

Key facts

- 7.2% of the Ugandan population are disabled of whom over half are children under the age of 18. This means that in excess of 1 million children in Uganda are disabled.[1]
- While disability is recognised as both a cause and consequence of poverty, many disabled children come from poor families and most disabled people are poor.[2]
- More than 38.5 % of the Ugandan population survives on less than 1\$ per day and a large proportion of these are people with disabilities.[3]
- Our research also shows that 43% of disabled children are not considered normal by their families and therefore discriminated against.[4]
- The commonest form of impairment among children in Uganda currently is that caused by epilepsy and by brain damage resulting from malaria. The incidence of cerebral palsy is on the rise.
- Barriers to accessing community based rehabilitation services commonly include lack of transport and lack of money to pay for services.
- 90% of medical and paramedical personnel in Uganda were found to have inadequate training and equipment to give appropriate medical care and advice to children with disabilities.
- Enrolment of disabled children in primary schools in Uganda has shown a steady increase since 2002. Almost all districts surveyed showed lower female enrolment than males for every year.
- USDC-supported districts were found to be twice as likely to have Occupational Therapists and a functioning orthopaedic workshop as non-USDC districts.
- 9.6% of disabled people accessed rehabilitation services in USDC-supported districts in 2002, while only 0.1% of disabled people accessed such services in those districts not supported by USDC.

[1] Uganda National Household Survey 2005/6, Uganda Bureau of Statistics.

[2] Charles Lwanga Ntale, Chronic Poverty and Disability in Uganda, 2003.

[3] Ibid, 2003.

[4] USDC Study on Accessibility and Relevance of Education for Children with Disabilities in Uganda, 2003.



AbleChildAfrica

Working with disabled children and young people

Disabled children in Uganda



their lives and our work with them

A study by Uganda Society for disabled children



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The booklet has been produced in memory of Salome Okayi who worked on this project but who sadly did not live to see it completed

1. Introduction



AbleChildAfrica is the new name for the Uganda Society for Disabled Children UK. USDC was founded as a UK-based international NGO working to improve the lives of disabled children in Uganda in 1985. In 2000 the Uganda office became an independent local NGO: Uganda Society for Disabled Children (USDC). The USDC UK

office continued, following the birth of the independent Uganda NGO, to provide technical support and advice and to solicit funds to work in partnership with USDC to implement a variety of activities in Uganda. Since 2003 we have been supported by Comic Relief through an Investment Grant which seeks to build the capacity of USDC as a local NGO in Uganda. One of the activities this grant supported was a baseline survey undertaken in 2005/6. The baseline survey was commissioned and carried out by USDC. It represents a review of twenty years of work by USDC and is at the same time the most comprehensive snapshot of the lives of disabled children in Uganda which has ever been undertaken. AbleChildAfrica now has a broader remit: we are continuing to work with USDC but are also supporting other African partner organisations to carry out life changing work with disabled children. We work alongside all of our partners to use their experience and learning to campaign for more widespread change in attitudes and practice. The close relationship we maintain with USDC inspires our commitment to African-led solutions, and places local ownership and leadership at the heart of our strategy for supporting organisations in Africa working to make a difference in the lives of disabled children.

2. USDC: our key partner in Uganda

The Society for Disabled Children (USDC) is involved in the medical, educational, and social rehabilitation of children and young people with disabilities in Uganda. Unlike many other disability organisations USDC works across a wide range of disabilities that includes physical, hearing impairment and some mental health problems. The USDC mission is to help disabled children and their families to access the resources and opportunities that can enable them to achieve their full potential, by working to remove attitudinal and societal barriers to access. All USDC programmes are underpinned by this people-centred approach to development.

The strategy of USDC is to increase the integration of services for disabled children into mainstream planning, budgeting, and development at all levels of government in Uganda. This work is guided by four objectives

- To increase awareness of disability issues among communities and policy makers.
- To advocate for better policy, increased resources, and better services.
- To build capacity at both government and family level to provide appropriate care and services for disabled children in Uganda.
- To improve the collection, management, and dissemination of information around disability to better inform policy and decision making in USDC, in government, and in partner organisations.

3. Evaluating our work in Uganda: the baseline survey

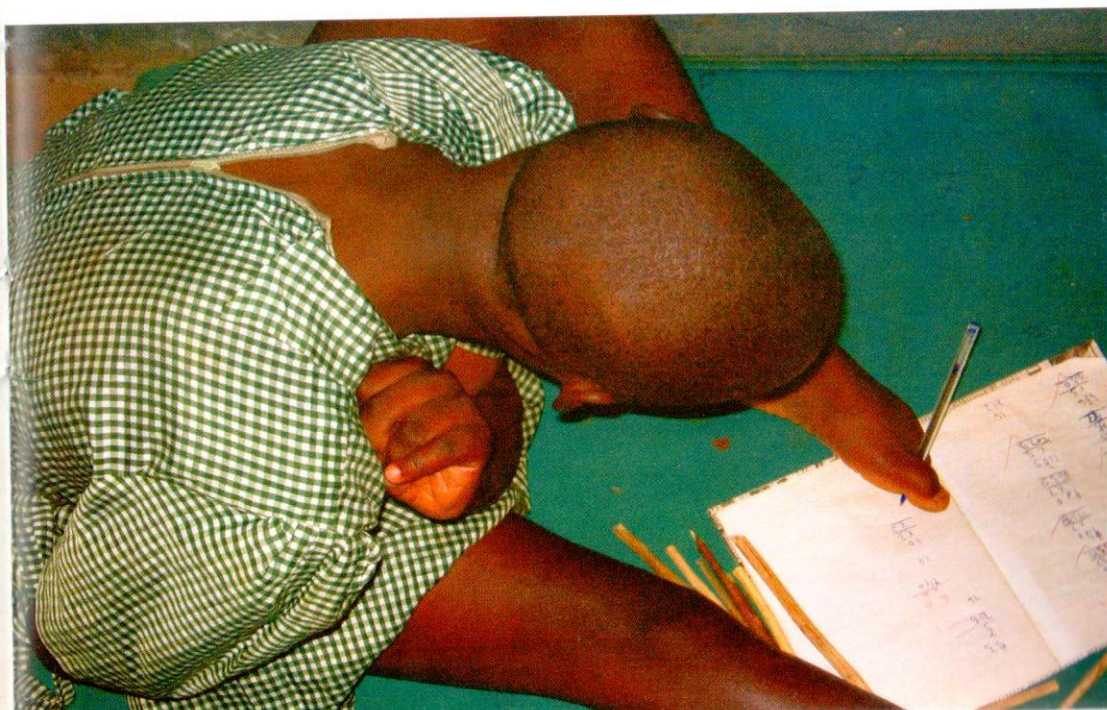
Between 2005- 2006 USDC carried out an extensive study of the situation within the disability field in Uganda, with special emphasis on disabled children. The aim of the survey was to:

- assess the broad impact of USDC's twenty years of work in the field of childhood disability in Uganda
- document best practice and lessons learned from USDC's work and that of other stakeholders in order to inform future development
- identify priority needs and strategic gaps in provision for disabled children in order to determine an effective new country strategy for USDC
- establish benchmarks against which to measure and assess USDC's future work

From within the framework of national development in disability, the survey reviewed progress in the policy arena and its impact on service delivery. The survey work was carried out in fifteen USDC programme districts and eight other districts in which USDC does not currently operate. Survey staff consulted disabled young people, members of parent support groups, leaders of disabled persons' organisations, teachers, medical professionals, special needs education coordinators, local councillors, and district political and technical leaders. Further data was collected from ministries, districts, disabled persons organisations (DPOs), non-governmental organisations (NGOs), community based organisations (CBOs), national bodies such as the Uganda Human Rights Commission, and from an extensive document review.

4. The lives of disabled children in Uganda

According to the 2005/6 Uganda Household Survey 7.2% of the population of Uganda are living with a disability. The prevalence of children under 18 with a disability was found to be 9% overall. Among the districts studied by USDC there is a wide range of disability prevalence. The island district of Kalangala has only 0.9% disability; most people with disabilities prefer to live with relatives on the mainland which has better access to the services they need. Arid and isolated Moroto district in the far east of the country also has a low disability prevalence rate (1.5%) since disabled people have greater difficulty surviving in a nomadic culture and hostile environment. The urban and industrialised Jinja district on the other hand has a disability prevalence rate of 10%.



Physical disability is the biggest element in the total number of disabilities found by the USDC study. The commonest disabilities reported in all districts surveyed are cerebral palsy, learning difficulties, and epilepsy. Epilepsy, although in fact a chronic neurological condition is often linked to mental health problems because of the fact that due to a lack of neurological specialists in Uganda medication for children with epilepsy is usually dealt with by mental health practitioners. Epilepsy is also considered a disability in Uganda because of the stigma attached to epileptic fits. Cerebral palsy is recognised as an increasing disability in Uganda. Physiotherapists also report rapidly increasing rates of impairment from 'injection paralysis' (paralysis of the sciatic nerve as a result of poorly administered intramuscular injections of quinine to treat malaria). Infection of the inner ear in children, with subsequent impairment of hearing that can result in speech and language difficulties, was reported as a significant problem in some districts.

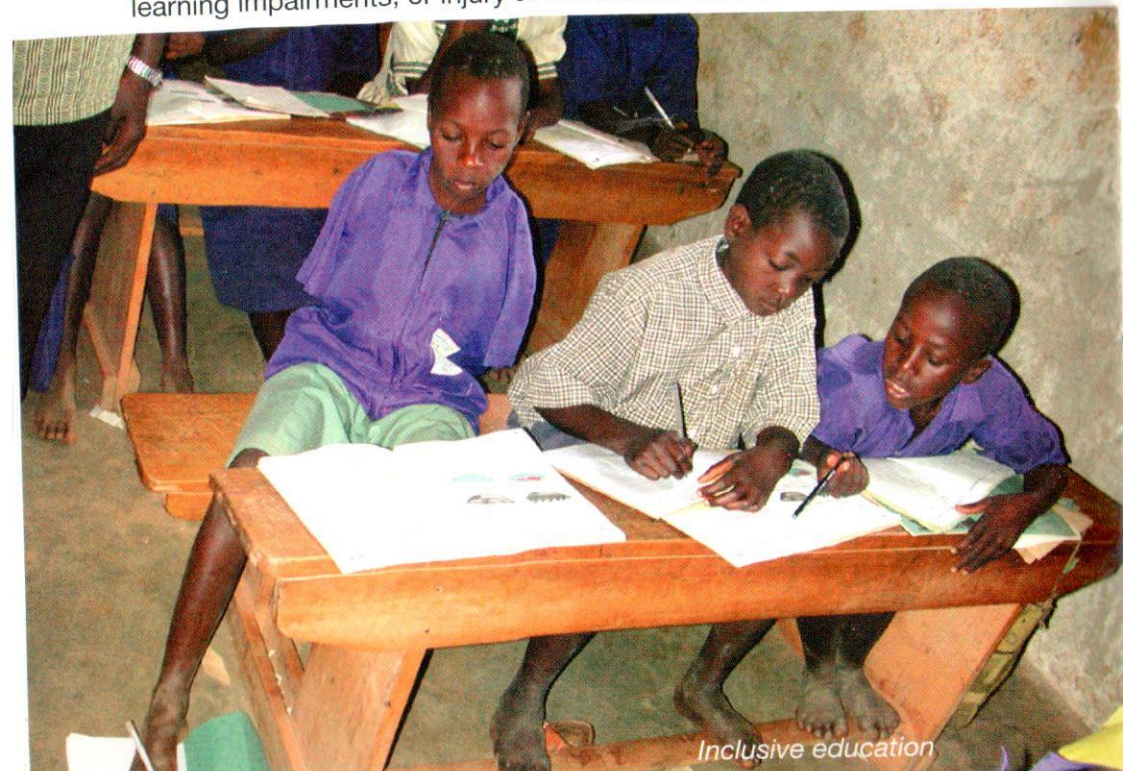
Interviews with parents and health workers suggest that the onset of impairment in children is commonly preceded by a fever. For example, severe forms of malaria can leave survivors with epilepsy, learning impairments, or injury to the brain. Post traumatic stress

disorder (PTSD) and amputation of limbs are among the causes of disability in children in conflict-affected districts of northern Uganda, where disability may also be caused indirectly by the breakdown of medical services and supplies of potable water. Leprosy is no longer reported among disabled children in any district studied by USDC, a fact attributed to a successful campaign of early identification and treatment of children affected. Similarly, a successful immunisation programme is reported to have virtually eliminated childhood polio among children born in Uganda. Children continue to develop blindness secondary to vitamin A deficiency and measles.

Mothers and traditional birth attendants in Uganda were found by USDC to be aware of the biological causes of disability in children, including poor management of pregnancy, failure to immunise young children, and exposure to early childhood illness. Ugandans are well aware of the disabilities that may result across all age groups from injuries, road accidents, war, and the explosive remnants of conflict such as landmines.

In addition to this knowledge, the findings show that many Ugandans believe disability can be caused or influenced by the spiritual world. Parents of disabled children, especially their mothers, often carry the stigma of having produced a child with impairments. Some forms of impairment in children may be considered the result of a curse on the mother from God or the Creator, or the power of ancestral spirits, or of witchcraft at work within the family, to be healed only by spiritual remedies. These beliefs on the part of parents and the wider community may be, to some extent, responsible for the ongoing mistreatment and marginalisation of disabled young people in Uganda. Parents reported to USDC that in the past some disabled children were killed at birth. Perceptions and beliefs that link disability to evil and revenge result in social rejection of disabled children as well as limitations or delays in accessing care, even when services are within geographical and economic reach of the family.

Disabled children were found to be conscious of these negative attitudes towards them, which manifest in denial, rejection, and social exclusion. They are aware that they are socially isolated, denied access to education and medical treatment, and unable to move about as a result of being denied assistive devices. Disabled children



reported to USDC staff that they face abuse directed towards their impairment, and may be teased and bullied by other children, and by adults, neighbours and family members.

These deeply ingrained negative attitudes towards disability, and to children and adults living with disability, which are by no means limited to Uganda nor to Africa, have been shown by USDC to extend to people in positions of responsibility in central and local government, and those charged with delivering social and medical care. This in turn manifests in a lack of commitment to provide for rehabilitation of the physical impairments of children and adults living with disability. Such attitudes lie at the core of the social model of disability which holds that attitudinal barriers transform physical impairments into disability, and experiences of exclusion and marginalisation.

In Uganda, disabled children and adults have historically lived with their families and communities, irrespective of the type and severity of their impairment. During the colonial era a small but significant degree of institutional rehabilitation was introduced to the country, which separated disabled people from their families and segregated some on medical grounds according to their diagnosis.

More recently, in Uganda as in other countries worldwide, disabled people and their allies are now demanding the ability to exercise their rights to dignity, participation, and equality. Approaches to rehabilitation and services have shifted from institutional provision towards community based approaches, which were first adopted in Uganda in 1989. Special needs education was established nationally with support from DANIDA. Significant political developments led to a change in the Ugandan Constitution allowing for the representation of people with disability at all levels of the political process. The Government of Uganda passed a law forming the National Council for Disability in 2003. Three years later came a National Policy on Disability and the National Disability Act (2006) which operationalises the UN Convention on the Rights of Persons with Disabilities. Uganda is one of the few countries that has a minister of state for disability and five members of parliament representing disabled people. So despite widespread and longstanding negative attitudes towards disability and those living with impairments, frameworks are now being set in place in Uganda for disabled children and their allies to use as levers to demand and exercise their human rights.



Parents' Support Group

5. The impact of USDC's work in the focus districts: key findings

The USDC survey focused on three broad areas:

- Awareness, knowledge, perceptions, beliefs and attitudes with regard to disability. These influence what preventive actions and support could and would be provided for disabled young people in Uganda. Better understanding of these attitudes helps to explain the gap between official policies on disability services and on-the-ground provision and experiences, and enables more targeted lobbying and advocacy efforts.
- Rehabilitative health care for disabled children. These provisions to a great extent determine the accessibility of education and skills training for disabled children and young people.
- Education and skills training of disabled children and young people. This is a key determinant of independence and productivity for disabled children, and of their social integration in the longer term.

a) Lobbying and advocacy

The USDC survey outlines an adequate national framework for the provision of services and inclusion of disabled people in national development and in their communities, especially in the light of the adoption of international instruments. However, while laws and policies have been developed in order to address needs, the budgeting processes does not allow these same laws and policies to be effectively translated into district-level budgets and tangible services for disabled children and adults.

At a national level, lobbying and advocacy has targeted the mainstreaming of disability issues in all national programmes in Uganda, especially through legislation, policy formation, the

become orphaned when their parents die of AIDS-related conditions (as well as other illnesses) become even more vulnerable. There are recognised difficulties in communicating safety messages around HIV infection and sexual activity to young deaf people through signing.

The study found that none of the districts and regional referral hospitals surveyed had all the required rehabilitation staff, and this applies particularly to remote districts which are unable to attract or retain staff. USDC-supported districts were better staffed as a result of lobbying district government to employ the required personnel. USDC deploys a strategy of placing rehabilitation staff in a district so that the role of the rehabilitation worker is understood and appreciated, often prompting the district to formally recruit the rehabilitation worker. For the year 2002, 9.6% of people with a disability received rehabilitation services in districts supported by USDC compared to only 0.1% in non-USDC supported districts. Children under eighteen years of age comprise two-thirds of those receiving rehabilitative services in USDC-supported districts, but are only 50% of service users in non-USDC supported districts.

Barriers to accessing rehabilitation services were found to include a lack of rehabilitation staff, the geographical distance to services, and lack of knowledge, money or transport. Service users or their parents may be influenced by concerns over getting good treatment from staff

of another ethnic group if crossing regional borders in circumstances of inter-tribal disputes. Duplication of outreach rehabilitation services offered by user-led organisations and NGOs often means that static services in hospitals suffer from a shortage of staff. Outreach work has been found to be useful, but only so long as services are of a high quality and are backed up with sufficient community-level personnel to provide follow-up care for disabled children. USDC has played a significant role in increasing the availability of rehabilitation workers in supported districts through the provision of mechanisms for the recruitment of trained workers and through in-service training.

d) interventions in the education sector

Certain social attitudes in Uganda routinely deny disabled children and young people the opportunity to engage in meaningful learning. The failure to recognise the special learning needs of disabled children is tantamount to lack of recognition of their rights as children. This lack of recognition undermines the self-esteem and confidence needed by all children to develop to their full potential. Some parents are reluctant to enroll their disabled children in school or pay their school fees, and the higher fees for special schools are prohibitive for many parents.

The USDC survey found that integrated education was suitable for children with mild impairments who have supportive parents, but blind and deaf children with sensory impairments struggle to thrive in the large class sizes and minimal teacher attention found in the average Ugandan school. The assessment and examination system rarely allows extra time for students with impairments. Special schools are few and far between in Uganda. Most were established by and continue to be supported by NGOs and faith-based organisations, and they receive little or no government support. Special schools were found to suffer from inadequate teaching materials and equipment. The lack of a career ladder for trained special needs teachers, and the absence of enhanced salaries make it difficult for special schools to recruit specialist staff. The very short training in special needs education for mainstream classroom teachers renders inclusive education difficult to implement. There is a widespread shortage of Braille equipment and teachers who can translate Braille. All of these factors adversely affect disabled children's performance and



Outreach services

6. The future

Disabled children in Uganda still live under the influence of negative attitudes which permeate not only family and school environments but also affect resource allocations at national and district level. Progress has been made in frameworks such as international conventions, national policies, and strategic plans. However, this progress has not yet translated into widespread tangible action for disabled children and their families.

User-led groups and NGOs, and especially USDC, have been found to play an essential advocacy role in service development in light of the ongoing low level of representation of disabled children. USDC has been found to have positively influenced budgetary allocations to disability in the districts in which it operates. Some districts have used the presence of USDC to fund rehabilitation services and embrace programmes as a district responsibility. However, one of the hindrances to district planning around disability is the lack of reliable data.

The baseline survey carried out by USDC is especially significant in light of the lack of a comprehensive national system for collecting data on disability for planning and monitoring purposes, beyond narrowly defined project-based data collection. Planning and advocacy at all levels is currently based on the World Health Organisation (WHO) estimate of a 10% prevalence of disability in the population rather than around Uganda Census data on disability. The magnitude of disability and its burden on families and the economy is not known, and therefore is not influencing plans and budgets.

For USDC, these survey findings provide an evidence base for influencing and advocacy within Uganda. In addition, the findings will support USDC as it begins to take on an enhanced role as a resource for AbleChildAfrica's wider work in the region, networking with other organisations to promote the rights of disabled children throughout Uganda and in other African countries.

Good progress has been made over the past twenty years in improving the lives of disabled children in education, rehabilitation,

and social integration. USDC has played an important role in influencing policy, service delivery and foregrounding the voices of disabled children and their parents and carers. The work of USDC to target disabled children and their parents, and to involve parents in district branches of user-led organisations has created opportunities to identify and work with disabled people at an early age and to successfully tackle low levels of self-esteem and skills. USDC has succeeded in building a supportive connection with parents, providing services and inputs at a pace in keeping with the capacity of parents and parents' support groups to provide rehabilitation services and better care for their disabled children, rather being driven by external or donor deadlines with little regard for capacity. However, disabled children remain among the most marginalised and poverty-prone members of every community in Uganda.



Physiotherapy unit



Child Rights Clubs

