalisation and therefore promoting community-based approaches; the need to strengthen child-parent relationships and community integration and children's wish not to go to integrated schools?



Recommendations for action

- ✓ Boarding schools, especially for children with major and severe disabilities (special schools) should be one option that parents can choose. Government should not close the door on this option in the name of non-institutionalisation or integration. Government should instead ensure that the standards of care and protection provided in these institutions meet the standards identified by MGLSD and MoE.
- ✓ Visits to the communities and other places important for their education and integration in the community should be arduously promoted as a necessary part of boarding school education of educational and community-integration.
- ✓ Core to the school policy of such schools should be the regular involvement of parents in the school.

6 “What we should learn in school”

Views are split in terms of the curriculum with many believing that the curriculum as it is suitable for CWD. But the curriculum is currently under review. The CWD perspective was only considered when agencies working with these children cried foul. Now there is an opportunity to influence the curriculum review to consider the needs of CWD.

However, certain trends need to be taken into consideration. CWD hardly complete P7 with many reasons being provided for the drop out. This holds true for children without disability as well. However, what needs consideration is the fact that the disability greatly limits any CWD progressing to post primary education – even if they wanted to. Education gets more expensive for them and opportunities less available. Several case studies have shown CWD who pass P 7 but fail to progress because of lack of opportunities.

Another concern about the current curriculum is that it is based on timed exams as opposed to continuous assessment. The method of grading and testing need attention. Due to disability length of exam time and examinations in themselves are unsuitable for CWD.

This situation was the reason given for a very strong call for CWD to study vocational skills while still in primary so that they are self-reliance when they complete. Parents of CWD are strong advocates for this are some of the local government officials. Interestingly CWD like and dislike subjects just like any other children. On the whole, disability does not in any way affect preferences for subjects. But parents and district officials are being pragmatic in proffering the option of a vocational curriculum.

Recommendations for action

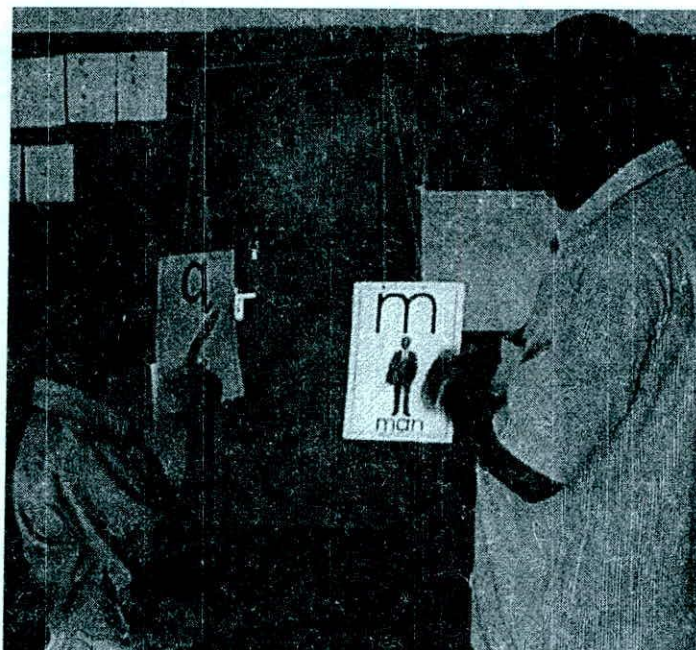
- ♦ The review of the primary school curriculum should seriously consider the inclusion of vocational skills for CWD.
- ♦ The opportunity of curriculum review should provide an opportunity to discuss continuous assessment and grading as an option to exams. Some propose affirmative action of additional points for CWD but this will not help if the post primary institutions do not have facilities to support CWD.

7“Let our teachers teach us”

The central government says that SNE teachers are enough to meet the need in the country. The headmasters say they are too few and some are not properly qualified. Kyambogo has raised the criteria for SNE admission and the quality is improving or is set to do so. The numbers however need to go up. If the ministry thinks the numbers are adequate what is happening to these teachers.

Teachers who qualify as SNE teachers either find other careers and SNE teaching is exhausting and not well paying, or they are posted to other duties in the school system e.g. administration. SNE teachers have been known to be the first to be struck off the pay roll so it is not considered prudent to stick to it. The SNE department says its hands are tied; decentralisation gave the districts and schools the power and authority to make decisions like this.

Given this scenario, many have advocated for a difficulty allowance for these teachers. MoE is against special allowances for SNE teachers and their argument is that the numbers balance out: yes, teaching children with disabilities takes more from the teachers but they have fewer numbers. Those teaching regular children do not have to expend so much energy but have huge class sizes to contend with and this takes it toll in marking, examination etc. Unfortunately the SNE teachers do not usually do only SNE – they are also regular teachers because of the government ceiling on the number of staff per school. This places an extra burden on them and hence their abandonment of SNE teaching.



Recommendations for action

- ♦ The government ceilings on the number of teachers per school should be raised for schools with special needs children.
- ♦ Teachers trained in SNE should be sent to schools that offer SNE
- ♦ Government should open ceilings for trainees of SNE at Kyambogo per year from 50/80 to 100/200 at least.
- ♦ Incentives for SNE teachers do not need to be fiduciary. Incentives can be exchange visits to see what works and how, in-service training, and bursaries for further education etc.

8 *"Don't bribe our parents"*

It has been proposed in several literature that parents are given incentives to take their children with disabilities to school. Many officials are against this idea because education is a right for all children and it is the parent's responsibility to take their children to school. Incentives appear as a bribe and this will create misconceptions and encourage lies and misrepresentation.

It is important to note that parent's demotivation in many cases arises out of the lack of facilities in the school and financial incapacity. Some support is indeed welcome therefore. Support provided to parents that helps their children achieve their full potential is welcomed. This support has been proposed as income generation activities, provision of assistive device, provision of instructional materials etc. However, incentives that create a dependency syndrome and encourage parents to abscond from their parental responsibilities are not welcome.



Another reason why CWD are not in school is because in spite of UPE some parents believe that children with disabilities are not useful and therefore they should not bother to send them to school. Many of the respondents proposed that punitive measures be meted to such parents.

Recommendations for action

- ✓ Parents who do not take their children with disabilities to school for no good reason be impelled by the full force of the law to do so. If necessary punitive measures be applied to them for causing their children's rights to education and absconding in their parental responsibilities. This should be a matter that can be handled in accordance with the provisions in the Children Act Cap 59.
- ✓ Families, communities, local government and the State should rally behind parents of CWD by providing them with support to meet their children's educational needs. Ultimately the State should take responsibility for this. But to be realistic the State and local governments can begin by coordination and showing political will to support this initiative—actively getting involved to show that it acknowledges its responsibility but is only limited by resources (if this is the real reason).

- ✓ Special schools for CWD should fall under the same criteria as UPE schools therefore being subsidised by the State and receiving UPE conditional grants. In allocating money to these schools the districts should be cognisant of the additional expenses necessary to run a special school. Education in these schools should ultimately go to completely free primary education. The curriculum in these schools should be flexible and CWD friendly. See point below on curriculum.
- ✓ For the already existing integrated schools that receive support for CWD from non-state actors; if they are UPE schools, CWD should have all direct education costs that are necessary for their education met by the State. This excludes the ordinary costs met by parents of non-CWD. This compromise is meant to support parents with the essentials without removing their responsibilities that are the same for every parent operating under UPE.

9 *“Our parents should actively engage with our schools”*

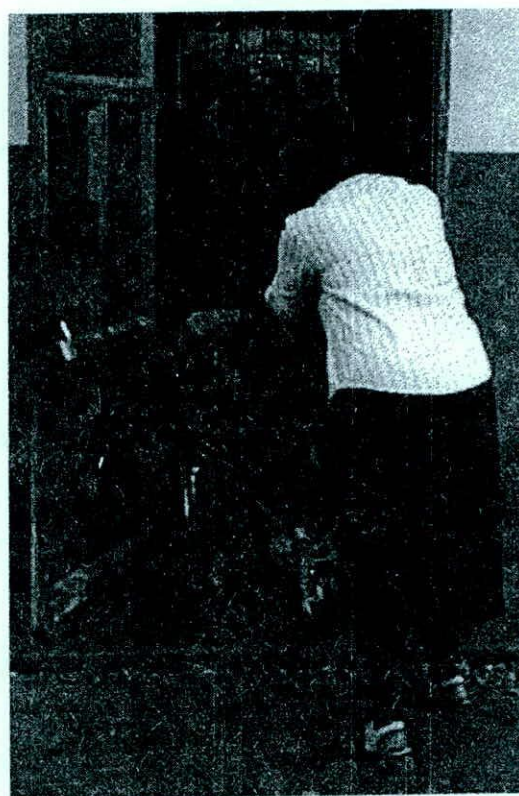
Three key issues come up here:

The school structure provides for School management Committees and Parent Teachers Association. The **parents of CWD** (as opposed to just a person with a disability) should be given an opportunity to participate as active members of both structures – especially the school management committees. As members they can champion the cause for CWD in the school and help the schools become disability friendly. These people can be identified as focal points through which other actors can channel technical support to the school management on CWD issues. This proposal is overwhelmingly supported and in some instances where it has happened, is proving very useful.

Whereas the SFG provides a design for school structures that are disability friendly, these standards are usually not adhered to because of weakness in the tendering system and monitoring at the district level. The technical evaluation committee is sometimes found to be insensitive to the need for these guidelines to be followed. This committee needs to understand the disability issues related to the design and promote it irrespective of the number of CWD currently attending the school in question.

One matter that constantly concerns schools that have CWD and the CWD attending schools is the fact that many parents of CWD neither visit their children at school nor, attend PTA and other school meetings aimed at discussing their children's performance. The worst-case scenario is when parents do not even pick up their children for holidays. Whereas some schools make the effort to involve them parents just do not get involved. This has a profound effect on the children who if in regular schools already have a lot to cope with.

Recommendations for action



- ✓ The Ministry of Education should set a standard and pass guidelines to the effect that one member of any SMC must if available, be a parent of a child with disabilities. MoE should monitor adherence to this guidance or standard during its support and supervisory visits and through its monitoring systems. Interested NGOs should work with the MOE to ensure that this is done.
- ✓ One of the members of the district technical evaluation team that approves SFG tenders should be a parent with disabilities. It is acknowledged that technical district officials make up this team but involvement and consultation if involvement is difficult with parents of CWD who are technically competent would be useful. In the event that there are non, CWD focussed CSO should act in their stead e.g. NUDIPU. This would boost the position of the parent of CWD sitting on the SMC that also monitors the building of the school.
- ✓ School should identify a way of compelling parents of CWD to visit their children to encourage the building of a family relationship.



10 “What about non-formal education?”

The non-formal education policy was developed to provide for children in difficult circumstances that made it difficult for them to access formal education. Among the target groups of the non-formal education policy are children with disabilities.

It was interesting to note that almost all the respondents did not even know of the existence of the non-formal education policy. Of the few who did, they had just heard about it. In Northern Uganda one respondent said the policy had failed due to insurgency – yet the policy also targets those in conflict-affected areas. Other challenges faced in implementing this policy are the difficulty in mobilising the target groups. Even if it was available, communities lack confidence in its curriculum and in the teachers delivering it, because they are in most cases unqualified teachers.

Recommendations for action

- ✓ The policy seems to have suffered a stillbirth. The need to explain it and resource it is critical if it is to impact on the lives of CWD.

11 “Don’t just blame them, help them”

Arguably, parents of children with disabilities are faced with many challenges. Limited resources, an unfavourable school environment for their children, negative cultural attitudes and practices, etc. However, many parents do not know how to deal with CWD. Information on services and opportunities available to support them is not easy to access. Information on prevention, rehabilitation and rehabilitative health hardly gets to these parents – the unknown engulfs them. In such matters we cannot blame them but instead reach out to them to tell them what they are supposed to do and how.

Several calls have been made for outreach programmes as a means of reaching these parents. Many of the government ministries have community-based workers who provide outreach services. More specifically however, proposals have been made for a disability centre to be established in every district and this to reach out to CWD. It has also been acknowledged that information dissemination is costly.

Recommendations for action

It is important that the following be promoted as part of the effort to help prevent disability and promote CWD access to education. The thrust of these activities are to provide parents with useful, timely and necessary information to guide their actions in supporting their children with disabilities and in preventing disability all together.

- Family care practices
- Health seeking behaviour
- Outreach programmes
- One disability centre in every district
- The use of role models
- Home visits

12 “Work together to support us”

MoH, MGLSD, MoE are key ministries in the lives of CWD. At district level these are represented by the DDHS, DPSWO/Community Services officer, District Education Officer and other related actors e.g. the District health Visitor, the District Inspector of Schools, the District Rehabilitation Officer, District Nursing Officer, the District Physiotherapist, Community Development assistants and Village health teams and the SNE department. Then there are the parents of children with disabilities, the Secretaries for children and secretaries for disabilities on the LCs and other non-state actors like NUDIPU and other CSOs. There is in some districts the CBR programme. All these together create an opportunity to create a protective web for CWD’s engagement with education. But they are so poorly coordinated the possible impact is not felt on the ground.

Many in the districts admit that collaboration is possible if only it is conscientiously tried. At the moment most officials do not know what other government policy apart from ‘their own’ say e.g. an official said ‘since I am dealing with formal education, I am not familiar with the non-formal education policy’. A shared mandate for CWD would help reach them more effectively, minimise replication of services, facilitate maximum use of resources and create a sustainable support system for CWD in education. At the moment the non-coordination and collaboration is leading to role conflict, inadequate facilitation and misuse of resources. If the various actors go their act together there would not be over reliance on NGOs to meet the needs of CWD.

Collaboration is badly required in 4 key areas:

- (i) Identifying and registering CWD (see above)
- (ii) Referral
- (iii) Monitoring and systematically recoding and reporting on impact.
- (iv) Funding; pooling resources

Recommendations for action

- ✓ A multi-sectoral approach at district level is necessary and possible. CWD deserve a shared mandate if progress is to be made in terms of their accessing education in our resource-limited country. The initiative only requires creative leadership, and willingness to try and work in collaboration. The time for turf wars are over – they only work to the detriment of CWD.
- ✓ The proposal from one of the respondents should be adopted by all districts and the necessary ministry (MOLG preferably provides guidelines accordingly. CAOs should cause departments that have cross cutting issues to form a joint forum for frank and open discussions on how they can work together to improve the lot of CWD in their district. This joint forum should coordinate their plans, pool resources, carry out joint mobilisation, discuss integrated services and treatment and ensure maximise the use of the meagre resources available.

13 “Clarify our share of resources”

In order for funds to be better allocated to CWD, the numbers need to be known. This said, the issue should not be swept under the carpet. District authorities have the capacity to establish the extent of support required for CWD in order for them to access education and then allocate resources accordingly. One of the most efficient and sustainable ways to deal with this situation is to pool resources from sectors with a common interest in CWD in general and their access to education in particular.

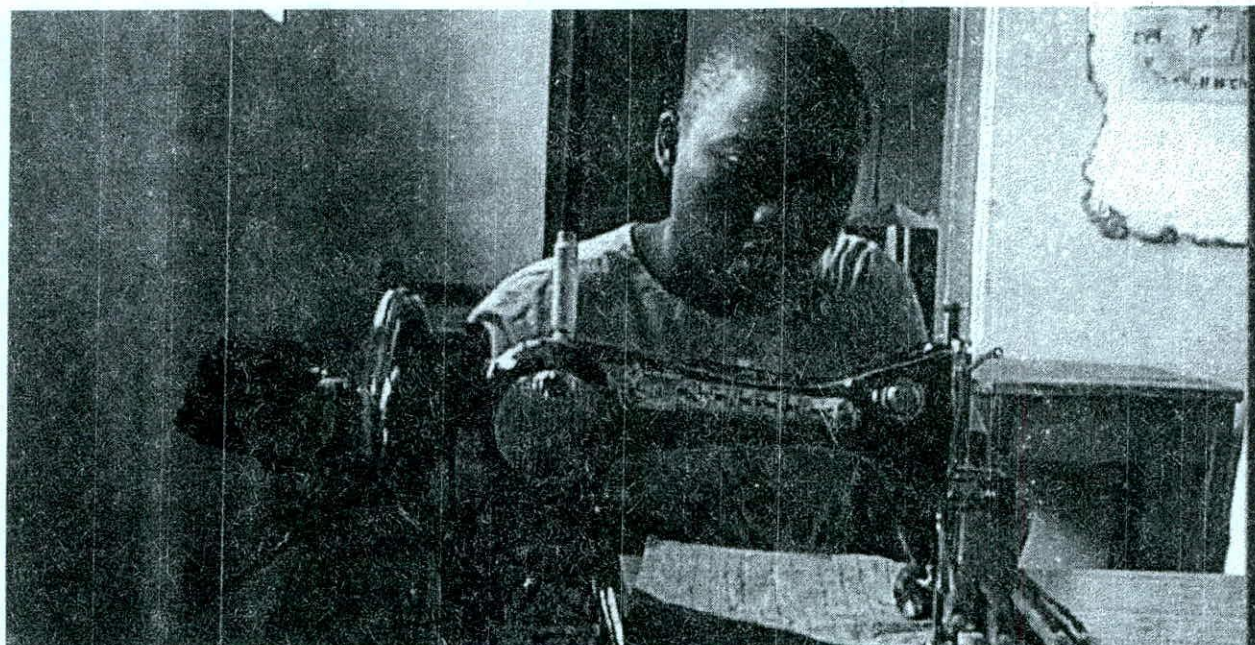
It is argued that ‘departments can never pool resources since budgets are supported and defined by parent ministries’. The option proffered here is that resources should be pooled before allocating money to the department and not after. The pooling of resources should be for the three collaborative areas identified above.

Proposals around providing guidance on percentages of the UPE grants to SNE, the centre said it had no authority. That is a decentralised function. Meetings with district officials to try to persuade them came to nought on the grounds that operationalising the policy was the difficulty. Some have proposed that since decentralisation is failing CWD, then the SNE function should be re-centralised; SNE should be facilitated from central government’s conditional grants and sent directly to the district.

It is also argued that if the government took seriously the education of CWD it would have found ways and means of reducing the cost of assistive and teaching materials for these children – Just as they have for ARVs.

Recommendations for action

- ✓ There is need to continually lobby for the reduced cost of instructional materials and identify cheaper options.



- ✓ There is need to sensitise headmasters on the need to provide for SNE. The buck stops with them regarding allocation of resources from the centre.
- ✓ Stakeholders need to support districts to establish how best allocation of funds to CWD can be operationalised. Guidance is required and should be provided.

14 “Monitoring our education”

How much are schools monitored for integrating CWD? Among the things that school inspectors and currently centre coordination tutors should monitor is enrolment, treatment and teaching of children with disabilities.

Education committees need to be strengthened and supported to effectively play their role in monitoring education provided to CWD at all levels – district to village level. These committees should work with the guidance and the involvement of district education officers.

As pointed out in 9 above, the involvement of parents of children with disabilities in school structures and governance will allow for proper monitoring of education for these children.

15 “Many of us are caught up in conflict areas”

Children with disabilities caught up in conflict areas are doubly jeopardised. Because many schools have moved away from their original locations to other schools or learning centres, CWD have double difficulty in accessing schools.

It is also known that children trek long distances to the town centres to seek protection from rebel attacks and abduction. In the mornings they trek back home or to school for the day only to trek back in the

evening. For children with disabilities, even this unfortunate situation is a luxury to them. Irrespective of the disability trekking to learning centres and back to town proves too much of a burden to them.

Besides making the daily journey to school and town, one questions the value added in putting in the extra effort to reach school. Most CWD find that in over-crowded, under-staffed and poorly structured schools with inadequate facilities, they do not benefit at all from the education being provided. The non-formal education option is further challenged by the security situation. The automatic option for them is not to bother trying to get to school in such adverse conditions.

Recommendations for action:

- ✓ Good practise and lessons learnt from efforts and initiatives by civil society groups like echo bravo and save the children alliance in providing education in conflict affected areas need to be replicated and the question of sustainability through the conflict and in the post conflict era need to be addressed.
- ✓ Special programmes for children with disabilities in conflict areas need to set up within town centres where these children seek refuge from the effects of the conflict.
- ✓ The coalition on education in conflict affected areas need to specifically recognise and address the needs of children with disabilities in these areas.

16 “Our parents have disabilities and it is affecting us”

Many of the respondents cited children of parents with disabilities as the forgotten category in the disability discourse.

Families in which parents/adults with disabilities cannot afford house-helpers, care or assistants pass the burden of providing this support to their children. As a result these children drop out of school to support their parents to provide a living for the family or simply to run errands on behalf of their disabled parents.

Children of PWD also cited little time to play and socialise with other children, a huge workload and the ever-present fatigue that comes along with the numerous tasks they perform and the workloads.

Another challenge that many tend to forget about is that these children are also subject to teasing and abuse from other children and members of the community because of the disability of their parents. Many do not mind dropping out of school because then they do not face the challenge of being teased by both teachers and pupils.

Households of people with disability in more cases than not are poor households requiring support to meet their basic needs. This poverty also affects the children's education as fees and other school related costs are difficult to meet.

Recommendations for action

- ✓ These categories of children would best benefit from non-formal education. Unfortunately this does not receive adequate financial and logistical support from the government.
- ✓ CAWODISA provides some good examples of how collaboration between agencies and donors can identify and support children of parents with disabilities. Lessons and good practise from CAWODISA need to be documented, shared and included in over all government policy and

programming. Special emphasis should be put on ensuring that activities in the OVC national strategic programme plan of intervention that targets these children are resourced, monitored for impact and scalability.

- ✓ Where as the Children Act Cap 59 calls for registration of CWD, these children too need to be registered and targeted for support. The same goes for policies that are meant to benefit CWD to access education; they should take into consideration these children of PWD and give them priority and preferential non – stigmatising treatment.
- ✓ Programmes aimed at reducing discrimination and stigmatisation of CWD should also target CWD. In addition the parents should also be supported in providing due care and support to their children as part of their parental roles and responsibility.
- ✓ The children do not wish to leave their parents unattended or unable to carry on with their daily lives. They propose that help is provided to their families to find carers, assistants or house helps so that their time is freed up for school and they have time to a childhood. Local governments and communities can come to their aid in this respect.

17 Wider issues

Respondents identified wider issues that affect CWD access to education. These include:

- ◆ Decentralisation: low tax base
- ◆ Social security
- ◆ Corruption
- ◆ Lack of accountability

Conclusion

This report presents some of the issues for which action is necessary if parents, communities, local and central governments are serious about enabling CWD, and those whose parents have disabilities, access to a meaningful education. In its advocacy drive for improved access to and quality of education for these children, UCRNN urges all key actors to pick up these issues and work with CWD and other stakeholders to improve the lot for these children.