Establishing Good Practice in Rights-Based Approaches to Mental Health in Kenya

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ESTABLISHING GOOD PRACTICE IN RIGHTS-BASED APPROACHES TO MENTAL HEALTH

IN KENYA

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Abstract

Mental health care is often characterized by coercion, abuse and ill-treatment. At the same time, there has been increasing interest in rights-based approaches to health. However, it is not always clear what the actual meaning of a rights-based approach is. This is particularly true in the field of mental health, and the dearth of scholarly research on this subject is especially pronounced in poorly resourced settings in low and middle-income countries.

In the context of the Doctoral Engagement and Translation for Action (DELTA) project of my Doctor of Public Health degree, I engaged with the Open Society Foundations to research the content of rights-based approaches to mental health and psychosocial support services in Kenya, where a significant amount of the organization's work on community-based mental health is located. I interviewed ten key stakeholders, including service providers and service users, to ascertain what they perceived to be rights-based approaches to mental health in terms of content and in terms of the potential contribution of these approaches to mental health systems. I also asked about the supports and barriers to implementing rights-based approaches to mental health and psychosocial support services.

Using an interpretivist methodology, I organized the interview data into three categories, namely: Key components of a rights-based approach to mental health; the contribution of a rights-based approach; and key barriers and supports related to implementation of a rights-

based approach. Central principles of rights-based approaches were identified and these principles inform the interventions that might be said to embody a rights-based approach, thus aiding in the key challenge of implementation. Participants noted some challenges to implementation, while also highlighting supportive factors.

Questions remain around the role of traditional healers and the acceptability of coercive practices, but this research highlights the central components of a rights-based approach that can guide interventions, facilitate standardization and inform future research. Moreover, in keeping with the goals of the DELTA, it provides a platform for further work on rights-based approaches to mental health at the Open Society Foundations, which hopefully will lead to better resourcing and increasing attention to these models.

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1. <u>Introduction</u>

This thesis concerns itself with the rights of people living with mental health conditions, particularly in low-resource settings in Kenya. I am interested in examining the ways in which organizations and service providers go about meeting the mental health care and psychosocial support needs of people affected by these conditions, using an explicit human rights orientation, or what has commonly come to be known as a 'rights-based approach'. This is an amorphous term that needs some clarification and theoretical interrogation as to its content and practical application. I am therefore seeking to provide insight into this concept.

I should start by highlighting some of the key terms that will be pervasive throughout the report, and perhaps in doing so, by clarifying my own biases. I use the term 'psychosocial disability' to refer to conditions that are elsewhere referred to as 'mental disorders' or 'mental illnesses'. This is in keeping with the language of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), an instrument that considers disability to include people 'who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others' (United Nations General Assembly, 2007) This terminology recognizes the environment as being 'disabling' rather than pathologizing an individual who may possess some form of neurobiological or emotional disturbance. It is also a term preferred by the World Network of Users and Survivors of Psychiatry (WNUSP), a global advocacy group made up of people living with psychosocial disabilities and their allies (Backman, 2018).

I also use the terms mental health service user (MHSU) and mental health care and psychosocial support (MHCSP) regularly, because consensus is clearly developing to support the idea that there is a need to address the psychosocial needs of an individual in a way that the

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mental health system alone cannot accomplish (Bracken, 2001; World Health Organization, 2014). However, this is also a central question of my research itself; namely, what constitutes a good practice model of mental health care and psychosocial support in a low-resource setting? I go into the details of what this term entails later, but it should be mentioned that it is made up of more than medical care or the intervention of the health system.

This study, for my DELTA (Doctoral Engagement in Leadership and Translation for Action) thesis, is being conducted as part of my work at the Open Society Foundations (OSF). It arises out of a study I completed for OSF in April 2018, in which I interviewed key international funders about their perceptions regarding mental health financing and funding for rights-based mental health programming. A key feature of their response to this latter question was that there is insufficient information about what constitutes a rights-based approach to mental health. There is even less information about how this might apply in low and middle-income countries. Therefore, apart from the intended benefit to academic knowledge, addressing this lack of information can be a key avenue through which funding for rights-based interventions might be encouraged.

Establishing good practice is not an exact science. In a project such as this one, it involves examining existing inputs to highlight their potential utility, although the probability of finding solutions that have been clinically trialled is extremely low. Instead, I am looking at ways in which organizations in Kenya have gone about applying their own interpretation of a 'rights-based approach' to MHCSP, and considering what factors are common between them. The question of 'impact' is difficult, also, because rights-based approaches seek to address systemic concerns and their effects on individual experiences, meaning they do not always lend themselves to clinical methodology. Unnithan (2015: 46) suggests that:

> *[Rights-based approaches] require additional ways of thinking about what constitutes evidence. This is because human rights are understood, applied, and taken up in a variety of ways by different institutions and individuals, and difficult to capture through the experimental methods of analysis used in clinical trials. Alongside evidence gathered on the basis of observation and controlled experimentation (as in evidence-based medicine), a 'subject-near' approach is necessary to ascertain what a human rights-based framework means and achieves. A subject-near approach entails adopting a social, cultural, interpretive, and experiential perspective.*

I therefore aimed to apply this perspective, highlighting the potential benefits of the approaches outlined by demonstrating their direct utility to the subjects of this research. I should also note that the purpose of this study is not to propose 'one size fits all' solutions, but to recognize that the 'social, cultural, interpretive, and experiential perspective' that Unnithan (2015: 46) refers to requires a contextual lens. It is therefore worth mentioning that I am not seeking to produce a recipe or checklist of interventions. Rather, what I hope to arrive at is a conclusion about what, in applied practice in resource-poor settings, the interventions are in the view of those providing them and those using them. I hope this will be of utility in my own work at OSF as I engage further with funders to generate interest in rights-based approaches to mental health care and psychosocial support and in the broader academic community as an indication of what a rights-based approach actually looks like in practice.

The thesis begins with an analytical platform, in which the extant literature on human rights, mental health and the rights-based approach is explored to more fully define the problem I am aiming to address. It also encompasses a consideration of how I have gone about investigating this problem, explaining the methodology utilized, the contextual background and the

organizational setting. I then explore the results and discuss their implications for theory and for

practice.

2. Analytical Platform

2.1. Models of mental health

Traditionally, mental health care has been an area where there have been considerable human rights violations (Drew et al., 2011). These have ranged from widespread neglect of people with psychosocial disabilities to incarceration and coercive treatments, many of which had no clinical validity (Monteiro et al., 2014). Problematic beliefs about mental health have been cited as some of the main drivers behind these erroneous and counter-productive ways of caring for people with psychosocial disabilities. These beliefs ranged from supernatural attributions for mental health conditions (Ie. The belief that an individual is possessed or has been a victim of witchcraft) to conceptions of such conditions as manifestations of 'feeble-mindedness' (Crabb et al., 2012; Mahomed, 2016). Arguably, these beliefs have shaped the way in which societies engaged with people with psychosocial disabilities. Other more malign used of mental health systems for political purposes were also prevalent as means of social control, practices which continue in some parts of the world to this day (Van Voren, 2016). Notwithstanding the abuses attributable to mental health systems, there has been some acknowledgment that these structural challenges require paradigmatic shifts, some of which have taken hold, though arguably not to a sufficient extent. What follows is an exploration of the evolution of thinking around mental health.

2.1.1. The biomedical model

Institutionalization of people with psychosocial disabilities became a primary source of care in many contexts, although this is not true in some parts of the world, where infrastructure for institutions has been less developed (Patel, 2007). Coercive treatment, usually at the hands of a psychiatrist or other mental health professional where these resources were actually available,

has been a clinical norm for centuries, and an emphasis on psychotropic medication as the standard of first-line care became a primary policy option, particularly in higher-income countries (Bracken, 2001). Similarly, our everyday mental health vernacular is largely derived from the Diagnostic and Statistical Manual of Mental Disorders, now in its fifth edition (DSM-V), which classifies the range of *'mental disorders'* and which is utilized widely as a basis for providing services or insurance coverage (American Psychiatric Association, 2013). These practices and tools have been criticized as over-emphasizing the biomedical basis of mental health and offering little insight or support to address the psychological, social, cultural, spiritual and economic determinants of mental health (Taylor & Brown, 1988; De Jong, 2006). This *'biomedical'* paradigm has also been criticized for its disempowering effect, viewing people living with psychosocial disabilities as impaired and relying heavily on medical professionals and psychotropic medication, at the expense of an approach that viewed people with psychosocial disabilities as having agency or autonomy to support and drive their own well-being (Pilgrim, 2008). In seeking to address some of these concerns, other models of mental health began to emerge.

2.1.2. The biopsychosocial model

Recognizing that medical and psychological conditions occur in a social, economic and political context, the biopsychosocial model emerged as a means to treat mental health conditions by focusing on the interacting components of biological pathologies as well as social and psychological determinants (Engel, 1977). Babalola et al. (2017: 292) refer to this model as the *'conceptual status quo'*, stating that it *'underpins'* the work of the World Health Organization (WHO) in the realm of mental health and beyond. The model has also been instrumental in informing best practice in mental health care, incorporating a diverse set of professionals such as

social workers and occupational therapists alongside psychiatrists and psychologists (Babalola, 2017).

Despite its contributions, the biopsychosocial model has been critiqued on some important grounds. Perhaps the most strident criticism relates to the idea that the biological determination of mental *'ill health'* is still centralised, with the psychological and the social aspects merely acting as tributaries, thus supporting a hierarchical view of the determinants of health (Alvarez et al., 2012). Another important criticism relates to the model's emphasis on individual pathology (and how social factors militate to *'create'* pathology), which in turn problematizes the individual (Inclusion London, 2018). Disabled people's organizations (DPOs) have also been critical of the biopsychosocial approach because it continues to *'medicalize'* mental health, and because it seeks to pathologize those who are otherwise-abled rather than taking into account the alternative abilities of such individuals (Inclusion London, 2018). This has been one of the most significant driving forces behind moves towards the social model and, ultimately, the rights-based model.

2.1.3. The social model

The social model considers *'impairment'* as the product of an individual's interaction with their environment. This is significant because it no longer views the individual as being pathologized or problematized, instead viewing the *'pathology'* as the social environment that does not accommodate those with alternative abilities and needs (Shakespeare, 2002). The model does not preclude the possibility of a biological or chemical determinant as a possible source of a mental health condition. Instead, it recognizes that such a condition interacts with an environment that does not provide the necessary accommodations to support an individual to live as an equal member of society. Moreover, as Michael Oliver (1996) notes, the model seeks to undo the

medicalization of disability that has traditionally dominated discourse, replacing it with a view of people within a system that is inherently discriminatory. He states:

> [D]isability according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure to discrimination institutionalised throughout society (Oliver, 1996: 33).

This model has been instrumental in shifting the thinking around mental health to support inclusion through adaptations in the environment and in social attitudes. It was key in informing calls for reform in laws and policies relating to disability (Shakespeare, 2002). Even so, the social model is not without its critics, with some suggesting that it does not account for diversity amongst the disabled and that it risks potentially marginalizing some groups of people with disabilities if not applied with the necessary acknowledgements of universality of rights and diversity among people (Inclusion London, 2018). Similarly, while the social model is seen as a useful explanatory model for disability, it has been critiqued for not offering substantial guidance for how to go about changing circumstances that marginalize people with disabilities (Degener, 2017).

The social model offers important insights into the lens through which disability can be viewed and through which the social determinants of psychosocial disabilities can be conceived of. However, the needs for disability to be valued as a facet of human diversity and for social justice to be a cornerstone of thinking around disability were still highlighted as important shortcomings that later came to be addressed through the human rights-based model.

2.1.4. <u>The human rights-based model and the CRPD</u>

Continued recognition of the need for a model of disability that places an emphasis on the disabling environment but also addresses the aspirations of social justice and values disability as a component of human diversity led to proposals for a new rights-based paradigm in the realm of disability (Degener & Quinn, 2002). At the same time, in recognition of the need for more humane mental health regimes, shifts away from institutionalization and towards care and support regimes that include measures such as non-coercive treatment and peer support programming began to occur in the late 20th century, primarily in countries in the Global North (Scallet & Robinson, 1991; Desjarlais & Eisenberg, 1995; Rosen 2006). These shifts notwithstanding, they remained, and continue to be, exceptions to the norms of the biomedical and, to some extent, the biopsychosocial model.

As calls for a *'human rights model'* (Degener & Quinn, 2002) became more vocal, the parameters of such a model became clearer, with supporters suggesting that a rights-based model would recognize the inherent dignity and value of people living with disabilities and that this model would emphasize equality and non-discrimination in all aspects of life, thus addressing the concern that the social model was merely explanatory in nature. Similarly, acknowledging that there was a continued need for the emerging shifts in mental health practice in the Global North to be entrenched and for a broader recognition of the rights of people affected by mental health challenges to be affirmed, organizations such as the WNUSP advocated for a strong focus on mental health in the shift towards the rights-based model. In 2007, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD), the first comprehensive treaty on disability rights. The Convention was opened for signatures on 30 March 2007 and, on the first day, 82 States signed up to it – the

highest number in history for the opening day of a Convention (Hacker, 2017). The CRPD's central guiding principles, are articulated as follows:

i. Dignity and Autonomy

ii. Equality and Non-discrimination

iii. Effective participation and Inclusion

iv. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

v. Equality of opportunity

vi. Accessibility

vii. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Commentators refer to the adoption of the CRPD as the culmination of a *'paradigm shift'* because it entrenches the social conception of disability in a normative instrument, and because it affirms that people living with disabilities are entitled to all of the rights and opportunities afforded to those without disabilities (Stein & Lord, 2007; Harpur, 2012). Full and equal participation and inclusion in society requires a shift from segregated and institutionalized care to community-based services, while the principles of equality, non-discrimination, dignity and autonomy incorporate an affirmation of the right to equal recognition before the law (Minkowitz, 2006; Cobigo & Stuart, 2010; Devi, 2013). In practical terms, this means that people with mental health challenges may not be coerced into treatment or involuntarily institutionalized under any circumstances, a provision that has proven to be controversial and, in some extreme circumstances, difficult to operationalize (Pearl, 2013; Freeman et al., 2015; Gooding, 2015).

The challenges and controversies notwithstanding, 177 states have ratified the CRPD, making it one of the most widely-ratified human rights treaties in history (United Nations Office of the High Commissioner for Human Rights, 2018). With specific reference to mental health, in 2017, the UN Special Rapporteur on the Rights of Persons with Disabilities reported that at least 32 countries had either undertaken reforms or were in the process of implementing reforms to their mental health laws and policies to incorporate the paradigm advanced by the CRPD (UN General Assembly, 2017b). This is illustrative of the (at least rhetorical) intent among states to domesticate a right-based model of disability and mental health. As Degener (2017: 56) notes, however:

> *Most of the States Parties' reports [on the CRPD] do not reflect a clear understanding of the human rights model of disability. While it has become unfashionable to rely on the medical model of disability, the paradigm shift to the human rights model has yet to be reflected in implementation.*

This is a strong indictment of the gap between adoption of a rights-based model in law and the actual application of rights-based approach at the level of implementation. While the CRPD is certainly a significant step forward, there is a need to address this lack of *'a clear understanding'* and to clarify what implementation of a rights-based approach, informed by the rights-based model of disability, might look like in practice.

2.2.   The *'implementation gap'* between the CRPD and the lived experiences of people
        with psychosocial disabilities

The widespread ratification of the CRPD might suggest a degree of impetus to realize the rights-based model of disability and mental health in practice. Yet there is no country in the world whose laws and policies are fully CRPD-compliant (Iriarte et al., 2015). Moreover, despite the criticisms of the biomedical model, this approach to mental health continues to predominate. In 2017, the United Nations (UN) Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (who is also a member of the committee supervising this thesis) listed the dominance of the biomedical model as one of the three key obstacles to the attainment of the right to mental health (UN General Assembly, 2017a). The other obstacles were power asymmetries and the biased use of evidence in mental health. These obstacles also reflect a biomedical lens, as power asymmetries affect MHSUs substantially in their relationships with medical practitioners and because the 'evidence' being referred to also supports the use of psychotropics at the expense of psychosocial interventions (UN General Assembly, 2017).

In 2018, the Lancet Commission on Global Mental Health and Sustainable Development issued its report on the mental health in the era of the Sustainable Development Goals (SDGs) (Patel et al., 2018). The report highlights the need for scaling up of mental health services, using largely biomedical terminology and approaches such as reference to *'mental disorders'*. Critics have suggested that, while the report recognizes that a purely biomedical orientation is not sufficient to address the needs of people with psychosocial disabilities, its recommendations *'still come from a biomedical starting point, and therefore fail to recognize fully both the psychosocial model of mental health and community services'* (Mental Health Europe, 2018). The report's influence on policy and practice is bolstered by its centralization at the Global

Ministerial Mental Health Summit, held in October 2018, an initiative that has also been criticized as neglecting the views of MHSUs, while over-emphasizing those of clinicians, thus further entrenching the biomedical lens (Mills, 2018).

At the individual and community levels, continued violations of the rights of people living with disabilities remains commonplace. A study of the most common rights violations affecting people with psychosocial disabilities in low and middle-income countries found that exclusion, marginalization and discrimination in the community was a key concern (Drew et al., 2011). Other violations included:

i.   The denial or restriction of employment rights and opportunities;

ii.   Physical abuse and violence;

iii. The inability to access effective mental health services;

iv.   Sexual abuse and violence;

v.   Arbitrary detention;

vi.   Denial of opportunities for marriage or the right to found a family;

vii. Lack of means to enable independent living in the community;

viii. Denial of access to general health/medical services; and

ix.   Financial exploitation (Drew et al., 2011).

The CRPD seeks to protect, promote and fulfil the rights of people living with disabilities. This means active programming and shifts in laws and policies, alongside the removal of barriers to effective participation and the monitoring of the attainment of human rights. In this sense, the absence of stigma-reduction programming or efforts aimed at inclusion of people with psychosocial disabilities in education and employment settings constitute human rights violations also (Rioux, 2013; Mahomed & Stein, 2017). Similarly, the lack of appropriate

community-based services, coupled with lack of adequate resourcing might also be thought of as a violation of the rights of people living with psychosocial disabilities (Mahomed & Stein, 2017). Stigmatization of mental health challenges by health care workers, denial of the right to participate in political life and the absence of effective monitoring have all also been documented (Stein & Lord, 2010; Kapungwe et al., 2011; Priestley et al., 2014).

Institutionalization, seclusion and other forms of coercive care and support remain common, and services continue to rely heavily on methods that are clinically and ethically unsound (United Nations General Assembly, 2017a). Inadequate capacitation and the lack of implementation of existing policies due to political inaction have also been referred to as systemic rights violations (Lang et al., 2011). Numerous examples of failed mental health deinstitutionalization programs in Europe and the US (many precipitating crises of homelessness) have highlighted the need for more than simply the absence of coercion and seclusion but, also, active efforts to encourage social integration (Dear & Wolch, 2014). In 2016, the administration of the Gauteng Province in South Africa cancelled a contract to house people living with psychosocial disabilities in a private institutional facility, commencing with a process of deinstitutionalization to community-based non-governmental organizations (NGOs). However, the lack of sufficient resourcing and capacity within these organizations proved to be disastrous, culminating in the deaths of over 100 people, illustrating that a lack of adequate capacity and an approach to implementation that is not technically sound can also result in gross human rights violations (Office of the Health Ombud, 2017). It is important to note that one of the rationales that precipitated the catastrophe in Gauteng was a desire to implement the provisions of the CRPD (Personal communication with Department of Health official, 2018). This demonstrates that, even where the intended outcome of an intervention is the realization of internationally-accepted human rights principles, considerations of adequate preparation and sound implementation are essential if human rights are to be protected, promoted and fulfilled.

These violations illustrate both social and system-level concerns as well as individual-level challenges that have at their roots a lack of protections and opportunities for people living with psychosocial disabilities and a lack of implementation of human rights principles. They also inform what a rights-based approach to mental health care and supports should be, given that such an approach will need to shift from a purely biomedical lens, will need to recognize the numerous rights violations that can occur and will need to address these violations in order to realize the rights of those affected. This, therefore, provides a useful basis upon which to examine the existing literature on the subject of rights-based approaches in the field of health, before turning to mental health specifically.

2.3.   Rights-based approaches in health: What do they mean and what can they add?

Gruskin et al. (2010: 129) note that:

Over the last 20 years the public health community has come to a largely shared perspective that a human rights lens on health helps shape understandings of who is disadvantaged and who is not; who is included and who is ignored; and whether a given disparity is merely a difference or an actual injustice.

Despite this *'largely shared perspective,'* a common and universally-accepted definition of what constitutes a human rights-based approach to health has not been articulated. The right to health itself is outlined in the International Covenant on Economic, Social and Cultural Rights (ICESCR). General Comment 14 from the Committee on Economic, Social and Cultural Rights, which provides interpretive guidance on the content of the right, establishes a now commonly utilized 'AAAQ' framework, meaning:

i.   Availability: Refers to functioning public health and health care facilities and a sufficient quantity of goods, services and programming

ii.   Accessibility: Refers to non-discrimination in ensuring access to services and facilities, including physical accessibility, economic accessibility and information accessibility. A specific emphasis should also be placed on marginalized and 'vulnerable' groups

iii. Acceptability: Refers to respect for medical ethics and services that are sensitive to culture, age and gender

iv.   Quality: Refers to scientifically and medically appropriate care

In 2003, the UN developed a *'common understanding'* of a rights-based approach in all interventions including in the health field. It encompasses an emphasis on goals, implementation and outcomes of an intervention, affirming that all programming should further human rights principles and should take guidance from international human rights instruments and lists six key principles for rights-based programming, namely:

i.   Universality and Inalienability
ii.   Indivisibility
iii. Inter-dependence and Inter-relatedness
iv.   Equality and Non-discrimination
v.   Participation and Inclusion
vi.   Accountability and Rule of Law

Gruskin et al. (2010: 134) state that this instrument adopts a *'lowest common denominator approach, privileging consensus over specificity. Its general nature has made it difficult to operationalize, and agencies have taken on different aspects of the Common Understanding, reflecting their respective mandates'*. Similarly, Klasing et al. (2011: 11) reviewed the definitions of a rights-based approach of various organizations in humanitarian settings, observing that *'an organization's 'rights-based approach' is determined not only by the legal framework, but by the organization's founders, governors, stakeholders, and others, rendering the term somewhat relative to the organization or group one happens to be addressing'.*

In the field of health, the WHO and the UN Office of the High Commissioner for Human Rights (OHCHR), drawing on both General Comment 14 and from the UN Common Understanding adopted a rights-based approach consisting of the following elements:

    i.   Availability

    ii.   Accessibility

    iii.   Acceptability

    iv.   Quality

    v.   Non-discrimination

    vi.   Participation

    vii. Accountability (WHO/OHCHR, 2009)

Table 1: Comparing guiding principles of the UN Common Understanding of rights-based approaches to Health, the 'AAAQ' framework of General Comment 14 on the right to the highest attainable standard of health, the WHO/OHCHR definition of rights-based approaches to health and the CRPD
*According to General Comment 14 of the Committee on Economic, Social and Cultural Rights (2000), accessibility, in the 'AAAQ' framework incorporates a commitment to non-discrimination

UN Common Understanding	General Comment 14	WHO/OHCHR definition	CRPD
Universality and Inalienability	Availability	Availability	Dignity and Autonomy
Indivisibility	Acceptability	Acceptability	Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
Inter-dependence and Inter-relatedness	Accessibility	Accessibility	Accessibility
Equality and Non-discrimination	Non-discrimination*	Non-discrimination	Equality and Non-discrimination
Participation and Inclusion		Participation	Effective participation and Inclusion
Accountability and the Rule of Law		Accountability	Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities
	Quality	Quality	

Gruskin et al. (2010) also contend that a key feature of a rights-based approach, specifically in the field of health, is an emphasis on process. Human rights principles should guide the planning, implementation and evaluation of policies and programs, in a manner that recognizes the rights to participation and autonomy of people affected. Unnithan (2015: 46) states:

> *A human rights focus in public health puts the spotlight not only on who is disadvantaged and who is not but, importantly, on whether a disparity in health outcomes results from an injustice. In so doing, it draws the attention of public health planners and policy makers toward process (mechanisms) as much as outcome, and to the workings of power*

Another key feature of a rights-based approach is the fact that it requires a cross-cutting emphasis, looking not only at the factors that directly contribute to health, but also on the social, cultural, economic and political factors that determine health outcomes. Thomas et al. (2015: 12) note that:

> *Human rights-based approaches, by their nature, cut across sectors and draw from multiple strategies. They might require legal or policy reform to create 'enabling' environments; the identification and capacity-building of 'rights holders'; comprehensive programs for education, health, and human rights literacy, advocacy, and empowerment; or the elaboration of more participatory accountability and oversight mechanisms. Human rights-based strategies are designed to redress deeply ingrained inequalities, and they aim to enable everyone to participate fully in economic, social, and cultural affairs toward the progressive realization of rights.*

Efforts to address health concerns from a rights perspective, therefore, may approach these challenges through avenues that address inequality, that promote inclusion and that foster accountability, at times outside the realm of the health system (Yamin, 2010). There have been some studies that have focused on the nature of a rights-based approach a few that have also examined the contribution that such an approach can make. These range from explorations of the normative contributions that a human rights lens offers to service provision and a recognition of the role of judicial review as a lever for accountability (the legal approach); to the use of human rights principles in advocating for the provision of services (the advocacy approach); to more direct applications of human rights principles in programming and the implementation of services (the public health approach) (Gruskin, 2006).
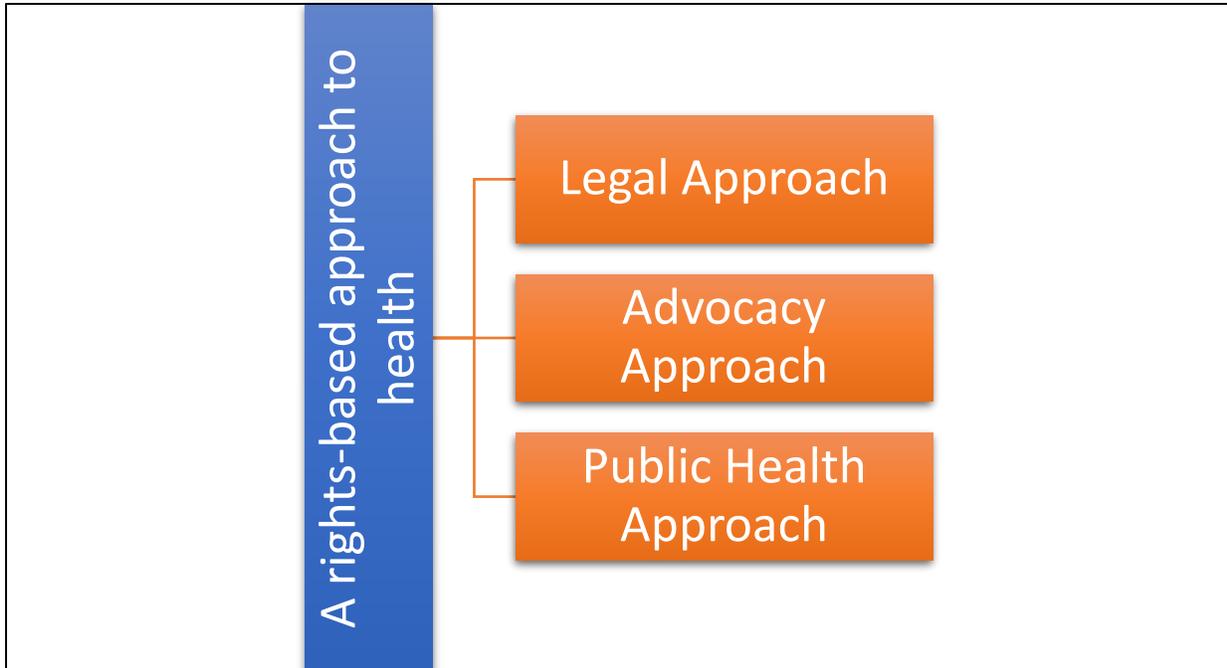
Figure 1: The three 'versions' of the rights-based approach to health, according to Gruskin (2006)

2.3.1. <u>The legal approach</u>

Yvonne Boyer (2016) utilizes a rights-based approach to health to consider the right to health of Canada's First Nation, Meti and Inuit women, examining provisions in international law such as the Universal Declaration of Human Rights and domestic laws such as the Canadian Charter of Right and Freedoms to consider how health outcomes vary between indigenous groups and other Canadians. London (2008) argues that human rights language and the incorporation of human rights norms into policy enhance accountability, while also ensuring that the same impetus given to civil and political rights is afforded to health. He cites the case of the Treatment Action Campaign in South Africa, which ultimately won access to antiretroviral treatment for thousands of people through judicial action, as a rights-based approach. He notes, also, that, to be effective, a rights-based approach should actively seek to afford a voice to those most affected and should endeavour to include all affected persons in decision-making (London, 2008). Similarly, a *'human rights-approach,'* in this conception, allows for involvement in policy

development and supports the mobilization of communities to work towards rights realization, including through engagements with governments and civil society (London, 2008).

Barros de Luca et al. (2013) examined the influence of human rights principles on laws governing sexual and reproductive health rights in Brazil, finding that health inequalities between rich and poor had effectively been eradicated and that access to, and knowledge of, contraception had increased significantly as a result of normative shifts. They, too, cite this as a rights-based approach, but also highlight the interventions that accompanied the shift in laws. Among the interventions that were highlighted as indicators of implementation of rights-based programming were provision of information and education to expectant mothers, confidential access to contraception and an emphasis on marginalized groups, including rural women, women with disabilities and indigenous women (Barros de Luca et al., 2013). This is illustrative of the fact that the *'legal'* front and the *'public health'* front can, and in fact should, interact significantly in pursuit of a rights-based approach to health. A similar relationship was posited by Mhango et al. (2013) to highlight how universal vaccination policies in Malawi reached the country's most vulnerable children, including through educational and awareness-raising activities. They found that the overall rate of vaccination improved as a result, demonstrating the potential to improve health outcomes when specific, targeted measures flow from rights-oriented policies.

The Pan-American Health Organization (PAHO), a regional body of the WHO undertook to incorporate a human-rights based approach to its work providing technical assistance and policy guidance to various countries in the region. It highlights the incorporation of international human rights standards into mental health laws in Argentina, Barbados, Belize, El Salvador, Granada, Paraguay, St. Lucia, St. Kitts, Trinidad and Tobago and Venezuela as being illustrative of the integration of a rights-based approach into its work, although the details of this integration are

not provided (PAHO, 2013). It also refers to policy shifts that focused on *'vulnerable'* groups,

including promotion of access to health services for Lesbian, Gay, Bisexual, Transgender and

Intersex (LGBTI) individuals and the provision of emergency contraception to adolescents as

illustrations of a rights-based approach (PAHO, 2013). These examples demonstrate the

breadth of what might be thought of as a rights-based approach with a legal and policy-oriented

perspective. Ultimately, the intent is for a direct link to implementation in programming, but it

seems that stakeholders and proponents have highlighted the passage of laws and policies

themselves as indicators of the adoption of a rights-based approach.

2.3.2. <u>The advocacy approach</u>

Civil society organizations are often key actors in advocacy-oriented rights-based approaches.

In Zimbabwe, a monitoring group, consisting of several civil society bodies as well as state

actors and academic organizations, was established to monitor the government's

implementation of the country's Health Action Plan. The Zimbabwe Association of Doctors for

Human Rights (2009) refers to this as an application of a human rights-based approach, noting

that the role of the monitoring committee and civil society actors was to support accountability

efforts and to advocate for implementation. Similarly, a report of the Uganda Commission for

UNESCO (2016) noted that health care providers are often important advocates for change in

the context of rights-based approaches, citing the example of a doctor who refused to perform

surgery in an untiled operating room because of the risk of infection. The support of community

members and civil society eventually led to action to address this risk (Uganda Commission for

UNESCO, 2016).

Lohman and Amon (2015) focus on the use of an advocacy approach by Human Rights Watch

to highlight the impact that campaigns to expand awareness of the need for, and access to, pain

medicine and palliative care have had in India, Kenya and the Ukraine. They suggest that *'public health programs adopting human rights-based approaches have been shown to improve service delivery, focus attention on marginalized populations and enhance equality, equity, inclusiveness, and accountability'* (Lohman & Amon, 2015: 152). By contrast, an advocacy approach focuses on the ways in which action by NGOs and other bodies can motivate political will and increase awareness of an issue. In this conception, a rights-based approach seeks to:

i. Elevate the voices of people affected by a rights violation;

ii. Analyze structural barriers;

iii. Clarify government obligations; and

iv. Advocate for change (Lohman & Amon, 2015).

They conclude that this version of a rights-based approach was useful to create meaningful change at national and international levels. This includes language in a regional treaty, as well as the development of a national specialization in palliative care in India and a curriculum to train practitioners. In the Ukraine, advocacy with lawmakers led directly to regulatory change, thus potentially laying the groundwork for programmatic efforts (Lohman & Amon, 2015).

Perkins (2009) documents the work of the El-Shehab Institution for Comprehensive Development in Egypt to illustrate the potential for an advocacy-oriented rights-based approach that seeks to address the social and economic determinants of health. By advocating for access to water, sewerage and electricity for marginalized groups and by providing legal assistance to women who have been abandoned by their husbands, El-Shehab promotes health and well-being, including mental health (Perkins, 2009). This illustrates that the legal and advocacy orientations often go hand in hand, and it also illustrates that promoting access to the social,

economic, cultural and spiritual determinants of health can be important factors in a rights-based approach to health.

2.3.3. The public health approach

A report entitled *Deadly Delays: Maternal Mortality in Peru* by Physicians for Human Rights (2007) also purports to utilize a rights-based approach to examine how social, economic and other systemic factors militate against safe motherhood. Among the challenges highlighted include the lack of available resources, the lack of effective remedies and discrimination against specific groups, thus contributing to rights violations. The approach emphasized in this report incorporates the removal of barriers to equality and participation in law as well as active promotion of rights realization through engagement with civil society, capacitation of health care workers on human rights, efforts to *'democratize the health sector'* through participatory governance and the widespread dissemination of information related to safe motherhood. This represents a public health-oriented rights-based approach, although it does include advocacy and legal components as well.

Similarly, Silberhorn (2015) refers to efforts such as insurance coverage for the poor in India, social auditing of facilities to improve user participation and involvement in governance and the provision of specialised care and support for survivors of sexual and gender-based violence as examples of rights-based approaches. These efforts seek to enhance accessibility, to focus on vulnerable groups and to improve accountability-perhaps a signifier of a legal and policy-oriented lens as well (Silberhorn, 2015). Smith-Estelle et al. (2015: 1722) found that the incorporation of a telephonic hotline to provide information regarding maternal and child health in Malawi, coupled with capacitation of hotline workers resulted in improved home-based and

facility-based practices for users, suggesting that this *'demonstrates a fulfilment of the right to health'*.

In Ethiopia, CARE International sought to shift its work to address the health effects of Female Genital Cutting (FGC) from a needs-based approach to a rights-based one (Igras et al., 2004). A key intervention that guided its work was an assessment of contextual factors, engaging local participants in focus groups and interviews that focused both on the health effects of FGC as well as the social, cultural and religious determinants of FGC as well (Igres et al., 2004). Engagement with community volunteers to provide outreach and information was another key activity. These examples illustrate the broad range of interventions that might be said to constitute a rights-based approach, particularly in the field of application in the public health realm. However, as demonstrated below, applying a rights-based approach can be challenging.

2.3.4. Challenges in operationalizing a rights-based approach

The CARE International project to address the health effects of FGC in Ethiopia highlighted some important challenges. Perhaps most notably, cultural and religious norms in a particular context may not easily comport with a rights-based approach, as evidenced by the backlash to CARE International's engagements with community members, with religious leaders and community elders expressing dissatisfaction with the imposition of human rights norms, seen as a 'Western' idea (Igres et al., 2004). This is indicative of the significance of contextual factors and the social, cultural and religious norms that might need to be navigated in seeking to apply a rights-based approach. Igres et al. (2004) suggest that effective navigation of these norms is, in fact, a substantial component of an effective application of a rights-based approach.

Work by the United Nations Children's Fund (UNICEF) and Concern Worldwide have utilized *'community dialogues'* as a means to improve participation and to foster accountability among community health workers (CHWs) in Malawi (Zimba et al., 2012). Even so, Smith-Estelle et al. (2015: 1717) report that *'although the community dialogue tool was fundamentally aligned with human rights norms, its actual use still saw health workers largely telling community members what to do rather than engaging in dialogue as equals'*. They cite this as an example of rights-based approaches that are not well-developed and may actually hinder rights realization, noting that other factors, such as requests for payment and attitudinal barriers among health care workers, proved to be problematic (Smith-Estelle et al., 2015).

Dyer (2015), also highlights the challenges inherent in implementing a rights-based approach, finding that the Human Rights in Healthcare Programme in the United Kingdom (UK), while shifting the perception of human rights commitments from a legal obligation to an avenue to improve the quality of care, was *'overshadowed'* by a systemic lack of support and an over-emphasis on 'efficiency'. Similarly, Williams and Brian (2012), using 36 indicators to assess the realization of human rights principles in a public health program in Papua New Guinea, found that none of these objectives had been fully met because of a lack of resources and technical capacity and because no efforts were made to include health service users. These results illustrate that human rights-based approaches, particularly in the public health realm, rely heavily on sound implementation, without which they may *'win political or financial support, but will fail to deliver a quality health service, available, accessible and acceptable to all'* (Williams & Brian: 255).

2.3.5. <u>Assessing the impact of a rights-based approach</u>

As noted earlier, while many of the studies cited claim that a rights-based approach can contribute to positive outcomes, evaluating the impact of rights-based approaches can be challenging. This is a key obstacle that proponents of a rights-based approach continue to grapple with. The lack of a standardized definition of a rights-based approach, coupled with the fact that the multi-sectoral and complicated interventions that often constitute this approach do not lend themselves to causal interpretations, have made it difficult to build an *'evidence base'* in the traditional sense (Thomas et al., 2015). Often, rights-based interventions can be lengthy, making them difficult to monitor, and their effects can be affected by extraneous variables (Thomas et al., 2015).

Unnithan's (2015: 46) conception of *'a subject-near approach [which] entails adopting a social, cultural, interpretive, and experiential perspective'* reflects a need to engage with the idea of evidence in a way that traditional health research does not always manage. The assessment of impact of a rights-based approach is a complex matrix of quantitative indicators (as many of the cited studies have sought to provide) and qualitative experiential narratives that take into account the value of inclusion, participation, autonomy and accountability for those affected. Key factors such as vulnerability, power dynamics and governance should be centralised in this approach, and Unnithan (2015) contends that these constitute *'evidence'* of their own kind.

Thomas et al. (2015), meanwhile, suggest that a multi-layered *'spectral'* approach to assessing the value of rights-based approaches can be of use. They recommend examining change from the individual, programmatic, structural and societal level, noting that the infusion of human rights principles at all these levels constitutes a rights-based approach (Thomas et al., 2015). Yet, despite the obligations to ensure the accountability and good governance of interventions,

very few rights-based programs actually concentrate substantially on monitoring for efficacy or evaluating for the realization of rights (Thomas et al., 2015). This is a major shortcoming of existing programming related to rights-based approaches to health and it bears relevance in the context of an exploration of the contribution such approaches can make. While there have been instances where rights-based approaches have been linked to substantive shifts, the lack of critical self-reflection may be said, in itself, to be contrary to human rights principles.

The literature on the subject of rights-based approaches has emphasized the legal and policy orientation, although there appears to be growing awareness of the need for normative guidance to translate into programming. As Smith-Estelle et al. (2015: 1713) note:

> *The application of human rights norms at the national policy level is well documented, but rigorous research focusing on the field level application of a human rights-based approach to health program design, implementation and evaluation, including measuring its impact on project outcomes, is still very much in its infancy.*

Recent attempts at establishing best practice in human rights-based programming in health care, such as the SaluDeRecho concept in Latin America (that brings together various stakeholders for the purposes of knowledge-sharing and collaboration) are encouraging (Escobar, Cubillos & Iunes, 2015), but it seems that there remains a considerable paucity of information on how best to go about operationalizing a rights-based approach in the realm of application rather than judicialization or advocacy. As demonstrated below, this is particularly true in the field of mental health.

2.4.   Rights-based approaches in mental health: Key interventions and best practice

The WHO (2014b) defines mental health as *'a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community'.* This, in itself, is an acknowledgment that mental health is comprised of more than simply biological interventions or psychotropic medication and that well-being is more than the mere absence of disease. A more holistic view of mental health incorporates services to address economic, social and spiritual needs. According to Saxena et al. (2007), it is comprised also of efforts to actively promote, protect and fulfil fundamental human rights. Recently, leaders in the fields of neuroscience and global mental health have called for:

> *A multilayered and multisectoral approach to prevention and treatment… including... provision of living and working conditions that enable healthy psychosocial development, promotion of positive interactions within and between social groups, social protection for the poor, anti-discrimination laws and campaigns, and promotion of the rights of those with mental disorders (Stein et al., 2015: 178).*

This is illustrative of the fact that a variety of factors need to be addressed in order to ensure that mental health and well-being are fostered. In a similar vein, the CRPD approaches mental health from the perspective of 'psychosocial disability', thus applying a social lens to the factors that contribute to mental health challenges and recognizing that the principles of autonomy, dignity, participation, inclusion, non-discrimination, respect for difference, accessibility and an acknowledgement of the evolving capacities of the child are incorporated into service provision (Bartlett, 2012). Still, as with other areas of health, there is no uniform understanding of what constitutes a rights-based approach and no standard-setting as far as interventions are

concerned (Backman, 2018). Backman (2018) concludes that the principles of the WHO/OHCHR definition align well with the CRPD, noting that these values serve, at the very least, as normative guidance. However, the actual scope and application of the rights-based approach remains somewhat nebulous. As noted earlier, there have been scattered applications of human rights principles in the mental health field, even prior to the introduction of the CRPD (Scallet & Robinson, 1991; Desjarlais & Eisenberg, 1995; Rosen 2006). Even so, there is a considerable paucity of research on the topic of explicitly rights-oriented approaches to mental health, particularly insofar as applied practice is concerned. Studies highlight differing features and demonstrate varying interpretations of the rights-based approach. To illustrate this, a brief exposition of the existing literature on this subject is turned to next.

The WHO has been spearheading the Quality Rights initiative, a program to advance CRPD compliant mental health legislation around the world, while also focusing on quality in inpatient and outpatient mental health and psychosocial support services. This initiative explicitly focuses on the promotion of recovery and independent living in the community, while seeking to develop a *'movement'* of people with psychosocial disabilities to provide mutual support, conduct advocacy and influence policy-making processes (WHO, 2017). The WHO has also produced a Quality Rights toolkit, aimed at standardising policies and protocols, and at enhancing the capacity of countries to implement rights-based approaches to mental health through, among others, the training of staff of national Ministries of Health (Personal Communication with WHO staff member, 2018). The Quality Rights Toolkit prioritizes five areas, which broadly are said to overlap with the provisions of the CRPD, namely:

  i.   The right to an adequate standard of living and social protection;
  ii. The right to enjoyment of the highest attainable standard of physical and mental health;

iii. The right to exercise legal capacity and the right to personal liberty and the security of the person;

iv. Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse; and

v. The right to live independently and be included in the community (WHO, 2012).

Quality Rights incorporates a monitoring component, seeking to comprehensively provide data on mental health and human rights in a systematic manner that has, to date, not been done before. Quality Rights assessments have been completed in countries in Africa, Asia, Europe and Latin America. The aim of the WHO is for these assessments to provide information for the development of norms and standards for rights-based implementation throughout the world (Personal Communication with WHO staff member, 2018).

Murray (2013: 161) states that *'rights-based models of mental health law are now widely considered to be the norm'*, noting, however, that rights-based legal frameworks need to be implemented if they are to actually contribute to meaningful change. The WHO's Mental Health Atlas (2014c) project examined the level of compliance of national mental health statutes with international human rights norms, finding that, of 149 countries surveyed:

i. 62% of countries had legislation that promotes the transition from institutionalised care to community-based mental health services;

ii. 67% of countries had legislation that promotes the rights of people with psychosocial disabilities to exercise their legal capacity;

iii. 75% of countries had legislation that promotes alternatives to coercive practice;

iv. 68% of countries had legislation that provides for procedures to enable persons with mental disorders to protect their rights and file complaints to an independent body; and

v. 60% of countries had legislation that provides for regular inspections of human rights conditions in mental health facilities by an independent body.

According to Eaton (2018), despite the existence of these provisions, compliance with them remains poor, particularly in low-income countries. Referring to the *'legislative rights-based approach'* in Ireland, Murray (2013) suggests that the Mental Health Care Act in that country represents a shift from an over-emphasis on institutionalization towards community-based care, but also continues to represent a paternalistic model of care that allows the judiciary and practitioners to make decisions on behalf of users. The Australian Human Rights Law Resource Centre (2009), in a submission to review mental health legislation in that country, refers to the right to refuse treatment as an integral component of a human rights-based approach, while also referring to *'consumer participation'*, external review and the continuous monitoring of consumer well-being as essential elements of such an approach. In doing so, it proposes legislative changes that may then influence practice. Similarly, Amering (2015) examines provisions in law in the US, the UK, Ireland, Australia, New Zealand and Canada regarding advance treatment directives, referring to these provisions as being demonstrative of a rights-based approach in law, while Kotzmann et al. (2018) focus on involuntary admission of young people in Australia, finding that the statutes do not necessarily comport with a rights-based approach and arguing for legislative change.

Using an advocacy-oriented rights-based approach, a group of MHSUs in Northern Ireland campaigned for changes in policies and clinical protocols to ensure participation in the development of benchmarks and indicators and to institute automatic follow-up for survivors of suicide attempts (McMillan et al, 2009). Due to the participatory nature of the policy change process, coupled with the provision of services to an especially vulnerable group and the establishment of an accountability mechanism, all achieved through the advocacy of users

themselves, McMillan et al. (2009) refer to this process as having utilized a rights-based approach. Other advocacy-oriented rights-based approaches include the 'Bun and a Blether' project, run by the Hope Café in Scotland, which was designed and implemented by people with psychosocial disabilities, providing a forum for conversations around mental health in workplaces, aiming to reduce stigma and to provide information that could be utilized for self-advocacy (See Me Scotland, undated). A similar project, entitled 'Activism on and Off Campus' was also designed to provide Scottish university students with information about mental health issues, citing this model as being informed by a rights-based approach (See Me Scotland, undated). These advocacy-oriented rights-based models illustrate that significant shifts can be achieved through education and empowerment of people living with psychosocial disabilities. Indeed, the findings of the Perkins (2009) study regarding the El-Shehab group in Egypt alluded to earlier demonstrate that advocacy, including advocacy for provision of the determinants of mental health, can be beneficial, and, in the interpretation of the authors, constitutes a rights-based approach.

The State hospital in Scotland began applying a rights-based approach within the confines of an institutional setting in 2005, demonstrating that, in this interpretation, institutionalization does not preclude application of a rights-based approach (Scottish Human Rights Commission, 2009). In 2009, the Scottish Human Rights Commission undertook to evaluate the effects of the approach adopted at this facility. The interventions applied in seeking to realize a rights-based approach in this case included the development of training materials on human rights for staff and the establishment of a human rights monitoring group to ensure sound implementation of rights-aligned norms and standards. Among those norms and standards included the formation of participation structures for service users, the development of materials to provide accessible information to users and the use of both internal and external accountability structures, including

a complaints-handling mechanism (Scottish Human Rights Commission, 2009). Regarding the prevention of violence and measures to address ill-treatment of users, the report notes that:

> *The review revealed that prior to the development of a human rights-based approach, the manner of dealing with patient violence was a through a 'blanket policy' of procedures rather than a process which took proper account of the context and individual circumstances in order to justify limitations on rights in each instance and also ensure effective risk management and protect the rights of other patients, staff and others (Scottish Human Rights Commission, 2009: 63).*

The report states that improved satisfaction among users and improved attitudes among staff were noticeable, highlighting significant decreases in the use of seclusion and restraint. It also suggested that the rights-based approach could be adapted to other environments, and concluded that, in spite of resource challenges and delays in implementation of some protocols, the rights-based approach was a success (Scottish Human Rights Commission, 2009).

Also in the UK, the Mersey Trust reportedly utilized a rights-based approach in the provision of mental health care services. This is according to the country's Equality and Human Rights Commission (2009). The interventions utilized that characterised such an approach included training and capacitation on human rights for all staff, including the Chief Executive, coupled with assessment of compliance with these principles by all staff, including the Chief Executive. The Trust applied a presumption of capacity, meaning all decision-making was devolved directly to users in line with the CRPD's affirmation of equal recognition before the law, although there is not substantial information regarding what supports were provided in such instances. User involvement in the development of protocols and governance were also cited as being components of the rights-based approach at the Mersey Trust (Equality and Human Rights

Commission, 2009). Benchmarking of user involvement was also noted, with a view to maximising involvement in all aspects of the users' care, and a questionnaire was developed to examine the self-reported experience of users regarding the fulfilment (or lack thereof) of their rights. Users were also directly involved in conducting research and evaluating the performance of the Trust (Equality and Human Rights Commission, 2009). A key component of the Mersey Trust's work was community engagement, working towards the reduction of stigma and discrimination and the integration of service users into their broader communities (Equality and Human Rights Commission, 2009). The Trust's work was cited as a successful and exemplary application of a rights-based approach.

In 2017, the Mental Welfare Commission for Scotland published its *'Good Practice Guide: Human Rights in Mental Health Services and Rights in Mind: A Pathway to patients' rights in mental health services'*. The stated goals of this particular rights-based approach are to incorporate human rights into decision-making; to develop better pathways for user participation; to foster strong working relationships in the care and support system; and to ensure that care is personalised (Mental Welfare Commission for Scotland, 2017a; Mental Welfare Commission for Scotland, 2017b). It also states that all users within the mental health service possess a right to an advocate, either through an individual or peer relationship or through collective advocacy groupings. It further outlines specific rights for service users in the community, including the right to access services. Similarly, it provides for education to all service users under the age of 18. These tools do not establish new rights, instead compiling existing rights and protocols such that they can be consulted by practitioners and staff members (Mental Welfare Commission for Scotland, 2017a; Mental Welfare Commission for Scotland, 2017b). They are accompanied by a series of video case studies that illustrate how a rights-based approach should be applied to the spectrum of users with which the mental health

system interacts. However, it is not clear how these tools are disseminated or how well-utilized they might be, perhaps illustrating that, here again, the question of implementation remains.

Glowa-Kollisch et al. (2014) note that they utilized a rights-based approach to provide mental health services and to monitor those services in the New York City penal system. They highlight the use of Electronic Health Records (EHRs) to allow for surveillance of vulnerable populations, to enable reporting and analysis of patterns of abuse and neglect and to improve continuity of care as service users traverse the system (Glowa-Kollisch et al., 2014). They note, however, that this system is susceptible to numerous challenges, including confidentiality concerns or tampering. However, they recognize the potential of this approach, referring to it as being rights-based. This was a prospective study that did not focus on results or impact.

These interventions represent some important models that providers and administrators conceive of as being rights-based, some of which are accompanied by evidence of change (McMillan et al., 2009; Scottish Human Rights Commission, 2009; Equality and Human Rights Commission, 2009). However, they are also illustrative of some important challenges that have informed my thesis research. Firstly, they are quite disparate in nature, representing interventions that took numerous differing shapes. Secondly, they illustrate that there is not yet a substantial body of literature on the subject of the public health approach to rights-based models of service provision. Thirdly, it is clear that the resources available and the contextual factors that are highlighted by these studies may not prevail in other parts of the world, meaning that the sparse literature that does exist on the subject may not be fully applicable to settings where circumstances are different.

A (non-systematic) review of the literature on applied practice of rights-based approaches to mental health services yielded just 10 studies in 2016 (including studies focusing on intellectual

disability and dementia, which are beyond the scope of this thesis), demonstrating the lack of a substantial body of research (Porsdam Mann et al., 2016). However, this paucity is even more glaring in low- and middle-income country contexts or those contexts where sociocultural factors may be different from the Western, developed-world context, with just two studies referring to rights-based approaches to mental health in these settings appearing in this review (Porsdam Mann et al., 2016). The PAHO report noted earlier is an example of a rights-based approach to mental health law and policy development, referencing several low- and middle-income countries in the region (although not providing substantial detail regarding the content of these rights-based approaches), while the WHO's Quality Rights Initiative, similarly, seeks to uniformly address rights-based barriers in policies and protocols, including in low- and middle-income countries. The work of the El-Shehab group in Egypt, explored above, also stands out as an exemplar of an approach that has positive mental health implications (Perkins, 2009). No other studies provide information about the application of interventions, demonstrating that this an area where more research is needed. Next, I will firstly explore the findings of those studies that do exist, including those under the ambit of the Quality Rights initiative, before highlighting the need for further research.

2.4.1. <u>Research on the application of rights-based approaches to mental health and support services in low- and middle-income countries and non-Western contexts</u>

The vast majority of studies cited above were concentrated in high-income countries in Europe, North America and Australasia, and this raises some important questions about the specificity of interventions and the potential for replicability. As noted, the criterion of acceptability, which is one component of the 'AAAQ' framework, is constituted of several factors, including the appropriateness of a particular service in terms of culture, sex, language and any other social characteristic. Similarly, services that privilege a particular culture, sex, language or other group

over others would not meet the standard of non-discrimination, a central feature of all of the definitions of a rights-based approach and a key guiding principle of the CRPD.

MHCPS services have generally tended to neglect spiritual elements and eschewed the use of traditional healers. Griner et al. (2006: 531) refer to *'the pervasive influence of Western values in psychotherapy and the widespread ignorance among psychotherapists regarding others' cultures'* as a major challenge, while Lee and Armstrong (1995) have noted that traditional healers can be important sources of knowledge about the way in which mental health is viewed and the way in which services can be rendered most effective. What this serves to illustrate is that contextually bound factors such as culture and spirituality require consideration in the development of MHCPS services. Similarly, Al-Krenawi and Graham (2000) note that specific models of family relationships, of social interaction, of religious practice and of help-seeking can be instructive in the provision of mental health services to users from disparate cultures. Ensuring the cultural and contextual relevance of MHCPS services can, therefore, also be an issue of quality, another component of the 'AAAQ' framework of the right to health.

There has been increasing consensus around the fact that, in order to be of good quality and in order to adequately serve users, MHCPS services will need to be tailored to context (Swartz, 1999; Fernando, 2010). This means ensuring that models of MHCPS are not exported wholly to settings where their relevance may be questionable because of specific contextual factors (Fernando, 2010). In human rights terms, a rights-based approach to MHCPS services should be mindful of the specific cultural and other contextual factors that will affect access and quality.

Globally, mental health is a neglected area for policy-making and resource provision (Becker & Kleinman, 2013). However, even against this background, there are specific parts of the world where resources for mental health are especially lacking, particularly in low- and middle-income

countries (Eaton et al., 2011). Moreover, a social approach to psychosocial disability takes into account needs beyond the immediate health care system; resources for education, for transportation, for housing and for social protections are also key components of service provision. Therefore, while there is a great deal to be learnt from interventions that have been applied in high-income countries, there is a considerable need to engage with the question of how to apply a rights-based approach in contexts where significant resource constraints might be evident. As noted, there is limited research on this subject, but the studies referred to below provide some insight.

In India, the National Human Rights Commission (NHRC) has been monitoring the observance of rights of people with psychosocial disabilities since 1997. Whereas it began by monitoring just three facilities, it reported in 2012 that it was supervising the human rights situation in all mental health facilities in the country (National Human Rights Commission, 2012). The NHRC's oversight led to, among others, the extension of social protections to elderly people with psychosocial disabilities, the abolition of seclusion wards in some facilities, norms for provision of food and water to service users and improved access to information for people with psychosocial disabilities and their families (National Human Rights Commission, 2012). In applying a psychosocial lens, the NHRC's approach also led to improved recreation and exercise facilities for service users and the development of mechanisms for participatory governance in some facilities (National Human Rights Commission, 2012). This illustrates the value that independent monitoring can have for the advancement of rights-based approaches. While the NHRC's approach did not abolish institutionalization or coercive care, its report concludes that the observance of rights became an important consideration in health care facilities in part because of its supervision (National Human Rights Commission, 2012).

Also in India, in Gujarat State, efforts to utilize the Quality Rights Toolkit included training for service users and for caregivers on human rights, provision of information relating to mental health for service users in the local language, focus group discussions with service users and the solicitation of feedback from users. Monthly support groups for service users and for family members were also instituted (Shah et al., 2017). Shah et al. (2017: 7) found improved adherence to treatment as a result of these interventions, suggesting that services users felt *'more trust in mental health services after implementation of [Quality Rights]'.* Beginning in 2017, Lebanon has begun the process of implementing the Quality Rights Toolkit's recommendations. The Lebanese Ministry of Public Health is seeking to incorporate the Quality Rights programming into its National Mental Health Plan, to be rolled out between 2018 and 2021 (Mental Health Innovation Network, 2018a).

Jonsson et al. (2011) highlight the use of a rights-based approach to ensure that mental health services are available on an equal basis for people living with HIV in South Africa with psychosocial disabilities and without. This, they note, is an exception, due to the fact that perceived risk of non-adherence and a lack of coordinated care usually leads to health care providers to deny equitable access, a discriminatory practice. They note the importance of a single-site unit that deals with both diagnoses and they point to the use of peer support networks as an important avenue for adherence counselling and for reducing the isolation that people with HIV, with psychosocial disabilities or with both often experience. Importantly, the model applied demonstrates that people with psychosocial disabilities are no less likely to be non-adherent than those without, provided they receive quality care (Jonnson et al., 2011). Their Luthando model also integrates vocational training and the tending of a vegetable garden to promote food security. Given the population served by Luthando, this is an important avenue through which to address some of the socioeconomic determinants of mental health and non-adherence, while also offering a valuable source of peer interaction (Jonnson et al., 2011).

In recent years, the Mental Health Innovation Network has become an important platform for knowledge-sharing and collaboration in the field of global mental health. This platform is also an alternative means for NGOs and governments to highlight innovations in mental health and psychosocial support service provision. This includes in the realm of rights-based approaches, and a growing interest in these approaches in low- and middle-income countries is also noticeable. Some of the interventions highlighted include:

i. The Chain-Free Initiative in Somalia originated to abolish the use of restraints for people with psychosocial disabilities in hospitals, homes and other environments, including the removal of chaining from hospital protocols and the provision of psychoeducation, trainings and home visits to combat stigma and misinformation about mental health. It has reportedly resulted in 1700 people being released from chains between 2007 and 2010 (Mental Health Innovation Network, 2018b);

ii. A program to address mental health stigma and promote recovery in primary health care in Peru, involving the training and recruitment of local community leaders, the use of recovery-based arts and the development of training materials and contact-based training modules. Originally developed and tested in Canada, this intervention was culturally adapted for the Peruvian context using a participatory action approach and showed lower stigma scores on a standardised measure (Mental Health Innovation Network, 2018c); and

iii. Self-help groups, established by the Presbyterian Community Based Rehabilitation (PCBR) program based in Sandema, Ghana, reportedly allowing for social and economic integration into communities, for the reduction of stigma and discrimination

and for the development of advocacy campaigns. 23 such groups reportedly exist, each

with at least 100 members (Mental Health Innovation Network, 2018d).

It, therefore, appears that there is an increasing recognition of the potential utility of some rights-

oriented interventions. Collectively, these might be said to constitute rights-based approaches to

MHCPS services. Even so, the relative dearth of literature on practical implementation of rights-

based approaches remains a significant barrier to operationalization. As I have noted earlier,

this also precludes investment in rights-based approaches to mental health, representing a

considerable obstacle to implementation. In addition, it is clear that the application of rights-

based interventions appears to be disparate in nature, with varied interpretations resulting in

varied applications. More information is needed to establish what is common between these

applications. As explored next, this is the central aim of my research.

2.5. Objectives and Organizational setting

2.5.1. Research Objectives

The objective of this study was to identify good practices in rights-based MHCPS for people with psychosocial disabilities in Kenya. Using mixed methods, I aimed to examine, from the perspectives of MHSUs themselves, as well as other key stakeholders, what factors constitute good practice where rights-based approaches may already be implemented.

In utilizing the approach outlined above, I was hoping to identify and disseminate the key common factors of a rights-based approach in low-resource settings for further inquiry and replication. The intention was not to produce a 'recipe' for all organizations or all settings, but rather to highlight the potential of certain interventions while also bringing attention and further conceptual clarity to what appears to be a poorly understood construct (ie. The rights-based approach to mental health).

In developing a stronger understanding of the rights-based approach to mental health care in practice, my aim is to contribute to the public health field in an area where further research is significantly needed, while also contributing to the work of advocates and supporters of the rights-based approach as they engage with policy-makers and with funders to advance models that affirm the rights of people with psychosocial disabilities. Ultimately, I hope to contribute to positive changes in the circumstances of people utilising mental health care and psychosocial support services through informing mental health approaches that consider the whole person and their environment rather than just their mental health diagnosis.

2.5.2. <u>Research Questions</u>

1. What, in the opinion of key stakeholders (including people with psychosocial disabilities themselves), are the key features of rights-based mental health care and psychosocial support services in Kenya?

2. What, in the opinion of key stakeholders (including people with psychosocial disabilities themselves), are key interventions that should be incorporated into a rights-based approach to mental health care and psychosocial support services in Kenya?

3. What, in the opinion of key stakeholders (including people with psychosocial disabilities themselves), are the practical barriers and supports to implementing a rights-based approach to mental health care and psychosocial support services in Kenya?

2.5.3. <u>Doctoral Engagement in Leadership and Translation for Action (DELTA)</u>

This research is being undertaken as part of the Doctor of Public Health (DrPH) program. The DELTA is undertaken during the third year of the DrPH, although it may be extended for an additional year in some circumstances. It is an immersive, practice-oriented research project, undertaken within an organization, culminating in a doctoral thesis and a leadership journey statement. The purpose of the DELTA, as the title suggests, is to translate knowledge into tangible action on the part of an organization, thus ensuring that research contributes to social change.

2.5.4. Host organization and Theory of Change

The Open Society Foundations (OSF) is an international grant-making philanthropic organization whose mission is to *'…work to build vibrant and tolerant democracies whose governments are accountable and open to the participation of all people.'* (OSF, 2017). The organization was founded in 1993 by its benefactor, George Soros, inspired by his pursuit of an 'open society' for all. The organization has branches in 37 countries at present and its work covers over 100 globally. The organization advances its mission mainly through grant-making, convening and advocacy. Given its explicit underlying ideology and ethics, the organization aims to influence policy-making both at national and international governance levels.

Mental health has been a neglected priority throughout the world, suffering from a lack of funding and a lack of resources (Funk, 2016). There has been some recognition of the need to improve access to mental health care services in influential settings such as the World Bank (World Bank Group, 2016) and through important global instruments such as the SDGs (United Nations General Assembly, 2015). It is therefore, conceivable that increased attention (and possibly increased funding) may be directed towards mental health reforms in future. OSF sees this as a potential opportunity to advocate for a rights-based approach within these platforms to ensure that mental health care is not only scaled up, but is scaled up in a manner that is rights affirming.

To support this work, OSF decided to conduct a scoping study of the perceptions of funders and the broader funding landscape for mental health, particularly considering whether existing funding supports rights-based approaches. As noted above, one of the key findings of this scoping study was that lack of sufficient information and understanding within funding bodies about the rights-based approach to mental health care and psychosocial support was a major

impediment to pursuing this model. It was suggested that funders and policy-makers take a strong interest in research relating to best practice, and that such 'evidence', particularly in resource-poor settings, is limited.

This study is therefore, intended to contribute towards filling a gap, both in terms of academic research as well as for use by the organization in future as an advocacy tool as OSF seeks to clarify to donors and policy-makers what interventions have demonstrated utility in advancing a rights-based approach to mental health care and psychosocial support in Kenya. It is therefore hoped that this research can not only offer a contribution to conceptual thinking and academic knowledge about the common factors of a rights-based approach in low-resource settings, but that it can also provide OSF and allies with a useful tool to advocate for the funding of specific interventions or for the capacitation of agency staff on the rights-based approach to mental health care and psychosocial support.

The project will be undertaken under the purview of OSF's Public Health Program (PHP) Mental Health and Rights sub-theme. The sub-theme has developed a new portfolio focusing on Mental Health Policy and Financing with an initial focus on East Africa. I occupied the position of Program Officer, responsible for this portfolio, while conducting this research.

2.5.5. Country context

Kenya is a country of approximately 50 million people, with a gross per capita income of 1,440 US Dollars in 2017, making it a lower middle income country (World Bank Group, 2019). There is limited data regarding the prevalence of mental health conditions in Kenya, with estimates ranging from 20-25% (Ndetei & Muhangi, 1979) to 42% (Ndetei et al., 2009) although this figure relies heavily on the biomedical model of mental health conditions. The mental health landscape

in Kenya is characterised by severe shortages of human and material resources, with the Kenya National Human Rights Commission (2011) finding that this lack of resource allocation constitutes the single most pressing human rights concern in the mental health system. Funding for mental health constitutes less than 1% of the total health budget in Kenya (Health Rights Advocacy Forum, 2018). The country has a six-tier health system, in which primary care is provided free of charge, while referral care (including mental health services beyond the dispensing of psychotropic medication) is provided on a fee-for-service basis. There is one specialised mental health facility in the country in the public health system, and this facility operates on a fee-for-service basis (Personal communication, 2019).

The mental health system in Kenya has been governed largely by the Mental Health Act, No. 10 of 1989. This legislation prohibited discrimination on the basis of mental health status by insurance companies, while also providing for the formation of a national Mental Health Boards for oversight of mental health services. However, this Act was never fully implemented, and it lacked any explicit reference to human rights. Moreover, the Act did not provide for the regulation of financing for mental health in Kenya (Health Rights Advocacy Forum, 2018). The country adopted a new Constitution in 2010, which provides that *'every person has the right to the highest attainable standard of health, which includes the right to healthcare services'*, prompting calls for reforms in the health system that would ensure services for the poor. An insurance subsidy for the very poor was launched in 2013, but it does not specifically mention mental health as an entitlement. Efforts to achieve Universal Health Coverage (UHC) began a pilot phase in four counties in December 2018, and some mental health conditions are part of this pilot phase (Ministry of Health, 2018). A civil society campaign is currently underway to advocate for the inclusion of mental health coverage as part of Kenya's eventual UHC rollout (Personal communication, 2019).

The National Mental Health Policy 2015-2030 was crafted with an explicit human rights orientation, stating that mental health is a human right, emphasizing a participatory approach to mental health interventions and mandating the principle of equity between all MHSUs regardless of gender, class or caste. It focuses on a multi-sectoral approach to mental health to engage with the social determinants of well-being, and also emphasizes mental health promotion alongside mental health treatment. The policy also aims to integrate mental health into primary health care at community level and to integrate traditional and alternative medicine into the care and support system. Because budgeting for health is devolved to county level in Kenya, the policy requires counties to mobilize resources for implementation and requires periodic monitoring of implementation every five years, with the first review in 2020.

In 2018, the Mental Health Amendment Bill was introduced in the Kenyan Parliament to bring mental health legislation in line with the Constitution. It lists as its guiding principles the promotion and fulfilment of the right to the highest attainable standard of health, the preservation of the freedom and dignity of every human being, the fair and equitable treatment of persons with mental illness, the protection of persons with mental illness from discrimination, accountability and transparency, co-ordinated public participation in policy-making and implementation and evidence-based care and support. At the time of writing, the Amendment Bill is being circulated for public consultation. Among the criticisms of the Bill are the fact that it lacks sufficient emphasis on implementation, including resourcing, that it does not offer adequate protections from abuse and/or exploitation and that it lacks any provisions for supported decision-making (Personal communication, 2019).

The mental health landscape in Kenya is evolving somewhat, but people with mental health conditions continue to be subjected to stigma and discrimination and rights violations continue to be commonplace (Muga & Jenkins, 2008; Users and Survivors of Psychiatry Kenya, 2015;

Ndetei et al., 2016) These violations also occur within the mental health system itself, both

private and public, thus necessitating a stronger emphasis on human rights approaches to

MHCPS. As such, this presents an opportunity to engage with what is needed in this particular

context, while also documented the ways in which some efforts (albeit marginal) have been

undertaken to meet those needs.

2.6. Methods

2.6.1. Epistemological position

Epistemology refers to a theory of knowledge, the basis upon which ideas are organized and the lens through which one views observed data. This is significant because epistemology informs the type of data collected, the methods utilized to collect that data and the meaning attached to the data (Snape & Spencer, 2003). An exposition of this study's epistemological position is important because I am considering the application of an idea (Ie. The rights-based approach) whose form is essentially a product of interpretation.

Realist philosophy views research as the pursuit of an observable 'truth', and there are elements of human rights law that, indeed, may count as observable facts. For example, it is might be said to be an observable fact that Kenya is a signatory to the CRPD, creating obligations and prohibiting violations. Even so, the application of a rights-based approach, which seeks the attainment of the rights contained in the CRPD as its end goal, is a product of policymaking, litigation, advocacy or programming, and this relies heavily on the interpretation of various actors. Similarly, research that focuses on examining these applications requires that the investigator recognize the construction of these interpretations as central to the eventual actions taken.

In applying an interpretivist position, I am seeking to avoid couching the data in a narrative of 'correct' or 'incorrect' applications of the rights-based approach, instead recognizing that the reality of a particular organization, user or practitioner is, in its own way, the 'truth' in a given context (Walsham, 2006). I am, therefore, accepting that, where an organization or individual

proclaims the use of a rights-based approach, their interpretation of such an approach is indicative of their particular understanding of this approach.

The significance of context in an interpretivist analysis is extremely important, and an in-depth examination of qualitative data is often the most useful way of engaging with context (Walsham, 2006). As already noted, human rights-based approaches do not necessarily lend themselves to clinical methods. The results are less clear and causation is difficult, sometimes impossible, to isolate. An interpretivist position, however, acknowledges that there is scope for documenting the lived experience of change, highlighting the impact from the *'subject near'* perspective that Unnithan (2015) refers to.

Ensuring rigour in interpretivist research requires a reflexive lens, in which the process of collecting data, analysing it and drawing conclusions is critically reflected upon. The researcher is also an interpreter of information in this sense, an *'instrument'* for making meaning of complex phenomena (Pezalla et al., 2012). Interpretivist research also relies on the following constructs to ensure rigour:

i.   Dependability: Similar to the concept of reliability, it refers to how likely others are to draw the same conclusions with the same information. To ensure dependability, interpretive researchers must provide adequate details about their phenomenon of interest and the social context in which it is embedded so as to allow readers to independently authenticate their interpretive inferences.

ii. Credibility: Refers to the 'believability' and strength of the conclusions drawn. It can be enhanced through sound data management, transcription of records and in-depth process reporting that allows for triangulation.

iii.   Confirmability: Refers to the extent to which the findings reported in interpretive research can be independently confirmed by others (typically, participants). It intends to gauge the level of objectivity that is applied to draw conclusions.

iv.   Transferability: Refers to the extent to which the findings can be generalized to other settings. The researcher must provide rich, detailed descriptions of the research context ('thick description') and thoroughly describe the structures, assumptions, and processes revealed from the data so that readers can independently assess whether and to what extent are the reported findings transferable to other settings (Lincoln & Guba, 1985).

Using this framework as a guide for ensuring the rigour of my research, I utilized qualitative methods and employed a thematic style of analysis. A detailed description of the research methods is provided below.

2.6.2. Site visits

As Pelz (2018) notes, *'interpretive research employs a theoretical sampling strategy, where study sites, respondents, or cases are selected based on theoretical considerations such as whether they fit the phenomenon being studied'*. In this case, two organizations were chosen as sites for this study based on their explicit orientation towards rights-based approaches to mental health in community-based settings. A description of these sites is provided below, to add to the 'thick' description demanded of an interpretivist lens.

The Kamili Organization is a Kenyan NGO that was set up in 2009 in order to take over two existing mental health clinics that had been created by another NGO. These clinics, in 3 county primary care locations in Nairobi, run 28 times a month, offering services that include

counselling, peer support programming and community psychiatry, all free of charge. The 'Kamili' model, as it has been christened, also involves livelihood generation through small scale social enterprises such as dressmaking and the bottling of juice from locally grown fruit to support it beneficiaries, all of whom are from low-income backgrounds. Micro-finance is a key component of this model as well. Kamili is involved in policy advocacy related to resourcing for mental health and to the reduction of stigma on the basis of psychosocial disability. The 'Kamili model' is also notable because less than 0.5% of the over 9,000 MHSUs served by its clinics have been referred to or admitted to traditional mental health facilities. Because this model emphasizes autonomy and places strong emphasis on the dignity and empowerment of people with psychosocial disabilities, it refers to its approach as being 'rights-based'.

Home of Brains (also known as the Center for Mental Health) is a community-based mental health organization based in Kisumu in Kenya, under the auspices of a larger organization, the Tinada Youth Organization. The organization's work focuses on the delivery of psychosocial supports through lay counsellors. Interventions also include mentorship programming, scholarships and skills training, along with the facilitation of peer support networks and efforts to raise awareness of mental health issues in the community through public education forums. The organization's services are provided free of charge. A key component of the work of Home of Brains is a cross-referral system with the local county and sub-county hospitals, wherein the organization refers MHSUs whom it feels may benefit from psychiatric intervention (including in-patient care) and where Home of Brains provides support to MHSUs referred by the hospitals as a means of re-integration into the community. The organization also hosts the Neighbourhood Mental Health Integrated Platform (NMIHP), which is a civil society forum for various organizations focused on poverty reduction, environmental rights, access to justice, gender and children's issues. Tinada is seeking, through the NMIHP, to embed an emphasis on mental

health into the work of these organizations as well, seeing this as a central component of an emphasis on the social and environmental determinants of mental health and well-being.

2.6.3. Key Informant Interviews

Key informant interviews are a useful way to gather the type of data that lends itself to 'thick description' and that offers an in-depth understanding of a particular phenomenon (Lincoln & Guba, 1985). Considering the need for a 'subject near' perspective (Unnithan, 2015), key informant interviews are also a good way to engage with this perspective. For these reasons, key informant interviews were chosen as the data collection method.

2.6.4. Sampling

Ten interviews were conducted as part of this study. These interviews emphasized the participation of MHSUs themselves, while also considering the experiences of other key stakeholders including implementers, clinicians and advocates. Sampling of key informants was purposive in nature to meet the objectives of the study, utilizing the assistance of the organizations. Key informants were chosen based on two main criteria, namely:

i. Familiarity with the practices of the organization;

ii. Diversity among interviewees (Ie. Professional orientation and/or identity as an MHSU or member of the executive leadership of the organization, gender and level of educational attainment); and

iii. Balance between sites (Ie. 5 interviews at each site).

Table 2 below outlines the sample.

Table 2: Summary of participants

Kamili	Identity	Gender	Level of education	Age
	Executive Leadership	F	University	56
	MHSU	M	2 years secondary school	28
	MHSU	F	Primary school	40
	MHSU/Peer educator	F	Completed secondary school	32
	Psychiatric Nurse	M	Nursing college	25
Home of Brains	Executive Leadership	M	Doctoral degree	39
	MHSU/Lay counsellor	M	1 year of university	21
	MHSU	F	Completed secondary school	60
	MHSU/Lay counsellor/Peer educator	F	Completed secondary school	30
	Psychiatrist	M	Completed medical training	36

2.6.5. Data Collection

Participants were approached and provided with an introduction to the study. An information sheet was provided (appended) and verbal consent was sought prior to interview (consent form appended). Eight interviewees were fluent in English, meaning an interpreter was not necessary. For two interviews (one at each site), the aid of an interpreter was employed, including for the consent process. Admittedly, this raises important questions about the role that such a process plays in affecting data itself and outcomes arising from the data. While it is not possible to control for all of the potential challenges that may arise, it is important to note that the interpreters were MHSUs from the sites in both cases, and were experienced in supporting researchers. Larkin and Dierchx de Caterle (2007) suggest that use of an interpreter who is aware of their role as co-creator of the research and who has been appropriately briefed on the purpose of the research, can be a useful way to minimize bias. Therefore, an initial briefing with both interpreters, seeking to provide context and to address any unintended biases.

A semi-structured interview schedule was developed (see Table 2 below) to examine the nature

of interventions and the values included in a rights-based approach and the perceived benefits

of such an approach, and this was used as a guide for the interviews. Additional probing

questions included those related to issues such as the barriers faced by implementers and the

resource and capacity needs for implementation of a rights-based approach to mental health in

these specific settings. Interviews were between 30-60 minutes in length and were recorded

with the verbal consent of participants and transcribed for analysis.

Table 3: Semi-structured interview schedule

Providers	Users

How do the CRPD principles inform your work in relation to provision of mental health care and support?	Please describe the mental health care and supports that you receive
	• Probe around:
	    o Institutionalization (ie. Mental health care in a locked or confined facility)
	    o Coercion (ie. Forced treatment)
	    o Biomedical interventions (ie. Psychiatric medication)
	    o Decision-making
	    o Psychosocial support (ie. Supports that are not medical in nature but may contribute to better mental health
	    o Community inclusion
	    o Livelihoods (ie. Being able to make a living for yourself)

Please describe the mental health care and supports that you provide
• Probe around:
    o Institutionalization
    o Coercion
    o Biomedical interventions
    o Decision-making
    o Psychosocial support
    o Community inclusion
    o Livelihoods
	How do you understand your own rights to make decisions for yourself and to live in your community?

What does a rights-based approach to mental health care and support mean to you?	Is the mental health care and support you receive respectful of these rights?
What are the key components of a rights-based approach to mental health care and support?	What aspects of the mental health care and support you receive make you feel like you are being respected?
How does your organization operationalize the rights-based approach to mental health care and support?	What aspects of the mental health care and support you receive make you feel like you are being disrespected, discriminated against or forced to accept care you do not want?
What have been the barriers and facilitating factors to implementing a rights-based approach to mental health care?	

2.6.6. Data Analysis

In discussing the proliferation of data analysis techniques that employ an interpretivist epistemology to understand qualitative data, Elliot and Timulak (2005: 148) state that *the 'brand names [tend] to be confusing and somewhat proprietary'*. They note that only minor differences exist between the various techniques despite the labels applied to them, and suggest that an emphasis on 'common methodological practices' is the most useful means to analyze qualitative data from an interpretivist lens.

The process of interpretive data analysis involves five steps that are intended to yield a full and intricate picture of the phenomenon in question, through the interpretation of research subjects (as subsequently interpreted by the researcher). These five steps resemble other qualitative methods, such as thematic content analysis (Labov, 1972), hermeneutic interpretive research (Packer & Addison, 1989) and empirical phenomenology (Wertz, 1983). They allow for inductive and deductive meaning making, which is important because, already, some taxonomies regarding rights-based approaches have been developed (eg. Gruskin, 1996), while further meaning-making and practical application is still required.

The first phase of the analysis involved preparation of the data. This meant transcribing of recordings and the reading and re-reading of data to ensure immersion. It also involved additional backgrounding to fully engage with context (Elliot & Timulak, 2005). This was followed by the technique of delineating and processing of meaning units to find an overall structure for the organization of the data. The process of delineating meaning units, akin to coding in traditional thematic analysis (Labov, 1972), involves separating out data that is meaningful from data that is superfluous, removing redundancies and providing an *'audit trail'*, such that the units can be easily located in context (Elliot & Timulak, 2005). This, then, provided a basis for

organizing these meaning units into an overall structure that captures the totality of the data and highlights the meaning of that totality within its context (Elliot & Timulak, 2005).

These processes were followed by the generation of categories and abstraction of the main findings. The goal of this step was to ensure that the full meaning of the data was captured. I had already set out to capture some key categories, namely an exposition of the key components of a rights-based approach and the contribution of such an approach. These, therefore, constituted *a priori* categories, but they did not rule out the possibility of emergent categories as well. Generation of categories was an iterative process, with multiple iterations taking place to capture the fullest picture of the data at hand (Elliot & Timulak, 2005). In this case, the goal of abstracting the main findings was to be met through extrapolating on how the interventions and approaches used might be applied in low resource settings elsewhere, to provide further content to the concept of a rights-based approach to mental health and to reflect on the utility of this approach in bringing about meaningful changes in the lived experiences of people with psychosocial disabilities.
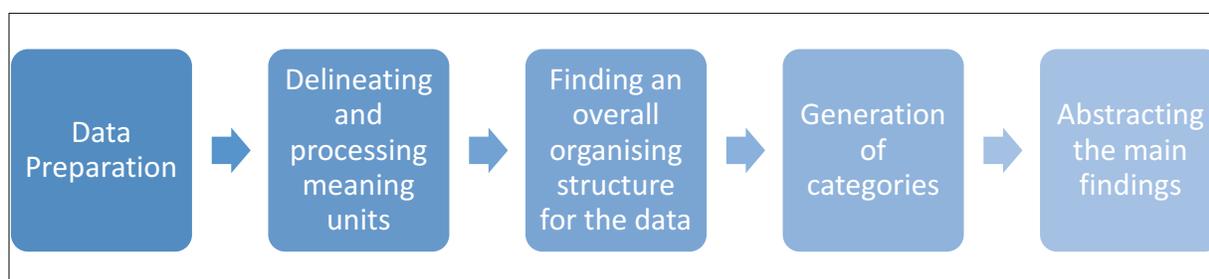
Figure 2: Interpretive data analysis (Elliott & Timulak. 2005).

2.6.7. Ethics

The Harvard School of Public Health granted an Institutional Review Board exemption for this study (IRB18-0839). There was some possibility of emotional distress for participants as I was

asking questions about the kind of care and support they receive and its impact on their life. However, given that the questions were about the ways in which the care and support they receive affirms their human rights, this proved to not be the case. The provision of supports for any distress experienced was, nonetheless, guaranteed, and participants were offered assistance in seeking support if necessary. None of the participants felt this was necessary following the interview.

Additional risks included reputational risk in being identified as a MHSU because of societal stigma. However, all interviews were completely confidential and participants retained the right to withdraw at any time, with no consequences. As mentioned, they received an information sheet providing the details of the study and the guarantee of confidentiality, and those who required additional explanation of the information were afforded this either by the researcher or the interpreter prior to commencing with interviews.

There is no documentation linking participants to this study, and I have deleted all recordings of interviews after transcription. Transcripts are anonymous and I will delete them after the research report is considered complete by my doctoral committee.

3. <u>Results Statement</u>

The interviews yielded some important results that have the potential to contribute significantly to our understanding of rights-based approaches to mental health. As the primary subject of interest was the actual content of these approaches, the largest portion of the results reflect this emphasis. Applying the iterative process of delineating meaning units as Elliot and Timulak (2005) suggest, a process of organising and re-organizing the data yielded a structure made up of three primary categories.

The 3 main categories were: Stakeholder perspectives regarding key components of a rights-based approach to mental health, stakeholder opinions regarding the contribution and efficacy (ie. the impact) of a rights-based approach to mental health and statements related to the barriers and supports to implementing such an approach. Within each of these broad organizational categories, sub-categories also emerged to aid in the organization of the data and the abstraction of the findings. A detailed exposition of the results follows. Quotes are anonymized to adhere to commitments to confidentiality.

3.1.   <u>Stakeholder perspectives regarding key components of a rights-based approach to mental health</u>

The results indicated that stakeholders view a rights-based approach both as a conceptual ethos as well as more concretely, in terms of interventions which they felt embodied those key principles. As such, these two categories were delineated as sub-themes under the broader category of key components of a rights-based approach to mental health.

3.1.1. Key principles

3.1.1.1.   Mental health as a human right and the right to access mental health care

A common perception among stakeholders was that the experience of mental health and well-being is, itself, a fundamental human right. A rights-based approach, in this sense, is dedicated towards fulfilling this entitlement. As one participant noted:

The purpose is the guiding factor…we want to ensure that people are healthy and we want to meet public health goals [but] we want also to fulfil the right to mental health itself

Similarly, another, referring to the effect of the environment on mental health, noted that:

I feel like I can be healthy, and as a human being, I can be healthy because all humans have it in them, but there are things that stop me

The idea that mental health and well-being is something that *'all humans have in them'* is arguably an indication that this speaker considers mental health to be a universal characteristic, and that the environment can be a significant hindrance to this universal right.

A rights-based approach to mental health and well-being must, it seems, begin from a position that mental health itself is a right, and that the factors which contribute to its realization or lack thereof are key determinants not only of well-being, but also of rights realization. One such factor is, of course, the cost of accessing mental health services in Kenya, with a respondent noting that its prohibitive nature has significant implications for access to care:

If I was to go to the hospital, I would pay thousands, maybe tens of thousands [of Kenyan shillings]. I shouldn't have to go bankrupt to be healthy

This is demonstrative that one of the key indications of a rights-based approach, as highlighted by organizations such as the WHO and the UN Office of the High Commissioner for Human Rights (2009), is the accessibility of the services provided, including financial accessibility.

3.1.1.2.   A focus on dignity and autonomy

Respondents were of the opinion that dignity and autonomy are key tenets of a rights-oriented model of MHCPS. There were several ways in which dignity was conceived of, ranging from the ability to participate more freely in society to the way in which an individual is perceived by others. One speaker stated:

Dignity is a difficult thing to quantify or even to define, but if it's mentioned in an explicit way, we know that it becomes a guiding principle, and we start to think about how it can become a reality

Dignity is also conceived of as a determinant of mental health and well-being itself, rather than as a stand-alone right, as demonstrated by the following quote:

We are talking about dignity because we know that the effect of disrespecting people with [mental health conditions] contributes to distress

Similarly, autonomy was a key theme in the interviews, with respondents highlighting the value of this principle both for the realization of mental health and well-being and as an inalienable

right. One participant, referring to previous institutional care and the shifts apparent in the organization's community-based model, noted that:

> *Before I had no freedom. I was not treated like a person. Nobody cared about what I wanted or what I thought. Now I have a say, I feel like a person*

This notion of *'having a say'* remains contentious, however, with one respondent noting that she sometimes experiences difficulty in operationalizing it as part of the organization's human rights-based model:

> *Of course autonomy and decision-making are important. We are here because too many people have been locked up, but sometimes we have to…when someone is going to get hurt…we have to*

This is illustrative of the fact that tensions continue to play themselves out in the realm of autonomy and decision-making. Evidently, even when organizations are purporting to implement a rights-based approach, they may qualify or limit a right when they feel they *'have to'*.

3.1.1.3.   Access to information

Access to information is closely linked with dignity and autonomy in the eyes of many respondents. Knowledge regarding human rights and mental health can significantly alter the way in which people with psychosocial disabilities are able to self-advocate or pursue their rights. One participant notes:

It starts with information. A rights-based approach requires that people know enough about their own rights and about their condition. Otherwise, they will not be able to make informed choices

Another participant illustrates this point as well:

I cannot [access] my rights if I do not know about them, and I cannot understand my mental health if I don't know about it…The truth is that people do not know enough, and I think this is a problem, especially in the hospitals

This is illustrative of the impact that access to information can have, and of the substantial difference between a traditional biomedical approach to mental health and a rights-based approach.

3.1.1.4. A user-centered and directed approach

Being *'user-centered'* and *'user-directed'* is closely linked with the ideas of dignity and autonomy, but it also appears to manifest as a more personalized and individualized idea. As one respondent notes:

Our model is about asking the person where they are…and then finding ways to meet them there

Another speaker highlighted the following:

I am not getting all the same [supports] that my friend is getting, and she is not getting some

of the [supports] that I am getting, because we need different things

This demonstrates that there is an emphasis on individualised support, aiming to *'meet'* MHSUs

where they are, and to recognize and accommodate difference. Referring to one of the

organization's programmes as being *'user-directed'*, an interviewee states the following:

Human rights requires that we provide [care and support services] that are actually wanted

and needed, rather than imposing them

In this way, this stakeholder argued that the organization's rights-based approach ensured an

emphasis on *'self-determination'*. Another highlighted the manifest difference that a user-

centered, rights-based approach can make, stating:

At the hospital, they don't pay attention to you as a person. They are interested in filling out

their numbers and meeting their targets. The attention you receive is minimum

For this participant, it seems that the sheer act of being paid attention to *'as a person'* is

indicative of the difference between a rights-based approach and a traditional biomedical

orientation.

3.1.1.5. Right to family life and life in the community

As noted, these rights, articulated in instruments such as the CRPD, offer useful guidance on

the content of a rights-based approach to MHCSP. This is confirmed by the results, which

illustrated that speakers believed community-oriented care and support to be especially

important as part of the philosophy of a rights-based approach. For example, one individual remarked:

Why should we be separate? We are not animals [to be kept] in a zoo…I want to be with others [in the community]…and I can take my treatment [at the organization] and still live [among them]

Not dissimilarly, respondents noted the key role that families play in promoting, preserving and restoring mental health. One individual noted that:

The family is the first source of community. Without my family knowing and understanding my condition, I would be in a much worse position

This is indicative of the fact that, although a user-centered orientation is required for a rights-based approach, it does not preclude addressing barriers in the numerous forms of community in which that individual resides, including the family.

3.1.1.6. Prevention and the need to focus on social, economic, cultural, spiritual and legal determinants of well-being

According to speakers, a focus on prevention is an important means through which to fulfil the right to mental health, because it highlights the point that, when barriers to well-being are addressed, distress can be averted. One participant notes:

This is what makes a rights-based approach different, isn't it? We aren't only thinking about circumstances in treatment, we're thinking about the right to be healthy so that treatment

isn't really necessitated…It doesn't mean we don't care about treatment, it means we think

that people shouldn't be facing the challenges that make them sick in the first place

An emphasis on the economic determinants of health has, according to some, a direct relationship with dignity and autonomy, as the following quote suggests:

I am better because I have a way to feed myself and my family. I don't have that stress

anymore, it has made me feel like the dignified person I used to be

Similarly, an important component of a rights-based approach to MHCSP is also the way in which societies respond to mental health conditions, with the problems of stigma and discrimination being a significant source of distress, and a human rights violation. One participant says:

A rights-based approach requires us to think about how people are treated in society and by

government. If we don't pay attention to how these things impact [mental health], we aren't

fully [engaging in] a rights-based approach

This is illustrative of the fact that social attitudes are important determinants of mental health and well-being, but it also highlights that the way people are *'treated by government'*, through laws and policies can play a key role. This naturally leads to discussion of another key principle, accountability.

3.1.1.7.　Accountability

Accountability is a key component of the rights-based approach espoused by the UN Common Understanding and the definition of the WHO and the UN Office of the High Commissioner for Human Rights (2009). Here, too, respondents highlighted that, over and above a need to ensure that laws and policies accurately reflect a rights-based approach, they must be implemented and invested in, and the commitments made by duty bearers must be fulfilled. Referring to impediments to accessing services because of failures in laws and policies, one participant stated:

> *How can we be well if there is no one that cares enough about this? [The government]*
> *doesn't care*

This reflects the point that political action (or lack thereof) may also contribute to mental health and well-being, and that addressing the political determinants of mental health may also be thought of as a key factor in implementing a rights-based approach to mental health. Another participant stated:

> *There's an emphasis on monitoring how well the government and other sectors such as*
> *donors are sticking to their promises*

In a similar vein, respondents noted that the health system, too, had a duty to be accountable to MHSUs, catering to their needs in ways that are respectful and transparent. One individual states:

I am the beneficiary, but sometimes [doctors and nurses] don't think they have any [duty] to

me

This is indicative of the apparent lack of accountability in traditional mental health systems, countered to some extent by more transparent approaches, expanded upon as follows:

Our aim is to build the model and the care as a collective, recognizing that we have to

answer to [MHSUs]…We try to do this periodically through participatory means…It's still a

work in progress, but our aim is to be accountable and responsive

This latter model reflects an effort to embed accountability as a core value, although the fact that it remains a *'work in progress'* is illustrative of the fact that accountability measures are often treated as something of an adjunct, despite their obvious importance.

3.1.2. Interventions embodying the rights-based approach to MHCSP

3.1.2.1. Quality, affordable mental health care and psychosocial support

As highlighted above, Kenya's health system relies heavily on a fee-for-service structure outside of basic primary health care and private insurance coverage can often be a key determinant of accessibility. However, in a context where resources are limited and the ability to access care and support is determined by financial factors, the right to access to treatment is significantly compromised. As one individual notes:

How can I pay ten thousand [Kenyan shillings] each time I come for counselling? I would not

have money for food. Without [the organization], I would not be able to see a counsellor

Fundamentally, however, the human rights-based approach means that quality of services are not sacrificed for the sake of affordability, as demonstrated by this quote:

We appreciate the fact that we need to work within our resources, so we try to be creative and actively look for ways to be more efficient…but to change the level of attention a beneficiary receives or to deny them the same level of care that a more wealthy person would get…that would be discrimination

The act of being *'creative'* with resources in this instance means finding ways to use the facilities of the government or other agencies, to promote peer support activities (as explored in detail below) and to develop a social enterprise as a means of contributing to providers' salaries. In terms of gauging the quality of services provided, one respondent states the following:

We promote quality care in a number of ways, using our networks to continuously train staff, providing beneficiaries with the opportunity to change their treatment plans if they feel they are not effective

A key part of the work is, therefore, continuous refinement of the human rights-based model to ensure quality service provision and democratic decision-making about treatment and support options by MHSUs.

3.1.2.2. Community, peer and family supports

Community-based mental health models naturally eschew the possibility that people with psychosocial disabilities might be institutionalized or otherwise removed from their communities. This, according to one respondent, is an embodiment of a rights-based approach:

We aren't taking people away from [their communities]. We are coming to them because they have a right to live with their people

Community-based interventions are, however, also about actually reaching the wider community, providing education that can help to combat stigma, mobilising resources to ensure service delivery and addressing living conditions that might contribute to distress. As one individual notes:

Our model targets the community as a way of reaching individuals. Because people are affected by the circumstances in their community, we want to make sure those circumstances, like stigma or ignorance, are also addressed. We see this as part and parcel of a rights-based model

Similarly, respondents spoke about the role of family supports, because often the family is the most direct determinant of an individual's mental health and well-being. As one speaker said:

The family have a right to mental health too, and they can benefit from therapies or education. This has direct benefit to our beneficiary too. It's a sort of virtuous cycle

Peer support was also mentioned as a key intervention, because people living with psychosocial disabilities might utilize these activities to develop self-efficacy or might find that they are less paternalistic forms of support than traditional approaches. A respondent notes:

Peer support initiatives are probably the most important thing we do. They allow our beneficiaries to be agents of their own well-being and the well-being of others, they ensure that care is always accessible in a way that may not be possible with clinical services and they help to build community and reduce isolation. If I had to say that any one thing speaks to a rights-based approach, it is peer support

Peer support initiatives include group counselling, the formation of sports teams and a collective to build autonomy and foster self-advocacy through the development of a user-led radio show, produced and hosted by MHSUs. Additionally, a story-telling collaborative in the community was mentioned as one means through which MHSUs can build community, share their experiences and seek and provide support among those with similar backgrounds.

3.1.2.3. Medical treatment as a support to psychosocial care

Rights-based approaches, in the organizations visited, did not emphasize psychotropic medication as a preference over psychosocial supports. Instead, they viewed medical treatment as one of several inter-related components of care, and arguably as a supportive mechanism for conducting other interventions. One participant noted:

We know that medicine can be an important thing…but we also know that it doesn't really [achieve the objectives] of helping a person live a whole, happy, healthy life…For those things, there's a lot more that needs to happen

The assertion that *'there's a lot more that needs to happen'* is also borne out in the following

quote:

> *When you go to the clinic, they give you your tablets and they send you away. How is that*
>
> *going to help me [realize] my rights? I need [the medication] but I also need to be able to*
>
> *work, and I need to be able to talk to others like a normal person*

This is indicative of the fact that biomedical interventions can be useful, and indeed can

significantly improve quality of life, but they are not, in themselves, sufficient to address the

numerous inter-related determinants of mental health and well-being.

3.1.2.4.   Education

As noted, a key component of a rights-based approach to MHCSP is an emphasis on access to

information. Initiatives to operationalize this right include education of people with psychosocial

disabilities themselves as well as education of communities. A participant describes the nature

and purpose of these interventions as follows:

> *Our organization sees the provision of education around mental health and the rights of*
>
> *service users as an avenue to foster dignity. Through individual education to users*
>
> *themselves, and to their families and the broader community, we are hoping we can*
>
> *counter untoward superstitions and empower people to obtain their rights. We do this*
>
> *through publications, through radio shows and through direct engagement, sometimes*
>
> *even door-to-door engagement*

Use of peer educators is a useful model, also, because it ensures that people with psychosocial disabilities become self-advocates and agents of change in their communities. This is borne out by the following quote:

As a peer educator, I can offer something that others can't. I can speak about the experience from a perspective that a doctor can't. The doctors don't know how alone you feel

Another key aspect is the incorporation of these models into formal mental health training. Supporting mental health training in universities and medical colleges can ensure that a human rights orientation is embedded in clinical practice. As one individual noted:

The truth is that mental health is not sufficiently focused on in medical and nursing training, let alone a rights-based approach. This is something we feel we can promote human rights in all mental health practice rather than in just in our organization, because there needs to be an effort to address the need

This quote reveals that even the biomedical approach to mental health is neglected, representing an area of concern, but also an opportunity for shaping efforts to *'address the need'*.

3.1.2.5.   Advocating for legal and policy change

Because Kenya's mental health system is in the process of transition, there is significant interest among the organizations in question to mobilise beneficiaries to claim their rights and to develop advocacy strategies to support reforms. One respondent states:

Our rights-based approach is a bit of a mishmash because we think that being involved in the political space is as important as being involved in service provision. Our goal is to support our clients to become involved in these processes themselves, and to align with other organizations who are interested in these issues

This is, perhaps, in keeping with Gruskin et al's (2006) assertion that advocacy is part and parcel of a rights-based approach, although it also illustrates that there may not be clear lines between the approaches outlined.

3.1.2.6.   Building livelihoods and meeting basic needs

Respondents were unanimous that a key stressor (and a key impediment to well-being) was access to a secure livelihood. Thus, supporting mental health and well-being requires an emphasis on this key determinant. Moreover, as one individual noted:

You can't claim that you care about rights and then not pay attention to people's right to work, or their right to learn and become self-sufficient, or their right to food. How can anyone be mentally well if they have no source of income to feed themselves and their families?

This also speaks to the various interventions that might be considered as part of a livelihoods approach. Efforts to provide support for receiving an education, to provide work opportunities or other sources of income and to promote food security can all be important and useful ways in which to address mental health and well-being needs.

Another speaker, applauding the cultivation of a community vegetable garden, tended by MHSUs themselves, notes:

The thing that I used to worry about the most, and that made me sick was how am I going to

feed my children?

This is demonstrative of the point alluded to earlier, that addressing the social and economic determinants of mental health through community-based initiatives such as a vegetable garden can and should be thought of as mental health interventions.

3.1.2.7. Access to justice and fostering accountability

The stigma and discrimination faced by people with psychosocial disabilities in Kenya contribute to numerous rights violations, with individuals denied access to their property and subjected to exploitation and abuse. Interventions to assist people with psychosocial disabilities to seek redress for these forms of injustice are seen as part of a rights-based approach to mental health and well-being in the eyes of some of the interviewees. A respondent's statement illustrates this point:

Our approach centers on the idea that people with mental health issues should be given

equal access to their rights, and this means that they sometimes need assistance to go to

court or to approach authorities. When you see a person with a mental health issue forced

off their land, helping them to reclaim it is also [a manifestation of] a rights-based approach

These interventions are closely aligned with objectives for educating people with psychosocial disabilities about their rights and judicial officers and other officials about their rights as well. In this sense, there is both a service provision and an advocacy component to this aspect of a rights-based approach to mental health and well-being. Organizations also highlighted that

efforts to foster accountability in government were sometimes the subject of mobilisation as well as legal actions. A respondent notes:

Our mobilization is about participatory approaches to holding government to account…We use various means to do so…but our primary goal is to work with beneficiaries to claim their own rights

Internally, efforts to foster accountability are equally relevant, and while they are deemed to be a *'work in progress'* (see above), they nonetheless also require critical engagement with MHSUs and communities. As one respondent notes:

We actively seek out feedback and we use methods like informal and anonymous complaints-handling…It's informal though, and it can be a challenge to implement because people aren't really accustomed to participating in these kinds of mechanisms. Still, we are trying to plant the seeds

This is indicative of the various ways in which accountability is conceived of. Ultimately, there may need to be strengthening of interventions to support internal accountability of organizations providing rights-based approaches to MHCPS, but efforts to *'plant the seeds'* of such mechanisms are seen by this participant as the makings of a rights-based approach to MHCPS. Similarly, the role of monitoring and evaluation as an accountability mechanism was also highlighted:

We're not saying we do it perfectly, but we are thinking about how to evaluate our work, so it becomes part of our monitoring and accounting to constituents and funders

Given the fact that monitoring and evaluation have been something of an oversight in many rights-oriented programs (Thomas et al., 2015), the emphasis on this activity as a component of accountability is certainly encouraging. However, it is clear that this is not yet a focus of the organization's work, meaning it will require scaling up, as discussed later in the section on barriers to rights-based approaches to MHCPS.

3.1.2.8. Providing care and support that is sensitive and receptive to diversity and accommodating of difference

Provision of gender, culture and language-appropriate services are important ways in which mental health care and support services can be rights-based. Participants highlighted the specific needs of particular populations and the potential benefit that a more sensitive or diversity-inclusive approach can have. As one individual states:

In the clinic, no one cares whether you are male or female, or whether you are Masai or Kikuyu. What if I need something [specific] because I am a woman or because I am Kikuyu? [The service provider] has to be [sensitive] to this

The way in which organizations go about encouraging or implementing diversity-sensitive practices is multi-faceted, focusing on training of staff to offer appropriate supports and to respond to varying needs, on building capacity in the organization that is diverse itself (including recruiting people with psychosocial disabilities themselves), on ensuring access to interpreters and on emphasising the user-centered perspective as a means of individualising supports provided.

Clearly, there is also a need for mental health providers and organizations that cater to the needs of people with psychosocial disabilities to also focus on individual needs that go beyond gender, culture and language. Gender identity, sexual orientation, religion and physical disability were also mentioned by respondents as sources of diversity, some significant taboos remain prevalent in Kenya, rendering an inclusive approach challenging at times. This subject is explored more in detail in the section below relating to barriers and supports for rights-based approaches, but it is nonetheless worth mentioning here as well.

It is also important to note that traditional approaches to mental health and well-being were mentioned, but that these were not well-understood nor were they relied upon as part of the 'package' of services provided. Some participants acknowledged the importance of culture-appropriate care and support, but viewed traditional approaches to mental health with suspicion, arguing that these interventions may actually violate human rights. The following quote exemplifies this stance:

> *Sure, there are traditional services but they are problematic to be honest. You hear about people being chained and beaten or about their bodies being mutilated by these so-called healers*

Another participant states:

> *I honestly don't know much about them. I'd like to be open to the idea that they are supportive of human rights, but everything I've heard is that they sometimes cause a lot more harm than good*

Essentially, this indicates that traditional mental health care and support are, at best, not well-understood and may require further elaboration while, at worst, they appear to be viewed with reticence or as rights-violating practices among the interviewees of this study. It may, therefore, be said that, in this instance, stakeholders did not include traditional mental health interventions as part of a rights-based approach.

Faith-based mental health interventions were the subject of some disagreement among respondents of this study. One participant said the following:

It's really difficult to say. I think that churches and mosques are essential sources of community, so we want to connect with them as much as possible, but some of the things you hear that come out of them about mental health are really chilling

Another participant states:

I went to the church and they told me I was mad, and that only God would stop this madness if I repent…They made me feel like I had done something wrong…I will never go back there

This is demonstrative of the tensions that might arise when mental health organizations and providers seek to ally with other organizations. The fact that *'churches and mosques are essential sources of community'* is clearly an important point and an indication of the ways in which religious institutions might be partnered with in seeking to ensure a holistic approach to mental health care and support service provision, but the *'chilling'* occurrences in some of these settings means that some MHSUs and organizations supporting them appear to adopt a cautious stance.

3.2.   Stakeholder opinions regarding the contribution and efficacy of a rights-based

approach to mental health

In the view of participants, the rights-based approach, somewhat amorphous as it is, has the

potential to contribute to mental health policy and practice in numerous ways. Some of these

have been touched upon above already, but these potential benefits do warrant some distinct

emphasis of their own as well. It should be noted that the primary focus of this research was to

focus on the content of rights-based approaches rather than on the efficacy thereof. This latter

question certainly warrants inquiry, but it also requires a longitudinal approach that could not be

accommodated in the context of a DELTA project. For this reason, the DELTA focused on the

actual framework of a rights-based approach to MHCPS, seeking to provide sufficient grounding

for later research to engage with the subject of efficacy. Even so, the results produced some

interested findings regarding the contribution that a rights-based orientation can make to mental

health practices and systems, and these are elaborated upon below.

3.2.1.   Dignity and self-esteem

Participants highlighted the effect of a rights-based model on dignity and self-esteem most

directly. For example, one stated:

The primary purpose and idea behind a rights-based approach is this idea of dignity. I know

it's difficult to operationalize or quantify, but you see it in the way that people live their lives,

going back to work or advocating in civic spaces or becoming part of the organization as

peer educators or lay counsellors. I think you have to apply a bit of a subjective lens and say

'I know it when I see it' and with a rights-based approach to mental health, I can see the

difference

Another participant states:

When I was just going to the clinic, I would get sent home with medication and left alone for another month. I don't think they understand that I want to [participate in society]. They think that I can't or maybe they think that I don't want to

Importantly, this individual is one of the participants who has since become a lay counsellor, and who views this as a testament to the validity of a rights-oriented approach. She goes on to note that:

I think what is different is that I was told I have a right to be healthy. I [had] never thought of it before, because I always thought I was just a burden to [my family]. It's different now, they treat me like [their equal]

This is illustrative of the contribution of a rights-based approach to dignity and, indeed, to the fundamental right to equality. While these are not quantifiable changes, they are indeed useful indicators of what can be gained from using a human rights lens.

3.2.2. The importance of a focus on social and economic determinants

Reducing stigma through community awareness-raising and education has been shown to contribute to improved mental health outcomes (Corrigan et al., 2012). This is borne out by the statements of participants as well. One participant states:

Fundamentally, what a rights-based approach seeks to do is address the unequal treatment of people [with mental health conditions], chiefly through the reduction of stigma…In doing this, we are reducing the distance between them and the rest of society, and this makes them feel like part of society, so we see that they become more enthusiastic and more motivated to be well

Similarly, another participant noted:

It used to be so depressing hearing people call me mad…I think that [itself] used to make me unhappy and then I used to isolate myself more, and that used to make me more depressed…When they stopped doing that, I noticed my health improving

Addressing social circumstances can, therefore, contribute substantially to well-being. The same is true, according to numerous interviewees, of initiatives to address the economic determinants of mental health and well-being. One respondent stated:

When I was able to provide for my wife and my daughter, I felt like I would be okay…It reduced my symptoms and it made me [motivated] to get better

This demonstrates the benefit derived from a livelihood programme for this MHSU. In the same vein, another respondent says:

I can honestly say that it has changed everything…When we started doing these livelihoods programs, we found that people participated more and that they were becoming well faster and staying well longer…it makes sense, because it is actually a core [component] of social justice

By focusing on economic and social justice, a contribution is therefore made to well-being in the fostering of rights-based approaches to MHCPS.

3.2.3. <u>Preventive benefits and the benefits (and possible limits) of autonomy</u>

Participants also raised the contribution of a rights-based orientation as a preventive measure, stating that it has the capacity to produce better mental health outcomes. This is exemplified by the following quote:

I don't use these five medications anymore. I don't get sick all the time the way I used to. When I was going to the hospital, I would get sick all the time…Now, I know when I am getting sick, and I can [take the necessary steps] to stop it [from getting worse]

The effect of the rights-based approach in this case has, therefore, been relapse prevention, but it was also highlighted that the provision of appropriate information and the practice of care in the community may have equally beneficial implications. As one respondent noted:

It has an effect on people to be removed from their homes and their communities unnecessarily. It makes no clinical sense. That power imbalance that you see in coercive care models and medical models seems clinically ineffective to me…Instead, what we want is for people to know how to identify their emotions and their symptoms and to recognize for themselves what supports they need

This indicates the substantial benefit to MHSUs of an autonomous model, based on information sharing and self-monitored care, although a key unresolved question relates to the subject of coercion, as demonstrated by the following quote:

Sometimes you need it, unfortunately…sometimes it can't be avoided…for people who are dangerous or who need protection, surely they have a right to be protected, and their health is better served that way

This, therefore, is a question whose answer remains somewhat ambiguous, with the health effects of coercion being a continuous debate, not unlike the situation described by Pearl (2013), Gooding (2015), Mahomed et al. (2018) and others. Even so, as the following quote illustrates, the benefits of a rights-based approach can be realized even when these contentious questions remain without an axiomatic answer:

It's absurd to say that a rights-based approach isn't being operated because of some very real unanswered questions. We do what we know for sure, and the things we don't know, we try to engage with

This also reflects a need for further documentation and elaboration of the clinical effectiveness of rights-based approaches and for further engagement with some of the complexities of applying this approach in prevailing systems. Participants noted that further inquiry and standard-setting can significantly alter the way rights-based approaches are perceived.

3.2.4. <u>The benefits to mental health service users and their families of peer and family supports</u>

Rights-based approaches to mental health and well-being incorporating a peer and family support component can aid in the development of self-efficacy among participants. This is highlighted as follows:

Now I am healthy myself but I also can help others…I wouldn't know how to help them if it were not for [the organization]…I would still be going to the hospital and getting told what to do like I am a child

Clearly, this relates also to the building of self-esteem as articulated earlier, but it also speaks to the fact that peer education can be a meaningful way in which to foster that self-esteem, while contributing to the mental health and well-being of others. This is perhaps best illustrated by the following quote:

[The peer groups] help me to share my feelings and make me think in a way that the clinic never did. I think that because of this my mind is more clear and I feel more supported

Similarly, family support systems and services can have a direct impact on MHSUs, while also contributing to more harmonised and supportive family systems. This can be a vital way to cater to family needs, in the process contributing to the realization of the right to mental health. As one individual noted:

I think [my family] understands me more now…I think they feel supported too…Because of this we are more at peace than we used to be

The fact that the family system is *'more at peace'* than it used to be is an important indicator of the way in which rights-based approaches focus on systemic as well as individual shifts, thus acknowledging the social determinants of mental health and well-being.

3.2.5. <u>Empowering mental health service users to be self-advocates and to participate in society, including civic spaces</u>

Respondents highlighted the fact that the ability to participate in society can be an indication of agency, which in turn contributes to mental health and well-being. The following quote illustrates this point:

> *It makes me feel better that I can use my own voice rather than asking the doctor or the nurse [to speak for me]…I feel happy*

Over and above this direct benefit to MHSUs, speakers also highlighted that policies and laws benefit significantly from the input of the people most directly affected by them. Therefore, the benefit of a rights-based approach is also its contribution to better lawmaking, in the process strengthening mental health systems. As one respondent states:

> *These are the people most directly affected…When they participate, they are able to direct laws and policies in ways that speak to their lived experience. That makes for better policy-making, but it also means that the mental health system as a whole can be more responsive to the needs of their users, and that the government doesn't allocate its resources in ways that aren't effective or efficient*

3.3. <u>Statements related to the barriers and supports to implementing a rights-based approach</u>

While participants were enthusiastic about the potential of rights-based approaches to MHCPS, they were also unanimous in voicing concern that these approaches remained nascent and

obscure in their context, suggesting that a number of barriers impeded their expansion and

scaleup in Kenya and arguably beyond Kenya as well. An exploration of these barriers is

articulated next.

3.3.1. <u>Factors which impede the implementation of rights-based approaches to mental</u>

<u>health care and support services</u>

3.3.1.1. Stigma on the basis of psychosocial disability

Stigma on the basis of psychosocial disability continues to be a pervasive challenge, and it has

the effect of causing mental health to be a neglected issue. In the opinion of participants,

governments and broader society fail to consider the needs of people with mental health

conditions, in part because psychosocial disabilities are stigmatised and not understood. One

participant stated the following:

> *I don't think [the government] cares about [mental health]. I don't think means anything*
>
> *to them because it's seen as a condition of the feeble-minded or the bewitched. Even*
>
> *among government officials, you hear these beliefs being repeated*

This indicates that stigma contributes significantly to the under-prioritization of mental health as

a whole, including traditional biomedical approaches. With respect to rights-based approaches

specifically, these appear even more marginalized because of the fact that the rights of people

with psychosocial disabilities are not well-respected as well, and because there remain

segments of society who do not believe people with mental health conditions should possess

the same rights as others. This is exemplified by the following quote:

You are talking about human rights and the rights-based approach, but what happens if

my neighbour does not think of me as a human being? What happens if my doctor does

not think of me as a human being?

The assertion that even health professionals might stigmatize people with psychosocial

disabilities and eschew rights-based approaches to MHCPS because of that stigma is a stark

illustration of just how pervasive mental health stigma continues to be, and how much of a

hindrance it can be to the advancement of rights-based approaches.

3.3.1.2.   Lack of resources

Mental health is clearly a neglected priority, faced with low levels of investment and a body

politic that is only beginning to engage with the needs of people with psychosocial disabilities.

Participants highlighted this as a major impediment to the advancement of rights-based

approaches to mental health, noting, for example, that:

We are talking about decades, perhaps centuries of neglect, and about needs that go

well beyond the rollout of drugs. I don't think governments and funders are willing to

admit that

This speaker suggested that the biomedical approach was seen as a more cost-effective way to

address mental health needs because it requires a more finite allocation of resources, perhaps

the mere *'rollout of drugs'.* A rights-based approach is, in the opinion of some, a more

substantial ask because of the social supports that characterise it. This, however, was not a

view shared by all participants, with one interviewee stating:

Actually I think these community-oriented models are actually cheaper to implement.

They don't require new investment in hospitals or a lot of salaries for highly specialized

staff and they aren't asking people to travel for miles and miles to access services

It, therefore, seems that further clarification is needed to consider what the actual resource allocation needs are for rights-based approaches to MHCPS, and whether allocating resources in this way is, in fact, more efficient than allocating for large-scale biomedical interventions. It is, however, important to note that this speaker also stated the following:

Even if they are more expensive, that is not the point…The point is what is the right thing to do? What will create more cohesive and healthier societies in the long term?

It therefore seems that economic considerations will need to be considered alongside the question of *'what is the right thing to do?'* The point about sustainable transformation of mental health systems is an important one as well, because it highlights that upfront expenditures in rights-based approaches may be beneficial far beyond the lifespan of a particular intervention. Ultimately, the lack of research and lack of clarity regarding rights-based approaches to mental health is a challenge that requires further attention, and this applies in a number of inter-related ways, as explored next.

3.3.1.3.   Lack of research to support rights-based approaches to mental health

In keeping with the rationale of this study, participants highlighted that policy-makers appeared to view the concept of the rights-based approach dubiously because there has been insufficient inquiry into its content as well as its efficacy. Research to establish standards in rights-based

approaches and to build an evidence base to support implementation of these approaches is sorely needed. An interviewee stated the following:

> *Governments and funders think in terms of evidence. They want to know that they are doing what works and that they are supporting best practice. When they hear this idea of a rights-based approach, they become wary because it's not been well-tested*

This, therefore, is a considerable impediment to the rollout of rights-based approaches. As one interviewee notes, this problem is particularly acute in low and middle-income countries:

> *There is very little [documented evidence] to show that rights-based approaches work in settings like Kenya…Even if you can show that rights-based approaches are effective, people will say it's because they have all these resources in Sweden and Canada that we don't have here*

This is indicative of the need for further research to support the implementation of rights-based approaches to mental health care and support in the Global South. On the subject of monitoring and evaluation specifically, another individual stated:

> *We want to monitor effectiveness, and we want also to improve delivery, but this is costly and technical…It's something we know we need to work on*

Essentially, this confirms the findings of Thomas et al. (2015), who noted that research, including monitoring and evaluation, are crucial interventions to build rights-based models into fully-fledged systems of MHCPS. Interviewees noted that these activities require further investment, and organizations providing rights-based approaches to MHCPS require

capacitation in order to undertake them. However, as demonstrated below, technical capacity is just one potential challenge that organizations face.

3.3.1.4.   Organizational challenges

A number of inter-related challenges within organizations can have the effect of making it difficult to implement and further develop rights-based approaches to MHCPS. These include lack of technical capacity, as highlighted above, and the short lifespans of some of these organizations due to funding constraints. A participant says:

> *Sometimes you see that it might be working, but then it happens that you can't sustain it, so you haven't been able to institutionalise a particular approach…Sometimes it's more a case of an organization applying one intervention but not really investing in the approach as a whole, maybe because they don't have the money or because they don't have the capacity*

Similarly, because good practice in rights-based approaches remains nascent, there may be disagreement about the form that such an approach should take or concerns about some or other aspect of it. As a respondent highlights:

> *We are all learning about this together…so there is no one way to do it…In a way, that's a good thing, certainly, but it does mean we are faced with a lot of questions to which we are still figuring out the answers*

Resistance within organizations to certain aspects of a rights-based approach might also be an impediment. The following quote illustrates this:

One of things we are talking about is supporting people with these so-called alternative lifestyles…transgender people and sex workers and so on…ideally we want to ensure that anyone who needs a service can get it…but we have to be aware that we are [operating] in a society that is conservative…Sometimes this raises challenges

This is demonstrative of the numerous ways in which rights-based approaches sometimes face challenges of implementation. Where organizations themselves face internal impediments to the implementation of such approaches, their potential impact may very well be affected.

3.3.2. <u>Factors which support the implementation of rights-based approaches to mental health care and support services</u>

3.3.2.1. Coalition-building

Participants noted that they were able to make significant progress in building a community of practice to engage on rights-based approaches to MHCPS through building coalitions with like-minded organizations. For example:

There are some other organizations also working in this field, and this has had the effect of helping to create a coalition…It makes advocacy easier…It makes it easier to think through some of the challenges we are grappling with like income generation schemes or stigma reduction programs

In this way, organizations that share an interest in rights-based approaches to mental health can act as partners. Even so, interviewees acknowledged that this was not always the case, particularly when competition for resources is prevalent. A participant stated:

I think it's one thing to have a coalition that acts in the same way or supports your work in an

advocacy sense, but if you are competing for the same grants, that makes cooperation more

difficult

This is demonstrative of the fact that competition for resources for rights-based approaches to MHCPS is a significant concern, and a potential hindrance to the actual scaling up of such services.

3.3.2.2. Self-advocacy by mental health service users

Respondents noted that a significant supportive factor in developing and advocating for rights-based approaches to MHCPS services is the fact that these services are preferred and argued for by MHSUs themselves. Having people with psychosocial disabilities as advocates for the adoption of these services is a significant source of support for implementation, as highlighted by the following quote:

I think there is no more powerful tool to advocate for rights-based approaches to mental

health than having someone who has used such a service state unequivocally that it is

the best way

Similarly, another respondent highlighted that key stakeholders, including policy-makers, may be more receptive to MHSUs themselves as a means of fostering participatory democracy:

Governments, at least nominally, have to listen to their constituents when they are

developing their policies and plans. The fact that this works and constituents are behind

it might make government listen…assuming government is interested in participatory

democracy

Ultimately, it seems that this enthusiasm for self-advocacy may also be somewhat tempered by

doubts about the receptiveness of policy-makers. Another participant states:

When I share my story, I think sometimes they are surprised…It makes them notice, but

I wonder what happens after they have noticed

Therefore, questions still remain about the receptiveness of policy-makers, but there is

nonetheless potential for MHSUs to act as self-advocates and because *'it makes them notice'*.

4. Discussion and conclusion

4.1. Discussion

Key principles of rights-based approaches to MHCPS were identified by this research, including

an emphasis on the right to mental health and the right to access mental health care and

support services, a focus on dignity and autonomy, a user-centered and directed approach,

respect for the right to access to information and the right to family life and life in the community,

and a focus on prevention, incorporating an approach that recognizes and addresses the social,

economic, political, legal, cultural and spiritual determinants of mental health and well-being.

These guiding principles form the basis for an ethos that underpins rights-based approaches,

providing a useful gauge for implementers to think about their work, and to consider how it

aligns with these central tenets. Ultimately, these principles might also be said to align well with

the CRPD's approach, because they focus not on the pathology of an individual, but rather on

the barriers to participation in society that arise from the way in which particular lived

experiences might be perceived, understood or stigmatized (Shakespeare, 2002).

The results have also demonstrated that, while the central guiding principles of numerous

definitions of a rights-based approach are indeed useful as overarching themes, there is a need

to add content to those principles and to engage with the actual interventions which might be

said to operationalize them. In keeping with Gruskin et al.'s (2010:134) criticism of many

definitions of rights-based approaches *'privileging consensus over specificity'* and their general

nature making them *'difficult to operationalize'*, the results show that it is in the interventions

described and the actual programming contemplated that rights-based approaches become

more implementable, making standardization for good practice possible. Given the significant

challenges of implementation of rights-based approaches, efforts to make them more

implementable and to encourage the development of good practice are needed. Moreover, efforts to engage with how the key principles of rights-based approaches align with, or indeed, deviate from, the content of programs can be a useful way in which to build a knowledge base that establishes good practice. Table 4 below seeks to engage with the subject of aligning principles elucidated by stakeholders with implementable interventions, such that a rights-based approach to MHCPS can be operationalized.

Table 4: Summary of key principles of a rights-based approach to mental health care and support and related interventions

KEY PRINCIPLES	INTERVENTIONS							
	Quality, affordable mental health care and psychosocial support	Education	Medical treatment as a support to psychosocial care	Providing care and support that is sensitive and receptive to diversity and accommodating of difference	Community, peer and family supports	Building livelihoods and meeting basic needs	Advocating for legal and policy change	Access to justice and fostering accountability
Mental health as a human right and the right to access mental health care	■		■	■				
A focus on dignity and autonomy		■	■	■		■		
Access to information		■						■
A user-centered and directed approach			■	■	■			
Right to family life and life in the community					■			
Prevention and the need to focus on social, economic, cultural, spiritual and legal determinants of well-being						■	■	
Accountability							■	■

The provision of quality, affordable MHCPS services is a central intervention, particularly because it ensures the accessibility of those services, in keeping with the framework of the WHO and the UN Office of the High Commissioner for Human Rights (2009). This framework also focuses on quality, and while there remains a great deal of work to be done to standardize and monitor quality in these approaches, already interventions to support this include continuous capacity-building and strengthening, and the refinement of care and support plans with MHSUs. In the long-term, rigorous monitoring and evaluation that takes into account the varied *'spectral'* layers of impact that a rights-based approach is seeking to effect (Thomas et al., 2015), will be needed to address questions of quality.

Other interventions include the provision of family and community-based supports, engaging with the needs of the MHSU and their support system, providing a basis for social inclusion, thereby reducing the potential for stigmatization and recognizing that these systems have a direct bearing on mental health and well-being. Supports to family members as caregivers are also important, given the significant responsibility of caring for a person with a psychosocial disability. Efforts to engage the community through stigma reduction are equally thought of as part and parcel of rights-based approaches to MHCPS services, because they promote equality and dignity and because they foster inclusion, all key principles of flagship human rights instruments, not least the CRPD.

Importantly, peer support was mentioned as perhaps the *'one thing'* that most signifies a rights-based approach to mental health, because it empowers MHSUs themselves to become sources of support for others, thus offering an avenue through which communities can be built and social isolation can be reduced. Moreover, it provides care and support from the perspective of an individual with the lived experience of a mental health condition rather than a clinician, operationalizing the principle of a user-centered approach. Participants noted, however, that

clinical biomedical treatment should also be thought of as a component of a rights-based approach, because it can support MHSUs to engage in other activities such as psychosocial support activities, including therapies. As such, a rights-based approach to MHCPS does not necessarily denounce biomedical interventions. Instead, it sees these interventions as adjunct or supportive methods to promote well-being.

It should be noted that the subject of coercive treatment did elicit some disagreement, particularly around the extent of its applicability and the potential for its usage. While the autonomy and dignity of participants was noted as a matter of considerable importance, some participants saw coercive practices as sometimes necessary to ensure the safety of MHSUs or to ensure that their right to treatment was fulfilled. This is a complex topic that mirrors debates currently underway in the literature as well, illustrating that, while we are making progress in giving content to the rights-based approach to MHCPS, there remain areas of contention that will need to be clarified and developed over time. Research is needed to develop this discourse further and to interrogate key debates thoughtfully and respectfully, including the development of supported decision-making measures that can be applied in low-resource settings such as the context of this study.

The trichotomy proposed by Gruskin (2006) to illustrate the ways in which rights-based approaches might be operationalized was somewhat challenged by these findings. While there was certainly mention of advocacy and legal activities as part of a rights-based approach to mental health, the suggestion that these are separate or even distinct seems tenuous. Instead, interventions that engage in all of these activities are thought of as part of a rights-based approach to MHCPS. This research suggests that advocacy to promote the rights of MHSUs, to inform legislation and policy and to argue for greater resourcing for mental health are all part of a broader rights-based approach, meaning that they exist in tandem with direct health

interventions rather than as separate endeavours. Similarly, participants noted that access to justice was a key component of a rights-based approach because the rights of people with psychosocial disabilities are so often disrespected or abused. Interventions such as legal education and the promotion of the rights of MHSUs in the judicial system are therefore, incorporated into a rights-based approach to MHCPS. Accountability was seen as a key feature of a rights-based approach, although it seems that efforts to hold external duty-bearers (such as the government or donors) accountable through efforts such as stakeholder mobilization were more well-developed than internal accountability measures, essentially highlighting the need for these to be strengthened and embedded more robustly.

Education is a central facet of the rights-based approach to mental health in the eyes of participants of this study, operationalizing the principles of dignity and autonomy and access to information. Education encompasses a number of inter-related components, including the principle of ensuring access to information for MHSUs and their families. Similarly, educating communities and broader society about mental health is a key component of a rights-based approach, recognizing that it aligns closely with the goal of addressing stigma and discrimination. In a similar vein, education, in the form of skills development was noted as a key intervention alongside other interventions to support MHSUs to build livelihoods and cater to their own basic needs as well as those of their families. Efforts to provide microfinance loans, to support food security initiatives like vegetable gardening and to build social enterprises were highlighted as useful means to operationalize the rights to work, to be free from poverty and underdevelopment and to dignity itself, thus demonstrating the strong link between economic and social justice and mental health. The fostering of livelihoods and the development of means to secure economic freedom are, therefore, key components of a rights-based approach to MHCPS.

There was also considerable discussion of the need for a rights-based approach to MHCPS to be mindful of diversity and difference and for services to cater to the needs of individual MHSUs differently, in keeping with the user-centered and directed principle. This means providing services that are sensitive to the specific needs of women and girls and of stigmatized populations such as the Lesbian, Gay, Bisexual, Transgender, Intersex and Queer (LGBTIQ) community and sex workers. Language-appropriate services and the use of trained interpreters were also mentioned as part of a rights-based approach to MHCPS.

Culture-sensitive services require a model that is welcoming and accommodating of cultural diversity, and while participants acknowledged the importance of culture in ensuring a rights-based approach, they also grappled with the question of indigenous and traditional approaches to mental health, noting that they had not engaged traditional healers as part of their rights-oriented approaches and expressing some caution in working with these modalities because of potential abuses. This was equally true of faith-based models of mental health care, with participants noting that there is much to be gained from the community derived from traditional and religious groups, but that the practices of traditional and faith-based institutions can sometimes be violating of rights. This represents an important area that needs further interrogation because, ultimately, the right to practice one's culture or religion freely is fundamental, and a rights-based approach ought to be supportive of the realization of all rights, including this one. There is therefore, room for further engagement on this subject between key stakeholders including the traditional and religious communities and organizations adopting rights-based approaches to MHCPS. However, as this study was primarily concerned with documenting the perceptions of key stakeholders themselves, these tensions were not interrogated fully in this instance.

While it was not the primary emphasis of this study, participants did engage with the subject of what a rights-orientation can contribute to mental health systems and to the lived experience of MHSUs. Similarly, there was discussion of the benefits of this approach. The advancement of dignity was seen as a core contribution, because dignity itself is a determinant of mental health and well-being, and because these rights-based approaches have the potential to foster improved self-esteem among people with mental health conditions by building their capacity and including them in their communities. The method of recruiting MHSUs as peer educators was seen as an important way in which self-esteem can be built and in which MHCPS services can better cater to the needs of those most directly affected.

The clinical efficacy of rights-based approaches to MHCPS services remains a key question because there has not been sufficient research or documenting of these approaches, and because the interventions themselves are so wide-reaching. This necessitates an emphasis on developing an evidence base for rights-based approaches, but it also brings to mind Unnithan's (2015) assertion that *'evidence'* and *'impact'* need to be thought of in multiple ways, meaning that research, employing various methodologies and establishing various forms of evidence to support the clinical efficacy of rights-based approaches, is needed. This is particularly true of low-resource settings and countries in the Global South, because, as has been described earlier, the vast majority of research continues to take place in the developed world. With this in mind, it is also important to note that OSF is working towards supporting research related to best practice in rights-based approaches in MHCPS and to determining the mental health outcomes of these approaches in an effort to establish the *'evidence'* base that can help spur investment and buy-in for these approaches. In this way, this DELTA project is one step in aiding that effort, while also stands on its own as a research endeavour.

Another area where there is a significant need for more research, as has been mentioned elsewhere in this report, is on the subject of coercion and autonomy. As the results indicate, this remains an area of substantial debate, confirmed also by authors such as Gooding (2016). It is therefore necessary to highlight that, while autonomy is a key feature of a rights-based approach, its limits (if any) require some elaboration and interrogation. In particular, in the context of a discussion of the benefits of a rights-based approach, an emphasis on outcomes research to examine the effects of coercion will be a useful addition to the literature.

Another significant contribution of a rights-based approach to MHCPS is its emphasis on social and economic circumstances. Addressing key determinants of mental health and well-being such as social isolation and stigmatization and the economic circumstances that either exacerbate, contribute to or flow from mental health conditions was mentioned as one of the most important ways in which a rights-based approach can improve mental health outcomes. Here, too, research to illustrate the direct or indirect mental health benefits of these interventions can significantly aid in the development of good practice.

Additional benefits of a rights-based approach to mental health articulated by participants included the fact that it maintains a preventive stance rather than focusing simply on remediation and the fact that it amplifies the voices of MHSUs themselves. By focusing on supporting self-advocacy, rights-based approaches to MHCPS can not only offer the contribution to self-esteem described earlier, but they can also promote participatory decision-making in policy and law, reflecting the ideals of the CRPD and, arguably, making policies and laws more effective by virtue of having the input of those most directly affected by them.

It should also be noted that participants highlighted the contribution of a rights-based approach not only in terms of the well-being of the MHSU him or herself but also in terms of the broader

system in which MHSUs find themselves. Addressing the needs of families and communities

through interventions such as psychoeducation and family counselling has the potential to

enhance the well-being of entire systems, thus promoting the right to mental health in a way that

a purely individualist stance would not be able to do. Fundamentally, it was argued that this has

the potential to embed changes in well-being to communities and societies beyond the course of

initial interventions because it addresses systemic concerns and because it promotes mutual

well-being, not dissimilar to what Thomas et al. (2015) refer to as a *'spectral'* lens. It has long

been documented that mental health interventions for caregivers of MHSUs can be an important

addition to services (Roth et al., 2009), but participants of this study highlighted that rights-

based approaches consider these as essential tools, and offer the possibility that communities

become sustainable sources of mutual support and recognition. Figure 3 below highlights some

of the key contributions that participants felt could be made by a rights-based approach to
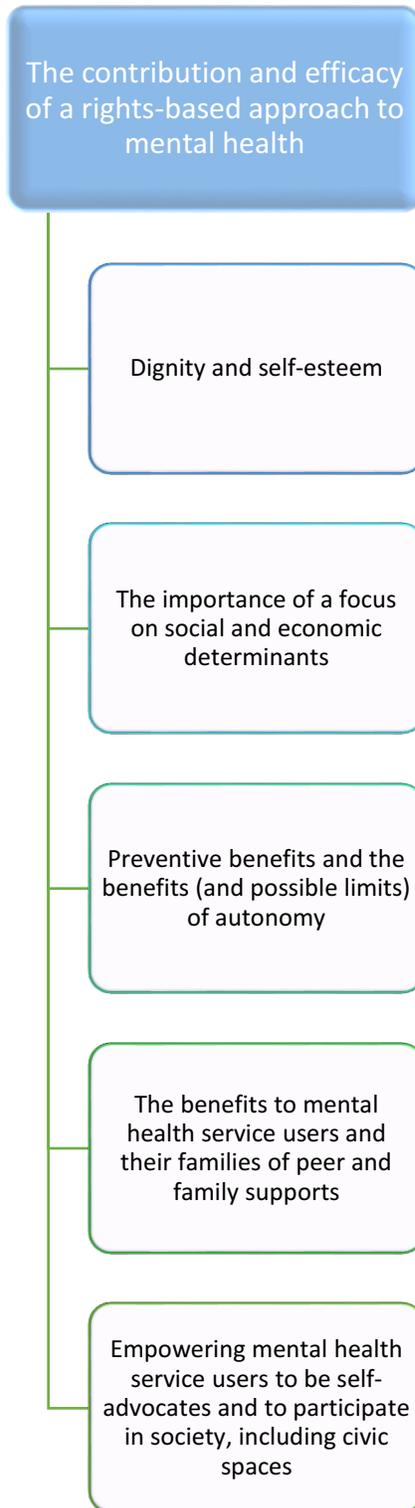
MHCPS.

Figure 3: Statements by stakeholders regarding the contribution and potential benefits of a rights-based approach to mental health and psychosocial support

Notwithstanding the potential benefits of rights-based approaches to MHCPS services, participants also highlighted impediments to the implementation of these approaches. In many ways, these have already been highlighted, but they may bear repeating. As noted, research is needed to support the development of good practice in rights-based approaches, and a solid *'evidence'* base can significantly contribute to investment and buy-in for these approaches. The lack of research is therefore, one major impediment. Another is the significant under-prioritization of mental health as a whole, arguably due to stigmatization and lack of understanding of the needs of MHSUs, including in policy-making spaces. Flowing from this lack of interest, prioritization and resourcing for mental health, there is a specific them acute lack of investment in the rights of people with psychosocial disabilities and concomitantly in rights-based approaches to supporting them. This will require additional efforts to engage with policy-makers and funders on the needs of MHSUs and to also ensure that whatever increased investment does arise out of such engagements, it does not simply repeat old mistakes. Importantly, this too, is a key component of the work of OSF's mental health financing portfolio as it seeks to ensure that human rights are respected in efforts to *'scale up'* mental health services in the wake of the Lancet Commission on Global Mental Health and Sustainable Development's report (Patel et al., 2018) and the Global Ministerial Summit on Mental Health (Mills, 2018). This, therefore, demonstrates the utility and relevance of this DELTA research to broader organizational and sectoral efforts.

Another impediment highlighted by this research was the capacity and/or willingness of organizations to implement rights-based approaches to MHCPS services. Among the challenges noted were the lack of technical skill to ensure that the rights-based approach was emphasized, the lack of sustainable resourcing to embed rights-based approaches and resistance within organizations to embrace these approaches. Sustainable funding for rights-based approaches remains wanting, and this is a significant impediment to them becoming

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embedded as mainstays of global mental health systems. This is a key challenge that, arguably, goes hand in hand with the need for advocacy to support these approaches and research to make these approaches attractive for investment. At the same time, because rights-based approaches are inherently meant to be tolerant of all forms of diversity and because they emphasize inclusion, there appear to be some challenges in terms of conservatism within organizations, based on social values that might prevail in broader society. This, along with the need to build capacity, requires a significant amount of engagement within organizations seeking to implement rights-based approaches.

Participants highlighted some key supports for the implementation of rights-based approaches as well, noting, for example, that there are growing calls for these approaches to be institutionalized as part of the mental health system, meaning that there are new coalitions forming to support these shifts. The strength of these coalitions as amplifiers for the voices of organizations supporting rights-based approaches was highlighted as one source of support. Similarly, the role of MHSUs themselves in advocacy to bring about change and to ensure that rights-based approaches are prioritized was noted as a considerable support for demonstrating the utility of these approaches and engaging with influential decision-makers. The voices of those most affected by mental health systems should therefore, be amplified and centralised as a means to promote rights-based approaches.

There are a number of important limitations inherent in the present study, and these bear mentioning, as do opportunities and avenues for future research. The findings of this study offer useful insight into the potential challenges and opportunities in low-resource setting but the small sample size and geographical limitation to Kenya mean that the transferability of these findings might be limited. Circumstances such as cultural norms, provisions in law and policy and social attitudes towards mental health might be substantially different in other settings,

despite their low-resource status. This, therefore, requires further interrogation and replication across various settings, and with larger cohorts, endeavours which time and resource constraints did not allow for in the present study.

As noted earlier, the purpose of this study was as an initial exploration of key components of a rights-based approach to mental health care and support from the perspective of service providers and MHSUs. As such, I applied an interpretivist lens, and did not seek to critique or augment the work of Kamili and Home of Brains. This interpretivist stance is useful as an initial grounding of the subject matter, and it has aided in the production of a set of guiding principles which might underpin all rights-based approaches to MHCPS services. Even so, a more critical or comparative stance might be needed as an additional step, considering the rigour of various interpretations of a rights-based approach and examining the ways in which different organizations mobilize these discourses. Similarly, a more empirical approach would be useful when these interventions are actually evaluated for their efficacy, a necessary step in building their evidence base. Therefore, longitudinal study that seeks to establish the impact of rights-based approaches on mental health outcomes would be a useful addition to the literature, although that was not possible in this instance given limitations on time and resources.

Alongside an examination of the practice of rights-based approaches to MHCPS, there is arguably a need for an interrogation of the perception of these approaches among policy-makers and funders to consider ways in which buy-in for them might be fostered. Increasingly, there is a need to engage with the subject of political will to support rights-based approaches to MHCPS if these approaches are to be mainstreamed, and understanding the barriers to the willingness of these stakeholders to take an interest in them is key to working towards fostering buy-in.

4.2.   Conclusion

In doing this research, I set out to explore a somewhat amorphous term (the rights-based approach to health) and to consider what it means in the estimation of key stakeholders whose work and lives interact with it in meaningful ways. I came across numerous definitions, many of which demonstrated considerable overlap, and I found a handful of interesting studies on the subject of rights-based approaches to health. In the field of mental health, the rights-based approach has clearly not been well-developed, and while the literature offered some useful guidance, it also demonstrated that this is an area where further research is needed. In particular, it became clear, from the literature review and from my work at OSF, that the rights-based approach to mental health needed more grounding in resource-poor settings or settings where there may be important distinguishing features in culture or language that rendered previous research only partially applicable.

This study therefore represents a modest contribution to addressing some of those needs, by giving content to this term and by highlighting the barriers that make it difficult for rights-based approaches to gain a foothold in mental health systems. In addition, what this research has demonstrated is that there are areas where further research and engagement between MHSUs, service providers and scholars is needed. I chose this project as my DELTA because of an implicit belief that rights-based approaches can make some meaningful contribution to otherwise coercive and often rights-violating systems. Having visited organizations that do this work, and having spoken to beneficiaries of this work, that belief has been reinforced. While there remains a great deal more to be done to make rights-based approaches to MHCPS a norm rather than an 'alternative', the potential contribution that they can make is becoming increasingly clear, and the work I have undertaken during my DELTA and will continue to undertake after my DELTA, is dedicated to building these models and making them scalable. I

am grateful for the opportunity and I am hopeful about the future of mental health systems,

largely because of individuals like those interviewed for this study.

5. <u>Bibliography</u>

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6. <u>Appendixes</u>

Appendix A: Participant Information Sheet

Dear Sir/Madam,

Thank you for taking the time to read this document. My name is Faraaz Mahomed, and I am a researcher from the Harvard School of Public Health. I am writing to invite you to participate in a study related to the experiences of people living with psychosocial disabilities and the organizations and facilities that provide care and support to them.

Participation of this study is entirely voluntary and, should you decide to participate, you will retain the right to withdraw at any time. If you do choose to participate, I will ask you a few questions regarding mental health care and service provision. The interview will last for approximately 60 minutes and an interpreter is available should we need one. The interview will be recorded for transcribing purposes. I will delete the recordings as soon as transcription is done. Transcripts may be shared with my supervisor. Transcripts will be anonymous and I will delete these once the study is over.

Your participation in this study will be of great assistance in providing insight into the experiences of people living with psychosocial disabilities and the care and support they receive. It will also assist in understanding the way in which mental health care can be provided and/or improved. There will be no documentation linking you to the study.

I am available to provide any more information should you require it, and I thank you again for reading.

Sincerely,

Faraaz Mahomed

faraazmahomed@mail.harvard.edu

Phone number where I can be reached: +1 617 935 1966

Address where I can be reached: To be determined

Appendix B: Informed Consent Form

Title of project: Developing Best practice for a Rights-Based Approach to Mental Health service provision in low-resource settings

Name of Principal Investigator: Faraaz Mahomed

Key Information

The following is a short summary of this study to help you decide whether or not to participate. More detailed information is listed later on in this form.

Why am I being invited to take part in a research study?
We have invited you to take part in a research study because the study is related to the experiences of people living with psychosocial disabilities and the organizations and facilities that provide care and support to them

What should I know about a research study?
- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You may discuss your decision with your family, your friends and/or your doctor.
- You can ask all the questions you want before you decide.

Why is this research being done?

Your participation in this study will be of great assistance in providing insight into the experiences of people living with psychosocial disabilities and the care and support they receive. It will also assist in understanding the way in which mental health care can be provided and/or improved.

How long will I take part in this research?

The interview will last for approximately 60 minutes.

You will be asked to answer a few questions relating to mental health care and service provision.

More detailed information about the study procedures can be found under the "What can I expect if I take part in this research?" section.

Is there any way being in this study could be bad for me?

There is some possibility of emotional distress related to taking part in this study. I will be asking questions about the kind of care you receive and its impact on your life. There may also be a reputational risk in being identified as a mental health care user. However, I can assure you that you will not be identified during the course of the study and your identity will be known only to myself. There will be no documentation that reveals your identity and transcripts of your interview recordings will be anonymous.

More detailed information about the risks of this study can be found under the "What are the risks and possible discomforts?" section.

Will being in this study help me in any way?

There are no direct benefits to you from your participation in this research. We cannot promise any benefits to others from your participation in this research. However, possible benefits to others may include a better and more standardized form of mental health care and greater resourcing for forms of care and support that affirms human rights.

What happens if I do not want to be in this research?

Participation in research is completely voluntary.
Your alternative to participating in this research study is to not participate.

Detailed Information

To follow, please find more detailed information about this study than already provided above.

About this consent form

Please read this form carefully. It provides important information about participating in research. You have the right to take your time in making decisions about participating in this research. If you have any questions about the research or any portion of this form, you can ask us at any time. If you decide to participate in this research you will be asked to sign this form. A copy of the signed form will be provided to you for your record.

Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt you, talk to the research team at + 1617 935 1966 or faraazmahomed@gmail.com

This research has been reviewed by the Harvard Longwood Medical Area Institutional Review Board (IRB). If you wish to speak with someone from the IRB, you may contact the Office of Human Research Administration (OHRA) at 617-432-2157 (or toll-free at 1-866-606-0573) or at irb@hsph.harvard.edu for any of the following:

- If your questions, concerns, or complaints are not being answered by the research team,
- If you cannot reach the research team,
- If you want to talk to someone besides the research team,
- If you have questions about your rights as a research participant, or
- If you want to get information or provide input about this research.

Participation is voluntary

You are invited to take part in this research because you are either a person involved in the provision of rights-based mental health care and psychosocial support or a mental health care user. It is your choice whether or not to participate. If you choose to participate, you may change your mind and leave the study at any time. Refusal to participate or stopping your participation will involve no penalty or loss of benefits to which you are otherwise entitled.

How many people will take part in this research?

About 10 people will take part in this research.

What can I expect if I take part in this research?

As a participant, you will be expected to complete the following:

One interview of approximately 60 minutes. The interview will be audio recorded for transcribing purposes.

What are the risks and possible discomforts?

There is some possibility of emotional distress related to taking part in this study. I will be asking questions about the kind of care you receive and its impact on your life. However, the questions are about the ways in which the care you receive affirms your human rights, so this possibility is small.

There may also be a reputational risk in being identified as a mental health care user because of societal stigma. However, I can assure you that you will not be identified during the course of the study and your identity will be known only to myself. There will be no documentation linking you to this study, and I will delete all recordings of interviews once they are transcribed. Transcripts will be anonymous and I will delete them after the research is complete.

Are there any benefits from being in this research study?

There are no direct benefits to you from your taking part in this research. The intended benefit to society is an increased understanding of best practice in implementation of rights-based mental health care services.

What happens if I say yes, but I change my mind later?

You can leave the research at any time it will not be held against you. If you choose to withdraw, any information you have provided will be immediately deleted.

Can I still get medical care at this facility if I choose not to participate in this research?

Yes, you may still receive mental health care and psychosocial support if you choose not to participate in this study. Your decision will not change the care you receive now or in the future.

Taking part in this research is your choice. If you decide to take part in this study, you may leave/stop the study at any time. There will be no penalty to you and your medical care will not be affected. If you would like to stop participating in this research you should let us know. We will make sure that you stop the study safely.

Will I be compensated for participating in this research?

No, there is no compensation provided for participation.

What will I have to pay for if I participate in this research?

There is no cost to you.

If I take part in this research, how will my privacy be protected? What happens to the information you collect?

Efforts will be made to limit the use and disclosure of your personal information, including research study and medical records, to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB and other representatives of this organization. Recordings of interviews will be deleted after they are transcribed. Transcripts will be anonymous and they will be deleted when the study is completed.

Can I be removed from the research without my OK?

No.

Statement of Consent

I have read the information in this consent form including risks and possible benefits. All my questions about the research have been answered to my satisfaction. I understand that I am free to withdraw at any time without penalty or loss of benefits to which I am otherwise entitled.

I consent to participate in the study.