

COMMUNITY PARTICIPATION IN HEALTH PLANNING AND DECISION-MAKING

A synthesis of evidence from
Kyankwanzi and Kampala
districts, Uganda

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EXECUTIVE SUMMARY

Introduction

This paper provides a synthesis of three studies conducted on community participation in health and health system governance. The studies were carried out as academic research by university students and as part of an action research project titled, “Health System Governance: Community Participation as a Key Strategy for Realizing the Right to Health”, implemented by CEHURD, Uganda, in collaboration with the Learning Network on Health and Human Rights, South Africa and funded by the International Development Research Centre (IDRC).

Objective

To explore contextual and empirical issues surrounding current approaches to community participation in health in Kyankwanzi and Kampala districts.

Methodology

This is a synthesis of three different studies conducted on the general topic of community participation as a strategy for realizing the right to health. The synthesizing process has traced, reconciled and threaded together highlights from each of the studies, with a view of identifying emerging contextual and empirical issues in community participation in health as it relates to different populations in the different rural and urban communities in Uganda.

Opportunities and obstacles to community participation in health

Decentralization Policy

The decentralization policy has devolved authority and responsibility for primary health care to the district level and put health centers under district and subcounty local governments. The district and subcounty local governments are responsible for appointing community representatives to Health Unit Management Committees (HUMCs) to oversee the running of government health centers and general hospitals.

The findings however, suggest that the decentralization process has not been used effectively to promote or achieve community participation in planning and decision making in health. Respondents cited persistent bureaucracy, low levels

of social accountability, and lack of flexibility in budgeting as key constraints to community participation.

A majority (68%) of the 149 household respondents in Kampala slums reckoned that they had “never” been involved in planning for health services; just over one half (53%) responded that they had “rarely” been involved in the identification of health problems; while just under half (46%) indicated that they had “never” been involved in decision-making on issues pertaining to health services.

Mobilization of community resources

Substantial financial and human resources can be mobilized from the community. The community may contribute in the form of providing accommodation, building and lands for functioning of health centers; or it may provide voluntary labor. Respondents felt that there is often lack of unity of purpose, a sense of belonging and social cohesion due to high levels of socioeconomic inequality, political differences and differences in religions.

An overwhelming majority (77%) of the 149 household respondents in Kampala slums were not registered members of the community where they stayed; and 62% reported to have never attended any community meeting.

Primary health care approach

Due to the limited resource envelope available for the health sector, the Health Sector Strategic and Investment Plan (HSSIP) recommends a minimum package of services to be delivered to all people of Uganda through village health teams (VHTs) and health center II-IV.

However, the desired reorientation and reorganization of health care delivery system have not yet occurred and there is still a higher concentration of health facilities and health workers in urban areas than in rural areas.

Awareness on the right to health

Household members and leaders alike had a very low level of awareness of the right to health. While all household respondents in Kampala slums agreed that all community members had a right to access health services “always” or “often”, they had no further understanding on their right to health. A majority (94%) of the respondents said that the right to health meant accessing health services without discrimination but very few were aware that the right to health encompasses more than merely accessing health care services.

Informal social activities

A majority of the respondents in Kampala slums reported regular contact with family and friends, and a few had contact with neighbors. The elderly (60 years and above) were reported to visit their neighbors more than those below that age bracket. The results show a higher level of social exclusion for individuals with low incomes, women, and those in ill physical and mental health. All other measures that were used to measure civic individual participation were reported to be done by only a small proportion of the respondents.

Conclusion

The decentralization program has, in principle, provided immense opportunities for communities to participate in health program planning and decision making in their communities and local governments. These opportunities have however not been fully exploited. Community resources have not been fully exploited to maximize community participation in health program planning and decision making. Some categories of people – the poor, elderly, women and people with ill health - are more socially excluded than others, which according to previous studies, interferes with community participation. Community members and their leaders have very limited knowledge of the right to health. There is the need to improve community sensitization on the right to health, including their right to participate in health program planning, monitoring and decision making.

LIST OF ABBREVIATIONS

ACHPR	African Charter on Human and Peoples' Right
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CEHURD	Center for Health, Human Rights and Development
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
EOC	Equal Opportunities Commission
ESP	Expanding Social Protection Program
GoU	Government of Uganda
HBRA	Human Rights Based Approach
ICERD	International Convention on the Elimination of All Forms of Racial Discrimination
ICESCR	International Covenant on Economic, Social and Cultural Rights
IDRC	International Development Research Center
HSDs	Health sub-districts
HSSIP	Health Sector Strategic and Investment Plan
HUMCs	Health Unit Management Committees
MTEF	Medium Term Expenditure Framework
NAADS	National Agricultural Advisory Services
NCDA	National Council for Disability Act
NGOs	Non Government Organizations
NHP II	National Health Policy
NUSAF	Northern Uganda Social Action Fund
PHC	Primary healthcare
PNFP	Private Not for Profit
PRDP	Peace, Recovery and Development Plan
PWDs	Persons with Disabilities
UCT	University of Cape Town
UDHR	Universal Declaration of Human Rights
UDHS	Uganda Demographic Health Survey
UNMHCP	Uganda National Minimum Health Care Package
VHTs	Village health teams
WHO	World Health Organization

1. BACKGROUND

1.1 Introduction

This paper provides a synthesis of three studies conducted on the value of community participation in health system governance. The studies were carried out as academic research by university students who received bursaries from Center for Health, Human Rights and Development (CEHURD) under an action research project titled, “Health System Governance: Community Participation as a Key Strategy for Realizing the Right to Health”.

The action research project was supported by the International Development Research Center (IDRC), and has been implemented in collaboration with the Learning Network for Health and Human Rights of the School of Public Health and Family Medicine at the University of Cape Town (UCT), South Africa, since February 2012. The Learning Network is a collaboration of academia and civil society, coordinated by UCT, working to explore, develop and operationalize methods and best practice for realization of the right to health.

The project was implemented at two sites – one in Uganda managed by CEHURD and another in South Africa, managed by UCT. Its aim was to test approaches and share experiences of community participation in health that advance health equity and strengthen governance systems for health. The project targeted health committees, civil society, health officials and local council leaders through training and capacity-building; building networks; sharing of experiences; and testing local systems for participation as a key strategy for realizing the right to health.

1.2 Objectives

This paper draws on evidence and analysis from the three student studies to explore contextual and empirical issues surrounding current approaches to community participation in health, particularly by rural populations, urban poor, and persons with disabilities (PWDs). Specifically, the paper attempts to:

- 1) Describe the nature, forms and level of community participation in health in two settings – one rural and the other urban – in Uganda.
- 2) Assess the extent to which different opportunities are used to achieve community participation in health and health system governance.
- 3) Explore community capacities to claim the right to health and the right to participation.
- 4) Outline constraints to community participation by rural populations, urban poor, PWDs and other vulnerable populations in Uganda.


1.3 Methodology

This paper is a synthesis of three different studies conducted for academic purposes at three different universities – Makerere University, Uganda Christian University, and International Health Sciences University. Two of the studies were for bachelor’s degrees (Bachelor of Laws), while one was for a master’s degree (Master of Public Health). All three studies focused on the general topic of community participation and the right to health but had different objectives and methodologies, and were conducted in the different settings of focus.

Comparison of three studies

Title	The contribution of community participation to the realization of the right to health: A cross sectional study of selected urban settlements in Kampala Uganda	Assessing the role of community participation in governance of health systems in Uganda: A case study of Kyankwanzi district	An examination of the law relating to persons with physical disabilities in Uganda: A case study of community participation in the rehabilitation process in Kampala
Researcher	Monica Wambugu	Arthur Junior Nsereko	Jesse Mugero
Degree/ University	Master of Public Health/ International Health Sciences University	Bachelor of Laws/ Makerere University	Bachelor of Laws/ Uganda Christian University
Objective	The contribution of community participation to the realization of the right to health	The effectiveness of community participation as a strategy for strengthening governance of the health system	How community participation enables PWDs realize the right to health
Population/ Respondents	Urban poor/ households and community leaders	Local government leaders	Health facilities and community leaders
Study area(s)	Three slums in Kampala: Kisenyi, Namuwongo and Bwaise	Kyankwanzi Town Council	Kampala
Methods	9 key informant interviews; 149 household questionnaires Independent variable: forms and levels of participation Dependent variable: awareness of right to health	20 key informant interviews Questionnaires	Case studies, Questionnaires, Observations, Key informant interviews

From the above comparison we can note that although the focus was on different populations and study areas, there was a common inclination toward community



participation as a strategy for realizing the right to health. This paper attempts to trace and thread together highlights from each study with a view of identifying emerging contextual and empirical issues in community participation in health as it relates to different populations in the different settings.

2. THE CONCEPT OF COMMUNITY PARTICIPATION

World Health Organization (WHO, 1991) defines participation in health as a process that involves groups and individuals exercising their rights by playing a direct and active role in the development of the needed health services and in ensuring the sustainability of better health. On its part, the Declaration of Alma-Ata defines it as a process whereby individuals and families take responsibility of their own health and welfare and also of the welfare of the entire community.

Participation of the population in all health-related decision-making at the community, national and international levels is an important aspect of the right to health (The United Nations Committee, 2000), and is recognized as both a human right and a responsibility. The Alma-Ata Declaration on Primary Health Care (1978) in particular states that “people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”

The direct involvement and engagement of ordinary people in the design, implementation and evaluation of planning, governance and overall development programs at local or grassroots levels has become an integral part of democratic practice in recent years (John Friedmann, 1992). In large part, this is due to the benefits it brings to health programs and interventions. Baum FE (1998) notes that participation is highly beneficial to health; it ensures effectiveness and sustainability of interventions ensuring that internalization, trust and support of the people are gained.

Community participation in primary health care and rural health service development has been argued to result in more accessible, relevant and acceptable services (National Rural Health Alliance 2002; Taylor et al.2008). In addition, it is often implied that community participation results in higher community satisfaction with health services, and indeed better health outcomes, even though evidence to support this assertion is limited (Kilpatrick 2009).

In spite of this evidence, participation has not always been understood or applied in a common way. Cornwall, A (2000) writes that the term has over the past decades been used to mean “nothing and everything”; with the different meanings informing different practices. According to Morgan L. (2001), these differences range from having only representatives sit at a meeting of policy formulation and decisions; to the community being involved in agenda-setting; to a democratic process where the governing bodies respond and account to the people; to cost-sharing and to the disenfranchised needy.

Rifkin et al. (1996) suggested two major approaches to participation: the “top-down” approach, where the people participate passively by responding to professional directions; and the “bottom-up” approach in which the participants identify, prioritize, and work together with professionals and government planners to solve problems. Labonte et al. (1994) has cautioned that the community may seem to participate at many different levels but it is possible that such participation may amount to little more than tokenism.

In Oakley’s (1989) view however, the process of participation is dynamic, unpredictable and unqualifiable. The author adds that community participation in household settings is not limited to a particular project but should be seen as a permanent and intrinsic feature of the community; that the crucial elements of participation are to increase the awareness of the people leading to the realization of the right to health.

Worley and Fikree (2006) have showed the different levels of community participation however; Loewenson (2000) further explains that moving up the ladder of the different levels of participation is an incremental process which requires a supportive political structure which in turn is reflected by the control the community has over the identification of problems, allocation of resources and the design and implementation of programs.

Rifkin (1986) showed the distinction between three approaches to community participation. In the first approach, community participation is conceptualized as activities which the community undertakes under the supervision of a medical expert with an aim of reducing illness. This approach was termed as the medical approach. The second approach adopts the WHO definition of health – “the physical, mental and social well being of an individual and not merely the absence of disease or infirmity”. This approach conceptualizes community participation as the mobilization of community members to take part in the delivery of health services. The third approach is the community development approach, which conceptualizes health as an outcome of social, economic and political development where community participation occurs when community members take action to change the conditions stated in the approach.

3. LEGAL AND POLICY FRAMEWORK FOR COMMUNITY PARTICIPATION

Under community participation, people are enabled to become actively and genuinely involved in a number of process, including defining the issues of concern to them, making decisions about issues that affect their lives, the formulation and implementation of policies, in planning, developing and delivering services and in taking action to achieve change (WHO, undated).

3.1 International framework

The United Nations has over the years advocated a rights-based approach to development, where the achievement of human rights is set as the primary objective of development (Twesiime Kirya 2013). The principles of the rights-based approach include participation, accountability, non-discrimination and attention to vulnerability, empowerment and express linkage top international human rights instruments (WHO 2012). The democratic principles of participation and accountability are central to the rights-based approach.

The International Convention on Economic, Social and Cultural Rights (ICESCR) casts participation as part of the right to health both as an underlying determinant of health and as a right to have a say in health matters, generally. The UN Committee on Economic, Social and Cultural Rights included participation in its definition of the right to health. It suggests that, like potable water or a safe workplace, participation is an underlying factor contributing to health. And later, the Committee separated its discussion of participation from its list of underlying factors and framed it as a decision-making or political aspect of the right to health (Halabi 2013). Community participation is therefore viewed as a pivotal strategy in enhancing human rights and development.

Uganda is also a signatory to the International Covenant on Civil and Political Rights and therefore has obligations towards the Convention. The Convention in its Article 25 makes particular provisions for participation.

Every citizen shall have the right and the opportunity, without any of the distinctions mentioned in article 2 and without unreasonable restrictions:

- (a) To take part in the conduct of public affairs, directly or through freely chosen representatives;
- (b) To vote and to be elected at genuine periodic elections which shall be by universal and equal suffrage and shall be held by secret ballot, guaranteeing the free expression of the will of the electors...

The Human Rights Committee of the United Nations has expanded on the meaning of Article 25 in its General Comment Number 25, which includes the following paragraphs:

Citizens participate directly in the conduct of public affairs when they exercise power as members of legislative bodies or by holding executive office. This right of direct participation is supported by paragraph (b). Citizens also participate directly in the conduct of public affairs when they choose or change their constitution or decide public issues through a referendum or other electoral process conducted in accordance with paragraph (b). Citizens may participate directly by taking part in popular assemblies which have the power to make decisions about local issues or about the affairs of a particular community and in bodies established to represent citizens in consultation with government. Where a mode of direct participation by citizens is established, no distinction should be made between citizens as regards their participation on the grounds mentioned in article 2, paragraph 1, and no unreasonable restrictions should be imposed.

Citizens also take part in the conduct of public affairs by exerting influence through public debate and dialogue with their representatives or through their capacity to organize themselves. This participation is supported by ensuring freedom of expression, assembly and association.

Community participation in the successful implementation of health programs is recognized in national, regional and international policies, laws and human right instruments. With regard to the laws, government policy and plan discussed above, it is evident therefore, that institutional frameworks are in place that would foster community participation in health system governance.

Regional instruments reveal that they make generalized provision for community participation in governance in terms of democratic and developmental participation and not specific to health governance. The Abuja Declaration, which is specific to health, focuses on disease, but does not provide for specific strategies to be adopted for involvement of young people.

International instruments extensively advocate for community participation in governance of the different areas of human life and activity. They call for active, direct involvement of locals in the management of their affairs. However, community participation in health requires a structure within which various partners, including financial investors in health care facilities and programs, health care providers, and beneficiaries of health services (users), can operate while meeting their obligations and enjoying their entitlements.

These international instruments do not make explicit provision for such structures and it is left to state parties to do what they deem necessary to facilitate

participation. The research seeks to find out what structures Uganda has put in place to meet her obligations outlined in international instruments.

The question that arises is whether Uganda, being signatory to all these instruments, has translated those obligations into domestic health obligations to which the government can be held accountable.

3.2 Regional framework

Uganda ratified the African Charter on Human and Peoples' Rights (ACHPR) in 1986, committing to the provision that every citizen shall have the right to participate freely in the governance of his country, either directly or through freely chosen representatives in accordance with the provisions of the law.

The 1990 African Charter for Popular Participation in Development and Transformation requires that the African people be fully involved, committed and, seize the initiative of popular participation. This can only be possible if they are allowed to establish independent people's organizations at various levels that are genuinely grass-root, voluntary, democratically administered and self-reliant and that are rooted in the tradition and culture of the society so as to ensure community empowerment and self-development. The charter further mandates African governments to yield space to the people, without which popular participation will be difficult to achieve.

In April 2001, heads of state of African Union countries met and adopted the Abuja Declaration on HIV/AIDS, Tuberculosis and other related Infectious Diseases. The declaration categorically highlights the need for a full and effective participation of Africa's children in the prevention and control of the pandemics. The declaration pays particular attention to the place of the young people in the fight against the pandemics, and specifically calls for their involvement as an essential ingredient to the success of the program.

3.3 National framework

In 1993, Uganda adopted a decentralization strategy that was aimed at bringing political and administrative control of services at the point where they were actually delivered. Uganda's Constitution provides for community participation in governance matters. It provides that the state shall be based on democratic principles which empower and encourage the active participation of all citizens at all levels in their own governance (National Objective II (i)).

It further provides that the state shall be guided by the principle of decentralization and devolution of governmental functions and powers to the people at appropriate levels where they can best manage and direct their own affairs (National Objective II (iii)).

The 1995 Constitution and the Local Governments Act of 1997 decentralized political administration from central government to lower tiers of administration, and put these local governments in charge of delivery of primary healthcare (PHC) and other basic social services. The main rationale was to transfer planning, decision-making and administrative authority from the central government to local governments; and to give people a greater chance to participate in development planning, decision-making and implementation (Mulumba 2004).

Within the decentralized system, the district is the main planning and implementation authority. As far as health is concerned, district local governments are responsible for planning, budgeting and implementing health policies and health sector plans. They have the responsibility to recruit, deploy, develop and manage human resources for district health services; to develop and pass health related by-laws; and to monitor overall health sector performance. Districts are in charge of public general hospitals and health centers (levels II-IV) – with subcounty local governments taking direct oversight over health center IIs and IIIs – and also supervise and monitor all health activities (including those in the private sector) in their respective areas of responsibility (Ministry of Health 2010).

The decentralization program has come with a proliferation of districts from 33 in 1986 when the current regime came into power to 112 in 2015. This has raised a number of governance issues. For example, an increase in the number of local government units results in additional pressure on the intergovernmental fiscal framework to maintain more political and administrative structures (Singiza 2011).

The second National Health Policy (NHP II; 2009/10-2013/14) makes specific provisions for community participation in health governance. It categorically states that the health sector shall continue operating a decentralized health service delivery system where focus shall be on strengthening district health systems to deliver the Uganda National Minimum Health Care Package (UNMHCP) including health promotion, disease prevention and early diagnosis and treatment. The policy recognizes that community participation and empowerment with respect to health service delivery had been very weak. The policy commits government to recognize communities and actively promote their participation in health service delivery and management. The policy also envisages two strategies for community

participation and these are expanding and exploring ways of sustaining village health teams (VHTs) as well as building capacity to ensure the participation of communities through VHTs and Health Unit Management Committees (HUMCs).

According to the Health Sector Strategic and Investment Plan (HSSIP), the provision of health services in Uganda has been decentralized, with districts and health sub-districts (HSDs) playing a key role in the delivery and management of health services at district and health sub-district levels, respectively. On partnership with communities, the plan asserts that community participation as a strategy in health service delivery is important as it ensures the availability of appropriate community based services and addresses barriers to accessing care.

The plan's assessment is that both the HSSP I and HSSP II promoted community participation and empowerment as an important strategy for enabling communities to take responsibility for their own health and well-being through active participation in the management of local health services. Two structures were established: the VHT and the HUMC. The NHP II asserts that VHTs and HUMCs have helped to increase participation of beneficiaries in planning and monitoring of community health programs. However there is no empirical evidence to this effect within this policy. It is for this reason that a research is warranted to confirm the assertion.

4. DISABILITY AND THE RIGHT TO HEALTH IN UGANDA

4.1 Magnitude of disability in Uganda

According to the 2002 Population and Housing Census, at least 4 out of every 25, or 16% of the population, are disabled (UBOS 2002). Applying this estimate to today's Ugandan population (approximately 33 million) would indicate that there may be some 5 million people with disabilities (PWDs) in the country. The northern and eastern region had more people with disabilities compared to other regions of the country. The northern region had the highest prevalence of disability (4.8%) while the western region had the lowest (2.9%). Eastern and central regions had rates of 3.6% and 3.1%, respectively. The 2002 census found the commonest disability to be difficulty with legs (29%), followed by sight problem (25%) and hearing problem (17%).

The disability rates also showed that the prevalence of disability increased with age. It ranged from 3% for the age group 5-9 years and rose to 5% for the age group 35-39 years. About 30% of PWD are children (aged 0-17), while 70% are adults (aged 18 and above). The reproductive age group (15-49) constituted 42% while the adults aged 18-59 constituted 47% of PWD. The data further showed that 17% of PWD's were youth (aged 18-30).

4.2 The legal and policy framework for PWDs and the right to health

The International Covenant on Economic, Social and Cultural Rights (ICESCR) commits its parties, including Uganda, to work toward the granting of economic, social, and cultural rights (ESCR) to individuals, including labor rights, the right to health, the right to education, and the right to an adequate standard of living. Under Article 12 (1), the Covenant recognizes the right of *everyone* to the enjoyment of the highest attainable standard of physical and mental health. The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) establishes an agenda of action for putting an end to sex-based discrimination. Under article 11 (1) (f), the Convention requires state parties to take all appropriate measures to eliminate discrimination against women in the enjoyment of "the right to protection of health and to safety in the working conditions, including the safeguarding of the function of reproduction."

In General Recommendation No.24, the CEDAW Committee calls on states to give special attention to the health care needs of vulnerable and disadvantaged groups, including women with disabilities. The Committee recognizes that women with disabilities often have difficulties with physical access to health services and

recommends that states “take appropriate measures to ensure that health services are sensitive to the needs of women with disabilities and are respectful of their human rights and dignity.”

The Convention on Rights of Persons with Disabilities (CRPD) requires parties, including Uganda, to promote, protect, and ensure the full enjoyment of human rights by PWDs and ensure that they enjoy full equality under the law. Under Article 25, State Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

State Parties are required (Article 25) to take all appropriate measures to:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people’s own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

At the regional level, the African Charter on Human and Peoples’ Rights (ACHPR) provides under Article 16 that every individual have the right to enjoy the best attainable state of physical and mental health. It also provides (Article 18(4)) “special measures of protection” for persons with disabilities.

At the national level, the right to health is not listed in the bill of rights (Chapter IV of the Uganda Constitution), but the supreme law states among its social and economic objectives in the Preamble that the state shall ensure that all Ugandans enjoy rights and opportunities and access to education, *health services*, clean and safe water, work, decent shelter, adequate clothing, food, security, pension and retirement benefits.

The Persons with Disability Act 2006 recognises (section 7(1)) the right of persons with disabilities to enjoy the same rights with other members of the public in all health institutions including general medical care. Furthermore, the Act makes reference to promotion of “special health services” required by PWDs. The National Policy on Disability aims to promote equal opportunities for enhanced empowerment, participation and protection of rights of PWDs irrespective of gender age and type of disability. Government commits to removing barriers that hinder access to and utilisation of facilities and services and to promoting user friendly facilities and infrastructure designs for the benefit of PWDs.

4.3 PWD access to health care

Langtree (2010) suggests a “Social Model of Disability” which considers the issue of disability as a socially created problem and a matter of the full integration of individuals into society. In this model, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence, the management of the problem requires social action and is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is both cultural and ideological, requiring individual, community, and large-scale social change. From this perspective, equal access for PWDs is a human rights issue of major concern.

And in the most recent development of this model, Longtree (2010) states that all human beings are equal and have rights that should be respected without distinction of any kind. People with disabilities are citizens and, as such, have the same rights as those without impairments (Longtree 2010). The author further suggests that all actions to support people with disabilities should be “rights based” and that the demand for equal access to services and opportunities should be based on the human rights argument.

The ICESCR Committee, in General Comment 14 (para. 12b), has stated that one of the core principles of international law on accessibility to health services is that of non-discrimination, especially for “the most vulnerable or marginalized sections

of the population.” Physical accessibility requires that health facilities, goods and services be within safe physical reach for all sections of the population, especially vulnerable and marginalized groups such as persons with disabilities.

The National Policy on Disability takes note of the fact that due to their vulnerability, PWDs have inadequate access to services, information, resources as well as limited participation in the development process. This is corroborated by Korpinen (2009) who found that PWDs in Uganda face extreme conditions of poverty, and have limited opportunities for accessing education, health, and suitable housing and employment opportunities.

The National Policy on Disability also takes note of the problem of accessibility. It points out that in Uganda, PWDs face difficulties in accessing health, education and sports facilities, and places of employment, cultural sites and other physical infrastructure. They are denied access to most buildings such as schools, hospitals, courts of law and stadia. This is due to the fact that many buildings do not have facilities such as ramps and lifts. The existing lifts do not have talking devices to enable the blind to access information. Roads do not have facilities for PWDs. In most cases, PWDs cannot access information provided by both electronic and print media.

The Human Rights Based Approach (HRBA) requires that programming should seek to minimise stigmatization and discrimination, which act as barriers to PWDs in accessing services. To this end, the policy provides that promotion and protection of the rights of PWDs will be upheld at all times by service providers. The policy also defines what it calls “policy priorities” to include accessibility.

However, the HRBA has not always been applied in health care programming and delivery. For instance, Were and Hasunira (2010) documented cases of violations of health rights of women living with HIV, including PWDs, in the public health facilities in Kawempe division of Kampala. The study found that poor attitudes among health workers and limited capacity have made delivery services to be of “unacceptable quality”. The authors reported that, some health workers treat HIV-positive mothers as if they are “too dirty to touch” and pregnant HIV-positive women with disabilities as if they are not supposed to have children or sexual intercourse.

The absence of general health legislation represents a challenge in the implementation of the right to health of persons with disabilities.

The National Council for Disability Act 2003 sets up disability councils at national, district and subcounty levels to act as a channels through which the

needs, problems, concerns, potentials and abilities of persons with disabilities can be communicated to government and its agencies for action (Section 5), and to investigate violations of the rights of PWDs and non-compliance with laws relating to disabilities (Section 6(f)). At present, however, less than half of Uganda's districts actually have a disability council (Human Rights Watch, 2010).

The Disability Act 2006 does not adequately reflect all the good aspirations of the National Policy on Disability (Mbazira 2009). The author notes that while the Act provides for the right to health for PWDs, it lacks a clear mechanism for its effective realization. The author recommends that in order to make the provisions on accessibility more effective, the Disability Act should have made the provisions (and even effected amendments) to the Town and Country Planning Act, the Local Government Act, and the Public Health Act and regulations made there under including the Public Health (Building) Rules to make the law enforceable.

5. OPPORTUNITIES AND OBSTACLES TO COMMUNITY PARTICIPATION IN HEALTH

5.1 Decentralized governance system

The decentralization program has devolved responsibility for primary health care to the district level. The local government structure goes down to the village level and has layers (local council I-V) that provide opportunities for community participation in health planning and decision making. Each level of governance has elected political leaders and an executive committee that has a secretary for health. The district and subcounty local governments are responsible for appointing community representatives to Health Unit Management Committees (HUMCs) to oversee the running of government health centers and general hospitals.

In spite of the accepted general principles of primary health care and community participation, findings from the studies informing this paper show that the traditional bureaucratic machinery continue to stand in the way of their translation into concrete actions through decentralized processes. The center has reserved financial power and many of the financial transfers to districts are “conditional grants” which offer limited flexibility in planning and budgeting by the recipient local governments. Respondents also reported unwillingness on the part of local government leaders to account to the people. As a result, real community participation has not taken root, and the benefits of the health care programs are not equally distributed, with PWDs and other vulnerable populations being left out in many aspects.

A majority (68%) of the 149 household respondents in Kampala slums reckoned that they had “never” been involved in planning for health services; while just about 3% reported that they were “always” involved, with another 3% reporting that they were “often” involved. In contrast, a larger proportion (33%) of respondents among community leaders reported that community members were either “often” or “sometimes” involved in the planning for health services.

Involvement of community members in identification of health problems also seemed low. Just over one half (53%) of household respondents reported that they had “rarely” been involved in the identification of health problems; 23% had “sometimes” been involved, and 18% had “never” been involved at all; while only 4% said that they had “always” or “often” been involved. In contrast, community leaders interviewed reported that community members were either “always” (33%), “often” (33%), or “sometimes” (33%) involved in the identification of health problems.

Just under half (46%) of household respondents indicated that they had “never” been involved in decision-making on issues pertaining to health services; 18% did “not know” whether they had been involved; 11% had “sometimes” been involved; 11% had “rarely” been involved. An overwhelming majority of the household respondents (82%) reported that they had “never” been involved in the budgeting process for health services. Like in the previous level, participation at this level was low with majority of the respondents showing their surprise at this question.

5.2 Mobilization of community resources

Community members can contribute to the better functioning of health facilities by providing accommodation, land and labor, among other things. However, while community leaders, such as local councils, are better positioned to mobilize such resources from the community, their ability to do so may be compromised by real or perceived lack of accountability to their constituencies. This may not be helped by the limited participation of communities in the design, planning and implementation of health care programs. Respondents felt that mobilization of community resources for common interest, such as public health care, was undermined by social differences, particularly socioeconomic inequality.

A majority (77%) of household respondents in Kampala slums were not registered members of the community where they stayed, and only 12% reported being registered. The rest of the respondents (8%) did not respond to this question. Some respondents expressed fear when this question was asked and wondered whether they were to be evicted for not being registered. This suggested a sense of powerlessness and insecurity and a feeling of being disadvantaged, excluded and vulnerable at the same time.

Findings suggest that attendance of community meetings, where collective decisions regarding the community are expected, is very low. A majority (62%) of the household respondents reported to have never attended any community meeting; 23% reported to have attended community meetings “rarely”; while 13% had attended meetings “sometimes”.

It is possible that highly unequal social and economic relationships among the people undermines creation of a community spirit, articulation of community aspirations and people’s participation in planning and managing community programs. Even in the cases of available successful examples of community participation where barriers have been removed by broad national policy framing, the community participation may merely mean giving vocal support to the local influential and getting a small share of the services and benefits by the weakest and neediest.

5.3 Primary health care approach

Because of the limited resource envelope available for the health sector, the Health Sector Strategic and Investment Plan (HSSIP) recommends a minimum package of services to be delivered to all people of Uganda through village health teams (VHTs) and health center II-IV. This package consists of the most cost-effective interventions and services addressing the high disease burden that is acceptable and affordable within the total resource envelope of the sector.

UNMHCP consists of the following services:

- (i) Health promotion, disease prevention and community health initiatives, including epidemic and disaster preparedness and response:
 - **Health promotion and education:** The key priority for health promotion and education is promoting individual and community responsibility for better health.
 - **Environmental health:** The environmental health component aims at contributing to the attainment of a significant reduction of morbidity and mortality due to environmental health and unhygienic practices and other environmental health related conditions.
 - **Control of diarrheal diseases:** Diarrheal diseases including acute watery diarrhea that is not cholera, dysentery and persistent diarrhea are mainly due to poor sanitation, low safe water coverage, poor domestic and personal hygiene practices and mass movement of populations. The main objective of the CDD component is to strengthen initiatives for control and prevention of diarrhea at all levels.
 - **School Health:** The School Health Program aims at improving the health status of the school children, their families and teachers and to include appropriate health seeking behavior among this population. It is expected that the school health program will improve the health of school children, reduce dropout rates and increase school performance.
 - **Epidemic Disaster Prevention, Preparedness and Response:** MoH is mandated to play a central role in the control, coordination and management of disease outbreaks. The EDPPR unit is responsible for prevention, early detection, reporting and confirmation and prompt initial response to health emergencies and other diseases of public health importance.
- (ii) **Maternal and Child Health:** Sexual and Reproductive Health (SRH), Newborn care, Common childhood illnesses, Immunization and Nutrition

- (iii) **Prevention, Management and Control of Communicable Diseases:** The priority health care interventions in the cluster of prevention and control of communicable diseases include; prevention and control of STI/HIV/AIDS; prevention and control of malaria; prevention and control of tuberculosis and elimination and or eradication of some particular diseases such as Leprosy, guinea worm, onchocerciasis, trachoma, lymphatic filariasis, trypanosomiasis, soil transmitted helminthes and schistosomiasis
- (iv) **Prevention, Management and Control of Non-communicable Diseases:** Uganda is currently experiencing dual epidemics of communicable and non-communicable diseases. The changing life styles have resulted in an increase in the prevalence of non communicable diseases like Diabetes mellitus, cardiovascular diseases, chronic respiratory diseases and cancer. It is an opportune moment for the ministry to give relevant attention to non-communicable diseases.

However, the desired reorientation and reorganization of health care delivery system have not yet occurred and there is still a higher concentration of health facilities and health workers in urban areas. This dichotomy in health services structure might suggest, however wrongly, that the VHTs who are volunteers and are normally not formally trained in medical practice are for the rural people, while the hospitals and medical specialists are for urban people. Obviously, in such an approach, equity in health is lacking and the primary health care approach collapses. Under such circumstances, the community level activities may not be provided with adequate support in the form of motivation, facilitation, supervision, training, essential supplies and effective referral arrangements. This has a dampening effect on community enthusiasm, VHT morale and community confidence in the health system.

5.4 Awareness on the right to health

Household members and leaders alike had a very low level of awareness of the right to health. While all household respondents in Kampala slums agreed that all community members had a right to access health services “always” or “often”, they had no further understanding in their right to health. A majority (94%) of the respondents said that the right to health meant accessing health services without discrimination but very few were aware that the right to health encompasses more than merely accessing health care services.

The respondents’ perception on whether it was their right to be given information about their health had a variation that was almost equally distributed with the majority saying “never” (26%), “rarely” (20%), “often” 19%. Only 12% said they were “always” entitled to information on their health and treatment. About 11% of

the respondents did not know. These results showed that most of the respondents were not aware that they had a right to be given information pertaining their health, diagnosis, prescription and treatment.

The majority did not think that patients had a right to making informed decisions on the type of treatment they should receive, with 39% saying they should “never” make informed decisions; 32% did not know whether this was a right; while 11% thought they should “sometimes” make informed decisions. None of the respondents thought it was part of their right to health for them to make informed decisions on their treatment.

With regard to community members to be given an opportunity to discuss health needs of their community as part of the right to health, a small majority 56% of household respondents said “sometimes”, and only 29% said they should discuss their health needs “always” or “often”. One fifth of the respondents reported that community members should “rarely” or “never” be involved in health needs discussions. Among community leaders, however, a higher proportion (78%) felt that health needs should be discussed with community members.

There was uncertainty on whether the community members should have access to information on the health expenditure from the relevant authorities where 32% of the respondents said “never”; 29% “sometimes”; 18% “rarely”; about 8% did not know. Those that said it was a right had the least percentage of 12%. The community leaders had similar perceptions to the community members.

5.5 Informal social activities

Participation in informal social activities – visits to or from neighbors, family or friends; visits to public places; attendance of sports, entertainment, parties, cultural gatherings, worship centers, restaurants, or funerals – was used as a proxy for social inclusion and ability of community members being involved in social interactions, discussions and information exchange.

From the correlation a majority of the respondents in Kampala slums reported regular contact with family and friends, and a few had contact with neighbors. The elderly (60 years and above) were reported to visit their neighbors more than those aged below 60. Respondents from households with lower incomes reported to visit and to be visited by their families less compared to respondents from households that had a higher income.

Even though they were few in number, respondents with high social isolation and poor mental health indicated less informal social interaction. Physical health was not evidenced to correlate with social interaction.

Whether the respondents had been to public spaces at least monthly varied greatly according to demographic characteristics and health measures. The majority had been to restaurants/ café of the listed places. Men were found to be going to social clubs more frequently compared to women.

The following categories of people were reported to visit restaurants/cafes: Respondents with higher education levels; from households of higher income levels; men; and those under 60 years; respondents that reported low social isolation; and those reporting good physical and mental health. The same patterns appeared for parties or dances with education status and education levels playing a significant role.

Participation in support groups and sports activities was the least frequent compared to formal and informal social activities considered. Being involved in sports correlated positively with being male; having a high education level; aged 60 and below; high household income and good physical health and better mental health and low social isolation.


Few respondents reported involvement with social support group activities with a high education status being the key players.

The only individual civic participation that notably emerged to have been done by the majority 74% of the respondents was going to meet their community leaders (Local Council chairpersons) individually.

All other measures that were used to measure civic individual participation were reported to be done by only a small proportion of the respondents. These included attending various meeting like council or protest meetings and going to meet leaders in higher offices like parliamentary representatives (MPs). Like men, women with a higher education level; good mental and physical health were found to have participated individually.

For collective civil participation, only 5% of the respondents reported to have participated in any of the activities in this category. Households with a higher income reported more involvement in political parties and trade unions. Individuals with higher education reported more civic participation in all activities compared to the others, however collective civic participation was generally low.

Participation in ethnic groups, school related groups, service clubs, churches/mosques and other volunteer organization was generally low. Involvement in school related groups was mostly by respondents under the age of 60 years. Older people participated more in ethnic groups and churches/mosques. More



women than men participated in school related groups and volunteer groups. Ethnic groups' participation was strongly associated with low level of education and higher age.

6. CONCLUSIONS

The decentralization program has, in principle, provided immense opportunities for communities to participate in health planning and decision making in their communities and local governments. These opportunities have however not been fully exploited. The central government retains too much control on finances and budgets, with the “conditional grant” approach limiting flexibility in budgeting and public expenditure by districts and lower local governments. The culture of social accountability has not been well appreciated by local government leaders and feedback mechanisms with community stakeholders have not been effective.

Evidence from Kampala and Kyankwanzi indicates that mobilization of community resources has not been exploited to promote participation in health. Inequality, politicking and high levels of perceived and real exclusion have undermined community cohesion and sense of unity. Community members do not seem to consider themselves to have a common destiny, which has resulted in apathy and resignation. Government programs, including in health, are not “owned” by communities. They are suspicious of well-intentioned interventions, such as registration and meetings.

Some categories of people were more socially excluded than others, which according to previous studies, interferes with participation. The elderly were found to visit their neighbors more, probably because they were home alone, bored and increasingly depend on neighbors even for necessities. Similarly it is possible that the reason why respondents with higher education frequented restaurants and cafes more was because they had a larger income and could afford these expenses. The above named exclusions from civil and social participation most likely interfere with the realization of the right to health.

Community members have limited knowledge of the right to health. The majority did not identify many of its components such as the right to information on their health, right to informed choice, and the right to be involved in health planning and decision making, including holding leaders accountable. They were all able to identify one component of the right to health (access to health services). This knowledge gap, also identified among community leaders, creates an unhealthy ground for promotion of the right to health. People are unlikely to claim the right to health if they do not know what it is and its components. This synthesis has shown that there is need to improve community sensitization on the right to health, including their right to participate in health planning and decision making.

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