i

MPhil (Multidisciplinary Human Rights)

Mini-dissertation

Exploring community based social mobilisation strategies for the advancement of the right to legal capacity for people with psychosocial disabilities in Zambia

By

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i

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Abstract

The aim of this study is to explore the importance of community based social mobilisation strategies in advancing human rights, in particular, strategies that could be used advance exercise of the right to legal capacity for persons with psychosocial disabilities in the face of societal barriers in the African context. The results of the study are aimed at providing useful and practical considerations in addressing the gap that exist in human rights implementation, between the promises of the law and its impact in reality.

To this end, secondary desk top data was collected from existing text on the CRPD, mental illness and social mobilisation strategies. The latter was based on an analysis of the mobilisation strategy employed by Tostan in West Africa to successfully challenge female genital mutilation/cutting. Primary data was obtained through focus groups held in Lusaka and at Nsadzu Mental Health Rehabilitation Centre in Chadiza, in rural Zambia.

The significance of legal capacity in Zambia was established and three main categories of concern emerged as barriers to the exercise of legal capacity: a) lack of state and community based supports and social networks; b) inadequate training of health and justice system officials; and c) stigma of mental illness and stereotypes. The benefits of social mobilisation in addressing these barriers are manifold, as demonstrated through the Tostan model.

Key words: Psychosocial disabilities; legal capacity; decision-making capability; informed consent; social mobilisation strategies

List of abbreviations

CDC   -   Centre for Disease Control and Prevention

CRPD   -   Convention on the Rights of Persons with Disabilities

CSO   -   civil society organisations

FGD   -   focus group discussions

FGM/C   -   female genital mutilation/cutting

ICCPR   -   International Covenant on Civil and Political Rights

MDAC   -   Mental Disability Advocacy Centre

MHUNZA -   Mental Health Users Network of Zambia

MoH   -   Zambia Ministry of Health

NMHRC -   Nsadzu Mental Health Rehabilitation Centre

OPD   -   Organisations of Persons with Disabilities

OSISA   -   Open Society Initiative of Southern Africa

PHU   -   Primary Health Units

UN   -   United Nations

UNDP   -   United Nations Development Programme

UNICEF -   United Nations Children's Fund

WHO   -   World Report on Disability

ZAFOD -   Zambia Federation for Persons with Disabilities

Table of Contents

Chapter 1 – Background, operational definitions and methodology

1.1. Introduction

Even though the human rights discourse and trajectory has been dominated by international *law,*[1] there now exists a valid school of thought and general consensus that human rights implementation depends on much more than what international legal instruments, mechanisms or even domestic law and legislation offer. In line with this thinking, this study explores community-based social mobilisation strategies as an important accompaniment of law in advancing human rights and particularly in tackling societal barriers that hinder exercise of the right to legal capacity for persons with psychosocial disabilities in the African context.

This exploration is based on provisions of article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) - equal recognition before the law[2]. It is timely in the African context given the concerns that have been raised by the CRPD Committee in its concluding observations to African State parties on article 12. The Committee's concerns in this regard predominantly focus on the different laws, legislation and policies that deprive persons with disabilities their legal capacity in particular persons with intellectual and/or psychosocial disabilities, and the legislative provisions that restrict their right to full enjoyment and exercise of their rights including the right to marry, to act as witness and vote, and parental rights.[3] The purpose of the study is to contribute to the discourse that seeks to identify practical solutions to address the gap that exist between the promises of law and its impact in reality.

1.2. Background

The way the CRPD frames rights is poised to specifically ensure that persons with disabilities enjoy their rights on an equal basis with others and in an equal society. This is important for persons with psychosocial disabilities and those with intellectual and cognitive disabilities because they often find themselves losing their rights in many spheres of their lives.[4] They are disproportionately disadvantaged among their peers with other disabilities because they are more prone to being denied their right to legal capacity. Due to the denial of legal capacity they are often excluded from participation in social and political processes, and in the development and implementation of laws and policies that concern them.[5] It is with this in mind that article 12 of the CRPD was drafted. The article amplifies legal capacity as an inherent right, accorded to all people and affirms that persons

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[1] B Cali & S Meckled-Garcia 'Introduction' in B Cali & S Meckled-Garcia (eds) *The legalisation of human rights: Multidisciplinary perspectives on human rights and human rights law* (2006) 1

[2] The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN in 2006 and entered into force in 2008. Article 12 'Equal Recognition Before the Law' of the UN Convention for Rights of Persons with Disabilities requires that States parties take appropriate measures to ensure exercise and respect for the right to legal capacity by persons with disabilities.

[3] See CRPD Committee concluding observations on equal recognition before the law (article 12) to the following State parties: Uganda (April 2016); Ethiopia (September 2016) Mauritius (September 2015) Kenya (September 2015) Gabon (September 2015) and Tunisia.

[4] G Szmukler, R Daw & F Callard 'Mental health law and the UN Convention on the Rights of Persons with Disabilities (2014) 37 *International Journal of Law and Psychiatry* 247

[5] N Drew, M Funk, S Tang et al 'Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis' (2011) 378 *Lancet Global Mental Health* 1668. See also CRPD article 4(3)

with disabilities (regardless of type of impairment) are not excluded from the enjoyment of full legal capacity.

1.2.1 Why explore strategies instead of focusing only on the law?

The CRPD as an international law instrument is a monumental achievement in the field of disability rights. However, advancing the rights it enumerates (as is the case with other human rights treaties) depends on more than what international law or even domestic law and legislation offer. The human rights trajectory to date is revealing the importance of addressing the 'discrepancy that exists between human rights ideals and the realities of human rights violations'.[6] Intrinsically focusing on the law is not wrong. However doing so in isolation of other societal factors will neither sufficiently diminish rights violations nor encourage communal respect for human rights within societies.[7] Taking into account existing social factors such as beliefs, values, structures of power and economic inequality would need to be a part of the strategy.[8] Doing so is likely to enhance understanding of human rights and provide some incremental breakthroughs in implementation and practice of human among other advantages for the following reason.[9]

Society as a living system is complex in nature. Within the complex system, the law is a single component of a society that it seeks to regulate. However other societal factors at play such as social norms, values and practices are in their own right complex in nature.[10] It would be naïve to believe that these can all be defined or regulated by law. Especially since the norms and practices over time may even be supported by law[11]. Distance in time has also degenerated some of these customs, and social values and practices into misconstrued, discriminatory prejudicial and stigmatising attitudes.[12] At worst these have perpetuated systems where human rights violations across a range of important spheres of life. An example is seen in the recent hike in reported cases of attacks, killings and human rights violations of person with albinism on the African continent. These are testimony of the toxic impact of misguided beliefs, value systems and practices about albinism developed over time such as the belief there are supernatural powers in the body parts of persons with albinism that can bring about luck and prosperity. These beliefs have taken deep root in various cultures on the continent[13]

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[6] M Freeman 'Putting law in its place: And interdisciplinary evaluation of national amnesty laws' in Cali & Meckled-Garcia (n 1 above) 45

[7] A Woodiwiss 'The law cannot be enough (human rights and the limits of legalisation)' in Cali & Meckled-Garcia (n 1 above) 34

[8] M Freeman 'On the interactions between law, social science and human rights' in F Viljoen (ed) *Beyond the law: Multi-disciplinary perspectives on human rights* 13

[9] Cali & Meckled-Garcia (n 1 above) 1

[10] Freeman (n 6 above) 4 suggests that a multidisciplinary approach to human rights as opposed to a law centric one is more poised to advance human rights implementation and as such law must needs to be based on an understanding of the society it seeks to regulate.

[11] The CRPD Committee has raised concerns in its concluding observations to African States parties about the derogatory or stigmatizing language or terms such as insane, unsound mind and lunacy that persists in legislation and policies of the State parties. See CRPD Committee concluding observations under general principles and obligations to: Uganda (April 2016); Ethiopia (September 2016) Mauritius (September 2015) Kenya (September 2015) Gabon (September 2015)

[12] M Kermode, K Bowen, S Arole et al 'Attitudes to people with mental disorders: a mental health literacy survey in a rural area of Mahashtra, India' (2009) 44 *Social Psychiatry* 1087

[13] UN Independent Expert Report: Enjoyment of human rights by persons with albinism https://documents-dds-ny.un.org/doc/UNDOC/GEN/N16/241/46/PDF/N1624146.pdf?OpenElement accessed on 11 December 2016

and are currently manifested in the reported killings, marginalisation, discrimination and other rights violations and attacks of persons with albinism. It is through such gradual acceptance of wrong as right over centuries, that has similarly created and underpins some of the societal barriers facing persons with psychosocial disabilities.

Such barriers and attitudes have unconsciously played a detrimental role in the way people with psychosocial disabilities are treated in the community and, sadly also by the mental health systems and professionals they depend on.[14] The result has manifested itself in the common and hugely unsubstantiated stereotypes that people with mental health disabilities, are dangerous, incompetent or of weak character. If unaddressed, these attitudinal barriers will continue to admonish individual autonomy of persons with psychosocial disabilities and their right to exercise of legal capacity.

This study supports the growing consensus that over dependence on law alone is a naive approach to human rights implementation.[15] However, it does not in any way seek to belittle the role that law plays in implementation and realisation of human rights. Rather, it suggests that an equal measure of non-legal interventions and campaigns aimed at addressing social and attitudinal barriers are critical for transforming a community to become more human rights respecting. Exploring various contextual measures that resonate with local norms, values and language of the local communities is important. [16] From the range of social transformation measures that could accompany legal strategies this study explores community mobilisation strategies employed by Tostan, an NGO working in West Africa to end FGM/C. It further explores how these same strategies could be applied in Zambia to advance the right to legal capacity for persons with psychosocial disabilities.

1.2.2 Why focus on Zambia?

The focus on exercise of the right to legal capacity in Zambia is motivated by the country's reasonably conducive disability rights legal framework by African standards. Zambia's Constitution is the supreme law of the country and values human dignity, equity, social justice equality and non-discrimination.[17] The country ratified the CRPD in 2010, but has not ratified its Optional Protocol which establishes an individual complaints mechanism for the CRPD. It has a Disability Act (2012) that recognises the right to legal capacity and there exists a draft mental health Bill due to be tabled before Parliament. If enacted, the Bill would provide for respect, autonomy, non-discrimination and the right to self-determination for people with psychosocial disabilities and could repeal the Mental Disorders Act 1951.[18] Importantly the Bill contains a community based approach to mental health provision.[19]

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[14] Drew, Funk, Tang et al (n 5 above) 1669 cite reports with evidence of negative attitudes towards people with mental and psychosocial disabilities from among mental health professionals.

[15] Freeman (n 6 above) 3 cites as increasing the consensus that 'a narrow approach is inadequate for both the understanding and implementation of human rights.

[16] A Kapungwe, S Cooper, J Mwanza, L Mwape et al 'Mental illness--stigma and discrimination in Zambia' (2010) 13 *African Journal of Psychiatry* 201 suggests that addressing stigma and associated attitudinal barriers requires other strategies such as awareness raising campaigns and education programmes in addition to revising and revamping mental health laws.

[17] Article 8(e) Constitution of Zambia (Amendment) Act, 2016

[18] Mental Disability Advocacy Centre (MDAC) and Mental Health Users Network Zambia (MHUNZA) Human rights and mental health in Zambia (2014) 22 http://www.mdac.org/sites/mdac.info/files/zambia_layout_web4.pdf accessed on 28 August 2016

[19] MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 22

5

Additionally, Zambia has a registered group of persons with psychosocial disabilities - the Mental Health Users Network of Zambia (MHUNZA), established in 2000.[20] MHUNZA has over the years collaborated with various national, regional and international organisations on research and other interventions which has significantly produced and enhanced availability of reliable country specific data sources.

1.3.   Research questions

Against the above background, the study attempts to answer the following research questions:

a) What is the significance of article 12 of the CRPD for persons with psychosocial disabilities?
b) What social or attitudinal barriers exist in exercising legal capacity for persons with psychosocial disabilities in Zambia?
c) How can community based social mobilisation strategies advance exercise of legal capacity for persons with psychosocial disabilities in Zambia?

1.4.   Operational definitions

The following terms used extensively in the study will be defined in this section to ensure a common and consistent understanding of the terms as they relate to the context of this study:

1.4.1 Psychosocial disabilities

As an evolving concept, disability has been widely accepted as resulting from the interaction of an individual's impairments with attitudinal and environmental barriers.[21] People with psychosocial disabilities are described as having impairments that, due to mental health conditions, restrict their ability to participate fully in life.[22] This description reflects both the challenges that people face as a result of their condition and the negative attitudes that communities frequently display towards them. With the advent of the CRPD psychosocial disabilities are no longer viewed within the context of health alone but rather more broadly points to the need for a shift in social attitudes to end stigma and discrimination, and greater provision of social support across society.[23] Dependent on the nature of impairment, some people constantly have to battle recurrent symptoms such as hallucinations,

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[20] MHUNZA is the only organisation that represents and focuses on promotion, protection and advancement of human rights of persons with psychosocial disabilities in Zambia.

[21] The WHO World Report on Disability 2011 states that 'beliefs and prejudices constitute barriers when health-care workers cannot see past the disability, teachers do not see the value in teaching children with disabilities, employers discriminate against people with disabilities, and family members have low expectations of their relatives with disabilities'.

[22] The Mental Health Council of Australia in its article 'Getting the NDIS right for people with psychosocial disability defines psychosocial disabilities as a disability that relates to social consequences. That is, 'the effects on someone's ability to participate fully in life as a result of mental ill-health.' Australia and Canada some of the countries with progressive policies and supports for people with mental illness. See https://mhaustralia.org/general/getting-ndis-right-people-psychosocial-disability accessed on 16 October 2016

[23] Paralegal Alliance Network (PAN), Prison Reform Trust (PRT) & The Ministry of Home Affairs (Zambia) 'Challenging disadvantage in Zambia: People with psychosocial and intellectual disabilities in the criminal justice system' (2015) 7-8 http://www.osisa.org/sites/default/files/pan-diszambia-web.pdf accessed on 5 October 2016

delusions, anxiety, or mood swings.[24] As such, these disorders significantly interfere with the ability of the individual to cope with usual day to day tasks hampering the individual from engaging in opportunities such as education, training, cultural activities, and achieving their goals and aspirations. However, it is important to note that not all people with mental impairments have a psychosocial disability and that psychosocial disabilities may only be episodic and are not always permanent. Others may have intellectual disabilities and still others may have both psychosocial and intellectual disabilities.

For purposes of distinguishing between intellectual and psychosocial disabilities, the Institute for Research and Development on Inclusion and Society (IRIS)[25] points at a definition by the American Association on Intellectual and Developmental Disabilities (AAIDD), which describes intellectual disabilities as

> 'a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills'.

Thus, persons with an intellectual disability face certain limitations in mental functioning and in skills such as communicating, taking care of themselves, and social skills. According to the Centre for Parent Information and Resources (CPIR),[26] these limitations tend to cause a child to learn and develop more slowly than other children and may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are also likely to have trouble learning in school. However , the Centre also stresses that it is important to note that even though they may have difficulties the children will learn, but it might take them longer than other children and there may also be some things they cannot learn.

It is important to note here that in Zambia persons with psychosocial disabilities describe themselves as 'mental health users', hence the network of mental health users of Zambia that operates as MHUNZA. Thus these terms will be used interchangeably throughout the mini-dissertation along with the term 'mental illness'. The term 'mental illness' is thus used numerous times throughout the dissertation given that, until the social model of disability the social model of disability or the advent of the CRPD, this was the term commonly used and not psychosocial disability. Subsequently people in Zambia are more familiar with the term and many of the available existing texts on persons with psychosocial disabilities make reference to mental illness, but change can be seen in more recent texts.

1.4.2 Legal capacity

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[24] N Rüsch, MC Angermeyer & PW Corrigan 'Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma' (2005) 20 *Journal of the European Psychiatric Association* 529

[25] According to the Institute for Research and Development on Inclusion and Society (IRIS) a Canadian organisation there is no single definition of intellectual disability. See Institute for Research and Development on Inclusion and Society (IRIS) 'The Employment of People with Intellectual Disabilities in Canada: A Statistical Profile' (2011) 1 https://irisinstitute.files.wordpress.com/2012/01/intellectual-disability-and-employment_iris_cr.pdf accessed on 16 February 2017

[26] Centre for Parent Information and Resources (CPIR) 'What is intellectual disability?' http://www.parentcenterhub.org/repository/intellectual/ accessed on 16 February 2016

7

Legal capacity is a universal human attribute[27] and a basic human rights principle inherent to all people of which without it, exercise of other human rights is difficult if not impossible.[28] Importantly, with legal capacity an individual is recognised as a rights holder.[29] As a rights holder, each and every individual ordinarily has both: a) the right to legal standing, in other words refers to recognition of an individual as person before the law; and b) the right to legal agency which implies the ability to act within the framework of a legal system simply by virtue of being human. Legal capacity to act under the law recognises that person as an agent with power to engage in transactions and create, modify or end legal relationships.[30] It is however important not to conflate legal capacity with mental capacity as these are two distinct concepts. Essentially legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency) - this is distinct from and not dependent on mental capacity.[31]

1.4.3 Mental capacity

Mental capacity in the context of this study is an individual's decision-making ability. An individuals perceived inability to make decisions (mental capacity) has been used widely as a basis for the denial of legal capacity in terms of the law in many jurisdictions globally. That is because society assumes that adults of average intelligence, psychosocial functioning and sensory ability should ordinarily have the ability to engage in all aspects of life on an autonomous basis.[32] Hence if an individual has difficulty in meeting the perceived standard expectations of society on these issues society therefore questions their mental capacity.[33]

It is important to note that psychosocial disabilities are not always permanent but the social consequences of the impairment affect the individual's ability to participate fully in life even though occurrence may only be episodic. It is also important to note that not all people with mental impairments have a psychosocial disability. According to Nicolas Rusch et al, people with mental health problems constantly have to battle recurrent symptoms such as hallucinations, delusions, anxiety, or mood swings.[34] As such these disorders significantly interfere with the ability of the individual to cope with usual day to day tasks hampering the individual from engaging in opportunities such as education, training, cultural activities, and achieving their goals and aspirations. Often the disorders have a taxing impact and challenging consequences on family members and friends of which when coupled with society's limited understanding of the disorders, the net result is stigma which hinder efforts to address and support the individual.[35] Stigma and associated stereotypes further

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[27] M Browning, C Brigby & J Douglas 'Supported decision-making: Understanding how its conceptual link to legal capacity is influencing the development of practice' (2014) 1 *Research and Practice in Intellectual and Development Disabilities* 38

[28] R Dinerstein 'Implementing legal capacity under article 12 of the UN Convention on the Rights of Persons with disabilities: The difficult road from guardianship to supported decision-making' (2012) 19 *Human Rights Brief* 9

[29] A Arstein-Kerslake & E Flynn 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law' (2016) 20 *International Journal of Human Rights* 474

[30] CRPD General Comment No.1 Article 12: Equal recognition before the law (2014)

[31] General Comment 1 (n 30 above) Paragraph 13

[32] Dinerstein (n 28 above) 9

[33] Arstein-Kerslake & Flynn (n 29 above) 475

[34] Rüsch, Angermeyer & Corrigan (n 24 above) 529

[35] PW Corrigan, A Kerr & L Knudsen 'The stigma of mental illness: Explanatory models and methods for change' (2005) 11 *Journal of Applied and Preventative Psychology* 179

exacerbate the plight of people with mental health disabilities in that these individuals find themselves marginalised and discriminated against.

1.4.4 Social barriers

Social barriers are barriers to entry in society which are related to the conditions in which people are born, raised, live, learn, and work – essentially barriers created by the culture of the community. These barriers can contribute to decreased functioning among people with disabilities and tend to impact employment, education, access to services including healthcare and justice.[36]

1.4.5 Attitudinal barriers

Stigma, stereotyping, prejudice, and discrimination are some of the attitudinal barriers within society. They may come from a society/community's ideas related to outsiders of the community/society. These barriers are the most basic and contribute to other barriers such as the social barriers described above.[37]

1.4.6 Social mobilisation

Social mobilisation is described quite succinctly in line with the intended definition of this study by UNICEF, as follows:[38]

> 'It is a process that through dialogue motivates a variety of stakeholders such as community networks, Psychicivic religious and other groups as well as members of institutions to raise awareness of and demand for a targeted objective in a coordinated way with planned messages.'

1.5. Literature review

The law on its own is unable to secure respect for human rights and scholarly suggestions dating back to the 1970s[39] rule out as unrealistic the ability of the law alone to bring about meaningful social change.[40]

There is no arguing with Woodiwiss's view that there is 'far more to rights than law alone'.[41] Although he identifies himself with the thinking of legal positivists who hold that rather than intrinsic, rights are

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[36] Centre for Disease Control and Prevention (CDC) provide a useful and descriptive list of common barriers to participation experienced by people with disabilities including social and attitudinal barriers. http://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html#ref accessed on 12 September 2016
[37] Centre for Disease Control and Prevention (CDC) (n 36 above)
[38] Social mobilisation is one of UNICEF's communication for development approaches along with advocacy and behaviour and social change http://www.unicef.org/cbsc/index_42347.html accessed on 12 September 2016
[39] Kostiner I 'Evaluating legality: Towards a cultural approach to the study of law and social change' (2003) 37 *Law and Society Review* 326. Kostiner cites Scheingold's work on the politics of rights who argues that legal norms and tactics are closely linked to prevalent hegemonic political culture and are therefore highly limited in their capacity to promote significant social reform. Scheingold's overall conclusion is rather sceptical with respect to the capacity of legal strategies to alter the balance of power in society and to bring about meaningful change.
[40] Kostiner (n 39 above) 325
[41] Woodiwiss (n 7 above) 34

created and attached to legal persons either through legislation or judicial decisions,[42] I am more inclined to be aligned with the thinking natural law theorists who view certain rights (such as in this case the right to equal recognition before law), as intrinsic or inherent to people by virtue of their being human. I do however agree with him in recognition that for rights to work much more than law is required, because of their dependency on a wider set of social relations, that produce and enforce behavioural expectations on duty bearers, rights holders and the community or society at large. Furthermore, I couldn't agree with him more in his interpretation that rights bearers have to be entities that are legally recognised as having legal capacity with the capability of taking decisions and accepting responsibility. After all central to the focus of this study is the advancement of the exercise of full legal capacity (both legal standing and legal agency). With this interpretation, this study argues that persons with disabilities are not lesser human beings whose legal personality must be detached from them simply because of their impairments.

However, even with the advent of the CPRD it is important as pointed out by Freeman to recognise that human rights are not just about developing human rights laws but rather the actual protection of peoples interest in their respective realities.[43] In this regard assumptions central to legal liberalism that hold the idea that marginalised groups struggling for social justice are bound to succeed only if their approaches are hinged on legal norms and tactics, should be taken with a glass of water. These assumptions are half-truths because, while legal norms provide an important framework to support human rights claims as entitlements, there now also exist evidence that there are barriers in society, at the family, community or institutional (state) level that are often not possible to addressed through law, legal norms, practices or institutions.[44] Thus, critics of legal theory such as normative theorists and empirical political scientists who hold that there is more to rights than law should be taken with significant levels of seriousness if meaningful alternatives or accompanying strategies are to be developed and effectively pursued.[45] This would no doubt go a long way towards addressing the existing gap between the promises of law and its impact in reality.

It is with this in mind that it becomes important and necessary for human right actors to also focus on measures and approaches that complement the numerous human rights oriented measures and campaigns that since the adoption of the Universal Declaration have been investing in legislative reform and the law. As already mentioned above, in Zambia the law and legislation have provided the country with a necessary skeletal upon which disability rights can be realised but not the flesh. A favourable legal and policy framework alone cannot fix or magic away the discriminatory and stigmatising attitudes that reside within an individual. Worse still, if these attitudes are held by a collection of individuals and especially if the group of individuals are the majority or more powerful. With this in mind it is important to acknowledge that the law remains an integral regulatory component in a complex living system and has a role in eliminating inequality.

1.6.   Methodology

Qualitative research was the choice methodology given the limitations of quantitative data in capturing nuances of social attitudes, behaviours and other societal barriers that may be faced by

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[42] Woodiwiss (n 7 above) 34
[43] Freeman M (n 6 above) 50
[44] Kapungwe, Cooper, Mwanza et al (n 16 above) 201
[45] Kostiner (n 39 above) 326

persons with psychosocial disabilities.[46] The focus group methodology in collecting primary date was viewed as the best option given that it is a tested means of collecting rich information within a social context.[47]

1.6.1 Data collection

Secondary desk top data was collected from existing text on the CRPD, mental illness and social mobilisation strategies among others. The latter was primarily based on the Tostan model of mobilisation that the organisation used in West Africa to address FGM/C. Primary data was obtained through three focus groups held in Lusaka at Chainama Hills Hospital and one (though not fully successful[48]) held at Nsadzu Mental Health Rehabilitation Centre (Nzadzu). The discussions took place between 29 and 31 August 2016 with groups comprising the following:

a) Eight mental health patients at Nsadzu. Two members of this group were women.

b) In Lusaka the group started off with the maximum ideal number (eight) of persons with psychosocial disabilities. However, two other people joined the group halfway through the discussions due to an over-subscription of invited participants. The eagerness and interest with which participants showed without any material incentive was testimony of the need that persons with psychosocial disabilities have for peer discussion forums which are not readily available to them as one participant expressed in a vote of thanks for participating in the discussions. All participants were members of the Mental Health Users Network of Zambia (MHUNZA) - one of which sits on the current Board of the organisation. Ultimately 4 of the participants were women.

c) Six family members of people with psychosocial disabilities in Lusaka. These comprised a 19-year-old son of a female mental health user, siblings, spouses and a niece who cares for her mother's brother.

d) Seven state officers involved in mental health service and support included officers from Zambia Police, Zambia Prisons Service, the Drug Enforcement Commission (DEC), Ministry of health (Chainama Hills Hospital) and the Department of Social Services officers. An eighth participant was a community activist and mental health trainer. These were all identified in consultation with MHUNZA and ZAFOD, because they were all known to be actively involved in the 'unstructured' state mental health services support system. Thus these officers have experience engaging and supporting people with psychosocial disabilities.

In total, the sample was 32 respondents. Each focus group was held not longer than two hours. To ensure that participants fully understood the purpose of the study ZAFOD and MHUNZA staff as well as a lecturer from the university of Zambia School of Law - Dr Lungowe Matakala - provided interpretation from English to Nyanja and vice versa. Thus, a detailed information and verbal explanation (both in English and Nyanja) about the background and purpose as well as the consequences of participation (which was voluntary) was provided to the participants. In turn

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[46] Kapungwe, Cooper, Mwanza et al (n 16 above) 193

[47] N Robinson 'The use of focus group methodology – with selected examples from sexual health research' (1999) 29 *Journal of Advanced Nursing* 905

[48] See section 1.7 (Limitations) for a more detailed explanation in this regard.

participants volunteered through signed consent forms and verbally agreed to digital recording of the discussions.

Ethical clearance to conduct the study was granted by the research ethics committee of the Faculty of Law at the University of Pretoria. Permission to hold the focus group discussions with mental health patients at Nsadzu[49] and at Chainama Hills Hospital was obtained from the Zambia Ministry of Health (MoH). MHUNZA and the Zambia Federation of Disabled People's Organisations (ZAFOD)[50] kindly assisted with the logistical coordination of the meetings.

The discussions were guided by questions that probed the kinds of government supports available; the general understanding of legal capacity and decision-making; how and if persons with psychosocial disabilities choose trusted support persons to assist them in exercising their legal capacity; most prominent barriers found in the communities; major concerns/fears/expectations of families, support persons and service providers.

1.6.2   Data analysis

The digital recordings from the focus group discussions were transcribed by the researcher and manually analysed using grounded theory to generate understandings from the data collected. The transcriptions are on file with the author. The primary aim of the focus group discussions was not to test theory but rather to enhance understanding and get insights on existing knowledge from a Zambia context. This was useful in establishing and understanding the significance of article 12 for persons with psychosocial disabilities in Zambia, as well as identifying prominent barriers to the exercise of legal capacity. All in all, analysis of data collected via focus group discussions as well as the secondary data sources utilised low levels of structure but was guided by the discussion questions described above and the research questions. This allowed for flexibility in the categorisation of the data of which I used my own interpretation rather than a formalised or proceduralised approach.

1.7.   Limitations

The study is limited to qualitative research methodologies. Focus group discussions in both a rural and urban setting were intended to provide a contrast between the circumstances of persons with psychosocial disabilities in different but basic community settings in Zambia. However, discussions with mental health users at Nsadzu was not very easy because all the discussants had advanced mental illness and as such it was quite difficult to probe the issues the study wished to explore coherently. Additionally, given that there are no alternative service providers except for the care and support staff at the centre it was not possible to have a group discussion with service providers.

Furthermore, given the setup at the Nzadzu Rehabilitation Centre it was not possible to have focus group discussion with families of the resident mental health users as they had been brought to Nzadzu from various parts of Zambia and some over decades that they had lost all contact with their families. Nonetheless interviews with FGDs with both the mental health service users and the service providers provided was all the same invaluable input into this study.

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[49] Nsadzu Mental Health Rehabilitation Centre is located in Eastern Province, Chadiza district in rural Zambia
[50] Zambia Federation of Disability Organisations (ZAFOD) is a legally constituted national umbrella organization for disability organizations in Zambia and has a long history of work in the legal reform and disability rights.

Consequently, the Nzadzu discussion were only used as additional information and not an empirical contrast of the two settings.

1.8.   Summary of Chapters

This mini-dissertation consists of four chapters:

Chapter 1 establishes the background, rationale of the mini-dissertation, research questions and methodology of the research.

Chapter 2 provides an understanding of article 12 and legal capacity, its significance for persons with psychosocial disabilities in Zambia and some social and attitudinal barriers to exercise of legal capacity.

Chapter 3 provides an understanding of social mobilisation strategies and how they would be useful in tackling the prominent social and attitudinal barriers to the exercise of legal capacity.

Chapter 4 contains the conclusion and recommendations.

Chapter 2 - Understanding article 12 and legal capacity, its significance for persons with psychosocial disabilities in Zambia and the societal barriers to exercise of legal capacity

2.1. Introduction

The CRPD sets out key rights that people with disabilities should enjoy in a fair society. It articulates them in a way that speaks specifically to this disproportionately marginalised group. By doing so, it makes up for the economic to almost nil specific reference of this group in other human rights treaties.[51] As highlighted in various analysis conducted on the CRPD, article 1 of the CRPD states that the purpose of the Convention is to

> 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.

Thus, all human rights and fundamental freedoms cited above can be interpreted as applicable to all human beings and thus the CRPD simply applies a disability lens to these rights. Arguably the Convention does not present a new set of rights for persons with disabilities given that most of the rights therein are already protected under some other UN human rights treaties.[52] It simply highlights the key human rights pertaining to persons with disabilities and describes the specific elements that states parties are required to take into account in the protection of the rights of persons with disabilities. The social model of disability adopted by the CRPD holds that disability results from the interaction between a person's impairments and attitudinal and environmental barriers.[53] It contends that with support of varying degrees, existing barriers that cause disability can be countered.[54] Given this understanding of disability, even though the CRPD does not provide a definition of disabilities it does provide the characteristics of disabilities and these include long term mental, intellectual or sensory impairments.[55] As such, persons with psychosocial disabilities are clearly well within the scope of the Convention.

With this background this Chapter provides context to the significance of article 12 of the CRPD to persons with psychosocial disabilities. It asserts equal recognition before the law as a civil and political right under international human rights law. It then provides some background to the CRPD's insistence on the exercise of legal capacity and equal recognition before the law. The Chapter concludes with a basic synopsis of the social and attitudinal barriers that impact or may hinder exercise of legal capacity of persons with psychosocial disabilities on an equal basis with others.

2.2. Persons with psychosocial disabilities and article 12 of the CRPD

It is critical to highlight at the onset that equal recognition before the law is a civil and political right that (as does all other civil political rights) attaches to an individual at the moment of ratification under

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[51] Szmukler, Daw & Callard (n 4 above) 245
[52] Szmukler, Daw & Callard (n 4 above) 245
[53] CRPD Preamble (*e*)
[54] Szmukler, Daw & Callard (n 4 above) 247
[55] CRPD Article 1

international law.[56] Thus the opposition that article 12 of the CRPD received from some circles particularly from the mental health professionals may seem astounding because the article does not present a new set of rights. It merely amplifies and reinforces a civil and political right enshrined in among other regional and international instruments, the Universal Declaration of Human Rights (Universal Declaration)[57], the International Covenant on Civil and Political Rights (ICCPR) and the African Charter on Human and Peoples' Rights (ACHPR).[58]

Through article 12, the CRPD calls on states parties to ensure that this right is enjoyed by people with disabilities on an equal basis with others of which states parties are obligated to take steps to immediately realise the right.[59] Furthermore, there are no permissible circumstances under international human rights law in which a person may be deprived of this right – not even in times of public emergency.[60] Thus the principle of progressive realisation of the right is also out-ruled. Instead, states parties are expected to include and consult people with disabilities and their organisations to take deliberate and immediate steps towards realisation of the right.[61] Importantly, article 12 affirms that full legal capacity is a right that is inherent to all including persons with profound disabilities.[62] The operative word here is 'full' meaning every individual as a rights holder, always has 'both' a right to being recognised as a person before the law, and to act within the framework of a legal system simply by virtue of being human.[63]

In spite the fundamental significance of legal capacity to the autonomy of people, persons with psychosocial disabilities are often denied full legal capacity. This is usually the tendency in many spheres of life in addition to some vehement opinions against provisions of article 12 especially from those in the field of psychiatry.[64] Thus, drafting of the article did not happen without controversy and debate.[65] Contentions hovered among other issues on how to secure the right to legal capacity without undermining sufficient protection for other rights, such as the rights to health and freedom from abuse and ill treatment.[66] Fortunately the CRPD General Comment 1 has since provided ample interpretation that illuminates further the rights enumerated in this article. Nonetheless, it is believed that due to the opposing views against article 12, equal recognition before the law in the context of disability has suffered the least progress in terms of its development in comparison to other articles

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[56] Arstein-Kerslake & Flynn (n 29 above) 480

[57] Article 6 Universal Declaration of Human Rights 'Everyone has the right to recognition everywhere as a person before the law.'

[58] International Covenant on Civil and Political Rights Article 16 'Everyone shall have the right to recognition everywhere as a person before the law.' See also the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) article 15 and the African Charter on Human and Peoples' Rights (ACHPR) article 3

[59] CRPD General Comment 1 (n 30 above)

[60] Under Article 4(2) of the ICCPR derogation of equal recognition before the law is prohibited even in times of public emergency. Through article 4(4) of the CRPD prohibits derogation from existing international law through any of its provisions

[61] CRPD General Comment 1 (n 30 above)

[62] Dinerstein (n 28 above) 9

[63] Browning, Brigby & Douglas (n 27 above) 37. See also CRPD General Comment 1 (n 30 above)

[64] Dinerstein (n 28 above) 8 elaborates on how article 12 was one of the most hotly contested articles during the treaty deliberation process. See also MC Freeman, K Kolappa, J Caldas de Almeida et al 'Reversing hard won victories in the name of human rights: a critique of the General Comment on article 12 of the UN Convention on the Rights of Persons with Disabilities (2015) 2 *Lancet Psychiatry* 845

[65] Dinerstein (n 28 above) 1 provides an account of the controversy that surrounded the drafting of article 12.

[66] Arstein-Kerslake & Flynn (n 29 above) 471

15

of the CRPD.[67] In Zambia, for instance, the stunted progress in this regard was evident during focus group discussions, as participants had very little knowledge of article 12, its provisions, state obligations or its implications.

However, with some professionals in agreement that disability should never be the basis for suspending a person's rights, opponents of article 12 particularly mental health professionals, argue that all persons should not be presumed to have both mental capacity and legal capacity. Their argument, consistent with the views of participants in the state officers' focus group in Zambia and with many existing legal regimes around the globe, is that legal capacity is dependent on one's mental capacity. Even after introducing article 12 and providing background to the article and its implications for persons with psychosocial disabilities, all respondents including persons with disabilities themselves were not ready to embrace the idea that mental capacity is not a precondition of legal capacity. A self-proclaimed community activist and mental health trainer in Zambia had this to say:

> 'From the perspective of a community activist I would <u>not even</u> say yes [legal capacity] is a right to the disabled because they are implications there' [*Community activist and mental health trainer*]

Similar sentiments were echoed by other participants in the group:

> 'In their condition I disagree they cannot make their [own] decisions because they have special needs. They need the relatives maybe to make those decisions for them.' [*Psychosocial counsellor at Chainama Hospital*]

> 'We look at what extent is their mind sound, so we need to know at what level should a person be to make a decision' [*Community activist and mental health trainer*]

Ultimately, as a group, state officers were unanimously opposed to the concept of legal capacity as an inherent right that is independent of mental capacity. The group was adamant that during certain times, particularly when an individual is going through a mental health crisis, the right to legal capacity should be withdrawn and should only be restored or granted when the individual is able to make their own decisions independently.

Essentially, what such opinions imply is that when an individual's mental capacity has become questionable, and a thorough psychiatric assessment has determined that an individual has a compromised mental capacity or decision-making capability, at that particular point on a given issue, legal capacity may or should be suspended and ceded to a third party.[68] Of course while the state officers in Lusaka were willing to recognise that there are some persons with psychosocial disabilities who could always exercise their right to legal capacity, still they insisted that mental capacity should always be a determining factor.

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[67] Arstein-Kerslake & Flynn (n 29 above) 473

[68] MC Freeman, K Kolappa, J Caldas de Almeida et al 'Reversing hard won victories in the name of human rights: a critique of the General Comment on article 12 of the UN Convention on the Rights of Persons with Disabilities (2015) 2 *Lancet Psychiatry* 845

> 'I know we could have those others who can have the right to legal capacity and make their own decision, who doesn't need special-needs depending on the severity of their problem.' [*Counsellor Drug Enforcement Commission in charge of education and awareness*]

Another argument against article 12 globally is that it threatens to undermine critical rights of persons with psychosocial disabilities, including the enjoyment of the highest attainable standard of health, access to justice, the right to liberty and the right to life.[69] In Zambia, a concern along this line of this argument was raised pertaining to the vulnerability of persons with psychosocial disabilities if they are presumed to have legal capacity at all times:

> 'if I've got interest over maybe someone who has got some properties. When he was ok we couldn't sell his property, now that he has some challenges now with his mental capacity that's when we shall say maybe ok he should sell his property, then you go ahead but your friend is in a crisis there, he is not able to reason and do one or two things for himself, he says yes let's sell. Don't you think now that (legal capacity) would be a weapon for criminals now to try to rob those people?' [*Counsellor Drug Enforcement Commission (DEC) in charge of education and awareness*]

This concern is not uncommon and of course is not the intention of article 12 because as stated by the CRPD Committee, 'the recognition of universal legal capacity does not imply lesser obligation to protect people with disabilities'.[70] And neither does it mean they trade their legal capacity in order to be protected. That is, protection of persons with disabilities must not come at the cost of legal agency.[71] In fact, the CRPD actually places a duty on Sates parties to ensure substitute decision makers are not permitted to provide consent on behalf of a person with disabilities. Still others contend that by upholding an individual's legal capacity at all times in-spite of their mental capacity could also result in harm to self or to others.[72] This, they argue, can conversely infringe the human rights of others for example family members and the public.

Nevertheless, as rightly pointed out by Arstein-Kerslake & Flynn rejecting the provisions of article 12 implies accepting and endorsing that people with disabilities can be denied their autonomy, personhood and decision-making power on a differential basis to those without disability.[73] Clearly this is discriminatory, violates the CRPD and is prohibited under international law. The CRPD Committee has raised concerns in its concluding observations to African state on

2.3.   Significance of article 12 for persons with psychosocial disabilities in Zambia

The widely documented historical ill-treatment and abuse of people with disabilities is one of the main reasons behind the CRPD insistence on article 12.[74] Persons with psychosocial disabilities are an

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[69] Freeman, Kolappa, Caldas de Almeida et al (n 69 above) 844

[70] CRPD General Comment 1 (n 30 above)

[71] Arstein-Kerslake & Flynn (n 29 above) 472

[72] Freeman, Kolappa, Caldas de Almeida et al (n 69 above) 846

[73] Arstein-Kerslake & Flynn (n 29 above) 473

[74] Human rights violations of people with psychosocial disabilities occur when individuals are denied their right to exercise their legal capacity. In many countries people with mental and psychosocial disabilities are deprived of their legal right to make decisions and the authority is handed to a third person, a guardian. See Drew, Funk, Tang et al (n 5 above) 1668

17

internationally recognised vulnerable group.[75] They often have difficulty functioning in social situations and may also have problems communicating effectively with others. Society's limited understanding of the nature of the disabilities exacerbate marginalisation, discrimination and curtailment of the right to legal capacity. In Zambia due to the high levels of stigma and discrimination, people with psychosocial disabilities are often abused in their homes, communities and in health and correctional institutions. A number of reports highlight the abuse that takes place in these institutions in Zambia.[76] Focus groups discussions revealed that abuse in their homes is often perpetrated by very close family members.

A female mental health user gave her own testimony in this regard:

> 'My sister and brother are always beating me up saying that I do not behave well. So I don't have a good relationship with them'. [*Mental health user currently under the care of her daughter and 19-year-old son*]

Her son also confirmed her testimony:

> '…instead of taking her [mother] or bringing her to the hospital, instead they [user's elder brother and the young sister] chained her.' [*19-year-old son of a mental health user*]

2.3.1 Why the CRPD insists on the right to exercise legal capacity

Given the above, article 12 is obviously an important phenomenon for persons with psychosocial disabilities, as it provides an authoritative means to challenge gruesome human rights violations they have contended with for centuries. The primary cause of the violations as mentioned above, has more often than not been due to the loss (in whole or part) of their legal autonomy and personhood. This loss restricts their ability to act according to their choices and preferences following their placement under forms of guardianship.[77]

Naturally, one of the most important aims of article 12 is to remedy the loss of the right to legal capacity because it is a universal human attribute possessed by all people and is a basic and general principle of human rights protection.[78] It is also 'indispensable for the exercise of other human rights'[79] and although states have the ability to restrict legal capacity of a person based on, for example, circumstances such as bankruptcy or criminal conviction, they must do so on an equal basis with all persons. Additionally, exercise of legal capacity is not always involved in all decisions or circumstances. This is important to note because when probing the understanding of legal capacity in the focus group discussions in Lusaka some scenarios presented by the participants do not involve legal capacity:

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[75] WHO Mental health and development: Targeting people with mental health conditions as a vulnerable group (2010)
http://apps.who.int/iris/bitstream/10665/44257/1/9789241563949_eng.pdf
[76] MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) and Challenging disadvantage in Zambia: People with psychosocial and intellectual disabilities in the criminal justice system (n 23 above)
[77] Szmukler, Daw & Callard (n 4 above) 247
[78] Browning, Brigby & Douglas (n 27 above) 38
[79] CRPD General Comment 1 (n 30 above)

'There are times when you want to eat some meals of say bubble fish and pig they [family] say don't eat bubble fish it's not good for your health, don't even eat pig it's not good for your health so you have to eat the meal they prepare for you.... even if you buy bubble fish.... Even too if it's your money.' *[Mental health user living with is parents and Elder brother's family]*

Legal capacity however significantly impacts the exercise of other rights that are pertinent for the dignity, autonomy, participation and independence of persons with psychosocial disabilities.[80] Prominent among the most impacted rights as mentioned earlier, are the right to access to justice, the right to health, freedom from involuntary treatment and detention, freedom of expression, the right to marry and to consent to sexual relationships, the right to consent to medical treatment and the right to vote and stand for public office.[81]

2.3.2   Decision-making and legal capacity in Zambia

Central to exercise of many of these freedoms is the ability to make independent decisions according to one one's will and preference. Hence the debacle around decision-making of persons with psychosocial disabilities who lose the opportunity to make their own decisions when they lose the right to legal capacity. According to Inclusion International society recognises or denies legal personhood of individuals with disabilities through the manner in which decision-making is treated in law. In Zambia 'unsound mind' laws are used to take away the legal capacity of people with psychosocial disabilities and thereby prevent persons with psychosocial disabilities from making decisions and participating fully in social, public and political life.

The consensus from the state officers' and the family members' focus group discussions was that while the right to make decisions cannot be taken away from people with disabilities generally, it none the less must be taken away from those who are determined to be of 'unsound mind'. On the other hand, on face value persons with psychosocial disabilities themselves seemed to concur with the service providers. Their initial view was that while it is important to be able to make their own decisions on issues affecting them at all times, some decision-making rights could be derogated in times of a mental health crisis. For the most part participants did not seem to have any issues or discontent regarding forfeiting the right to consent to treatment to their families during times of a mental health crisis.

'…do we feel that it's important at all to make our own decisions on things. Ok yes.' [M*ental health user and law student at the University of Zambia*]

The unilateral consensus among all respondents was that when individuals were in crisis or appear to be in need of mental health treatment the first and primary priority was to get them the necessary medical attention. This need not be in accordance with their choice at the time. The rationale behind this assertion was that, their ability to make decisions during a crisis is usually compromised with a high likelihood of making bad decisions that were not in their best interest.

'When you have a relapse sometimes you can't tell that you have a relapse, but people outside can see especially your relatives. So in that case it is important for them to decide whether to take you to the hospital or to the witchdoctor'. [M*ental health user and law student*]

Interestingly though the above respondent continues his statement with legal capacity implications in terms of his preference of health care options. He said:

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[80] Arstein-Kerslake & Flynn (n 29 above) 480
[81] CRPD General Comment 1 (n 30 above) section IV Relationship with other provisions of the Convention

19

> '… but I prefer to be taken to the hospital than to the witchdoctor, because when you are taken to the witchdoctors the problem doesn't finish it doesn't get solved it gets worse. But when you are brought here [Chainama hospital] you are reassessed and you are rehabilitated.' [M*ental health user and law student*]

Another mental health users had this add:

> 'Some decisions are supposed to be taken by the care giver themselves [the family] without asking you' [M*ental health user and father of 3 living with his parents and elder brother's family*]

> '…that's why they are my care givers, they have to decide when I have relapse because sometimes you cannot make the right decisions when you are not on good condition you can't' [*Mental health user*]

State officers obviously supported this view albeit with a somewhat condescending tone that seemed to imply that persons with psychosocial disabilities should simply not be taken seriously.

> 'There people with certain categories, those whose mind is not sound, I guess you know what I mean, they could not be given the right to make a decision.' [*Community activist and mental health trainer*]

> '…we are the people assisting these people to make decisions, we are the people assisting them to say, looking at this person the way he is, he can't make his own decision to say that I need to go to hospital… [*Counsellor Drug Enforcement Commission in charge of education and awareness*]

In a setting like Zambia where persons with psychosocial disabilities are heavily dependent on their families, without alternative forms of community or state support such position are understandable wrong as they may be from a human rights perspective. Mental health users expressed this position because they are very aware that their conditions can at times cause harm to themselves and/or to others without early treatment. [82] Evidently, substitute decision-making occurs informally in Zambia as there are no formal guardianship laws in Zambia. However, while entrusting decision-making to family or trusted other is well within the concept of the right to legal capacity as it is presented in article 12 of the CRPD Committee 'encourages States parties to develop effective mechanisms to combat both formal and informal substitute decision-making'.[83]

On the other hand, persons with psychosocial disabilities felt that they needed to be able to make their own choices and decisions on issues affecting them:

> 'I have an experience, we are three in the family I'm the second born and we had a house which was left behind by my mother [after she died]. Now we couldn't agree on keeping the house so we decided to sell the house, but what happened is, when we sold the house the proceedings, the process of selling the house was left to my brother and my sister and they excluded me on the basis of my illness. And even when the money came they decided to put the money where they wanted to put it because they felt I didn't have the capacity to take care of the money even if I am married person and I am able to make my own decisions.'

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[82] T Gergel & GS Owen 'Fluctuating capacity and advance decision-making in Bipolar Affective Disorder – Self binding directives and self-determination' (2015) 40 *International Journal of Law and Psychiatry* 92
[83] General Comment 1 (n 30 above) Paragraph 52

[Mental health user with bipolar disorder]

Another mental health user added:

> 'I've also had an experience where the late dad and mum left a house in Ndola. So me being the first born I was supposed to be the landlord but because of my condition it was given to my young brother and later on he ended up selling it. He sold it without my concern. So for me I understand that there are some people who don't allow me to make decisions. They make decisions for me which is not good like in terms of voting I know many users don't vote because was even written under the constitution that you are not supposed to stand as an MP or counsellor on any political position if you have mental disorder. They call it you are of unsound mind. They say you are stateless so there is no legal capacity.' *[Mental health user whose illness is as a result of drug abuse earlier in his life]*

2.3.3 Supported decision-making

As aptly stated by Browning et al, 'just as people with physical disabilities need a ramp to ensure that they are reasonably accommodated to access a building, supported decision-making is seen as a vehicle to reasonably accommodate people with mental health and cognitive disabilities to exercise their legal capacity.'[84]

> '…when we choose we choose very well what we like and so we must be given the opportunity to choose for ourselves what we want.' [M*ental health user*]

Given that legal capacity is a philosophically driven position embedded in human rights principles that are yet to be realised in practice[85] numerous models of decision-making have been proposed that are in line with human rights based models of disability that focus on supported decision-making instead of substituted decision-making. To this end proposals of supported decision-making models that emphasise an 'individual's autonomy; presumption of capacity; and the right to make decisions on an equal basis with others exist.'[86]

There exist supported decision-making models that include trusted others to enforce treatment and constraint when necessary.[87] Such models can come with advance directives which help ensure that the will and preference of the individual always remain at the core of the decision made on behalf of the individual with a disability. Their right to choice and decision-making must be supported as called for by the CRPD. Concern has been expressed by the CRPD Committee to African State parties about the substituted decision-making and guardianship regimes for persons with disabilities that prevail in the State parties. The Committee recommends the amendment or repeal of these laws, and the development and implementation of supported decision-making models that respect the autonomy,

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[84] Browning, Brigby & Douglas (n 27 above) 36
[85] Browning, Brigby & Douglas (n 27 above) 38
[86] Dinerstein (n 28 above) 11
[87] Dinerstein (n 28 above) 11

will and preferences of the person and that safeguards against undue influence and conflict of interest in line with Committee's general comment on article 12.[88]

CRPD espouses the need for support that enables people with disabilities to retain their legal capacity and at the same time allowing them to choose to receive support in exercising this right when they desire it and when it is needed.[89] For persons with psychosocial disabilities this may take the form of advance directives as a form of support as this provides opportunity to plan and state their will and preferences in advance of a crisis. States parties are thus called upon to provide various forms of advance planning mechanisms to accommodate various preferences.[90]

2.4. Social and attitudinal barriers to the exercise of legal capacity in Zambia

With the understanding that denial of legal capacity takes away the right to choice and informed consent, three main categories of concern emerged as barriers to the exercise of legal capacity during focus group discussions: a) lack of state and community based supports and social networks; b) inadequate training of health and justice system officials; and c) stigma of mental illness and stereotypes.

2.4.1 Lack of state and community based supports and social networks

The right to enjoyment of the highest attainable standard of health as provided for in article 25 of the CRPD includes the right to healthcare on the basis of free and informed consent of persons with disabilities prior to any treatment. In this regard States parties are obligated to ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available.[91] All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities.[92] They should also ensure to the best of their abilities that assistants or support persons do not substitute or have undue influence over the decisions of the persons with disabilities. States parties in this regard must provide access to independent support.

In Zambia progress in this regard appears quite limited and it is unfortunate that in a country where HIV prevalence stands at 14.3% among the 15-49 age group[93] and its associated stigma has been linked to increases in the need for mental health support, mental health has not been adequately prioritised and consequently the exact percentage of the health budget meant for mental health is not available under Zambia's National Health Strategic Plan 2011-2015.[94] The situation remains the same with the country's health budget representing a meagre 8.3 per cent of the total national budget in 2016 down from 9.6 per cent in 2015.[95]

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[88] See CRPD Committee concluding observations on equal recognition before the law (article 12) to the following State parties: Uganda (April 2016); Ethiopia (September 2016) Mauritius (September 2015) Kenya (September 2015) Gabon (September 2015; and CRPD General Comment 1 (n 30 above)

[89] Drew, Funk, Tang et al (n 5 above) 1670

[90] CRPD General Comment 1 (n 30 above)

[91] CRPD General Comment 1 (n 30 above) Paragraph 42

[92] CRPD General Comment 1 (n 30 above) Paragraph 41

[93] UNICEF Zambia - HIV and AIDS Key statistics http://www.unicef.org/zambia/5109_8459.html accessed 28.09.16

[94] MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 18

[95] Source: UNICEF Zambia health sector budget brief: Review of budget performance and 2016 allocations http://www.unicef.org/zambia/HealthBudgetBrief-4.pdf accessed on 4 September 2016

22

Consequently, Zambia has limited mental health services that are under-resourced and inaccessible for the vast majority of the population especially those in the rural areas. [96]

> 'As a government we should take retrospect like in Zambia we have only Chainama here in Lusaka, now when somebody is affected in Chipata [approximately 600km away from Lusaka] what are they doing looking at it in that way. That person will be vulnerable for the families will not have public transport to bring that person from Chipata to here in Lusaka.' [*Assistant Superintendent Police Officer under the Director of Community Service*]

The accessibility problems inhibit a large part of the population from having proper access to mental health services because they cannot afford the journey and the transportation systems are unreliable.[97] There is an absence of community-based mental health care in Zambia which means there is a disproportionate reliance on Chainama the only psychiatric institution in the country as the main provider of mental health services.

> '… in terms of activities I really don't know maybe for some who stay in Lusaka maybe near to the services we talking about the services and facilities that maybe available to access. To say ok maybe you need to spend time somewhere maybe like occupational therapist, like me, I mean I have to talk to those ones, those facilities are not much there.' [*Mental Health User*]

Furthermore, in the absence of community based supports as disclosed by focus group discussants, the burden naturally falls on the families who have to cope the best they can to support their relatives with psychosocial disabilities. It is usually this general lack of alternatives and very minimal to no support for families in dealing with their relatives with challenging behaviours that drives or leads people to constrain, shackle and enforcing treatment be it traditional or conventional psychiatric institutions or even prison cells. Consequently, others especially those with the means and access to institutions feel they have no option but to institutionalise their relatives and often without their consent of which it is at this juncture that legal capacity is most severely compromised.

> 'In the first place even the way they are brought to the hospital usually its either they tied, they are very few rare cases the one that we are going say who is willingly come to say have come to get medicine.' [*Counsellor Drug Enforcement Commission in charge of education and awareness – trained clinical officer*]

The family typically sees this as a pragmatic solution to contain a person for their own welfare and for that of people around them. [98]

On the other hand, prevailing mental health stigma has adverse effects on the willingness of persons with psychosocial disabilities to access appropriate care and adhere to treatment regimes. [99]

> 'The problem is that many people including users themselves have an ugly picture about Chainama they fear Chainama they think Chainama is the end of the road is a dead end.' [*Mental health user*]

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[96] MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 24
[97] Drew N, Funk M, Tang S et al (n 5 above) 1667
[98] MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 24
[99] Kapungwe, Cooper, Mwanza et al (n 16 above) 193

People in Zambia avoid or delay seeking mental health care at Chainama hospital due to stigma associated with the institution and would be more comfortable seeking treatment in their communities at primary health care clinics which do not carry the stigma attached to Chainama.

> 'When I got out of Chainama I wasn't leaving well because there was too much stigma in the community. I was stigmatised by my friends, family members and community.' [*Mental health user*]

Some people in communities as well as healthcare practitioners reportedly harbour immense fear towards mental illness.[100] This fear is connected to the perceptions that mental illness is transmittable and that people with mental illness are generally dangerous.

If only healthcare services were closer to people and readily accessible to their communities at clinics that do not carry the negative connotations of a known mental health facility people would seek early treatment. Such closer to the community services would also provide a useful tool for community support structures that promote human dignity, individual autonomy and the exercise of legal capacity.

That said, it is important to note that in the Zambia context mental health treatment for some people is not restricted to conventional medical health facilities but also encompasses religious/faith based and traditional healers.[101] The decision on which route or option of 'treatment' to take during times of a mental health crisis was highlighted as one of the contentious decision-making issues which give rise to family disputes.[102][103]

> '…me and my other brother we looked for money and our parents took him (their brother with psychosocial disability) to a traditional healer where he stayed for about 4 or 5 months. They (traditional healer) were just hanging him by the rope and the traditional healer used to beat him with a rope.' [S*ibling of a mental health user*]

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[100] Kapungwe, Cooper, Mwanza et al (n 16 above) 198

[101] About 70-80% of people with mental health problems consult traditional health practitioners before they seek help from conventional health practitioners. MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 18

[102] It is worth noting that traditional healing is recognised under international law as an indigenous knowledge system. Hence there are a number of international instruments that provide for individuals and communities' right to practice their religion, culture or scientific. See C Oguamanam 'Between reality and rhetoric: The epistemic schism in the recognition of traditional medicine in international law' (2003) 16 *Saint Thomas Law Review* 59.

[103]MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 29 points to the following International and African Charter instruments and provisions Article 27 of the Universal Declaration of Human Rights (UDHR), Article 1 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), Article 27 of the International Covenant on Civil and Political Rights (ICCPR), International Labour Organisation (ILO) Convention No. 169 of 1989 part 5, Articles 23 and 24 of the UN Declaration on the Rights of Indigenous Peoples 1993 (UNDRPI) guarantees the right to traditional medicines and practices including the right to the protection of vital medicinal plants, animals and minerals, Articles 17 and 29 of the African Charter on Human and Peoples' Rights (ACHPR), Article 6 of the African Cultural Charter (ACC) and Articles 3, 13 and 21 of the African Charter on the Right and Welfare of the Child (ACRWC), Protocol to the African Charter on the Rights of Women in Africa

Generally, the trend in Zambia is that the ultimate decisions in health option choices are usually made in accordance with the will and preference of the families or guardians of persons with psychosocial disabilities and not the individual with disabilities.

> 'Somehow they should be able to ask you like me when they brought me to Chainama. They didn't tell me that they are bringing me to Chainama. They are supposed to ask me, where should we take yo, because I had two decisions, whether I go to church they pray for me or I come to Chainama. There are decisions they are supposed to ask where they should take you not taking you by force.' [*Mental health user and volunteer pre-school teacher*]

The CRPD calls for respect of legal capacity of persons with disabilities to make decisions at all times even in crisis situations. This respect of legal capacity applies in spite of whether the guardian or support person are in agreement with the will and preference of the individual with a disability or not.

Bottom line is that forced treatment by psychiatric and other health and medical professionals is a violation of article 12 and an infringement of the right to personal integrity, freedom from torture and freedom from violence exploitation and abuse. This practice denies the legal capacity of the person to choose medical treatment. Through article 12 the CRPD calls on states parties to abolish all policies and legislative provisions that allow or perpetuate forced treatment.

2.4.2 Inadequate training of health and justice system officials

The inadequate training of community, health and justice system officials perpetuate arbitrary detention and non-consensual psychiatric confinement which undermines not only equal recognition before the law and legal capacity but also the right to liberty and the right to the enjoyment of the highest standard of health. Persons with psychosocial disabilities not only in Zambia, but also globally, are arbitrarily detained and psychiatric confinement can be ordered by the justice system or others in positions of power without any basis. The practice prevails unabated in Zambia where people are often locked up in hospitals or detention centres for years and subjected to psychiatric interventions without informed consent. Police officers in the focus group discussions confirmed the inadequate training of officers to identify and/or handle a person with a psychosocial disability when they enter the justice system. [104]

These are their comments on the matter:

> '… from a law enforcement point of view we are trained in different ways and it may be very difficult for a law enforcement officer who is not well vested in issues of psychosocial disabilities to determine one who has a psychosocial challenges and allow that person to decide whatever that's there.' [*Law enforcement officer Zambia Police*]

> 'I wouldn't say everyone is cable of determining the condition of the person and the law itself is very blurry it doesn't look at the condition…so now when an officer who's on duty or who's attending to this is unable to identify a person with psychosocial disabilities will treat him like any other person.' [*Assistant Commissioner of Police in charge of Community Service*]

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[104] Drew, Funk, Tang et al (n 5 above) 1667

In line with the above self-confessed inadequacies, documented evidence shows that people in Zambia can be detained by the police simply based on inconsistent and unstructured assessment procedures.[105] Nothing more than fickle observations, perceptions and judgement of untrained officers. Disturbingly, how dirty or smelly an individual appears, or the difficulties they may exhibit when trying to express themselves can result in the detention of people in Zambia.[106]

> 'There are certain situations whereby even if not schooled in psychosocial you can be able to say no this particular person needs this kind of help without even asking him or asking her you do it on your own and this is normally what happens whenever you see someone behave in a certain way you know this is Chainama case.…Without even asking the person you drag that person into the vehicle rush to the hospital' [*Law enforcement officer Zambia Police*]

This situation is obviously worrisome to say the least, from a legal capacity perspective and violates not only article 12 but also article 14[107] of the CRPD. The CRPD Committee has severally stated in concluding observations that forced treatment and arbitrary detention by psychiatric and other health and medical professionals is a violation of article 12 and at the same time infringes on the right to personal integrity.[108]

Zambia's Mental Disorders Act of 1951 currently empowers magistrates to sign 14-day detention orders without obtaining the views of the persons concerned. While this is obviously problematic given the provisions of the CRPD to which Zambia is party, the long awaited enactment of a proposed mental health bill drafted in consultation with people psychosocial disabilities through MHUNZA and ZAFOD, would repeal this archaic law.[109]

There was also a sense from the mental health users that officers are detaining people outside of the provisions of the law.

> 'me I didn't come here just from the community to this centre I passed through the high court, [in 1979] they have to make a decision because. But as of today people just come maybe from the community suburb they fight or maybe he's drunk or maybe he's done that, they say oh Chainama will be a good place.' [*Mental health user*]

> 'I can say something about especially here at Chainama [hospital] they just do everything what they want they say he is a mentally confused person.' [*Mental health user and patient of Chainama since 1979*]

Existing stereotypes also exacerbate the challenges to exercise of legal capacity posed by untrained state officers. The CRPD Committee cites the importance of training 'police officers, social workers

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[105] Challenging disadvantage in Zambia (n 23 above) highlights that due to a lack of awareness of disability, practitioners in the justice system tended to determine whether one has mental disabilities through mere visual observation of an individual's demeanour.

[106] Challenging disadvantage in Zambia (n 23 above) highlights that due to a lack of awareness of disability, practitioners in the justice system tended to determine whether one has mental disabilities through mere visual observation of an individual's demeanour.

[107] CRPD article 14 provides for the right to liberty and security of persons

[108] CRPD article 17, Protecting the integrity of persons

[109] There currently exists a draft mental health bill due to be tabled before parliament of which if enacted it provides for respect, autonomy, non-discrimination and the right to self-determination for people with psychosocial disabilities and could repeal the Mental Disorders Act 1951.

and other first responders to recognize persons with disabilities as full persons before the law and to give the same weight to complaints and statements from persons with disabilities as they would to non-disabled persons'.[110]

2.4.3 Stigma of mental illness and stereotypes

For the most part people with mental illness struggle with the symptoms and disabilities that result from the disease and at the same time are challenged by the stereotypes and prejudice that result from misconceptions about mental illness.[111] Focus group discussants confirmed that stigma prevails among relatives, communities, and health care professionals as well at the government and policy level.[112]

This is on a background of Zambian traditional culture which is reportedly dominated by a general belief that supernatural forces in the spirit realm influence daily lives. In this vein when the spirit of the ancestors is adequately revered it is believed they bring good luck and prosperity and conversely misfortune befalls those who have not properly appeased the spirit. With these belief mental illness is believed to result from either spiritual curses, bewitchment or demon possession.

> 'yah mostly the way it is like here in Zambia as someone who has experienced that, they so no maybe he has been bewitched' [*Mental health user and law student at UNZA*]

Another mental health user believes her aunt is responsible for her illness:

> 'There is also another aunt who made tattoos on her body and it's because of those same tattoos that she found herself here in Chainama.' [*Female mental health user*]

A state officer summed it up and said:

> 'There is a lot of things which are involved looking at issues pertaining to mental illness. Zambians like many other countries in Africa, most of our communities they don't believe in this as just an illness. Its associated with witchcraft.' [*Assistant Commissioner of Police in charge of Community Service*]

Religion on the other hand is reported to have a critical role in mental health in Africa. Although Zambia is a constitutionally declared Christian nation the Church is reported to have a limited connection with mental healthcare in the country.[113] Some churches however (mainly Pentecostals) are reportedly amassing huge followers who seek mental health healing among other illnesses.

> 'Then another good part is I diverted from my Christianity I'm a catholic so, when I was away from my church things were going bad for me. But when I returned things are ok for me.' [*Mental health user*]

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[110] Paragraph 39 CRPD General Comment 1 (n 30 above)
[111] Kapungwe, Cooper, Mwanza et al (n 16 above) 196
[112] Kapungwe, Cooper, Mwanza et al (n 16 above) 200 confirms that indeed inn Zambia the biggest challenge appears to be mental illness stigma which extends beyond the individual and impacts family members across generations and even a neighbourhood and the mental hospitals too.
[113] MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 29

In addition to the above cultural beliefs there is also the understanding that drug and alcohol abuse induces mental illness and as such there is a tendency to blame the individual and show disapproval rather than compassion and understanding.[114] Also, there is a tendency to assume that when one has a mental health illness then they also have HIV/AIDS. This compounds the levels of stigmatisation people with psychosocial disabilities are subjected to given that HIV/AIDs is also highly stigmatised in Zambia.[115] HIV prevalence in the country stands at 14.3% among the 15-49 age group[116] and its associated stigma has been linked to increases in the need for mental health support. The experience of the stigma of AIDS has been likened to that experienced by people with psychosocial disabilities in various ways which although not within the focus of this study will be important to explore through further research. [117]

It is possible that the foregoing is the reason why stigma of mental illness is rife in Zambia. Either way stigma and stereotypes hinder equal access to social and economic opportunities such as employment and thereby constrain full participation in the communities and access to justice. Furthermore attitudinal barriers such as stigma towards people with psychosocial disabilities have pernicious implications for prevention and the quality of life of those who suffer from mental illness as well as their rehabilitation.[118] Stigma is not only an emotional and social affliction but causes increased levels of violence. [119]

2.5.   Conclusion of Chapter 2

Equal recognition before the law is a civil and political right that (as does all other civil political rights) attaches to an individual at the moment of ratification under international law.[120] Persons with psychosocial disabilities are no exception to this right yet they are subjected to, abuse in their homes, communities and in health and correctional institutions and face widespread abuse of their human rights particularly due to deprivation of the right to legal capacity. In Zambia it has emerged that stigma and associated stereotypes further exacerbate marginalisation, discrimination and curtailment of the right to legal capacity because of limited understanding of the nature of psychosocial disabilities. In this regards article 12 of the CRPD is obviously an important phenomenon as it provides an authoritative means to challenge rights violations and provides remedy to the loss of the right to legal capacity.

This is especially important in Zambia because state officers are inadequately trained to deal with persons with psychosocial disabilities in a rights respecting manner. Due to limited knowledge and understanding of article 12 were initially unanimously opposed to the concept of legal capacity as an inherent right that is independent of mental capacity. There was a general sense from across all respondents that during certain times, particularly when an individual is going through a mental health crisis, the right to legal capacity should be withdrawn and should only be restored or granted only

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[114] Kapungwe, Cooper, Mwanza et al (n 16 above) 198
[115] Kapungwe, Cooper, Mwanza et al (n 16 above) 201
[116] UNICEF Zambia - HIV and AIDS Key statistics http://www.unicef.org/zambia/5109_8459.html accessed on 28 September 2016
[117] PW Corrigan, FE Markowitz & AC Watson 'Structural levels of mental illness stigma and discrimination' (2004) 30 *Schizophrenia Bulletin* 482
[118] Kapungwe, Cooper, Mwanza et al (n 16 above) 193
[119] MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 26
[120] Arstein-Kerslake & Flynn (n 29 above) 480

when the individual is able to make their own decisions independently. In conclusion the implications of full legal capacity and decision-making models were not fully understood.

However, with the limited understating of the concept of legal capacity on the part of all respondents three main categories of concern emerged as barriers to the exercise of legal capacity: a) lack of state and community based supports and social networks; b) inadequate training of health and justice system officials; and c) stigma of mental illness and stereotypes. Of these three mental illness stigma appears to be an underlying driver of the other barriers.

Chapter 3 – How social mobilisation strategies can address societal barriers to the exercise of legal capacity

3.1.   Introduction

Chapter 2 provided an understanding of article 12 and legal capacity, its significance for persons with psychosocial disabilities in Zambia and some social and attitudinal barriers to the exercise of legal capacity emerged. Social and attitudinal barriers constructed over centuries, even if premised on unfounded and meaningless pursuits, can become the standard norm of a given society. For example, people in China chose to bind their daughters' feet (foot binding) for no good enough reason, save for the fact that the practice had over centuries become a normal way of life.[121] The practice had no health benefits what so ever, was disfiguring and caused lifelong debilitating pain. Similarly, female genital mutilation or cutting (FGM/C), another centuries-old cultural practice for some communities in parts of Africa and a few pockets of the Middle East has no health benefits what so ever, is also extremely painful and often a root cause of life threatening conditions and fatalities.[122] Likewise, of the emerging barriers to the exercise of legal capacity in Zambia, stigma of mental illness and stereotypes appear to be the underlying driver of the other barriers. Stigma and stereotypes are predominantly hinged on cultural values and beliefs of a society. These in turn tend to perpetuate forced treatment; illegal detention of individuals and arbitrary deprivation of liberty which includes chaining or shackling of people; exclusion in family, community and public life, and many other human rights violations.

The work of Tostan, a non-governmental organisation (NGO) that develops and implements social mobilisation and community empowerment programmes in West Africa, is an excellent example of alternatives to more legalistic approaches that frequently lack understanding of communally based cultures.[123] Tostan promotes social change by building people's capacities to become the agents of positive change in their communities.

In this study, the Tostan methodology is useful in exploring social mobilisation strategies that include human rights education campaigns and proved a successful strategy in addressing FGM/C a socially complex issue in West Africa. Chapter 3 therefore provides an understanding of social mobilisation strategies and how they would be useful in tackling the prominent social and attitudinal barriers to the exercise of legal capacity.

3.2.   Understanding social mobilisation strategies and how they influence societal change

The denial of legal capacity for person with psychosocial disabilities in Zambia implies they have to trek a journey to equal recognition before the law, riddled with social and attitudinal barriers. A journey their non-disabled counterparts do not have to make because, by virtue of being a non-

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[121] The *New York Times Magazine* 'The art of social change' (2010)
http://www.nytimes.com/2010/10/24/magazine/24FOB-Footbinding-t.html?_r=0 accessed on 4 October 2016
[122] FGM/C is an ancient rite of passage in many African and some Middle Eastern countries considered to make girls clean and pure and ready for marriage. The practice involves cutting of part or all the genitals usually with a razors or a knife and often without anaesthetic.
[123] D Gillespie & M Melching 'The transformative power of democracy and human rights in non-formal education: The case of Tostan' (2010) 60 *Adult Education Quarterly* 25

disabled human being, societal norms and practices dictate that they already have legal agency and legal standing. Existing barriers such as those identified in Chapter 2 and depicted in Figure 1 below are huge and will take years to dismantle.
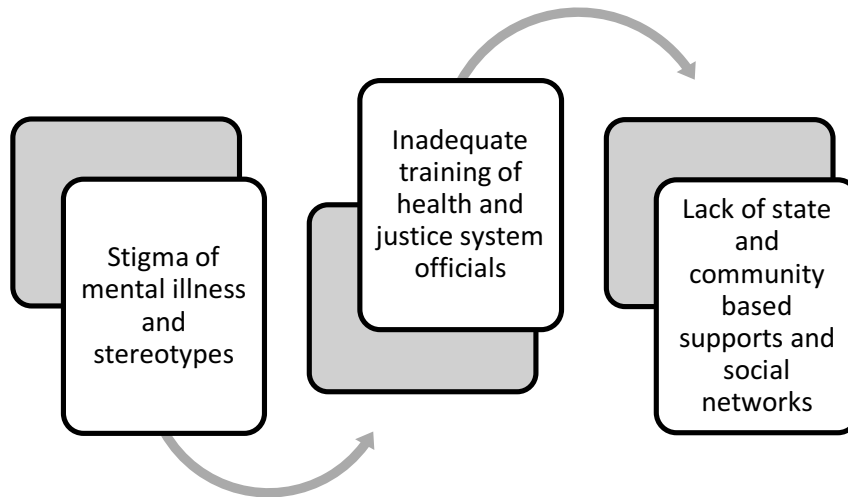

Figure 1: Emerging social and attitudinal barriers in Zambia established in Chapter 2 (own concept and design)

Even though the journey might be long, it is nonetheless very possible because beliefs, attitudes and behaviour are attributes that are neither fixed nor concrete and experts in the field have already shown that these can be changed.[124] Even though social change is slow,[125] it is nonetheless possible through strategic social mobilisation strategies such as those employed by Tostan. Hence the social, structural and individual changes necessary for advancing human rights are a realistic expectation.[126]

The benefits of social mobilisation in general are many and what is clear is that they can fill the gap that law and legislation cannot always meet in advancing human rights. For example, a move by the government of Senegal to criminalise those who violate the integrity of the female genitalia typifies the limitations of law and legislation on practices that are influenced by age old belief systems and culturally based issues - no matter how devastating they may be to the human rights narrative and principles. By criminalising FGM/C, hundreds of thousands of Senegalese faced the possibility of up to five years in prison and yet this did not deter the practice. Instead many girls were cut in the months following the legal proclamation in retaliation and deliberate violation of the law.[127] Consequently, this whole episode derailed the work of Tostan as they had to halt operations because of the public outrage on the government's move. Fortunately, this derailment was short lived and the organisation managed to get its programmes back on track with the conviction that once enough people in the

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[124] Gilbert DT, Fiske S & Lindsey G 'Stereotyping prejudice and discrimination' Handbook of social psychology (1998), asserts that behaviours and attitudes such stereotyping, prejudice and discrimination are individually controllable and responsive to social structures.

[125] R Goodwin 'Changing relations: Achieving intimacy in a time of social transition' (2009) 2 suggests that every society is usually in a fluid state and social changes are thus 'relatively small and gradual

[126] Advocates for youth strategies guided by best practice for community mobilization http://www.advocatesforyouth.org/storage/advfy/documents/Factsheets/strategies%20guided%20by%20best%20practice_8-11-14.pdf accessed on 4 June 2016

[127] The *New York Times Magazine* 'The art of social change' (n 112 above)

31

community had changed their mind-sets on FGM/C they would stand up together and pledge allegiance to new practices.[128] This strategy paid off because it was applied with a dialogue of mutual respect, one that was free from self-congratulation. In the end Tostan managed to rally a core group of converts who committed to new practices that took into account the traditions of the community.[129] Hence, the Tostan programmes are an excellent example of how social mobilisation can empower individuals to positively transform their communities.[130] Such transformation is critical in building social movements that can play a significant role in transforming legal rights into practice.[131] It is therefore easy to imagine how similarly powerful social movements in support of the autonomy and dignity of persons with psychosocial disabilities, would advance exercise of their legal capacity on an equal basis with others.

Overall, the Tostan strategy has been commended for being locally inspired and different to other international attempts to deal with FGM/C. It is non combative and does not set out to put blame on anyone nor does it insult tradition or imply that FGM/C practitioners are evil. Rather it takes into account the extraordinary challenges the communities face.[132] Thus similar caution and tact should be exercised in Zambia with focus directed on the challenges Zambian communities face every day, for example those linked to the barriers identified in chapter such as: a lack of access to health care services outside of Chainama; lack of basic and general information about mental illness; inadequate training of health and justice system officers, including the lack of the resources required to support their training; and the inadequate to lack of general and basic state and community based supports and social networks.

3.2.1 Social mobilisation engagement

Sustainable social and behavioural change requires many levels of involvement, from individuals to community, to policy and including legislative action.[133] It also requires working with key local sectors and community groups. Change can take place at various levels.[134] Change at the individual level requires working with individuals and families in their local communities. However C Panter-Bricka, SE Clarke, H Lomasa et al point out that knowledge and attitudes are easiest to change at these levels than behaviours which they suggest as 'much more challenging'.[135]

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[128] The *New York Times Magazine* 'The art of social change' (n 112 above)
[129] C Panter-Bricka, SE Clarke, H Lomasa et al 'Culturally compelling strategies for behaviour change: A social ecology model and case study in malaria prevention' (2006) 62 *Social Science & Medicine* 2811 highlight attributes of successful interventions that include the need to build on existing local practices, skills and priorities
[130] Gillespie & Melching (n 124 above) 2
[131] Freeman (2006) (n 6 above) 46
[132] Gillespie & Melching (n 124 above) 8
[133] WHO 'Advocacy, communication and social mobilization to fight TB: a 10-year framework for action / ASCM Subgroup at Country Level' (2006) 16
http://www.stoptb.org/assets/documents/countries/acsm/tb_advocacy_isbn.pdf accessed on 10 November 2016
[134] Goodwin (n 126 above) 2
[135] C Panter-Bricka, SE Clarke, H Lomasa et al (n 130 above) 283

When discussing how communities could be mobilised to advance legal capacity in Zambia, focus group discussants were aware of the knowledge gap as well as potential within the families and communities at large:

> 'we need to start with the family itself then to the community once the family is educated and they are empowered with knowledge, attitudes will change. Knowledge changes our attitude...' [*Community activist and mental health trainer*]

Structural changes can be achieved by influencing policy/decision makers. This requires working with all levels of government and representatives from national structures.[136]
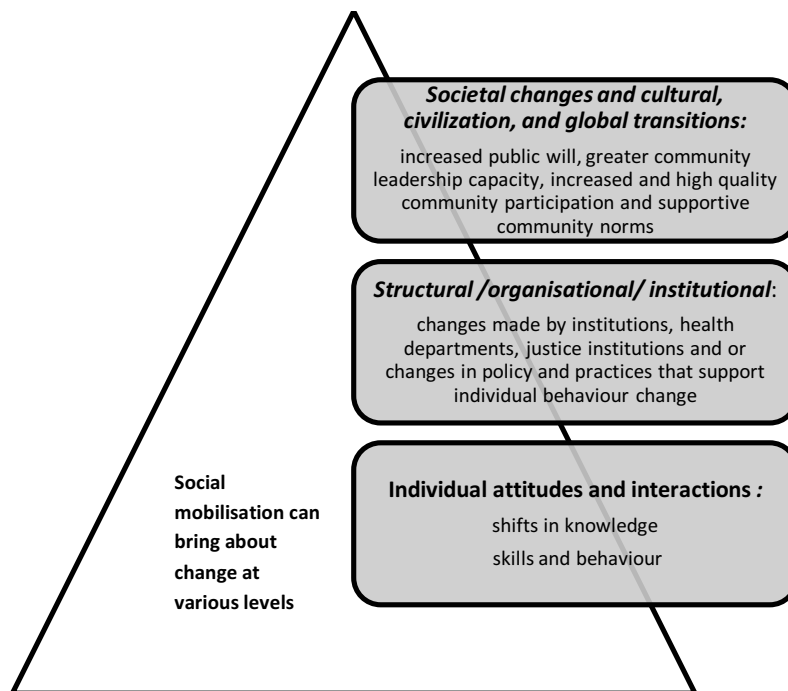

Figure 2: Changes that can be significantly influenced by social mobilisation (own concept & design)

Regardless of the levels at which change is targeted or anticipated, a social mobilisation strategy brings together a range of players and generates dialogue, negotiation and consensus, of which is the bedrock of Tostan strategies and programmes. The organisation brings together multiple and practical inter-sectoral allies and stakeholders to create local solutions to local problems.[137] The model infuses and manages the complex interactions between national and local government, communities or civil society and donors.

Change has been observed in the communities that Tostan has worked with respect to perceptions of FGM/C and is something that could happen in Zambia. In this regard the Tostan programme mobilised

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[136] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)

[137] C Panter-Bricka, SE Clarke, H Lomasa et al (n 130 above) 2812

communities to be united around the need to abandon practices previously justified by custom or tradition and now viewed as obsolete due to the community's new awareness. Senegalese respondents to the 2008 evaluation of the long term impact of the Tostan programme from some of the communities that Tostan worked, stated that FGM/C is no longer practised in their communities.[138]

3.3. The social mobilisation cycle

Dismantling each of the barriers identified above requires a robust social mobilisation strategy. Central to the Tostan strategies is the ability to bring a community together to create local solutions to local problems.[139] By allowing communities to define their own problems, set common goals and work together to achieve the goals, Tostan strategies inevitably change the communities in a lasting way because the communities take ownership of the programmes.[140] Given that social mobilisation cannot be effectively achieved overnight, and involves processes that require commitment from all parties it must be led by the communities themselves. Throughout the mobilisation process a cycle of initiatives that need constant attention to ensure success of the strategy emerged from Tostan model and these are discussed further below.

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[138] Although it is possible that the practice could be continuing secretly, in some parts of Senegal particularly in the Kolda region. See Population Council Report 'Evaluation of the long-term impact of the TOSTAN programme on the abandonment of FGM and early child marriage: Results from a qualitative study in Senegal, (2008) http://pdf.usaid.gov/pdf_docs/Pnadl816.pdf accessed on 4 May 2016

[139] C Panter-Bricka, SE Clarke, H Lomasa et al (n 130 above) 2812, rightly argue that 'in order to be culturally appropriate, culturally compelling, or effective, the design of interventions must nestle within the social and ecological landscape of local communities'. See also Florida department of health, community mobilisation web page https://www.myctb.org/wst/floridacommunityprevention/mobilization/default.aspx accessed on 13 November 2016 and Advocates for youth strategies guided by best practice for community mobilization (n 127 above)

[140] An evaluation of strategies employed by C Panter-Bricka, SE Clarke, H Lomasa et al (n 130 above) 2819 on case study for behaviour change in malaria interventions conducted in the Gambia, villagers emphasised the sense of local ownership because of their involvement in the strategies which included songs they had composed themselves in their local indigenous language
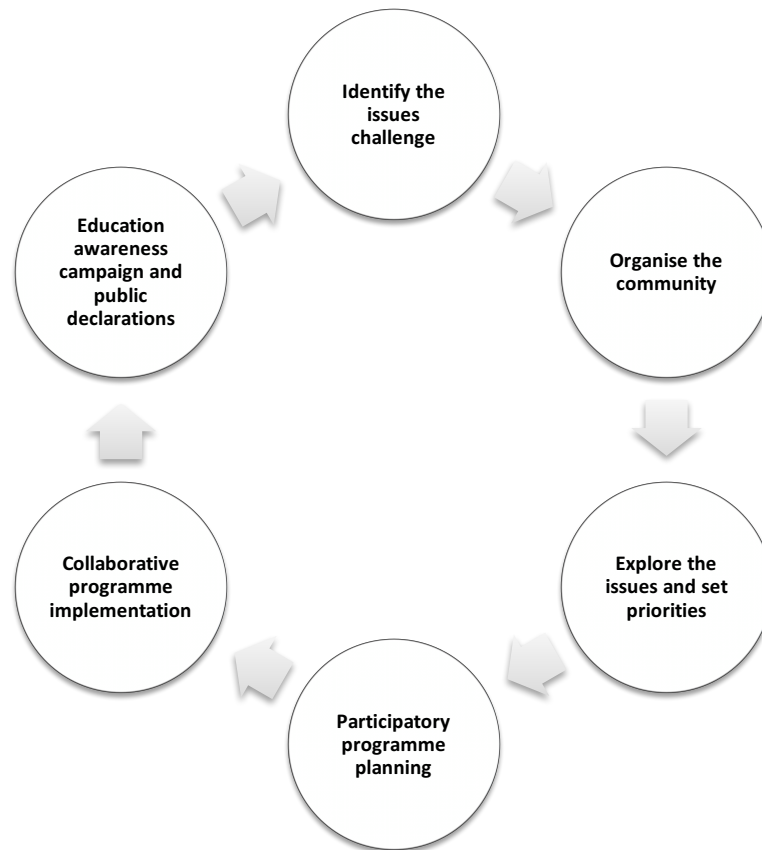
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Figure 3: Chain of initiatives within the Tostan strategies (own concept and design)

3.3.1. Identify the community issues or challenges

The main purpose of a social mobilisation strategy is obviously to address a particular issue or challenge in a given community in a way that allows people to think and understand their situation and to act on the situation on their own volition.

In Senegal Tostan targeted ethnic tribes where prevalence of FGM/C was high - upwards of 60% to nearly 80%. The national prevalence of FGM/C at the time was approximately 28% which apparently concealed the wide disparities among ethnic groups.[141] On reflection, FGM/C is a practice that has for a protracted period of time attracted condemnation from international communities and has received widespread attention and funding from a number of international agencies. Because of Tostan's work in the country there has been some traction toward ending the practice but the battle remains far from over. With this reflection mental health issues are yet to gain similar traction in terms of international concern and support, and condemnation of the abuse and violence faced by persons with psychosocial disabilities has not consistently topped the agenda of many international agencies. So the question that needs to be answered by the mobilisation strategy is how to get communities to identify with the problems faced by persons with psychosocial disabilities. That is, to look beyond the disability and recognise that behind it, is a human being who has the right to dignity and who holds aspirations and needs that every human being has - including those who might not be able to express

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[141] Population Council Report 'Evaluation of the long-term impact of the TOSTAN programme on the abandonment of FGM and early child marriage: Results from a qualitative study in Senegal, (2008) http://pdf.usaid.gov/pdf_docs/Pnadl816.pdf accessed on 4 May 2016)

35

this for themselves. Throughout its social mobilisation cycle, Tostan takes into account the needs of the people and reaches out to different sectors of a community. In doing so it creates partnerships that focus on, and ultimately address a mutually pressing issue. However, identifying the issues alone is not enough, the issues must resonate with the community and be accepted as a common cause for concern.

Thus, identifying barriers depicted in Figure 1 above is one thing, but it is quite another task to get the general community members to accept they need to concern themselves with these issues. Mental health users in Zambia themselves are aware of how this is an up-hill challenge, but a sense of dejection could be traced in one participant's comment:

> '…how can we make people out there accept and understand us?' [*Mental health user*]

Hence, communities in Zambia would need to be introduced to, the concept of equal recognition before the law and the challenges posed by denying persons with psychosocial disabilities their right to legal capacity. Through the research communities get an opportunity to truly understand and appreciate the concept of legal capacity as a communal problem that deserves their concern. It is possible that they might realise that stigma of mental illness for example is a barrier to exercise of legal capacity that they need to collectively address. An approach that looks at the consequences of stigma on for example healthcare services in the broader sense and not just for persons with psychosocial disabilities might actually resonate with the needs of the community.

> '… in Africa or in Zambia in particular when they identify that somebody is sick, or they have physical disability or mental disability such persons are discarded… let's try to ensure that family consolidation is made. It's not their [mental health users] choice and this mental illness can affect anyone. So when we are doing awareness we should talk about how anyone can be affected.' [*Assistant Commissioner of Police in charge of Community Service*]

Attaching the general human rights approach on access to healthcare, an issue that affects and resonates with the general community members, and combining those with the challenges faced by persons with psychosocial disabilities is likely to attract consensus for need for communal action. Simply because access to healthcare services and the dearth of funding and services provided by government is problematic for many and not just persons with psychosocial disabilities. Ensuring appropriate, rights respecting and timely treatment for persons with mental health problems will make sense to community members when they fully appreciate the consequences of not having early access to services and treatment by persons with psychosocial disabilities.

Essentially without access to early treatment and support mental health deteriorates and this can at times lead to an escalation of a mental health crisis where situations can get out of the control of the individual and may in some cases, lead to harm to self or to others.

> 'We need people to accept us where we are with our condition, because sometimes we hide our condition and we just bring out the best of us.' [*Mental health user*]

At times poor mental health may even lead to criminal activity in the absence of access to appropriate care and treatment among other challenges. Obviously poor mental health negatively impacts a large array of social and civic life that indirectly places an unnecessary burden on families and the community, and yet this could be avoided with access to appropriate healthcare and other supports.

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Furthermore, it has been established that the lack of community based supports, social networks and naturally occurring community supports in Zambia impact the right to free and informed consent to health and perpetuate psychiatric confinement and arbitrary detention. Through social mobilisation activities that encourage reflection on the prevailing beliefs and value systems that propel stigma, communities in Zambia would also begin to understand the scientific causes of mental illness. That mental illness is a health condition that can be managed or treated.

> '…stigma is there because even with here at Chainama they think that only those who eat from the garbage and whatever are affected [yet] people from higher learning institutions of learning, from intelligence, name it, there is no one who is immune to loss of mental thought everybody is vulnerable. You can laugh at your friend today but even you tomorrow might find yourself you are here.' – [*Mental health user coping with the illness since 1979*]

3.3.2. Organising the community

There is no verifiable data to ascertain the precise number of people with psychosocial disabilities in Zambia, and as highlighted by MDAC this seriously hampers the development of services for people with psychosocial disabilities in the country.[142] Nevertheless, with a clear issue to address, the Tostan model demonstrates the need to engage different organisations, community leaders and the community members on action to be taken. In this model Tostan's target communities generally contribute a great deal to programme introduction and implementation, but other stakeholders that reside beyond the boundaries of the community itself proved important to involve.[143] Reaching out to organisations and key players that are outside of the obvious stakeholders is necessary and can include groups such as traditional healers, religious leaders, businesses, policy makers, media personalities and others. These groups have significant influence in the communities even though they might seem far from or unconnected to the problem or challenges. Ultimately the idea is to engage stakeholders who are most likely to support the cause including other human rights and community based civil society organisations.[144] It was clear from the focus group discussions with state officers/service providers that there was a willingness or a sense of preparedness to learn and act towards advancing exercise of legal capacity for persons with psychosocial disabilities. Even the self-proclaimed community activist who, at the beginning of the focus groups discussions, declared '*I would not even say yes [legal capacity] is a right to the disabled*' and had seemed adamant that there was no way legal capacity could be guaranteed to all persons with psychosocial disabilities without taking into account their mental capacity had changed her mind. She lamented:

> 'It's unfortunate that this area has been given less attention but if all players could be enlightened for the sake of this person whose rights we are trying to preserve.' [*Community activist and mental health trainer*]

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[142] MDAC and MHUNZA Human rights and mental health in Zambia (n 18 above) 18

[143] A leader in one of the communities that Tostan worked in Senegal explained that as part of a community of 10 villages it was importance to convince other villages to accept the principle of abandoning circumcision in order to avoid marginalization. If they were to abandon FGM/C as a single village out of the 10 they would have faced rejection and marginalized amongst the other villages.

[144] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)

This proves there exists opportunities to enlighten the communities. With appropriate knowledge and educational information it is worthwhile to engage specific groups within the community such as the youth, women, parents, educators, healthcare providers, traditional healers, social service providers, legal aid service providers and justice system agencies.[145]
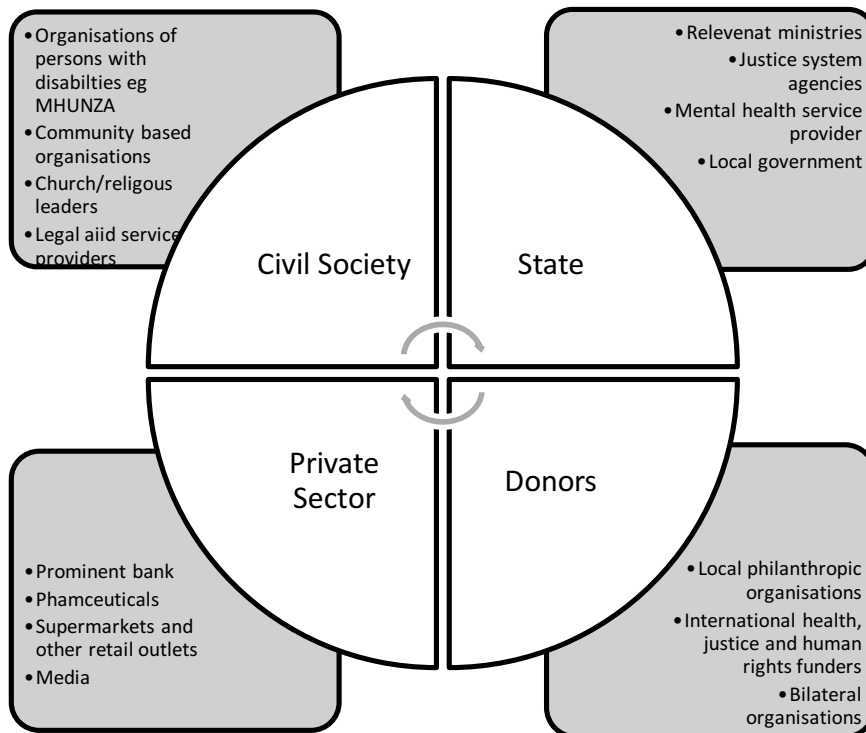

Figure 4: Potential stakeholder participants in Zambia on legal capacity (own design)

When organising the community sensitivity to cultural norms and values is of utmost importance for the success of the programmes. In the FGDs with service providers one discussant expressed:

> 'For me I think I'm just looking at how we need to strengthen the community service providers to these people. The community if there is good support then it becomes very easy to help these people. So if those things are not strengthened we will talk about *this legal what, this legal what*, but at the end of the day we are not helping much. [*Counsellor Drug Enforcement Commission in charge of education and awareness and a trained clinical officer*]

In this regard, Tostan programmes and campaigns are sensitive to local norms and traditions. They are neither harsh judgmental messages nor are they presented as impositions from the outside. Campaigns that are contrary to this ideal fail to obtain substantial social change and have been proved to be counterproductive and in some cases have even stimulated resistance to change.[146] For example a campaign launched by the Church of Scotland to eradicate FGM/C in Kenya back in 1929 failed dismally with a large number of Kenyans leaving the church. This was due to the church's message being viewed by nationalist politicians as a colonial attack on traditional customs. In retaliation they

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[145] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)
[146] R Blair, P L Murray & S Foster-Cox 'Female circumcision: Alternative rites and advocating for change' (2013) 17 *American Association of Behavioural Social Sciences Journal* 42

campaigned for a rebellion against the church's call. Consequently as a show of cultural preservation and civil disobedience the practice reportedly became even more entrenched.[147]

Hence, reaching out to wider social networks is an inevitable part of social mobilisation as the Tostan communities later realised. Without the wider intercommunity consensus, the initial Tostan communities realised how impossible it would be to abandon a centuries old practice such as FGM/C.[148] Thus, the social mobilisation process of public declarations to abandon FGM/C involved neighbouring communities that had not been a part of the Tostan Programme. Nonetheless it does mark the beginning of steps towards abandoning FGM/C for the peripheral community.

Establish formal structures

As mentioned earlier in this chapter, a social mobilisation strategy brings together a range of players and generates dialogue, negotiation and consensus. Hence effectively organising the community will require establishment of a strong and clear steering and management structure. Such a structure will assist in bringing together multiple and practical inter-sectoral allies and stakeholders in a useful and effective manner. In essence a structure that infuses and manages the complex interactions between the various players of which a basic structure could look like that depicted in Figure 5 below.
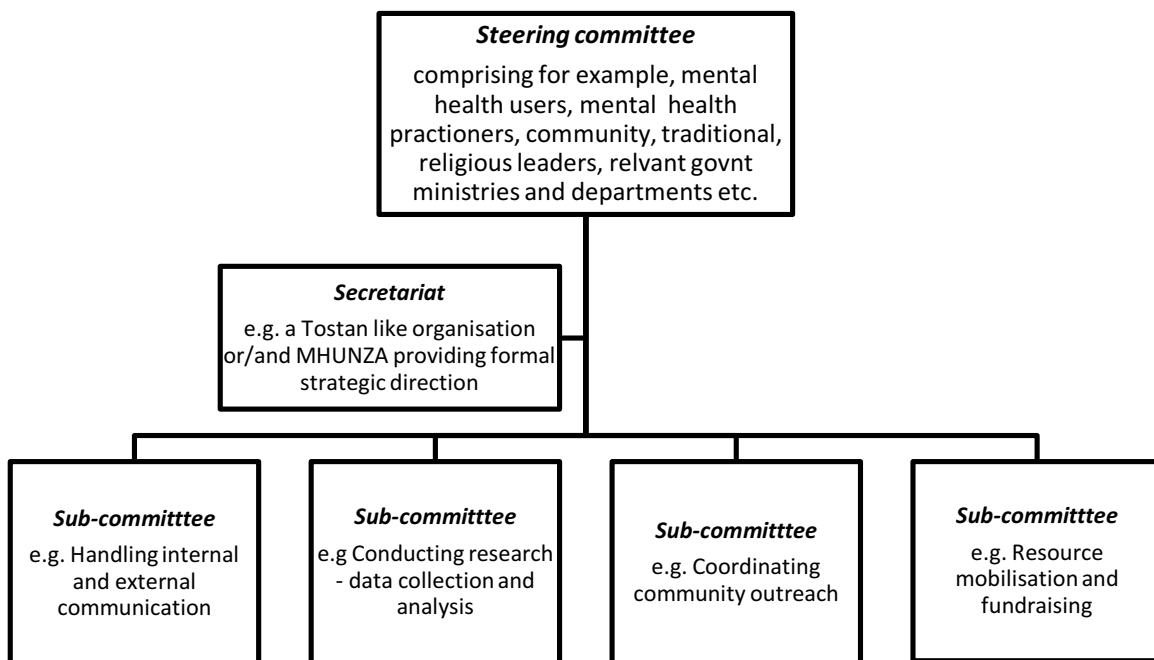

Steering committee
comprising for example, mental health users, mental health practioners, community, traditional, religious leaders, relvant govnt ministries and departments etc.

Secretariat
e.g. a Tostan like organisation or/and MHUNZA providing formal strategic direction

Sub-committtee
e.g. Handling internal and external communication

Sub-committtee
e.g Conducting research - data collection and analysis

Sub-committtee
e.g. Coordinating community outreach

Sub-committtee
e.g. Resource mobilisation and fundraising

Figure 5: Example of a basic formal mobilisation structure (own design)

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[147] The same is true for a similarly documented campaign in Sudan in the 1940s. See The *New York Times Magazine* 'The art of social change' (n 112 above)
[148] Evaluation of the long-term impact of the TOSTAN programme (n 162 above)

Key coordination structures or mechanisms may include specific committees such as those depicted in figure 5 above. These include steering committees that can providing formal strategic direction; sub committees can be responsible for managing data collection and analysis, mobilising funding, managing data collection and analysis, or coordinating community outreach; organisational charts; codified rules of operation (such as by laws) policy statements adopted by the partnership; formal letters of agreement for those who lead organise; and participate in the community wide effort. [149]

The basic formal structure depicted in Figure 4 above will be fleshed further with specific functions in the following discussions given its significance in the mobilisation strategy. However, the basic principles of effective execution of any plan requires that there be a basic structure organisational structure.
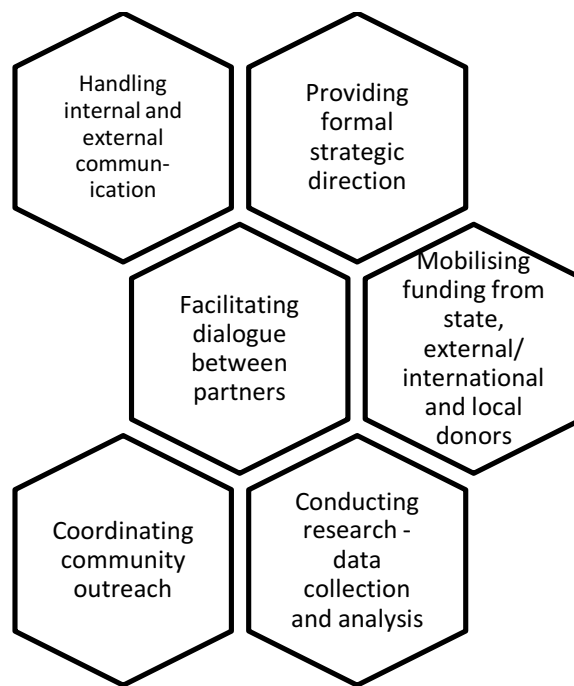

Figure 6: Key functions (non-exhaustive) of a formal structure of mobilisation strategy (own design)

A basic formal structure includes a number of key functions such as those illustrated in Figure 6 above and incorporated as examples in Figure 5, within the mobilisation strategy. Naturally the functionality and effectiveness of the structure requires a strong leadership of the programme that includes both individuals of the community who take on the work as well as organisations that spearhead collaborative efforts within the sub committees. To ensure a fully localised approach as far as possible, Tostan facilitators are selected from the same ethnic group as the communities. In this way Tostan was able to engage communities in the local language which facilitated the establishment and development of rapport between the participants and the facilitators who had a clear understanding of the needs of the community.[150] What was clearly missing in the focus groups discussions in Zambia

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[149] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)
[150] Blair, Murray & Foster-Cox (n 147 above) 46

was the full and common understanding of certain terms and concepts, including and especially legal capacity, its exercise and its relevance in the Zambian languages, norms and practices.

Thus, the lead organisations in the mobilisation cycle and its processes and initiatives should possess a number of key characteristics including the will to serve as the leader of the community mobilisation effort over a protracted period of time. In Zambia, such an organisation could be for example MHUNZA as an established representative organisation of people with psychosocial disabilities with the support of an organisation such as Tostan. If MHUNZA is the right organisation, it would be required to have financial stability, capacity to provide both infrastructure and human resources as well as the respect and support of the community. Hence it is critical that the individuals and organisations that are in leadership positions of the programme or campaign have adequate support and resources.

Tostan initiated through respectful dialogue the creation of the workspaces known as the classroom.[151] The classroom could at times be a mere set up under a tree, or a straw hut in relatively good condition able to protect participants against inclement weather. The classroom was created through a participatory process involving various parties. Decision making in the communities Tostan worked was generally shared, but often according to a certain hierarchy. For example the village chief not only authorised the creation of the classroom, but also had sole decision-making power over its location.[152] Thus it is important to identify critical decision maker in the community setup and secure support of the leadership as they can support the driving of the community wide efforts. Once the classroom is established Tostan thereafter provides the educational material and facilitates (not lead) the coordination of community wide efforts. [153]

3.3.3. Explore the issues and set priorities

Best practices show that a solid understanding of the current state of the issues in the community is important and so is conducting an environmental scan and community mapping process. [154] In this regard Tostan's curricula is informed and carefully selected by the communities themselves. This ensures communities prioritise the issues that are most important to them. The Tostan model as already mentioned earlier in the chapter communities to conduct their own research around the identified issues.

This provides an interactive and participatory mode of raising community awareness while at the same time finding common cause or clarifying a common problem on an issue they all felt was important to them.[155] A Senegalese example in this respect is that of women's health and sexuality which generated intense interest among the women participants of the Tostan programme and not FGM/C per se. The net effect of such an approach is that when community members identify with their common problem/cause they easily take ownership of the problem and become more willing to take ownership of the development of solutions.[156]

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[151] Evaluation of the long-term impact of the TOSTAN programme (n 162 above) 8
[152] Evaluation of the long-term impact of the TOSTAN programme (n 162 above) 9
[153] Evaluation of the long-term impact of the TOSTAN programme (n 162 above) 8
[154] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)
[155] Blair, Murray & Foster-Cox (n 147 above) 48
[156] Blair, Murray & Foster-Cox (n 147 above) 48

In the Tostan case engaging participants in imagining and discussing their future aspirations at the beginning of the programme allows community members to express their own understanding of their indigenous conceptions of human rights and discover connections to more general formulations of human rights.[157]

Set priorities

Setting priorities is important for defining campaign objectives. For example, if tackling stigma of mental illness is the priority of the campaign. It becomes necessary to breakdown this issue to the root cause and start to build an understanding of the issue at hand, among the community members.

3.3.4. Collaborative planning and implementation

The success of the Tostan programme is partly due to the participatory and locally inspired curricula as well as the manner in which the programmes are introduced to the communities. While key success factors of the Tostan model can be identified at the introductory phases of the programme, it is clear that the community itself plays a major role in introducing and implementing the programme, and participates fully in the activities. This way once the process of negotiation is complete, the level of programme acceptance is elevated.

However, the participatory and locally inspired part of this process will first of all have to find ways of overcoming the stigma that exists in the communities:

> '…the area we live in, in as far as interaction is concerned with the community there is still stigma, stigma is still around still here.' [*Mental health user*]

Because of this, the process of negotiations requires (as already suggested earlier in the chapter) sensitive, educative and non-aggressive approaches. In Zambia for instance as is the case globally, mental health practitioners are usually the fiercest opponents of the concept of exercise of full legal capacity of persons with psychosocial disabilities, due to the compromised mental capacity they experience from time to time. Thus these will have to be approached and engaged as primary target together with traditional and religious healers, with a great deal of tact, non-aggressive or even legalistic approaches. Doing so effectively will ensure a buy in from the key community members and it is thereafter possible to solicit a similar effort or gesture from the Zambian communities, such as that made by community members in Senegal, of providing resources such as classrooms and accommodation for facilitators, even though they were very poor. By involving a broad spectrum of community members early on and throughout the campaign, the community members become even more committed to finding viable and locally developed solutions.[158]

Success in the Tostan concept could also be partly attributable to its pedagogical approach and curricula that effectively integrates local traditions, West African proverbs, songs, stories, plays, and

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[157] Gillespie & Melching (n 124 above) 15
[158] Tostan's strategy of requiring the village to contribute resources more or less constitutes a pledge of ownership. See Blair, Murray & Foster-Cox (n 147 above) 49

dances gathered by travelling from village to village listening and recording the oral tradition.[159] It is also very possible to similarly gather information and identify the most viable and socially appealing local traditions that will be effective in drawing the interest and attention of the Zambian communities.

The above is the reason why it is important to keep in mind the following for successful planning and implementation:

a. *Strategic Planning Framework*

The importance of a strategic plan that lays out the explicit ways that the community partners are going to address the issues/barriers identified and the objectives and activities that will be carried out in pursuit of the goals is of utmost importance.[160]

When brainstorming ideas of how to get various community members on board as part of the community mobilisation strategy one focus group discussant suggested numerous initiatives:

> '…go to the people at the churches, go to schools and we go to the clinics and antenatal clinics … we also meet the neighbourhood watch we ask them to just group people during say the health days…sensitising door to door for people on how much they understand mental illness and also how do they identify a person with mental illness…but then to broaden it up we are looking at players are the pastors aware? What about the poor police officers who are always the victim how much sensitisation has been done to victim support officers?' [*Community activist and mental health trainer*]

These are all good suggestions but are in themselves loaded and require detailed step by step plans of how they can be effectively and efficiently executed. A strategic plan should thus identify the social, structural and individual changes to be targeted, that will lead to advancement of the exercise of legal capacity. [161] The goals and objectives of the strategic plan should ordinarily be SMART (specific measurable, achievable, realistic and time-bound) as is the principle for development of goals and objective.

b. *Sufficient time allocation*

Given that changing long held cultural beliefs requires an investment of will, that can go for the long haul, when identifying issues or challenges it is important at the onset to ensure sufficient allocation of time for programme implementation. Tostan allocates on average 24-30 months for its programmes.[162] Insufficient allocation of time to the programme can be detrimental as it was in the FGM/C campaign in Kenya. Consequently, the campaign was not as effective as the Senegalese campaign. Consideration must also be made for commitment that goes beyond the programme

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[159] World Bank IK Notes 'Senegalese women remake their culture' (1998) 3
https://openknowledge.worldbank.org/bitstream/handle/10986/10835/multi_page.pdf?sequence=1&isAllowed=y accessed on 19 February 2016
[160] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)
[161] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)
[162] Blair, Murray & Foster-Cox (n 147 above) 46

implementation cycles. Molly Melching the founder of Tostan has remained committed to the cause in West Africa for over 30 years which partly explains why impact of Tostan is now very tangible.

c.   *Process outcomes (indicators) and evaluation*

It is important to be able to assess impact and this can be done by deciding in advance how the partnerships are going to define success. This helps set appropriate milestones and benchmarks that along the way can provide an indication of progress in a verifiable manner. Thus, it is advisable to design both process and outcome indicators and intervals at which they should be evaluated. Process evaluations will help determine for example how many community members participated in each activity and whether the activity was carried out as originally planned. Outcome evaluations of the other hand help assess whether the partnership resulted in expected changes in the community.

d.   *Create a fundraising strategy*

Explore a wide range of funding opportunities to ensure that the strategies and activities can continue beyond the life of the original lifecycle. [163] As mentioned earlier social change that requires dismantling long held belief and cultural practices is a long haul investment that can take decades to achieve. It is therefore imperative to consider diverse sources of funding including foundation grants, individual donors, in kind donations from organisations and businesses close to the communities. [164] Focus on local resources is also important as it is more sustainable than dependency on external funding.

e.   *Establish effective channels for internal communication*

Communication is key to keeping the wheels of any campaign turning and thus it is important to ensure a flow of information by adopting formal communication strategies that allow for frequent, deliberate and productive exchanges between partners. Depending on available resources a skilled communicator is the most ideal as this individual is responsible for continually informing members about what the partnership, the committees and even individual members are doing to advance the mission. [165]

3.3.5. Education, awareness campaign and public declarations

Community sensitisation and public education and awareness campaigns have been cited as primary approaches in addressing social and attitudinal barriers particularly those created by widespread stigma.[166] Article 8 of the CRPD mandates states parties to adopt measures to initiate and maintain awareness campaigns and human rights training to promote a greater understanding of the skills merits and abilities of persons with disabilities.[167]

The goal of public education campaigns thus, is to generate awareness, motivate action, encourage funding and keep the community focused on the issue at hand. [168] Education provides information so

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[163] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)

[164] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)

[165] Advocates for youth strategies guided by best practice for community mobilization (n 127 above)

[166] Kapungwe, Cooper, Mwanza et al (n 16 above) 198

[167] Drew, Funk, Tang et al (n 5 above) 1669

[168] P Byrne 'Stigma of mental illness and ways of diminishing it' (2000) 6 *Advances in Psychiatric Treatment* 67

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that the public can make more informed decisions about mental illness. Investigators who in the field have suggested that persons who evince a better understanding of mental illness are less likely to endorse stigma and discrimination.[169] Hence, the strategic provision of information about mental illness seems to lessen negative stereotypes. Several studies have shown that participation in education programs on mental illness led to improved attitudes about persons with these problems.[170]

Messages to the community must be strategically tailored to the community containing relevant data that is meaningful to the needs of the community. These should obviously be linked to the issues or challenges collectively identified by the community as priority issues for example one of those depicted in Figure 1 i.e. mental illness stigma or as those described in 3.3.1 and 3.3.3. Spokespersons for the campaign must be charismatic individuals who resonate with community. Kapungwe et al suggest that challenging mental illness stigma may need to go beyond providing correct information and education, at least amongst health care providers. It may entail providing a space for people to engage with and be open and honest about the fears separating those that are realistic from those that are irrational. Such professionals need to be made aware of and encouraged to take cognisance of their own attitudes and the ways in which they may produce and reproduce stigma.[171]

> 'The community care providers should be in a position to go sensitise the community the neighbourhood …giving knowledge to the community about this and educating people' [*Community activist and mental health trainer*]

That said, the ability to educate and inspire the community is another key success factor of the Tostan model and through interaction with the MHUNZA Executive Director and even the majority of focus group participants, identifying suitable individuals in Zambia in this regard appears a non-issue and can be easily done. Social mobilisations campaigns should be able to hold forums, engage local media, design public service announcements, create billboard campaigns drafting position papers and editorial letters, launching web based and social media campaigns or holding roundtables and conferences. Some of these are already in existence in Zambia through projects such as the ZAFOD and MHUNZA project[172] as well as the Paralegal Alliance Network (PAN) Zambia project.[173]

Another important factor in The Tostan campaigns was the involvement of men which expedited the abandonment of harmful practices such FGM/C. Without the support of religious leaders, husbands, fathers, and brothers efforts on the part of women and girls would have been limited.[174] In two neighbouring villages for instance in order to convince the villagers of the importance of a local decision to abolish FGM/C two men who had taken part in the Tostan programme (one a Tostan Facilitator and the other an elderly Imam) travelled form village to village to discuss the negative

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[169] P W Corrigan, A C Watson 'Understanding the impact of stigma on people with mental illness' (2002) 1 *World Psychiatry* 1617
[170] Corrigan & Watson (n 170 above) 1617
[171] Kapungwe, Cooper, Mwanza et al (n 16 above) 202
[172] The Zambia Federation of Disability Organisations (ZAFOD) and the Mental Health Users Network of Zambia (MHUNZA) are working on a project to advance the right to legal capacity for people with psychosocial and intellectual disabilities through a community development approach in three communities in Zambia.
[173] The Paralegal Alliance Network (PAN) is implementing a project on the interaction between disability rights and the criminal justice system (Challenging Disadvantage in Zambia) which seeks to enhance knowledge on the intersection between people with psychosocial and intellectual disabilities and the justice system and implement concrete steps to protect their rights.
[174] Gillespie & Melching (n 124 above) 18-19

effects of FGM/C with local people. Similar tactic must be employed in Zambia identifying and targeting the not so obvious but key champions of the campaigns who will amplify the voice and add weight to the campaigns of persons with psychosocial disabilities. Furthermore, as women in Senegal declared their intention to abandon FGM/C to journalists, they also discovered they were connected to a larger human rights movement both within their own country and across national borders and thus they felt less isolated and reached out to educate others and find out how they were solving their problems.[175]

3.4. Conclusion of Chapter 3

The denial of legal capacity for person with psychosocial disabilities Zambia implies they have to trek a journey to equal recognition before the law, riddled with social and attitudinal barriers. A journey their non-disabled counterparts do not have to make as they are already guaranteed legal agency and legal standing.

However, through the Tostan model, it transpires that social change even though slow, is nonetheless possible. The benefits of social mobilisation in general are many and what is clear is that they can fill the gap that law and legislation cannot always meet in advancing human rights. Such strategies require many levels of involvement, from individuals to community, to policy and including legislative action. It also implies working with key local sectors and community groups as well as with individuals and families in their local communities

Central to the success of the Tostan strategies is the ability to bring a community together to create local solutions to local problems. By allowing communities to define their own problems, set common goals and work together to achieve the goals, Tostan strategies inevitably changed the communities in a lasting way because the communities assumed ownership of the programmes. Securing such ownership in Zambia appears the primary challenge given the limited understanding of the concept of legal capacity for person with psychosocial disabilities and the existing stigma of mental illness. That said, even though social change takes time it is possible. What is of paramount importance to ensure that strategies to address the barriers and associated challenges involve and to where ever possible be led by the communities themselves. Careful attention must nonetheless always be paid to all processes in the mobilisation cycle of initiatives on a continuous basis.

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[175] Gillespie & Melching (n 124 above) 17

Chapter 4 – Conclusion and recommendations

4.1. Conclusion

The importance of law or a robust legal framework must never be underestimated. This study has made a case that it should however always take into account and be accompanied by other societal considerations and measures such as social mobilisation strategies. Other measures beyond the law must be explored in order to ensure exercise of the right to legal capacity of persons with disabilities on an equal basis with others. More so for the groups within the disability movement whose legal capacity is often denied particularly in the name their protection. However, all efforts must be mindful not to mistake this paradigm shift to imply lesser obligation to protect people with disabilities. The UN Committee on the Rights of Persons with Disabilities encourages protection of all human rights and of the individual through empowerment, recognition of decision-making and the provision of support. The societal barriers that emerged as being most problematic in Zambia - lack of state and community based supports and social networks; inadequate training of health and justice system officials; and stigma of mental illness and stereotypes - and these impede advancement of human and are usually resistant to legal strategies. As illustrated by the Tostan model, and given that social barriers stem from centuries old learned values and cultural practices, it follows that a multidisciplinary approach to human rights suggested by Freeman, wherein a combination of the study of law (in practice such as legal and policy reform strategies) and other disciplines such as social sciences (in practice for example transformative social mobilisation strategies) would be a more successful approach to confronting and addressing social barriers than would a sole discipline approach.[176]

Against the backdrop of a conducive legal framework which is a mere skeletal in the human right anatomy social mobilisation strategies provide the flesh that covers the bones and the blood that pumps the body into life. This is so because social mobilisation strategies have the ability to bring together various players and stakeholders to the field to address and bring about necessary societal changes. Without the necessary social shifts and changes in attitude of the various players in a given society, the rights enshrined in the CRPD such exercise of legal capacity will remain abstract, theoretic and unattainable.

A comprehensive programme that offers participants problem solving tools and deals with the crucial problems of the community should be supported and implemented in Zambian communities for the advancement of legal capacity. The Tostan models illustrates the utility and possibility of implementing well-studied and tested programmes on social mobilisation rather than developing new ones. Tostan has shown that individuals from villages with minimal resources can improve their lives and environment through a solid programme leading to greater autonomy and self-sufficiency. An evaluation of the programmes sanctioned by UNICEF registers the programmes viability and tangible impact on community life and individuals[177] as does a number of other evaluations conducted on the

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[176] Freeman (2006) (n 6 above) 46

[177] The impact of the Tostan Programme on both women's and men's wellbeing had been substantial. See Evaluation of the long-term impact of the TOSTAN programme (n 162 above) and Gillespie & Melching (n 124 above) 3

impact of Tostan programme.[178] Indeed, the results show that after delivery of the education programme numerous changes took place in the communities. The programme is said to have improved knowledge of rights and responsibilities among both participating and non-participating women, particularly with respects to the place and role of women in the community.[179]

Education campaigns such as those used by Tostan are viewed as a necessary precondition for social reform and they have been used widely to advance public understanding on mental health, reduce stigma and discrimination and for the promotion of human rights. The Tostan model successfully demonstrates this in West Africa amidst evidence provided by others that attest to the viability of social mobilisation campaigns in that they lead to improved public knowledge about mental health conditions, increased awareness of mental health services and effective treatment, knowledge about mental health and attitudes towards people with mental and psychosocial disabilities and increased demand for and use of community based mental health services.

Even though outside of the scope of this study alongside efforts towards addressing attitudinal barriers in the communities, states parties must provide mental health and other services in the community to improve both access and quality of services and promote independent living in society in accordance with article 19 and 25 of the CRPD.[180] This must however be supported by a broad set of services or programmes that enable people to attain and maintain maximum independence and full inclusion in society. These may include rehabilitation services, including vocational and life skills development but also in-home residential personal assistance and other community support services.

4.2. Recommendations

There are many potential recommendations however the following would be what I would like to highlight:

In trying to establish the significance of article 12 of the CRPD for persons with psychosocial disabilities in Zambia it became apparent through focus group discussions that there is a very limited understanding of the concept of legal capacity and how it is entwined with decision-making capability. The existing texts appear skewed to an understanding of legal capacity in the more westernised views and autonomy. In the African context, this may need further elaboration for a common consensus of the concept given the prevailing setup of family and community setup. It would therefore be important to delve deeper into how the legal capacity can be broken down in the local languages of the local communities for enhanced understanding of what really is legal capacity and its impact on individual autonomy.

To fully appreciate how community based social mobilisation strategies could advance exercise of legal capacity for persons with psychosocial disabilities in Zambia it would be prudent to develop and implement a pilot of the Tostan strategies in Zambia to advance exercise of the right to legal capacity.

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[178] Evaluation of the long-term impact of the TOSTAN programme (n 162 above) and Gillespie & Melching (n 124 above) 3
[179] Evaluation of the long-term impact of the TOSTAN programme (n 162 above)
[180] Drew, Funk, Tang et al (n 5 above) 1670

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