THE SELF ADVOCACY TOOL KIT: For users of mental health care services

Uganda
patience koburunga
Organization type:
nonprofit/ngo/citizen sector
Budget:
$100,000 - $250,000
Website:
http://www.basicneeds.org/

- Disability
- Disability rights
- Health care
- Economic development
- Mental health
- Vulnerable populations

Project Summary

Elevator Pitch

Concise Summary: Help us pitch this solution! Provide an explanation within 3-4 short sentences.

The self Advocacy tool kit for users of mental health care services pulls together the most useful materials and resources to enable users of mental health care services demand for needed changes in delivery of Mental Health and Development services and encourage patients to take a more active role in their own care.

About Project

Problem: What problem is this project trying to address?

An estimated 3.6 million Ugandans are suffering from severe mental disorders. According to the Ministry of Health only 15% of these have been served. Lack of access to treatment, poverty, stigma, discrimination and human rights abuse are major obstacles to the rehabilitation of people with mental disorders. Laws and policies in Uganda especially deprive users of mental health care services the right to self determination and the right to health. Self advocacy is not sufficiently utilized to empower People with Mental Disorders to demand for and monitor quality service delivery. The consumer movement does not have defined self advocacy processes, resource materials, training manuals to guide member groups on how to conduct evidence based local level advocacy. Yet this is essential to drive legislative reforms, policy formulation and consumer determined service delivery. The voice of users is lacking in policy development, legislative reforms and Programme development, implementation and evaluation.

Solution: What is the proposed solution? Please be specific!

Give a man a fish and you have fed him for today, teach him to fish and you have fed him for a lifetime. This Chinese proverb adequately sums up the concept of self advocacy. Historically, users of mental health care services have been excluded from mainstream society and they have become accustomed to an environment where decision making, advocacy and responsibility are all taken care of by others. The self advocacy toolkit for users of mental health care services as developed by BasicNeeds Uganda is the first toolkit that defines a self advocacy process, incorporates the unique needs of Persons with mental disorders and empowers patients to demand for change. Emphasis on self-advocacy or self-empowerment (patient empowerment) in the psychiatric field started in the 1970s. It refers to an individual’s ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions (VanReusen et al., 1994). Unfortunately the strategy of self advocacy has previously not sufficiently been used to empower poor People with Mental Disorders and Epilepsy especially in Uganda. This is beginning to change by training self help groups of users of mental health services in self advocacy using the self advocacy tool kit. The toolkit which draws on experiences of self advocacy processes in Uganda by women, children and people with disability, gives step by step guidelines and suggests activities using Participatory Rural Appraisal tools that can be used by Self Help Groups or individuals to demand for involvement in mental health service delivery and policy development.

Impact: How does it Work

Example: Walk us through a specific example(s) of how this solution makes a difference; include its primary activities.

Training using the self advocacy toolkit equips members of self help groups of People with mental disorders/epilepsy and their carers with skills in self advocacy to enable them to negotiate for inclusion and spaces in the decision making processes within their districts. The impact so far includes: 1.Greater access to information for users of mental health services. 2.Increased access to treatment at government facilities and involvement of patients in planning health service delivery. 3.Increased opportunities for People with mental disorders/epilepsy and their carers to earn an income for self sustenance. 4.Development, implementation and monitoring of advocacy plans and campaigns by patients and their carers.
5. Reduced stigma, discrimination and change in community perception about mental health. 6. Improved health outcomes as a result of advocacy efforts for example establishment of a maternity health unit at Kaseeta health center II. Less deaths due to epilepsy and mental illness related causes. While 18 known epilepsy related deaths were reported in the period immediately prior to the intervention, only 2 have been reported since onset of the advocacy campaign. 7. Demonstrated understanding of the concept of self advocacy as a tool for empowerment to demand for inclusion in mental health care service delivery. Grasping the concept of human rights concept especially the right to health and self determination has led to increased awareness of self and of others i.e. that members are human beings first then persons with mental disorders/epilepsy and most importantly rights come with responsibilities.

About You

Organization: basicneeds uk in uganda

Section 1: You

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patience

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Section 2: Your Organization

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Your idea

Country and state your work focuses on
KMP

Website URL
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Innovation

Do you have a patent for this idea?

Impact

Actions

1. The toolkit is hinged on human rights especially right to self determination.

2. The toolkit is packaged to be learner centered using practical learning methods such as group work, role plays and open debates.

3. The use of animation skills during training to encourage, motivate and challenge the users.

4. The toolkit is a coaching process where the users are charged with carrying out their advocacy campaigns themselves in order to learn through experience.

5. Collection of data and evidence from the communities by the users to back up their advocacy issues like human rights violations and lack of access to treatment.

6. Involvement of the district technical teams in the process.

7. There is a provision for interpretation of the self advocacy toolkit into local languages since the majority of SHG members are illiterate.

8. Risk management, ensuring we put resources (financial, human) to the best use.

Results
1. Growth of a consumer movement that actively advocates for inclusion in service delivery and influences changes in laws and policies.

2. Grasping the concept of human rights empowers patients to actively demand for needed changes in the service delivery.

3. The active participation of users of mental health care services builds their self esteem, combats stigma, discrimination and changes community perceptions. It also ensures the voice of users in policy development, legislative reforms and Programme development, implementation and evaluation.

4. Interface with district technical teams enables the users to interact with decision makers, familiarize themselves with government structures and gather information.

5. Interpretation in local languages ensures that the illiterate users who are the majority are involved in the advocacy process.

6. Learning centered approach and use of animation skills is meant to motivate and empower patients to be actively involved in their disease management.

**What will it take for your project to be successful over the next three years? Please address each year separately, if possible.**

2011- Strengthening a movement from the grass roots to a consolidated national movement using the self advocacy through:

1. Training and equipping of trainers of trainers (TOT) in self advocacy using the self advocacy toolkit for users of mental health care services.

2. Conduct a nation wide training programme for self help groups of persons with mental disorders/epilepsy and an awareness raising campaign for communities.

3. Persistent sharing of information with users of mental health services on advances in the field of mental health care.

2012- Pressurize government using the power of voice and numbers to influence budgeting, resource allocation, monitoring and integration of community mental health services in district development plans. Lobby for better recognition of mental illness as a disability, recruitment of psychiatric nurses in every district and development of district mental health associations. Ensure better representation in planning and users of mental health care services benefit from agricultural initiatives.

2013- Find alternative ways to fund community mental health for example through community based insurance schemes, drug banks and provide seeds for income generating activities.

**What would prevent your project from being a success?**

1. Restraint in finances or otherwise that would obstruct the dissemination to the Self advocacy toolkit thus hindering the transformation of users of mental health services into self advocates.

2. Shortage of free or subsidized drugs for users while they undertake the self advocacy process to create sustainable change.

3. Inability of the self help groups to generate their own fund because our experience has shown that groups engaged in income generating activities yield better successes in advocacy.

4. Political instability

**How many people will your project serve annually?**

1001-10,000

**What is the average monthly household income in your target community, in US Dollars?**

Less than $50

**Does your project seek to have an impact on public policy?**

Yes

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**Sustainability**

**What stage is your project in?**

Operating for 1-5 years

**In what country?**

Is your initiative connected to an established organization?

Yes

If yes, provide organization name.

BasicNeeds

**How long has this organization been operating?**

More than 5 years

**Does your organization have a Board of Directors or an Advisory Board?**

Yes

**Does your organization have any non-monetary partnerships with NGOs?**

Yes

**Does your organization have any non-monetary partnerships with businesses?**

Yes

**Does your organization have any non-monetary partnerships with government?**

Yes

Please tell us more about how these partnerships are critical to the success of your innovation.

We are able to benefit from their resources for example the local expertise and experience, utilize infrastructure e.g sub county halls to conduct training. The partnerships ensure sustainability since district personnel and community development officers adopt coaching the groups to pursue advocacy campaigns. Partnerships are critical to ensure a holistic approach to mental health by ensuring its integration in other development and
health initiatives. They are also critical in the dissemination of information and results, exchange of ideas, broadening of stakeholders, analysis of current issues and also in linking up users and members of user groups to opportunities in district development programs.

**What are the three most important actions needed to grow your initiative or organization?**

1. Strengthening of user movement from grass roots to national level using the self advocacy toolkit by nation wide training of self help groups of users of mental health care services and their carers.
2. Constant, accessible, affordable and appropriate treatment.
3. Strengthening of income generating activities for users of mental health care services.

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**The Story**

**What was the defining moment that led you to this innovation?**

For a long time now, the poor in Uganda have looked to handouts for survival which meant that at first the Self Help Group approach which was introduced in Uganda in 2003 disappointed them. Persons with mental disorders/epilepsy are accustomed to an environment where decision making, advocacy and responsibility are all taken care of by others because they are excluded from mainstream society.

During presentations on mental health, Christian Ntulo the social innovator behind this idea was often asked if she is a user of mental health care services, why else would she be so passionate about the subject. With this came the realization that if users’ mental health care services could be empowered to advocate for their own issues, it would catalyze the realization of changes needed in legislative reforms, policy development and service delivery would. Furthermore it would change community perception and combat discrimination and stigma.

**Tell us about the social innovator behind this idea.**

Christina Ntulo graduated from the United States International University, Africa with a Degree in Psychology in 1997. Her first job was as Head Teacher for St. Peter’s School an establishment for moderately and severely mentally handicapped children. She then joined the Federation of Women Lawyers in Kenya (FIDA-KENYA) where she set up the Counseling Department providing psychological and emotional support to survivors of gender based violence. Her department also ensured clients were psychologically ready for court.

Christina joined BasicNeeds in 2003 where she currently serves as the Director for New Initiatives and is responsible for the development and contribution of thinking behind diversifying the organizations resource base. In addition to this she continues to manage the Uganda programme. Christina is the vice chairperson of Trans cultural Psychosocial Organization (TPO), the treasurer of the Uganda National NGO Forum. She also serves as the representative to the board for the social inclusion thematic group which includes NGOs working in the field of gender, children, disability and minority ethnic groups.

**How did you first hear about Changemakers?**

Newsletter from Changemakers

**If through another, please provide the name of the organization or company**

50 words or fewer

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