

## Strategic Objectives, Goals and Strategies

**Health:** To facilitate access to specialised and appropriate health services (including HIV / AIDS voluntary testing and treatment) for at least 1,000 children born with Down's Syndrome from birth up to the age of 20 years by 2016.

To achieve this, UDSA enhances the capacity of affected families to enable their children access specialised health 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.

However, the long term plan is to construct a self contained, integrated and self sustaining specially designed and tailored health facility for children with DS by 2016 once the funds are available.

**Education:** To have by at least 1,000 children born with Down's Syndrome that have accessed specialised education and vocational training by 2016 and have attained a potential to lead productive lives as adults.

In this regard, UDSA strives to 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.

**Counseling Services:** Our strategic goal is to mitigate psycho-social effects of Down's Syndrome in at least 7,000 victims and their parents/caretakers by 2016.

The strategy is; enhancing the capacity of affected families to enable them reduce the stigma and vulnerability of children born with DS and/or HIV / AIDS through; creation of awareness, strengthening coordination mechanisms, networks and alliances, and linking them to counseling services providers and meeting costs of those services as well as provision of material assistance.

**Income Generation:** Our goal is to have viable and sustainable income generating projects and product value chains that lead to the beneficiaries' household incomes and livelihoods increase by at least 50% by 2016. The UDSA approach is oriented towards developing entrepreneurship and vocational skills and

value chains that address unique economic challenges faced by victims of Down's Syndrome in the following enterprises: Boer goat rearing; Pig production; Poultry farming; Bee keeping.

### Association Core Values:

In order to give effect to our vision and mission, the following are our team, personal and professional values:

**Equity:** To promote equity by providing equal health, educational, socio-economic and counseling opportunities for all to benefit. serve and excel by upholding fairness and justice.

**Trust:** To practice trust by being a team that is reliable, dependable, committed and honest with each other and stakeholders as we serve people with Down's Syndrome and their helpers.

**Respect:** To value and accommodate other people's opinions, views, and contributions and to acknowledge their values, traditions and customs irrespective of their status in society.

**Diversity:** To recognize, accept and value the differences that exist within the people we work and live with, and use their differences as a learning experience and to enrich our work.

**People centeredness:** To work in a manner that values people for who they are and to enable them to participate in and have ownership of their development efforts to address Down's Syndrome issues.

**Professionalism:** To exhibit maximum professional conduct in the facilitation of the provision of sustainable health, education, counseling and economic services in order to satisfy beneficiary expectations.

**Dignity:** To recognise and value the uniqueness and worth of every individual in society in their own right.



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

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### Background Information on Down's Syndrome and its Effects

Down's syndrome (DS) is a genetic abnormality which randomly affects about 1 in 700 to 1,000 of babies born throughout the world. Down's syndrome is caused by an extra copy of chromosome number 21 inside each of the body's cells.

Children born with DS in Uganda are estimated at about 1 in 1,000 births. With a Ugandan population of 32 million, this translates to about 32,000 people with DS in Uganda.



*Two of the children the Association is helping*



People with Down's syndrome are mentally retarded and suffer from a wide array of other illnesses and frequent opportunistic infections such as; Alzheimer's disease, autoimmune disease, hypothyroidism, leukemia, and heart defects among others. Newborns with Down's syndrome and

adults 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.

### Strategic Challenges in the Ugandan Context

- ☞ Lack of Specialised Health Care Services
- ☞ Lack of Specialised Educational Services
- ☞ Lack of Counseling and Social Welfare Services
- ☞ Poverty among affected households
- ☞ Lack of Community, Civil Society and Government's Awareness

### Background Information on UDSA



*Executive members chatting after a meeting held in its head office*

UDSA is duly registered under the Non-Governmental Organisations Registration Statute, 1989 as a local NGO (Certificate No. S. 5914/6639). 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.

### Thematic Focus

The association works in the following sectoral areas: 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 and they are integrated into all the project sectoral area strategies and annual operational plans.

### Geographical Areas of Operation

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 five years (20014-2016),

### Target Group and Associations's Focal Areas of Support

The association target group are children below the age of 20 years that have Down's Syndrome and their families or care taking households. Our special focus is on poor households and families that can not 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 projects 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 HIV/AiDS so as to enable them improve on the victims' core and management.

### Current and Projected Beneficiaries

Currently the association has over 100 children registered with us that have Down's Syndrome in Kampala District in Nakawa and Makindye Divisions alone. Taking the average family size in Kampala of six people per family, this means that 600 more family members are set to benefit from the association's services bringing it to a total of 700 people in the two divisions of Nakawa and Makindye alone.

Using the same working targets of 700 people per district as in Kampala, by 2012, the direct beneficiaries will be over 2800 people in total having expanded to Amuria, Pallisa and Soroti Districts.

### Project's Present Technical Capability

The association's current blend of multi disciplinary expertise consists of 13 professionals.

They are: Chairperson for overall policy oversight and relations management; 1 Chief Executive Officer for Strategy Development and Planning; 1 Education Coordinator; 1 Health Coordinator and 2 Health Practitioners; 1 Legal Advisor; 1 Finance Officer; 1 Income generation Coordinator; 1 Social Services and Welfare Coordinator; 1 Counseling Coordinator, 1 Records/Clerical Officer. One more Coordinator for Market Access is planned for during 2012.

### 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"*.



*Some of the members in an executive meeting held at the association office*

**Mission:** The UDSA mission is: *"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.