

# ROWAN'S DOWN SYNDROME AWARENESS CENTER

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*"support for people with Down Syndrome"*



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## RDSAC ANNUAL REPORT FOR 2022

NO	ITEM	DESCRIPTION
1	<b>Membership</b>	<b>REGISTERING ALL PEOPLE WITH DOWN SYNDROME IN BUNYORO</b>
	Objectives	<ul style="list-style-type: none"> <li>To register all the people with Down Syndrome in Bunyoro for mutual support and therapy.</li> <li>To provide information concerning Down Syndrome to all families having people with Down Syndrome.</li> </ul>
1.1	Target of the program, (participants to reach out)	<b><i>All people with Down Syndrome in Bunyoro</i></b>
1.2	Summary of what happened, including achievements. Insights of what the program entailed	<ul style="list-style-type: none"> <li>We registered some new members and now the organization is having a total of 80 people with Down syndrome from the four districts of Bunyoro where by 22 in Masindi, 34 Hoima, 14 Buliisa and 10 Kikuube District, having 42 males and 38 females registered for mutual support and therapy.</li> <li>We lost 2 members this year and died because of heart complications. The prolonged period of fundraising have been a big limitation to us saving the children we have identified at an advanced age.</li> </ul>
1.4	Challenges, what are those things that posed a threat to the successful implementation of the program	<p>We faced the following challenges while implementing this program</p> <ul style="list-style-type: none"> <li>There was denial among some parents who never wanted to believe that their children are having the condition.</li> <li>There are so many misconceptions in the community which make parents hide their children from the general public making it hard for us to identify them.</li> </ul>

		<ul style="list-style-type: none"> <li>There is a lot of ignorance in the community about the condition in a way that it's not easy for people including some health workers to identify Down Syndrome.</li> </ul>
1.5	Recommendations, way forward (what were the follow up actions)	<p>Going forward in the next year, the following actions Must be taken</p> <ul style="list-style-type: none"> <li>Increase on the awareness creation strategies including radio talk shows and extending the trainings to VHTs</li> <li>Recruiting more volunteers to assist with the program activities.</li> <li>Request members to become ambassadors in the identification of new cases in the community.</li> <li>Using our members as ambassadors to reach out to more people within their communities.</li> </ul>
<b>2</b>	<b>Therapy Services</b>	<b>PROVISION OF APPROPRIATE THERAPY SERVICES TO PEOPLE WITH DOWN SYNDROME.</b>
2.1	Objectives	<ul style="list-style-type: none"> <li>To ensure functional independence among people with Down Syndrome.</li> <li>To promote the quality of life among people with Down Syndrome.</li> <li>To prevent further deformity among people with Down Syndrome.</li> </ul>
2.2	Target of the program, (participants to reach out)	<b><i>All people with Down Syndrome with a priority to children below 8 years</i></b>
2.4	Summary of what happened, including achievements. Insights of what the program entailed	<p>In the year 2022, the program conducted and implemented the following activities</p> <ul style="list-style-type: none"> <li>Started up a weekly therapy activities day which happens every Friday of the week at the offices in Kanenankumba.</li> <li>Continued with the monthly outreaches for provision of the services and conducted 12 therapy sessions at Kigorobya HC IV and, 8 therapy sessions at Kibaire HC II. Initiated a play scheme treatment approach at Kigorobya HC IV.</li> <li>Started up a monthly Speech therapy clinic at the offices in Kanenakumba where by 6 speech therapy sessions have been conducted and benefited 15 members who normally turn up for the session and speech therapist comes once in every month to help our children with speech defects.</li> <li>Started up a monthly Special Speech therapy clinic at the offices in Kanenkumba.</li> </ul>
2.5	Challenges, what are those things that posed a threat to the successful implementation of the program.	<p>The following posed a challenge to the program activities</p> <ul style="list-style-type: none"> <li>The number of children who receive the therapy services is still so high to be worked on by a few of our therapists.</li> </ul>

		<ul style="list-style-type: none"> <li>• Lack of a speech therapist, we still have not been able to recruit a permanent speech therapist as its expensive and hard to find one who speaks our local language. We however have a SLT who comes in once a month.</li> <li>• Lack of patience among some parents who expected to see results of therapy in just a few weeks.</li> <li>• There was a habit of providing transport refund (by other organizations) to parents who always took their children for therapy and hence some came expecting it from us yet our mission was just to support the children.</li> <li>• Too much expenditure on transport as we try to reach out to some children from their nearest health center.</li> <li>• Some parents believe in the misconceptions and end up doing things they hear from the community which are harmful to the children.</li> </ul>
2.6	Recommendations, way forward (what were the follow up actions)	<p>Going forward the program must do the following to implement program activities smoothly</p> <ul style="list-style-type: none"> <li>• Continue with the training of parents about Down Syndrome on the days they take their children for immunization so that they can understand the condition and forget about the misconceptions.</li> <li>• Training parents to take a lead part in play therapy and to continue with therapy at home as advised by specialist.</li> <li>• Provide play toys to parents to use at home during play therapy.</li> <li>• Seek for partnerships with other implementing partners to bridge the gap of limited equipment and staff.</li> <li>• Getting an organized transport means for the organization to access its beneficiaries in an orderly and timely manner.</li> <li>• Recruit more volunteers to support in the implementing of the services.</li> </ul>
<b>3</b>	<b>Medical Services</b>	<b>ASSESSMENT OF OUR MEMBERS FOR HEALTH RELATED ISSUES</b>
3.1	Objectives	<ul style="list-style-type: none"> <li>• To assess all children and find out any other health related issues.</li> <li>• To provide a solution for all the health related issues identified.</li> <li>• To connect our members to other organizations that offer medical support for different related conditions that may require surgery i.e</li> </ul>

		hirschsprung's disease, gastro-esophageal reflux disease congenital heart defect e.t.c
3.2	Target of the program, (participants to reach out)	<b><i>All people with Down Syndrome.</i></b>
3.4	Summary of what happened, including achievements. Insights of what the program entailed	<ul style="list-style-type: none"> <li>• Carried out an ECHO test for three of our members.</li> <li>• Carried out a Thyroid Function Test for two of our members i.e Michael isingoma, Mackline Atusingwize.</li> <li>• Sadly, we lost two of our members to heart disease due to prolonged periods of fundraising.</li> <li>• We had a meeting with Hearts of Joy an organization which supports Heart surgeries who connected us to another organization that supports children for heart surgery Gift of life.</li> </ul>
3.5	Challenges, what are those things that posed a threat to the successful implementation of the program or project	<p>The following challenges were meant throughout our implementation</p> <ul style="list-style-type: none"> <li>• The tests done are very expensive and some cannot be done in Uganda.</li> <li>• Most Health centers cannot do Echo tests, ECG and Thyroid these are crucial during our screening and assessment.</li> <li>• Lack of enough funds to make tests for all the children.</li> <li>• Congenital heart disease still a big challenge as children with down syndrome need to be operated on in first year of their lives. Most time they are brought to us late and weak which makes their chances of survival less.</li> </ul>
3.6	Recommendations, way forward (what were the follow up actions)	<p>We recommend the following for the program to move smoothly</p> <ul style="list-style-type: none"> <li>• Continue running fundraising drives to seek for funding to support our members.</li> <li>• Fundraise for testing equipment for ECO ECG tests at Health centers</li> <li>• Recruit a person with skills in community fundraising to support our activities</li> <li>• Make continuous applications and proposals for funding of our project programs.</li> </ul>
4	<b>Support Groups</b>	<b>SUPPORT FOR GROUPS AND INDIVIDUALS TO IMPROVE LIVELIHOODS OF PEOPLE WITH DOWN SYNDROME AND THEIR CARE TAKERS</b>
4.1	Objectives	<ul style="list-style-type: none"> <li>• To support care takers who lost their jobs so as to care for people with Down Syndrome.</li> <li>• To provide basic skills, materials and equipment with training for people with Down Syndrome and their care takers</li> </ul>

		<ul style="list-style-type: none"> <li>• To provide basic knowledge of business management.</li> <li>• To minimize dependency on the organization for supporting the people with Down Syndrome.</li> <li>• To emphasize the saving culture among the members.</li> <li>• To provide a safe space where rural young people with Down Syndrome can engage in income generating activities and express themselves as productive citizens of the country</li> </ul>
4.2	Target of the Program	The care takers of people with Down Syndrome
4.3	Summary of what happened	<ul style="list-style-type: none"> <li>• We are in the process of starting 4 livelihood groups from different places including Hoima East, Hoima West, Kigorobya, Bugambe, Buhnika and Kibaire. Some groups have completed their registration and others are pending registration. They have already chosen activities to involve in after various interactions.</li> <li>• We are going to set up a livelihood support center in each district starting with Hoima City. The centers will provide start up materials, equipment and training in art, craft and tailoring for individuals and/or groups to begin their livelihood improvement.</li> </ul>
4.4	Challenges	<ul style="list-style-type: none"> <li>• We lack equipment, training in its use, materials and equipment for the art, craft and tailoring work space.</li> <li>• Some groups were not having funds required for registration</li> <li>• Some groups had challenges with group dynamics in choosing leaders</li> <li>• Some group members had different interests on the income generating activities to take up.</li> </ul>
4.5	Recommendations	<ul style="list-style-type: none"> <li>• Bring trainers with experience in art, craft, tailoring, poultry and goat rearing.</li> <li>• Bring trainers in managing groups to provide some knowledge to the members on how they can handle issues within a group.</li> </ul>
5	<b>Awareness</b>	<b>ENSURING THAT THE COMMUNITY IS FULLY AWARE OF THE CONDITION AND HOW TO MANAGE IT.</b>
5.1	Objectives	<ul style="list-style-type: none"> <li>• To create awareness about the condition in the community</li> <li>• To clear all the misconceptions heard in the community</li> <li>• To change the attitude of the community towards People with Down Syndrome and also end stigma.</li> </ul>

		<ul style="list-style-type: none"> <li>To advocate for inclusion of people with Down Syndrome in school, work, community</li> </ul>
5.2	Target of the program	All community members
5.3	Summary of what happened, including achievements	<ul style="list-style-type: none"> <li>We carried out trainings at 46 Health centers in Hoima, Masindi, Kikuube and Buliisa districts. These training sessions were attended by health workers and VHTs at the respective facilities.</li> <li>We held 26 trainings for parents during immunization days at Health facilities in Hoima, Kikuube and Masindi Districts</li> <li>We held 8 radio talk shows about Down Syndrome and its management.</li> <li>We held two training at schools for teachers emphasizing inclusive education.</li> <li>We are having a monthly Zumba session in which people with Down Syndrome interact with other members of the community and have so far engaged in 5 sessions.</li> <li>We took part in 2 community outreaches organized by Rotary Club of Hoima Kitara and Omugo Development Foundation.</li> <li>We took part in a community outreach organized by reproductive health Uganda</li> </ul>
5.4	Challenges	<ul style="list-style-type: none"> <li>Limited funds to run the program effectively</li> <li>Ignorance among the community members.</li> <li>Big expenditure on reaching out to some areas which are a bit distant.</li> </ul>
5.5	Recommendations	<ul style="list-style-type: none"> <li>Seek for more partnerships in creating awareness.</li> <li>Involve community leaders in the program.</li> </ul>
6	<b>Fundraising</b>	
6.1	Objective	<ul style="list-style-type: none"> <li>To raise funds to support various activities of the organization.</li> </ul>
6.2	Target	Local and international community
6.3	Summary of what happened	<ul style="list-style-type: none"> <li>We made T-shirts, caps and socks for sale as a means of collecting some funds to support our activities.</li> <li>We have put donation boxes at various places including Kabalega Resort, Kontiki Hotel, HB Hotel and Talk Gadgets Hoima.</li> <li>Reached out to friend's family and well-wishers. This connected us to M3 company in the UK, Marafiki DK of Netherlands, Benedicto and Henrico from Italy, Fricky and Daeng From thailsnd.Friends and well-wishers in Hoima, a few corporates in Hoima Town who have been supporting our programs</li> <li>We started up a Gofundme Link for donations on our website.</li> </ul>

		<ul style="list-style-type: none"> <li>We also have an MTN Momo Line for free transactions to our Organization.</li> </ul>
6.4	Challenges	<ul style="list-style-type: none"> <li>Limited response to all calls of fundraising.</li> </ul>
6.5	Recommendation	<ul style="list-style-type: none"> <li>Recruit someone with skills in community fundraising to support our drives.</li> </ul>
<b>7</b>	<b>Administration and capacity building</b>	
7.1	Objectives	<ul style="list-style-type: none"> <li>To build capacity of the members, board and staff to perform to organizational vision and mission.</li> <li>To coordinate with other development partners for the success of Rowan's Down Syndrome Awareness Center.</li> </ul>
7.2	Target of the program (participant reach out)	Members, board members, staff, volunteers, beneficiaries and other development partners.
7.3	Summary of what happened, including achievements.	<p>We managed to accomplish this in our first quarter</p> <ul style="list-style-type: none"> <li>Signed Memorandums of Understanding with Office of the prime Minister, Hoima City, Masindi, Kikuube and Buliisa districts.</li> <li>Recruited two volunteers to support our activities.</li> <li>Recruited a speech therapist on a part time basis.</li> <li>We had an outreach at Kyaninga Child Development Center in Fort Portal and Angels Center in Wakiso where our staff received some training.</li> <li>Joined the Children's Trust Fund forum which holds bi annual meetings intended at networking for all NGOs supporting people disabilities</li> <li>We have made a partnership with one carpentry training center, one tailoring school (Assorted trends Africa) and a shoe making center for training vocational skills to our members</li> </ul>
7.4	Challenges, what are those things that posed a threat to the successful implementation of the program or project	<p>Challenges includes</p> <ul style="list-style-type: none"> <li>Limited funds to motivate the volunteers to give in their best.</li> <li>Lack of enough experience in the way of work for NGOs.</li> </ul>
7.6	Recommendations, way forward	We recommend having staff development meetings with different organizations to learn from a wide spectrum of people and situations.

### Concluding Remark

In general our organization has achieved much more than expected with very little funding in a short time. Considering all the challenges stated above. With enough funding, staff and support from key stake holders, we believe we can make a very huge difference in the lives of people with Down Syndrome. We are thankful to all the support from our member's friends, Family and

well-wishers. We call upon other stake holders, community leaders, religious leaders, political leaders to support our programs.