



## The Uganda Down's Syndrome Association (UDSA)

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# Association's Document Paper Executive Summary

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## Association Executive Summary

**1. Background Information on Down's syndrome**

Down's syndrome (DS) is a genetic abnormality which randomly affects about 1 in 700 to 1,000 babies born throughout the world. It accounts for approximately 5-6 per cent of intellectual retardation. Down's syndrome is caused by an extra copy of chromosome number 21 inside each of the body's cells. Accurate figures on the number of children with DS in Uganda are not available although the number of babies born with DS is estimated at about 1 in 1,000 births. With a Ugandan population of 32 million, this translates to about 32,000 people with Down's syndrome in Uganda and this number continues to grow.

People with Down's syndrome are mentally retarded and suffer from a wide array of other illnesses, such as premature aging with development of Alzheimer's disease before the age of 40, short stature and flaccid musculature, frequent opportunistic infections, autoimmune disease, hypothyroidism, leukemia, and heart defects among others. Newborns with Down's syndrome may be lethargic, rarely cry, and have extra skin around the neck. Children and adults with Down's syndrome may have slanted eyes, flattened nose, large tongue, small ears, short fingers, and broad hands, and have difficulty performing routine daily activities. Children have learning disabilities and impairment of some kind and have significant hearing and sight problems. Chances of developing thyroid disease, senile dementia and heart problems are relatively high.

**2. Background Information on UDSA**

UDSA acts as a coordinating, facilitating and enabling body of and for individuals, groups of persons, communities and organizations/institutions involved in helping people with Downs Syndrome. The Association is a charitable, non-profit making, non-political, non-denominational, voluntary Non-Governmental Organization.

The Association works in the following sectoral areas (SAs): Health (including HIV / AIDS voluntary testing and treatment), Education, Income Generation and, Counseling and Social Welfare Services. Awareness raising, lobbying, advocacy, HIV / AIDS, gender and environment are all cross cutting themes in our work.

The Association is currently operating in Kampala District but, intends to extend to Eastern Uganda in the districts of Pallisa, Amuria and Soroti over the next four years (2012-2016). Thereafter, the Association could spread to the entire country using those ten initial target districts as a "spring board". The Association target group is children below the age of 20 years that have Down's syndrome and their families or caretaking households. Our special focus is on poor households and families that cannot afford most of the basic social services.

For children, the Association facilitates their access to and supports them in receiving specialised health services (including HIV / AIDS voluntary testing and treatment), specialised education and vocational training and counseling services in order for them to be able to lead meaningful and productive lives as adults.

And, for the victim's families/households, the Association promotes and supports income generating Associations and product value chain development in order to contribute to their families' improved household incomes and livelihoods. In addition, the Association provides counseling and social care services to them in order to mitigate the psycho-social stigma and effects associated with having some family members with Down's syndrome and/or H IV/AI DS so as to enable them improve on the victims' care and management. The income generation component also serves to ensure sustainability of the Association.

### **3. Strategic Challenges**

#### **4.**

#### ***Lack of Specialized Health Care Services***

Children born with DS in Uganda do not get the necessary routine specialised health care services that they require. Because of their unique position in the society, they need specialized attention of specialists such as; Physiotherapists, Pediatricians, Ophthalmologists, Dermatologists, etc. In addition, bureaucracy involved in medical institutions is long and discourages parents of the children from having them access the necessary specialized medical care. More so, the existing centers for children with disabilities in the country tend to concentrate only on other physical disabilities such as blindness and bodily physical handicap and no special attention is paid to children with Down's syndrome. This overall situation makes the life of children born with DS very unbearable and precarious in that, they are not able to access the appropriate medical facilities and they do not attend specialized medical centers.

#### ***Lack of Specialized Educational Services***

In Uganda, the major concern is that there are no special support services for children with DS and yet they can not cope in a relatively structured environment of general special needs education. The result is that fewer children with DS in Uganda do not attend both mainstream and special needs schools. The existing centers for children with disabilities in the country tend to concentrate only on physical disabilities such as blindness and bodily physical handicap and no special attention is paid to children with DS. The few that exist are very expensive, have limited capacity and facilities. This is compounded by the fact that parents do not bother to take these children to school thinking that their fate is sealed at birth. And, the few who happen to go to school, teachers neglect them as these children cannot easily cope up with the rest in class as they are slow learners. At the end of it all, they get discouraged and abandon school altogether. In addition, there are no tailor made vocational training courses for these children.

However, children with DS can develop and learn throughout life, increasing skills in the same way as other children, but at a lower space. A child may seem "stuck" at a certain stage, but during such phases new skills are being consolidated, and new foundations laid for the next step. With the correct type and level of support, many of the children with DS can develop academic skills.

#### ***Lack of Counseling and Social Welfare Services***

The major problem faced by children born with DS in Uganda is that of neglect by parents, relatives and state institutions. There is little parental care of these children as parents/guardians neglect them and are in most cases confined indoors under unbearable conditions. Also, local communities always reject children with DS

and there is segregation. These children are most often than not denied access to basic things like food, beddings and clothes and are also not allowed in most cases to eat or mix with the rest of the children.

### ***Poverty***

A large proportion of families with children with DS that the Association is targeting are not engaged in income generating activities for social transformation and the poorest of the poor are not being helped at all!. Hence, their productivity and household incomes are very low. Also, parents willing to take their children school cannot do so because the fees in existing special needs education centers are very high and prohibitive.

### ***Lack of Community, Civil Society and Government's Awareness***

There is very little input from Government, NGOs and local communities into these children's education, health and socio-economic well being. For instance, save this Association, there is no other single association or group of individuals that is directly involved in assisting people with DS leading to lack of coordination and collaboration between and amongst families with children with DS. This has meant that, parents of the children are not mobilized for the common cause of helping their children. This is compounded by the fact that, their parents/guardians are ignorant about DS facts and issues.

## **5. Association Purpose Statement**

**Vision:** The vision of UDSA is: *"A healthy, literate and economically secure Uganda Down's Syndrome community with equity that is well integrated into the overall Ugandan society".*

**Mission:** *"To have a well organised and facilitated Down's syndrome community that has access to specialised health, educational and counseling services and contributes towards poverty reduction in Uganda".*

**Core Business:** Our Core Business is empowerment of victims of Down's syndrome with a focus on children under 20 years and their families/caretakers.

## **6. Association Strategic Objectives and Strategies**

- i. To facilitate access to specialised and appropriate health services (including HIV / AIDS voluntary testing and treatment) for children born with Down's Syndrome in order to enable them to lead healthy lives. To achieve this, DOSH EWPU shall enhance the capacity of affected families to enable their children access specialised health <sup>1</sup>services (including HIV / AIDS voluntary testing and access to ARVs treatment) by; creating awareness and linkages and, strengthening coordination mechanisms, networks and alliances, and linking them to health services providers as well as meeting costs of those services rendered.
- ii. To facilitate access to specialised education and vocational training for children born with Down's syndrome in order to enable them learn, achieve their full potential and lead meaningful

and productive lives as adults. In this regard, UDSA shall enhance the capacity of affected families to enable their children access specialised education and vocational skills training by; creating awareness and linkages and, strengthening coordination mechanisms, networks and alliances, and linking them to special needs education and vocational training services providers as well as meeting costs of their education.

- iii. To provide counseling and welfare services to children born with DS and their families or caretakers in order to mitigate psycho-social effects on them and improve on the victims care and management. We shall enhance the capacity of affected families to enable them reduce the stigma and vulnerability of children born with DS by; creating awareness, strengthening coordination mechanisms, networks and alliances, and linking them to counseling services providers as well as meeting costs of those services.
- iv. To promote income generating activities and improve the livelihoods of households and families that have or that care take children born with Down's syndrome and ensure sustainability of the Association. The UDSA approach shall be oriented towards developing entrepreneurship and vocational skills and value chains that address unique economic challenges faced by victims of Down's syndrome and results in improved livelihoods and incomes of the beneficiaries.
- v. To raise awareness at all levels on the magnitude and associated health, educational, socio-economic and development implications of Down's Syndrome on the Ugandan society.

## **6.0. Stakeholders and Strategic Partners**

Our stakeholders and strategic partners are: the Local Community; Central and Local Governments; Civil Society; Private Sector and Development Partners:

## **7.0. Health Sector Implementation Plan**

It is the strategic intent of this Association to provide health care services to these children by facilitating and supporting their access to specialised and appropriate health services (including HIV / AIDS voluntary testing, counseling and treatment) in order to enable them to lead healthy lives.

In order to achieve that, the Association shall ensure that, from birth up to the age of 20 years, children with DS have contact with specialised health professionals. These shall be government hospital based consultants or consultants in private practice who the Association shall pay for their special services. In that case, the Association intends to enter into various Memoranda of Understandings (MoUs) with various institutions and health service providers for the provision of specialised medical and health care services to children with DS that the Association will be working with.

In that regard, the Association intends to do the following:

- Enter into an arrangement with Health Service Providers (HSPs) for the provision of health services to the children born with Down's syndrome;
- Sign a health service provision contract with HSPs renewable every after year in line with the contract date for a period of five years;

- For the first 2 years, the Association will provide health services for 100 children (from Kampala), and for the next 3 years 400 children (including 300 from Pallisa, Amuria and Soroti).

## **8.0. Education Sector Implementation Plan**

This Association endorses the government of Uganda policy on Universal Primary and Secondary Education believing that, all children will receive the appropriate level of education. On the same note, the Down's syndrome Association believes that, it is the duty of the central government and all local authorities and municipalities to provide the best education and care for all children with disabilities. This should include both mainstream and special education needs provision.

However, this Association notes that, mainstream education may not be appropriate for all children with DS. It should be recognized that some children have complex and profound needs that they require support offered by Special Needs Schools. In that regard, parents and children with DS must be part of the decision making process from the beginning regarding the most appropriate educational environment. The central and local authorities should therefore support the educational choice made by the parent and child, by putting the appropriate facilities and resources in place that will help support the successful inclusion of the DS children in school throughout their years within the chosen educational environment.

The amount of support required in relation to supporting children with DS in the classroom, differentiation of the curriculum and helping them to be included within the school community will have to be adapted to support their needs. They should have choice and support to attend mainstream or specialized schooling as appropriate. Young people with DS should be supported to stay on at school until the age of 20. After this, options should include further education, youth training and work experience. Vocational training areas targeted include tailoring, cookery, masonry, carpentry, poultry and animal husbandry.

It is therefore, the intention of this Association is to have children born with Down's syndrome access specialised education and vocational training and be able to achieve their full potential and lead productive lives as adults. To that end, UDSA will enhance the capacity of affected families to enable their children access specialized education by; creating awareness, strengthening coordination mechanisms, networks and alliances, and linking them to special needs education services providers as well as meeting costs of the education of the children. Pre-school children shall benefit from early intervention in physiotherapy, occupational therapy, speech and language therapy and special educational help. However, parents will meet costs of texts books, uniforms, beddings, clothing and personal effects. We shall also advocate and lobby for material and financial assistance for the victims to enhance their welfare at school. However, the ultimate goal is to construct an integrated and self sustaining school facility once the funds are available.

In that regard, the Association intends to do the following:

- The Association will enter into special arrangements with several Schools of Special Educational Needs and sign MoUs with them for the provision of specialized education to children with DS
- The school enrolment for the first 2 years will be 20, the next 3 years 50;
- The Association will meet the costs of tuition, feeding and boarding for each;

- The parents will meet costs of; beddings, uniforms, text books and personal effects;

## 9.0. **Counseling and Social Welfare Sector Implementation Plan**

In Uganda, the birth of a child with DS to a family in itself causes a lot of family breakdowns. Husbands often accuse their wives as being responsible for the fate of their child with DS. In the process, there are a lot of family conflicts and quarrels. The situation is aggravated further in some families where the couples have also fallen victim to HIV / AIDS. More often than not, these couples end up separating and this makes life of the children with DS even more vulnerable. In nutshell, there is a lot of stress and tension in most families with children that have DS and these needs to be addressed.

Our strategic goal is to mitigate the psycho-social effects of Down's syndrome in children born with it and their parents or caretakers. In that regard, the Association's immediate objectives in this sector are to:

- i. Train the parents/careers of children with DS on the skills of care and management of children with DS;
- ii. Train and develop Psycho-Counseling Assistants to provide emotional and psychological support to children with DS and their families;
- iii. Conduct outreach visits and offer counseling services to the affected families in particular and the general community in particular;
- iv. Offer peace building and conflict resolution services to families that are experiencing conflicts; and Develop a Down's Syndrome Training and
- v. Counseling Manual based on the experience in the field.

## 10.0. **Income Generation Sector Implementation Plan**

A large proportion of families with children with DS that the Association is targeting are not engaged in income generating activities for social transformation and the poorest of the poor are not being helped at all. Hence, their productivity and household incomes are very low. Also, parents willing to take their children to school cannot do so because the fees in existing special needs education centers are very high and prohibitive.

This Association therefore, seeks to promote income generating Associations and product value chain development in order to contribute to the victim's and their families' improved household incomes and livelihoods and to ensure the sustainability of the Association. The overall aim of this sector is to generate funds for the future sustainability of the Association beyond the first ten years of the seed donor funding by using the internally generated funds from the income generating projects. The strategic goal is to have viable and sustainable income generating projects and product value chains and the beneficiaries' household incomes and livelihoods improved and the projects well integrated and self sustaining.

To achieve that, the following enterprises have been selected depending on their viability, sustain ability and support in the targeted districts:

- Boer goat rearing;
- Pig production;
- Poultry farming

- Bee keeping
- Tailoring project

The outputs shall include but not limited to: milk, goats, weaned piglets, off layers, eggs, honey and associated by products. The target markets being: higher institutions of learning, NGOs, hospitality industry, lower and higher government institutions/departments, business community and local community.

The Beneficiary Outreach Program (BOP) shall *see* the establishment of the targeted income generating enterprises at household level targeting specifically those households with children with DS. The aim of the BOP is to improve household incomes of parents/carers of children with DS. It will also serve as a means for them to generate some funds to assist the Association run the health, education and welfare sector in form of token community contributions. Such contributions may include scholastic materials and personal effects for their children while at school. The BOP shall be run exclusively by Association beneficiaries with financial and technical support and backstopping from the Association staff.

In order to enhance beneficiary capacity and to adequately empower them, the Association shall conduct house level and on farm training courses for beneficiaries focusing on modern production technologies for small ruminants, poultry and bees. Lastly, but not least, the Association shall enter into special arrangements through MoUs with the National Agricultural Advisory Services (NAADS) to provide livestock advisory services to the communities within the Association's areas of jurisdiction and operation.

The Beneficiary Outreach Component (BOP) shall be directly linked to the Board and on-farm propagation programs headed by the Farm Manager (FM) of the Association Managed Program (PMP) through the respective Enterprise Management Committees (EMCs). The day to day running of family and household level Association supported initiatives shall be the overall responsibility of the respective beneficiaries' families/households. All the revenues, profits and other benefits thereof accrue directly to the respective households.

However, the Association Board and Secretariat shall play a leading role in terms of policy, strategic planning, technical support provision and oversight functions. More particularly, the role of the Association at family/household level shall be to:

- Select with the assistance of the existing local government structures the initial target beneficiary households;
- Provide each beneficiary family/household with initial funding and inputs for the identified and agreed upon enterprises;
- Develop in consultation with the beneficiaries a detailed guidelines on supply chain system of the animals and poultry in order to cover all the intended beneficiaries;
- Provide free of charge the subsequent beneficiaries in the expanded program in the districts not in the current 10 year program with the under mentioned inputs from the PMP's farm after the initial ten year donor seed funding;
- Provide beneficiaries with entrepreneurship and vocational training skills on various enterprise production and development;



- Provide household level extension and outreach services;
- Provide household level technical advice and back stopping from the technical arm of the Secretariat;  
Create networks, linkages and partnerships with the various sector key players;
- Develop market value chains for the various enterprises;
- Market the various products and services;

## 14.0. Overall Association Budget

Table 1 below shows the overall Association budget for the five year planning period. However, this budget estimates only indicate the funding gap where donor funding is required. The beneficiary, local community and founder member contributions are not included.

**Table 1: Overall Association Required External (Donor) Funding (2011 to 2016)**

| Sector                        | Qty /No of children                      | Freq per year. | Rate in US \$ | Year 1        | Year 2        | Year 3        | Year 4        | Year 5        |
|-------------------------------|--|----------------|---------------|---------------|---------------|---------------|---------------|---------------|
| <b>Health</b>                 |  |                |               |               |               |               |               |               |
| Medical bills (basic needs)   | 100 kids for y1, y2 and 300 for y3, - y5 | 4 visits       | 12.5          | 5,000         | 5,000         | 15,000        | 15,000        | 15,000        |
| <b>Sector Total</b>           |  |                |               | <b>5,000</b>  | <b>5,000</b>  | <b>15,000</b> | <b>15,000</b> | <b>15,000</b> |
| <b>Education</b>              |  |                |               |               |               |               |               |               |
| Schools fees cost             | 20 for y1,y2 and 50 for y3-5             | 3 terms        | 150           | 9,000         | 9,000         | 22,500        | 22,500        | 22,500        |
| <b>Sector Total</b>           |  |                |               | <b>9,000</b>  | <b>9,000</b>  | <b>22,500</b> | <b>22,500</b> | <b>22,500</b> |
| <b>Awareness Raising</b>      |  |                |               |               |               |               |               |               |
| Staff SDA/DSA                 | 5 – 10 staffs                            | 12 month       | 100           | 6,000         | 6,000         | 12,000        | 12,000        | 12,000        |
| Materials                     | Lumpsum                                  | 12 month       | 50            | 600           | 600           | 1,200         | 1,200         | 1,200         |
| Consultants' fees             | Once,y1,y2and twice y3-5                 | 4 times        | 200           | 800           | 800           | 1,600         | 1,600         | 1,600         |
| Participants meals, transport | 50 people for y1,y2 and 100 for y3 - y5  | 4 times        | 50            | 10,000        | 10,000        | 20,000        | 20,000        | 20,000        |
| Venue hire                    |  | 4 times        | 1,000         | 4,000         | 4,000         | 4,500         | 4,500         | 4,500         |
| <b>Sector Total</b>           |  |                |               | <b>21,400</b> | <b>21,400</b> | <b>39,300</b> | <b>39,300</b> | <b>39,300</b> |
| <b>Income generation</b>      |  |                |               |               |               |               |               |               |

|   |   |                   |     |                |                |                |                |                |
|---|---|-------------------|-----|----------------|----------------|----------------|----------------|----------------|
| Goats                                   | 50 for y1,y2 and 120 y3 – y5            | Once              | 400 | 20,000         | 20,000         | 48,000         | 48,000         | 48,000         |
| Pigs                                    | 50 for y1,y2, and 120 y3 – y5           | Once              | 100 | 5,000          | 5,000          | 12,000         | 12,000         | 12,000         |
| Poultry (incl. transport, initial feed) | 2,500 birds for y1,y2 and 5,000 y3 – y5 | Once              | 5   | 12,500         | 12,500         | 25,000         | 25,000         | 25,000         |
| Bee keeping                             | 250 bee hives y1, y2 and 1,600 y3 – y5  | Once              | 100 | 25,000         | 25,000         | 60,000         | 60,000         | 60,000         |
| <b>Sector Total</b>                     |   |                   |     | <b>62,500</b>  | <b>62,500</b>  | <b>145,000</b> | <b>145,000</b> | <b>145,000</b> |
| <b>Office running</b>                   |   |                   |     |                |                |                |                |                |
| Volunteer allowances                    | 10 people for y1, y2 and 15 y 3- y5     | 12 month          | 200 | 24,000         | 24,000         | 36,000         | 36,000         | 36,000         |
| Office                                  | Once                                    | 12 month          | 100 | 1,200          | 1,200          | 1,500          | 1,500          | 1,500          |
| Electricity                             | Once                                    | 12 month          | 50  | 600            | 600            | 650            | 650            | 650            |
| Water bills                             | Once                                    | 12 month          | 20  | 240            | 240            | 300            | 300            | 300            |
| Telephone                               | Once                                    | 12 month          | 50  | 600            | 600            | 650            | 650            | 650            |
| Transport costs                         | 10 people y1, y2 and 15 for y3 – y5     | 12 month          | 50  | 6,000          | 6,000          | 9,000          | 9,000          | 9,000          |
| Stationery                              | Lumpsum                                 | 4 times in a year | 100 | 400            | 400            | 450            | 450            | 450            |
| <b>Sub-total</b>                        |   |                   |     | <b>33,040</b>  | <b>33,040</b>  | <b>48,550</b>  | <b>48,550</b>  | <b>48,550</b>  |
| <b>Grand Total</b>                      |   |                   |     | <b>130,940</b> | <b>130,940</b> | <b>270,350</b> | <b>270,350</b> | <b>270,350</b> |

