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Beyond the stigma: Exploring the role of mental health advocates with lived experience, in advocating for better mental health systems and awareness in Nepal.

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Abstract

"There is growing recognition within the international [development] community that invisible disabilities, such as mental health is one of the most neglected yet essential development issues in achieving internationally agreed development goals" (The United Nations, n.d., para. 4). Yet with little expenditure in the Global South on public health, let alone mental health, and lack of awareness and difficulty in accessing treatment, non-governmental organisations (NGOs) are increasingly filling the gap in service provision.

The aim of this research is to explore the role and impact of one NGO Koshish and its employees, who are mental health advocates with lived experience, in advocating for better mental health systems and greater awareness of mental health in Nepal. In order to address the aim, there are two research questions which ask 1) How are mental health advocates with lived experience involved in advocacy for mental health in Nepal through local NGO Koshish? And 2) To what extent does active participation of former beneficiaries in advocacy lead to increased awareness and access to mental health services in Nepal?

This qualitative research project draws on the case study of Koshish, a mental health advocacy NGO, and its employees who have lived experience of mental illness. This project involved collecting both primary data and analysing secondary sources. As such, data was gathered through semi-structured interviews with key informants and via a thematic analysis of various policy, strategic and operational documents, such as the unimplemented Nepal Mental Health Act and Koshish's NGO website. The theoretical lens of an asset-based community development (ABCD) approach was then applied to this research to understand how harnessing existing assets and working in the field of advocacy can have a positive impact on government policy and awareness. This furthers our understanding as to how an ABCD approach can be applied in a broader context to other organisations working in advocacy in the hope of creating change for areas lacking government support and awareness.

In terms of key findings, stigma is one of the primary prohibiting factors to accessing treatment for mental illness in Nepal. However, those with lived experience of mental illness involved in advocacy are having a positive effect on increasing mental health awareness and the importance of treatment through using their existing assets such as their voices and stories. Despite some gains, barriers are still being faced due to the lack of mental health workers, lack of awareness (largely due to stigma), and no existing mental health act. Overall, the work of Koshish Nepal in the advocacy space has seen some positive changes occurring in Nepal's mental health sector.

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This project was inspired during my first ever visit to Nepal in 2013 where I discovered the plight of those living with mental illness in Nepal. Here I am 8 years later writing on this topic and am grateful to everyone who has supported me on this journey.

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"To prevent suicide, let's listen to others and tell our own to others"

- Matrika Devkota (founder of Koshish, 2020)

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Abbreviations

ABCD Asset-based community development

CPN-M Communist Party of Nepal Maoist

IMC International Medical Corps

NGO Non-governmental organisation

OHCR Office of the United Nations High Commissioner for Human Rights

PTSD Post-traumatic stress disorder

SATP South Asia Terrorism Portal

UN The United Nations

UNCRPD Convention on the Rights of Persons with Disabilities

UNDP The United Nations Development Programme

WHO The World Health Organization

Chapter one: Introduction

1.1 Introduction

Mental health in developing counties is under-resourced and over-burdened (Balon et al., 2016; Tol et al., 2010). Improving awareness of mental illness is a global challenge and forms a key aspect of Nepal's mental health policy, which has not yet been implemented (Arun and Adhikari, 2009). In the context of Nepal, less than 1% of health care expenditures by the government are directed towards mental health (Arun and Adhikari, 2009) and there is widespread stigma regarding mental health issues. The small amount of research on mental health in Nepal outlines the lack of services and funding for the sector, alongside the fact there are huge gaps in the understanding of Indigenous healing and illness concepts (Chase, Sapkota, Crafa and Kirmayer, 2018). Additionally, there is recognised need for research driven by local stakeholders with a focus on their needs and interests, especially that which draws on the expertise of people with the lived experience of mental illness and traditional healers (Chase et al., 2018). Research looking at the state of mental health in Nepal must recognise the context of the country, meaning the issue cannot be looked at from simply a westernised point of view. Thus, this research seeks to enquire further into this topic from the view of local people, primarily those with lived experience of mental illness.

My interest in this topic goes back to 2013 when I visited Nepal for the first time and had documented in my travel diary "I found an article in today's newspaper in Kathmandu (see Figure 1: Newspaper article from 2013) about the lack of care for mental health in Nepal. People turn a blind eye. Local or international intervention programmes to address these issues barely exist."

Mentally ill man confined at home for 18 years

DIPENDRA SHAKYA / SANKHUWASABHA, OCT 5

AGAM Gurung of Madimulkharka VDC-8 in the district, who is suffering from a mental illness has been confined in his house for the past 18 years for want of treatment.
His family members said they were forced to tie him in a hut beside the house after he started running amok. "He hurls whatever he gets at us and villagers when he is free from the confinement," Agam's father Lekhmani said.
He said that Agam, who crawls on the ground and is hearing impaired started suffering from the disease when he was just two. Agam's mother Tara said that they tie him all day long and take him inside the house at night. She said that Agam cannot eat rice himself.
She said they took him to witch doctors but to no avail. "I feel sad at such condition of my son. We cannot treat him due to abject poverty," she said.
The family hopes that Agam can be treated if he is taken to hospital. He is yet to get citizenship certificate and thus deprived of the allowance given to the disabled people. Tara said it is difficult to take him to the government office for the card and that she urged the officials concerned to help Agam get the card.
Ganesh Rai, secretary of the District Disabled Association, said the state should provide services to disabled and mentally ill people.

Figure 1: Newspaper article from 2013. Source: Author.

I will never forget the accompanying image displayed in the newspaper article from 2013: a man locked in a cage with long matted hair, which demonstrated the extreme marginalisation and maltreatment of people with mental illness due to stigma, discrimination and few services. Since then, it has remained an interest of mine and pushed me onto the path that has led me to where I am today. Hence, this research will seek to further understand the context of mental health in Nepal, and look at the impact that those with lived experience of mental illness have on raising awareness and policy development and implementation through their advocacy work.

1.2 Research aim and questions

In order to keep with the core values important to this research such as inclusion, and prioritising the voices of those who are the most impacted, as mentioned this project looks to understand the lived experience perspective. This research will include a case study approach on a local NGO Koshish and how they are tackling discrimination, stigma, marginalisation and the lack of available, appropriate and accessible mental health services in Nepal. This research will be guided by the following aim and two research questions:

> **Aim:** To explore the role of mental health advocates with lived experience in advocating for better mental health systems and greater awareness of mental health in Nepal through an NGO, and its effectiveness.

Research Q.1: How are mental health advocates with lived experience involved in advocacy for mental health in Nepal through local NGO Koshish?

Research Q.2: To what extent does active participation of former beneficiaries in advocacy lead to increased awareness and access to mental health services in Nepal?

The work of NGO Koshish Nepal will be considered in relation to the ABCD theoretical lens. As will be explained in chapter 2, this lens marries well due to the grassroots nature of Koshish and the fact they are utilising their own assets and strengths as a collective (as opposed to needs-based top-down development approaches), which in turn empowers the collective to work together on advocacy and raising awareness to reduce stigma and increase access to mental health services in Nepal. [1]

1.3 Nepal overview

Nepal is a landlocked country in South Asia, located between India and China and sitting along the Southern slope of the Himalayas (see Figure 2: Map of Nepal). In 2008 after a decade long period of violence and turbulence due to the Maoist insurgency, the monarchy was abolished, and Nepal was declared a democratic republic (Proud, Zuberi, Karan and Rose, 2020).

Figure 2: Map of Nepal. Source: Karan, P., Proud, R., Zuberi, M and R., Leo E. (2021).

[1] The term mental health is used broadly and will be used interchangeably with mental illness, mental ill health and wellbeing.

Nepal is one of the 48 least developed countries in the world, aiming to graduate to a developing country by 2022 (United Nations Development Programme (UNDP), n.d). In 2018, the UNDP Human Development Report listed the population of Nepal at 28.1 million people, with the birth registration (% under age 5) sitting at 56%. Among the population of Nepal, 19.7% live in urban areas and the remainder of the country live rurally. This has led to a high rate of employment in agriculture (% of total employment), which sits at 70.1%. The population living below the national poverty line is 25.2% and the population in multidimensional poverty is at 34% (UNDP, n.d). In looking at mental health, and suicide rates in Nepal, the suicide rate among the male population was at 9.7 per 100,000 people and among the female population was 7.9 per 100,000 people (WHO, 2016). Looking at the same statistics for New Zealand in 2016, the rate for male suicide was 17.9 and for female suicide was 6.6 per 100,000 people (WHO, 2016). Although the suicide rate appears higher for men and fewer for women in New Zealand, suicide often goes under-reported in Nepal, which will be discussed in the literature review, this could lead to incorrect statistics and reporting. Contributing factors to mental health issues in Nepal include the Maoist insurgency and the 2015 earthquake, which saw many people displaced and lives lost.

1.3.1 Nepal earthquake

Alongside being a low-income country, Nepal is also prone to natural disasters, ranking 11th worldwide for earthquake risks (Dhital, Shibanuma, Miyaguchi, Kiriya and Jimba, 2019). In April 2015, Nepal experienced a major 7.8 magnitude earthquake followed by many aftershocks. Over 8000 people were killed, and more than 6,000 severely injured, with damage to over 400,000 homes and 16,000 schools (Dhital et al., 2019). The earthquake had negative effects on both physical and psychological health, with conditions such as depression, anxiety and post-traumatic stress disorder (PTSD) emerging as a result (Jan, Ko and Kim, 2018). In the aftermath of earthquakes, PTSD is commonly identified as the most apparent mental health disorder, with symptoms lasting for many years if left untreated. This in combination with the shortage of health professionals, especially mental health professionals, in low and middle-income countries exacerbates issues such as this (Dhital et al., 2019).

1.3.2 Nepal Maoist Insurgency

For a decade between 1996 and 2006, there was ongoing fighting between the Government of Nepal and the Communist Party of Nepal (Maoist party) which saw an armed conflict that

affected the whole country with both sides committing human rights violations and abuse, and seeing killings occurring in 73 out of 75 of Nepal's districts (United Nations Human Rights Office of the High Commissioner (OHCHR), 2012). The conflict began on the 4th February 1996, when the Maoist party requested a range of social, economic and political agendas via a 40-point demand to the government and warned of an uprising if the requests were not met. One week later, demands were not met and an armed insurgency was launched against the Government of Nepal (OHCR, 2020).

Economic and political factors drove the insurgency, with contributing factors such as ethnic tensions, poverty and grievances of the marginalised (Acharya, 2009). This conflict has its roots in Nepal's social hierarchies and caste system that have traditionally shaped the country's political, social and economic life. Moreover, the Communist Party of Nepal Maoist (CPN-M) had strong dissatisfaction with gender and caste inequality, and low-quality governance (Luitel et al., 2015). It was a common view that the economy in Nepal favoured the rich, with economic and political power being centralised, and a low representation of those living rurally, despite the fact that the majority of Nepal's population lives in rural areas (Tol et al., 2010). The 40-point demand to the government outlined the concern with Nepal's increasing rate of poverty, soaring rate of unemployment and a widening gap between the rich and the poor, and towns and villages. The demand also expressed anger at the lack of interest from the government toward the welfare of the country and it's people, rather their interest lay in foreign imperialists (South Asia Terrorism Portal (SATP), 1996).

When the newly named Communist Party of Nepal (Maoist) began to rise in 1995, also named the 'Peoples War' this saw a surge in recruitments of the poor who were seen as ideal candidates for their communist ideal (Journeyman Pictures, 2008). Officially, the war ended in November 2006 with a peace agreement between the Maoists and the political parties, and in 2008 assembly elections were held with the intent to draft a new constitution within two years. However, after four years, no constitution had been written and consequently the constituent assembly was dissolved in 2012. After a year of political deadlock, a new interim government was formed which successfully completed the election of a second constituent assembly in November 2013 and power was handed over to the newly elected representatives (Luitel et al., 2015). This period has been termed as the Nepalese civil war (Bownas, 2015) and has resulted in an increase in

mental disorders reported for those affected by the Maoist insurgency (Tol et al., 2010). It has also resulted in serious implications for Nepal's health care system (Luitel et al., 2015). For example, access to health care was reduced greatly during this period as health professionals were warned to not provide treatment to any suspected Maoists, and those physicians who did not report suspects faced imprisonment. Additionally, medicines were stolen from pharmacies and suppliers, and numerous health care infrastructures were destroyed by bombings (Tol et al., 2010).

With these factors that have impacted Nepal's mental health care system, services are few, and what is available is of poor quality. With a lack of funding and government support in this area, NGOs such as Koshish have had to step up to fill the gaps in service provision as well as raising awareness about mental illness.

1.4 Introducing Koshish Nepal

Koshish Nepal is an NGO based in Nepal's capital Kathmandu working to provide mental health and psychosocial support (Koshish Nepal, 2020). Koshish was founded by Matrika Devkota, following his experience with psychosis, and since then has developed into an organisation that's based on a model of community-based rehabilitation programmes, including transition homes for those with mental illnesses, as well as advocacy programmes to influence society and policy and to raise awareness. The word Koshish means, "making an effort" (Koshish, 2020, para. 1) and since 2008 Koshish has been advocating for the inclusion and dignity of persons with, and who are at risk of, mental illness. Their mission states: "Koshish seeks to ensure [a] dignified life for people with psychosocial issues through improving and implementing policies and legislation and expanding community-based mental health and psychosocial support" (Koshish, 2020, para. 4), Koshish have a vision that that there should be good mental health and psychosocial wellbeing for all.

As listed on a banner on their organisation website,

> Koshish advocacy programs are focused on encouraging right holders, communities and lawmakers to take steps for review, adaptation and implementation of laws, policies, and programs that protect and promote human rights of persons with and who are at risk of mental

health and psychosocial disabilities through increased awareness and advocacy (Koshish, 2020, para.1).

1.5 What constitutes mental health advocates with lived experience?

The Oxford definition of lived experience is "personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people" (Oxford reference, n.d). The Mental Health Coalition of South Australia (n.d.) has an NGO lived experience workforce programme, which defines lived experience as "a person who is employed in a role that requires them to identify as being, or having been a mental health consumer or carer" (para. 1). For the purpose of answering the outlined research questions, the focus will be on members of NGO Koshish Nepal who have the previous experience of living with a mental illness who are now well and working with Koshish. The definition of wellness will be guided by Koshish, as once someone is recovered (gone through their residential support programme), they rehabilitate that person back into the community and some have since joined Koshish as members of staff. The residential support programme that Koshish runs provides specialised care including psychiatric treatment, psychosocial counseling, nursing care, medication, as well as food and accommodation. Various recreational and therapeutic activities are also offered. Following on from this, they are then reintegrated back into their community once deemed fit to do so.

1.6 Overview of this report

Chapter one has introduced this research, outlining the research issue, as well as my personal interest in this topic. The research aim and questions were outlined, followed by a brief overview of Nepal and two major events that have influenced mental wellbeing in Nepal. The NGO Koshish Nepal was introduced as the case study for this research and will be further discussed in the following chapters.

Chapter two presents a review of the literature to locate this research, discussing mental health in developing countries, narrowing down to focus on Nepal. The barriers to mental health treatment in Nepal such as stigma and discrimination, and the lack of awareness regarding what mental illness actually is (often being associated with evil spirits, with traditional healers being sought) is discussed. It is here that the theoretical framework of this research, the ABCD approach, is explained.

Chapter three outlines the role of non-governmental organisations (NGOs) and moves on to discuss their involvement in advocacy programmes, why these exist, and provides examples of successes of NGOs working in the realm of advocacy. It also provides ways in which NGOs intersect with the ABCD approach, and the correlations between these two.

Chapter four is where I move onto present methodology and methods of this research. This chapter begins with my chosen methodology and methods for this research, outlines ethical considerations, as well as my data collection and data analysis stages. This chapter also discusses the challenges and limitations due to covid-19, which meant I was unable to do planned fieldwork and had to revise my approach to data collection multiple times.

Chapter five presents the findings of my research in seeking to answer my two research questions. The key themes identified in the interviews and documents will be discussed.

Chapter six looks to discuss the key findings in relation to the ABCD framework and the aim of the research. Concluding remarks are offered.

Chapter two: The landscape of mental health and the ACBD framework to development

2.1 Introduction

This chapter will define global mental health as well as focusing in on the current landscape of mental health in Nepal. Mental health in Nepal is greatly over looked and underserviced, and one of the primary factors hindering access to mental health services and awareness about mental illness is stigma. People who are mentally unwell are stigmatised due to religious and cultural beliefs as to the cause of mental illness. This sees families or individuals with mental illness more likely to seek help from traditional healers as opposed to those within the formal health systems. A key to improving access to treatment of mental health conditions is through increasing awareness of mental illness and continued advocacy in order to improve availability of services alongside access to services.

2.2 Defining mental health – global perspective

Mental ill health is a global issue and one that has greater implications for the most vulnerable in society, often due to lack of awareness and difficulty in accessing treatment, as well as being associated with creating marginalisation, poverty and social disadvantage (Chisholm et al., 2007). WHO (2019) found that globally, one in four people will suffer from poor mental health in their lifetime, and that mental disorders are one of the leading causes of poor health and disability globally. In 2016, the World Bank and The World Health Organization held a meeting titled 'Out of the shadows' aimed at shifting mental health from the "margins to the mainstream of the global development agenda" (The World Bank, 2016, para. 2). The justification was that depression was found to affect 350 million people globally, and mental health issues have a huge impact on the disease burden among societies worldwide. Despite the prevalence of mental disorders, mental illness often remains in the shadows due to factors such as prejudice, stigma and fear (The World Bank, 2016). Addressing this issue is becoming increasingly urgent in today's societal landscape with increased conflict and forced migration occurring in many countries, which has implications for people's mental wellbeing (The World Bank, 2016).

The Sustainable Development Goals call for no one to be left behind (The United Nations, 2018), yet those with mental health conditions are often excluded as a group in terms of the

development agenda, and must be reached. The most important priority for global health is argued to be the scaling up of mental health services, as the services available are not sufficient for the number of individuals requiring treatment (Chisholm, et al., 2007). Given that 30% of the population faces some form of mental illness every year, and less than a third of these people receive treatment, even in countries better resourced. It is clear that mental health services and peoples access to these will need to increase, this is significantly so in low and middle-income countries who have a huge deficit in services for their population (Chisholm et al., 2007; Markkula et al., 2019).

The highest suicide mortality rates for women are seen in the South-East Asia region (The World Health Organization, 2019), with the levels of anxiety and depression within the South Asia region being reported as some of the highest globally, labeling it one of the "hidden tragedies in South Asia" (Patel et al., 2007, p. 217). Literature also suggests there cannot be a homogenous approach to mental health, as research and data from Western studies on the issue may not be suitably applicable to the South Asian context (Patel et al., 2007). This comes down to factors such as cultural beliefs, whereby socio-economic and regional factors such as the such as spiritual traditions present in Nepal (particularly in rural areas with less access to services), as well the importance of soul, heart–mind, brain– mind, body, and its connection to social status (Chase et al., 2018). Due to such factors, the NGO sector plays a key role in mental health care as their roots are often "firmly entrenched in the community" (Patel and Thara, 2003, p. 1) and so they understand best experiences of the community. NGOs play an important role in strengthening civil society (Mathie and Cunningham, 2005) as they are better placed within the communities and understand their needs.

2.3 Mental health in Nepal – Current landscape

Data reflecting the prevalence rate of mental illness in Nepal demonstrates that around 20% of the population has experienced mental illness (Nepal Public Health Update, 2017). However, mental health in Nepal is under reported due to stigma (Kohrt and Harper, 2008), meaning there will be a greater number than what is currently reported. While stigma might be one reason that results are under reported, other factors could include lack of capacity to diagnose and to capture such data (Arun and Adhikari, 2009; Luitel et al., 2015; Petersen et al., 2017). When discussing the challenges of strengthening mental health system governance in six low- and middle-income

countries, which included Nepal, Petersen et al. (2017) found that mental health information systems were overall poor across all the countries researched which has a negative effect on decision-making based on reliable data and the planning and monitoring of carrying out services. Mental health statistical information is not routinely collected in Nepal meaning that they have no real knowledge about the mental health situation. WHO (2018) outlined that non-communicable diseases (NCDs) (which mental health is encompassed within) are responsible for a large (and growing) number of deaths and disability globally. For example, a survey conducted in 2008/2009 by the Family Health Division of the Ministry of Health Nepal, identified that in women of reproductive age, suicide is reported as the leading cause of death.

In order to promote mental health in Nepal, a mental health policy was formulated in 1996 with the key components being:

1. To ensure the availability and accessibility of minimum mental health services for all the population of Nepal;
2. To prepare human resources in the area of mental health;
3. To protect the fundamental human rights of the mentally ill; and
4. To improve awareness about mental health (Nepal Ministry of Health, 1996).

However, this policy has not yet been implemented, and there is no Mental Health Act (Regmi, Sligl, Carter, Grut and Seear, 2002; Upadhaya et al., 2014). Therefore, continuing challenges to moving mental health forward or addressing mental health issues in Nepal is the fact the 1996 mental health policy is not yet implemented and there is absence of a Mental Health Act (despite multiple draft revisions) and the lack of consultation and participation for mental health policy formulation and planning at a district-level (Upadhaya et al., 2017). Patel et al. (2007) discuss additional contributing factors such as lack of mental health services and suicide not being included in the public health agenda. They also note negative attitudes towards mental illness, lack of awareness about illness and treatment, easy access to lethal methods of suicide, people with serious mental illness are often managed in the justice system as opposed to the health system, and religious and socio-cultural condemnation of suicidal behaviour as factors.

There is an urgent need for treatment options for mental illness in low and middle-income countries, with Luitel et al. (2015) arguing that 4 out of 5 people in these countries (including Nepal) will not access treatment. As mentioned in the introduction, the decade long conflict that ended in Nepal in 2006 negatively impacted the health system, as well as the mental wellbeing of the displaced and general population (Luitel et al. 2015; Regmi et al., 2002; WHO, 2003). As a result of this conflict, anxiety and depression were found to affect as much as 80% among the displaced population (Regmi et al., 2002). Additionally, Nepal has a limited number of mental health specialists, with services being concentrated to the larger cities, with “0.22 psychiatrists and 0.06 psychologists per 100,000 population” (Luitel et al., 2015, para. 3). In comparison, in New Zealand there are 28.540 psychologists per 100,000 of the population (WHO, 2016). Moreover the authors argue that there has been no advocacy via the public health sector; rather, the NGO sector has been filling this gap, however this may often only capture a minority (Nyamugasira, 2010).

Focusing on approaches to treating mental illness in Nepal, Upadhaya et al. (2017) specified that there is only one psychiatric hospital based in Nepal’s capital Kathmandu, which is scant considering the population of Nepal as a whole, which at 2018 was 28,087.87 (The World Bank, 2018). Those who can afford to travel to Kathmandu do, while those who cannot, visit traditional healers. Thus, factors such as poverty, stigma and geography act as major barriers in accessing mental health treatment (Upadhaya et al., 2017). Such factors lead Arun and Adhkari (2009) to describe the state of mental health services in Nepal “dire” arguing that services are primarily based in urban centres, within hospitals, and are largely disorganised (p. 186).

In an attempt to address this gap, the first ever ‘International Mental Health Conference’ was held in Kathmandu in February 2018, which brought together the Ministry of Health, the Government of Nepal, as well as multiple stakeholders to set objectives for advancing mental health treatment and awareness (Mental Health Awareness Nepal, 2018). Additionally, The World Health Organization in their country cooperation strategy with Nepal outlined mental health as a priority to be tackled in the next three years, declaring, “the National Health Research Council is conducting the first ever national mental health survey” (WHO, 2018, p. 12). The deliverables from the country cooperation strategy (CCS) included the following:

- The basic health package for each level of care is defined and agreed upon, including NCDs, mental health, preventive and promotional activities (WHO, 2018, p. 21).
- Mental Health Act and National Suicide Prevention Strategy developed through a consultative process with parties' concerned and technical support provided for implementation (WHO, 2018, p. 33).
- Reducing risk factors for non-communicable diseases - Provide technical support to ensure that legal, policy and strategic frameworks required are in place to accelerate implementation of mental health action plan 2013–2020 (WHO, 2018, p. 33).

2.4 Stigma attached to mental ill health

Stigma is understood to be when someone views you in a negative way because of your mental illness. This leads to discrimination where someone treats you negatively because of your mental illness (Victoria Department of Health & Human Services, 2015). Stigma surrounding mental illness is apparent globally, a great deal higher than stigma attached to physical illnesses (Patel et al., 2007). The reasons behind why mental health care is lacking in Nepal must be explored in order to address this issue, with stigma found to be one of the primary prohibiting factors. The United Nations (n.d.) found that stigma and discrimination is common with persons with mental and psychosocial disabilities. Therefore, those with mental health issues often face exclusion in society, which is alarming considering the fact one in four people will experience a negative mental health condition in their lifetime (The United Nations, n.d.). This places stigma and discrimination regarding mental illness in Nepal as one of the main barriers to accessing treatment (Luitel et al. 2015).

Within the context of Nepal, Brenman, Luitel, Mall and Jordans (2014) quoted a KII Auxiliary Nurse Midwife speaking of stigma surrounding mental illness: "there are still educated people, who believe that it is not mental illness but some kind of spirit possession "bokshilaageko"" (para. 27), which negatively effects the social status of an individual in Nepal (Kohrt and Hruschka, 2010). This demonstrates that stigma aids as a key barrier to seeking treatment for mental illness, and stigma must be addressed in order to increase access to treatment (Heim, Kohrt, Koschorke, Milenova and Thronicroft, 2020). Alongside this, both contextual and cultural factors are now recognized as influencing every aspect of mental ill health, with beliefs and values being factors that shape one's experience of mental ill health (Chase et al., 2018).

In understanding culture's effect on mental health, Kohrt and Harper (2008) conclude "local mind-body divisions" must be understood in order to address the stigma surrounding mental illness in Nepal (p. 486). The authors proceed to provide two stories of individuals with mental health issues, both of whom refused to accept that their illness was of the "dimaag (brain-mind)" (Kohrt and Harper, 2008, p. 464), rather labeling their illness as physical in order to avoid discrimination. The term "paagal (mad)" which can also be understood as "crazy, mad, or, in medical terms, psychotic" is otherwise used to describe people with mental illness in Nepal (Kohrt and Harper 2008, p. 471). Mental illness is believed to be contagious; therefore, the sufferer and the wider family are feared. The individual and the family are prevented from marrying, which is why people are hidden away as mental illness is denied. Dimaag and its importance in Nepalese conceptions of oneself is therefore emphasised and leads to discrimination when their dimaag is not deemed to be functioning properly (Kohrt and Harper, 2008).

There is clear discrimination and stigma toward persons with mental illness in Nepal, with those affected being discriminated against socially. As social relations and status are important in Nepal, "any dysfunction that impairs social positioning is strongly stigmatized" (Kohrt and Harper, 2008, p. 472). This social discrimination allows for the personal rights of those labeled mentally ill to be violated (Regmi, Pokharel, Ojha, Pradhan and Chapagain, 2004). Mentally ill people are treated unfairly, often beaten, and lose their social status, with husbands also being allowed to divorce their wives because of her mental illness (Regmi et al., 2004). It is a legality that either party can divorce their spouse in Nepal based on mental illness, which is outlined that "mental disorder can become a ground for filing a divorce if the spouse of the petitioner suffers from incurable mental disorder and insanity and therefore it cannot be expected from the couple to stay together" (Nepal lawyer, 2019, para. 5). However, divorced women face immense social stigma in comparison to men (The Womens Foundation Nepal, n.d).

2.4b Work on reducing stigma

In attempt to tackle stigma and thus discrimination, the United Mission to Nepal attempted to redefine the terminology used for mental illness, instead using the concept of "nerve disease (nasā rog)" with the aim of making it more socially acceptable (Harper, 2014, p.125). However, Chase et al. (2018) thought that creating new terminology could in turn create new spaces for

stigma. When addressing mental health within minority populations, "a culturally unique 'language'" could prove beneficial in overcoming challenges, therefore being more effective in reducing stigma among the population (Stacciarini, Shattell, Coady and Wiens, 2011, p.495). In Adhikari, Pradhan and Sharma's (2008) research on Nepalese perspectives of stigma toward mental health, they found that the majority of patients who had been hospitalised reported stigma as well as rejection by family members and colleagues as a common experience that they faced. The authors advised that stigma is apparent toward those experiencing mental illness treatment; suggesting advocacy is a way to work on reducing stigma as well as having health professionals displaying positive attitudes toward mental health treatment. Additional ways to address stigma is through increasing awareness, and by doing this through trusted figures in the community (Brenman et al., 2014).

2.5 Religion and mental health

Literature on Indigenous perspectives of mental health is globally well documented (e.g. Māori views on mental health), however remains lacking for Nepal. Given the fact that Hinduism is the predominant religion in Nepal at 81.3% (Ministry of Foreign Affairs Nepal, n.d), literature on religion, Hinduism and mental health has however been well considered. According to Hinduism, when it comes to mental health any illness is considered to have a biological, spiritual and psychological component (Kang, 2010). Psychiatry and religion up until the early nineteenth century were closely connected, with majority of mental health 'healing' taking place within the place of worship (Bartocci and Dein, 2007, p. 47). Still standing today, there is a Hindu temple, Hanumanthapuram, in India where the main deity Sri Agora is believed to cure the mentally ill if they visit this temple, and the resident exorcist is said to purge the evil spirits that cause mental illness (NPR, 2010). Thus, it is considered there to be a spiritual component associated with mental ill health in countries where Hinduism is a dominant religion.

Spiritual, religious and alternative healing is very popular in dealing with mental health issues in the region of South Asia. This includes ayurveda, faith healing and unani medicine, as well as an increasing popularity of using yoga (Patel et al., 2007). Looking at mental health in Nepal, Regmi et al. (2004) touched on religion stating that when people are affected by mental illness, they are often viewed as crazy and possessed. Despite this, the authors argue that mental health is not often discussed due to the stigma and fear attached to it, although they suggest health care

professionals are becoming more aware. They argue that a large number of the rural population of Nepal believes that mental illness is bad luck, and people visit local faith healers for a cure. Both Regmi et al. (2004) and Acharya (2009) suggest that in Nepal the concept of mental illness being caused by biological factors is non-existent, rather it is believed to be related to stresses or conflict and is often associated with evil spirits. Despite the achievements of medicine to date, there is still the flourishing of alternative forms of medicine that are drawn upon for treatment (Bartocci and Dein, 2007).

Whilst exploring mental health and religion amongst those living in tents after the Nepal Earthquake, Jang, Ko and Kim (2018) reported that people most frequently turn to religion when they encounter a lack of resources to face situations. Additionally, research on children and youth in crisis in South Africa found that the most common coping strategy in this study was collaborating with God through prayer for intercession to deal with crisis, which empowered children to fight hardships (Gunnestad and Thwala, 2011). This aligns with research based in Nepal where people generally face greater psychological distress when they struggle to overcome the negative effects of difficult situations (Jang et al., 2018), in instances where human resources are not enough to cope with critical situations (Gunnestad and Thwala, 2011). However, as mentioned earlier there is a need for further study on the relationship between religion and mental health, as well as the mental health situation before the earthquakes, and the impact of the lack of human and social support networks and resources on the mental health of disaster survivors. In addition, further research is needed on the importance of religion to children and adolescents in the Hindu culture, including their religious attitudes and behaviour (Jang et al., 2018).

2.6 Asset-based Community Development (ABCD)

Having outlined the mental health situation in Nepal as well as the immense stigma attached to those experiencing mental illness in the above sections, this section now outlines the ABCD approach, which has a focus on people's assets and strengths underlined by the notion "they will use what they have to secure what they have not" (Mathie and Cunningham, 2008, p.1).

In order to target the minority populations within public health, Stacciarini et al. (2011) found that community-based approaches are effective, although the inclusion of mental health was still

relatively new. Patel et al. (2007) suggest that mental health professionals' partner with grassroots NGOs with an existing foundation to capacity build in order to utilise existing resources in the community. This marries well with ABCD, whereby communities seek to focus on their assets, such as social assets which includes leadership, support networks, shared knowledge and their capacity in pursuit of development goals (Mathie and Cunningham, 2008). This approach in focusing on the assets and strengths that a community possesses, recognises the "strengths inherent in community-based associations and other social networks" (Mathie and Cunningham, 2005, p. 177), thus outcomes are argued to be better. This approach then gives the communities a proactive role as "agents of development" therefore mobilising their own assets to access advantages to which they are entitled to, such as health care and education (Mathie and Cunningham, 2008, p. 328). The authors discuss the effectiveness of ABCD, outlining that utilising social assets and realising potential within informal networks can then influence larger networks such as government and formal community-based networks. This is said to sustain the community development focus, with local assets being utilised to address needs. The success of this model is compared to problem-focused and needs-based development, although well intentioned, often disempowers and criticises the country and communities in which they are trying to assist which then leads to reliance, and ultimately is not sustainable (Mathie and Cunningham, 2008).

With focus on a community-based approach, Raja et al. (2012) conducted a case study on the Basic Needs model, which was founded in 2000 and was built upon a community-based integrated Mental Health and Development (MHD) model. The MHD model was "inspired by development theory, which emphasises user empowerment and community development, as well as strengthening health systems and influencing policy" (Raja et al., 2012, p. 1). This points to the partnership approach to development, which was advocated for in 1995 by Robert Chambers (1995) who stressed the importance of putting the last first in development. This approach is important as Shukla et al. (2012) argue that if change is to be made in developing countries, then developing appropriate frameworks must be done in collaboration with local communities and those with personal experiences with mental illness. However stigma must be addressed as well as the need for cultural adaptation of interventions (Heim et al., 2020). People's assets and capacities help to build their sense of identity and purpose, therefore "in a related sense, assets

are also the basis on which people take action; they can empower people to challenge the structures that determine the way in which resources are allocated" (Mathie and Cunningham, 2008, p. 178).

A study undertaken by the Ministry for Foreign Affairs of Finland focused on developing a community mental health model in Nepal and found that using community mental health workers can be effective, especially in poorer countries, suggesting further trials in Nepal should be set up (Markulla, 2019). This was due to the reduction of depressive and anxiety symptoms observed within the community. Based on these findings it is recommended that lay psychosocial counseling be used as a fundamental part of mental health systems in low and middle-income countries (Markulla, 2019). This draws on the ABCD principles, as the layperson is the asset in this instance. NGOs therefore play a critical role in mental health care, using community-based models of care (Patel et al., 2007).

Assets are also seen to be a source of identity, related to agency, therefore Mathie and Cunningham (2008) argue that assets and agency reinforce each other and are consequently expressed in action, often at a community level. This was demonstrated in the work of Bebbington and Foo (2014) who discuss social capital, giving an example of it being understood as "properties of social organisation that facilitate coordinated, collective action" (Putnam, 1993; Woolcock, 2010, as cited in Bebbington and Foo, 2014, p. 153). In accordance with this approach, Kretzmann and McKnight (1993) believe that development must start from within the community, including those who are marginalised:

> It is essential to recognize the capacities, for example, of those who have been labeled mentally handicapped or disabled, or of those who are marginalized because they are too old, or too young, or too poor. In a community whose assets are being fully recognized and mobilized, these people too will be part of the action, not as clients or recipients of aid, but as full contributors to the community-building process (pp. 25 – 26).

In taking hold of collective action with a community, this is when the reach can stretch further to larger collectives such as the government (Mathie and Cunningham, 2008). This has the potential to influence policy at a national level. In doing so however, the need for "culturally appropriate

and inclusive research methods/approaches with minorities/underserved populations" has also been advised (Stacciarini et al., 2011, p. 495).

Acts of community-based mental health and psychosocial support services bodes well with participatory development. Mohan (2014) discusses participatory development, initially outlining that Paulo Friere (1970) was an advocate for participatory action research, and going on to argue that this approach seeks to involve the local people to express their needs and achieve their own development, which in turn this capitalises on their current assets and social capital which are used in advocacy to effect policy.

Despite the empowering and participatory view of the ABCD approach, there are criticism's in regard to it having a lack of evidence and theoretical depth, as well as it not addressing macro-level causes of disempowerment (Ennis and West, 2010). It is seen as an approach to development, not considered a model or renowned theory of practice and many macro level issues are left unexplored in literature regarding the ABCD approach (Ennis and West, 2010). In improving the lives of disadvantaged communities, ABCD has been argued to not address the structural barriers that these communities face (Healy, 2005), barriers such as oppression and lack of power, which ABCD does not directly address (Mathie and Cunningham, 2003). Another criticism is about its legitimacy, with research supporting the ABCD approach regularly focused on small community projects, often written by the agency undertaking the project (Ennis and West, 2010). This provides little "analytical depth" (Ennis and West, 2010, p. 407) and it is often qualitative research. Despite this, qualitative research is praised for its ability to provide depth and to give voice to those who do not often have the opportunity (Stewart-Withers, Banks, McGregor and Meo-Sewabu, 2014).

2.7 Summary

In conclusion, it is clear that mental health in Nepal is incredibly under-resourced and often neglected due to factors such as stigma, shame, and lack of awareness and understanding. Alongside this, government support is lacking, finances are limited and there is a dearth of mental health professionals. NGOs frequently intervene and seek to fill the gaps left by the government, often working at the community level with what existing resources and assets they possess, at times being human and social capital.

Chapter three: The role of NGOs in advocacy and former mental health beneficiaries in advocacy for mental health in Nepal

3.1 Introduction

Non-governmental organisations (NGOs) have become an integral pillar in international development, and frequently fill the gaps left by the government with their work often discerned by service delivery and advocacy work. NGOs range vastly from larger northern NGOs and smaller southern NGOs, as well as small grassroots NGOs who possess a specialised focus. This chapter explores NGOs and their development over time, outlining their services and examples of NGOs working in the field of advocacy. This chapter will describe the way in which the ABCD approach intersects with NGO advocacy. A summary of the effects of NGOs working in advocacy will be given, with the ability to influence policy and procedure at a government level. References to the work of Koshish Nepal are included and how it intersects with the ideas that have been discussed.

3.2 NGO overview: strengths and limitations

Since the 1950s, NGOs have increasingly become involved in development policy and practice and are seen as important actors in the political landscape of development. They are often termed the “third sector” (Panda, 2007, p. 257) due to being separate to the government and the private sector. While separate, NGOs also seek to collaborate with governments and aid agencies with the idea that NGOs can offer an alternative model of development (Desai, 2014). Korten (1990) describes four generations of NGOs over time known as 1) relief and welfare 2) community development 3) sustainable systems development and 4) people’s movements. This shift in generations was caused by NGOs awareness that governments were not effectively addressing the fundamental causes of “human tragedy” (Korten, 1990, p. 6) therefore NGOs were seen as filling a gap that the government would or could not. NGOs were also seen to more effectively reach the poor and give them voice in the political space (Korten, 1990; Nyamugasira, 1998; Martinez 2008) as NGOs tend to be more “hands on” and accountable where the state is both unaccountable and bureaucratic (Mohan, 2014, p. 133). Critique of the government possessing a “growth centred vision” (Korten, 1990, p. 3) resulted in NGOs arguing transformation was what was in fact required. Globally, a number of NGOs are working according to the transformative

agenda, with people-centered development at the heart of their work (Korten, 1990; Lewis, Kanji and Themudo, 2020; Martinez 2008). This agenda places sustainability, inclusiveness and justice as the principles that define "authentic development" viewing development as "a people's movement" (Korten, 1990, p. 5).

Sustainable development is defined by the Brundtland Commission (1987) as 'development that meets the needs of the present without compromising the ability of future generations to meet their own needs', which attempts to balance social equity without depleting natural resources for current and future generations. With the call of the United Nations to "leave no one behind" (The United Nations, 2018), when striving to reach the Sustainable Development Goals, inclusivity must be set as a development cornerstone, and bodes with the work of NGOs in targeting the most vulnerable in society.

Grassroots NGOs deliver bottom-up approaches defined by an emphasis on community participation, local decision-making, and grassroots movements with awareness building an important aspect of this (Martinez, 2008; Panda, 2007). Martinez (2008) outlines grassroots NGOs by their work in marginalised populations, intervening at a community level by utilising a particular method "(grassroots support)" and working toward a clear goal "(sustainable development)" (p. 342). NGOs are also known to have more flexible funding channels, meaning there is higher chance of grassroots and community participation (Lewis et al., 2020). Additionally, NGOs have been seen as more cost-effective and innovative when it came to the development agenda, therefore attracting further interest from development activists (Lewis et al., 2020).

Within the context of South Asia, Sen (1992) looked at the rise of NGOs in India and found that the increase in Christian missionary presence and the emergence of the radical middle class were factors in this rise. Other areas of NGO action within South Asia such as microcredit provision and loans were derived from traditional local self-help activities such as dhikiri in Nepal, which involves rotating credit groups where people formally agree to contribute a fixed amount which then results in everyone receiving shares or other benefits that have been laid out (Lewis et al., 2020).

With the growth of NGOs, there has been criticism over their association with buzzwords such as empowerment, participation and partnership (Lewis et al., 2020), where these words tend to lose their integrity. It has also been argued that NGOs are just another form of missionary action and modernise communities and their economies in Western tradition, therefore taking over traditional forms of reciprocity in communities (Lewis et al., 2020). In seeking the best way to improve quality of life for those NGOs are working for, it has been criticised that their focus on locally-led development and empowerment was not addressing the structural issues that cause poverty, therefore being inadequate in promoting broader structural change (Rugendyke, 2014). Thus, in order to seek broader change, an increase in NGOs commitment to advocacy became more evident (Rugendyke, 2014).

3.3 Advocacy and its role in development

NGOs in recent decades have turned toward advocacy and campaigning, in order to maximise impact and become more cost effective in their work (Rugendyke, 2014; Vedder, 2007). In part due to the fact they had been hugely challenged as to whether they were actually making a difference focusing on local development and empowerment alone. Subsequently, advocacy was seen to have potential to influence policy and global systems to transform institutions that were the root cause of poverty (Rugendyke, 2007), as opposed to humanitarian relief and its short-term effect (Banks and Hulme, 2012; Rugendyke, 2007; Schneider and Libercier, 1995). Many NGOs start out with a focus solely on service delivery (Korten, 1990), however, move toward integrating policy advocacy when they see the need to look upward in order to have a wider impact. This enables such grassroots NGOs to form ties with the government and play an important role in building social capital (Desai, 2014).

Three main roles are undertaken by NGOs; "service delivery, advocacy on behalf of the poor and empowerment, that is, enabling the poor to become advocates for themselves" (Desai, 2014, p. 569). However there tends to be a distinction between organisations that engage in advocacy and those that just provide services according to NGO scholars and practitioners (Farid, 2019). Despite this, many NGOs combine their advocacy and operational work and "act as both advocates and practitioners" (Farid, 2019, p. 539). This is the case with Koshish who place emphasis on their work in advocacy, alongside their work in rehabilitation and transit homes for those facing mental illness.

Advocacy is a term that includes individual, organisational or public support, alongside recommendation and activity to influence a cause or policy through means other than governing (Farid, 2019). NGOs are now frequently involved in policy advocacy where they seek social change through influencing attitude, policy and practice, and lobbying for policy changes and reformation of state services (Desai, 2014). This is observed in the form of participatory advocacy, where they harness the power of knowledge and information to promote change within the wider structure of government and large-scale aid organisations. This information and knowledge are often gained through their own experience of working at the grassroots level (Desai, 2014).

A concurrent theme observed amongst NGOs working in advocacy is the power of public action. Prakash and Gugerty (2010) write about NGOs as "collective actors" (p. 1) saying they face collective action problems, collaborating with other actors involved in advocacy. This form of collective is discussed by Cornwall (2000) who agrees that most advocacy work is undertaken by "organised actors" (p. 2). This parallels with the community-based approach to development where the strengths and assets of a community are drawn upon in order to act and achieve development goals. When participation occurs in development, civil society then participates in policy advocacy, enabling them to have a say in the decisions that affects their lives (Cornwall, 2000). The successes of NGOs working in advocacy has been the growing awareness of the power of public action in contributing to policy changes, and that the shift toward changing these systems and values has strengthened NGOs in their work to influence policy and systems (Rugendyke, 2007).

The term advocacy is often used by NGOs when referring to campaigning, which aims to change public opinion and lobby to change policies and practices that "institutionalise poverty and related injustice" (Anderson 2003, p. 35; Rugendyke, 2014). Government collaboration with NGOs is often beneficial due to lack of capacity and expertise within the government, as NGOs tend to have specialised knowledge and relationships with the communities and can pilot projects that the government can use (Desai, 2014; Farid, 2019). This demonstrates NGOs are now important political actors who have capacity to impact policy and legislation. However, Farid (2019) seeks to determine whether this is the case for smaller grassroots NGOs. Grassroots NGOs have particular interests and goals and work toward change as a collective, addressing

specific issues and displaying an important platform for civil society in public matters (Desai, 2014). The capacity to impact policy and legislation is being investigated in this research on Koshish as a grassroots NGO involved in mental health advocacy.

3.4 Intersecting ABCD and NGO advocacy

Due to NGOs position as separate from the government, this allows them to lobby and campaign for social change (Rugendyke, 2007), which attempts to positively affect people's lives through influence of policy. NGO work is often closely linked with minority groups employing a participatory approach, which fits with the ABCD approach as it is based on the experiences of working with local people to access their knowledge as well as understanding of "local needs and capabilities" (Rugendyke, 2007, p. 6). This is addressed by Schneider and Libercier (1995), who give the example of Action Aid referring to their work as "participatory advocacy" which is defined as "people centered advocacy" (p. 15). This is when civil society organisations are involved in voicing the voices and rights of the poor within the political space (Schneider and Libercier, 1995).

If change is to be made, it involves those in higher levels hearing the voices of the poor rather than those in positions of power such as development professionals or academics. This however, is easier said than done. Both North and South NGOs often miss the poor and marginalised, but their voices are important, and must be listened to. They are often missed due to factors such as being less educated, less access to services and being invisible (Chambers, 1993; Nyamugasira, 2010). As Chambers (1993) states:

> ¼ Visitors could easily spend a week in a village without either seeing or speaking to the poorer of its inhabitants; and without ever entering one of the colonies where many of the poorest live. Visitors tend to see, meet, and interact with, only the more influential and better off rural people (p. 28).

Such is the case in Nepal, where 80% of the total population live in rural areas (The World Bank, 2019), with many areas having no road access. Additionally, some Southern NGOs have ties to their Northern partners, meaning the NGO was not built within the community in which they are serving (Nyamugasira, 2010). Thus it can be quite difficult for NGOs to truly reach the most marginalised, but is vital if development seeks to be inclusive and target the most vulnerable.

> We must seek to empower the poor to advocate for themselves so that in advocating for them we avoid giving the impression that someone somewhere owes them a living, and that this someone is most probably the government, primarily their own (Nyamugasira, 2010, p. 306)

This quote marries well with the grassroots nature of Koshish, where the lens of ABCD applies as they are utilising their own assets and strengths (social capital) as a collective, as opposed to needs-based top-down development approaches. This in turn empowers the collective to work together on advocacy and raising awareness in order to increase access to mental health in Nepal. The ABCD approach relies on people's knowledge and strength to enable citizen led development, often through advocacy by utilising their existing resources for collective action (Mathie, Cameron and Gibson, 2017). This is a strength-based approach, which focuses on people's agency and is argued to better lead to empowerment and change, demonstrating that citizens are both active and capable. Mathie et al. (2017) refer to the term "low hanging fruit" to outline initiatives that build on one's existing assets and strengths without the need to look for external assistance (p. 61). It is suggested that the ABCD approach requires governments, donors and NGOs to rethink their own role, as if citizens are demonstrating their agency to achieve their own development, the external institutions must work with communities either in partnership or responding with action to citizen-led initiatives (Mathie et al., 2017). This demonstrates the power of advocacy by NGOs and what it can achieve.

Through the efforts of NGOs in support of mobilising the poor and marginalised by way of campaigning and attempts to influence public policy, "NGOs have become key actors in a process of transformatory development" (Desai, 2014, p. 570). Desai (2014) terms this "bottom-up democracy" suggesting it may lead to "top-down political change" (p. 570). This is achieved through advocating in their areas of strength and interest, which in the case of Koshish is mental wellbeing for all. The intersection of NGO work and the theoretical lens of the ABCD approach is demonstrated in Table 1 below with literature that correlates similar ideas.

Table 1: Key tenets – intersecting of NGO and ABCD

NGOs	ABCD approach
Ability to more effectively reach the poor and the marginalised (Korten, 1990; Nyamugasira, 1998).	Development must start from within the community, including those who are marginalised (Kretzmann & McKnight (1993).
Filling a gap left by the government (Korten, 1990; Nyamugasira, 1998).	This approach focuses on the assets and strengths that a community possesses, "particularly the strengths inherent in community-based associations and other social networks" (Mathie & Cunningham, 2005, p. 177).
Authentic development; people's movement (Korten, 1990).	Focus on people's assets and strengths underlined by the notion "they will use what they have to secure what they have not" (Mathie and Cunningham, 2008, p.1).
Transformative agenda. People-centred development at the heart of their work (Korten, 1990; Lewis et al., 2020).	The success of this (ABCD) model is addressed, compared to problem-focused and needs-based development, though well intentioned, often disempowers and criticizes the country and communities in which they are trying to assist (Mathie and Cunningham, 2008).
Higher chance of grassroots and community participation (Lewis et al., 2020).	Bebbington and Foo (2014) discuss social capital, giving an example of it being understood as "properties of social organisation that facilitate coordinated, collective action."

3.4.1 Examples of the power of NGO advocacy:

A key question asked of NGOs is "how is the effectiveness of NGO advocacy work evaluated, and by whom?" (Schneider & Libercier, 1995, preface xi). To demonstrate the effectiveness of NGO advocacy, an example of the 'Jubilee 2000 campaign' was given by Rugendyke (2007), outlining that this campaign and its petition managed to get world leaders to agree on cancelling $100 billion of debts owed by the poorest countries (p. 575-576). In response to the question

“how best to help the poor in Tanzania”, Julius Nyerere’s stated, “change public opinion in your own country” (Burnell 1991:240 cited in Rugendyke, 2014, p. 574). This example demonstrates the effect of advocacy over time, with Schneider and Libercier (1995) outlining that the cumulative effect of campaigning can progressively affect change and policy, as opposed to a single event having an effect.

During the years of 2009-2012, Farid (2019) examined 22 grassroots NGOs in China in terms of being catalysts for policy innovation and found that many were not limited to just service-delivery. Over 90% of those interviewed, expressed that although they are categorised as service delivery NGOs, they were concerned with policy influence in their work. This was due to the fact influencing policy was possible when those in a position to create policy are seeking new approaches and methods.

External actors such as policy makers, NGOs and advocates can be used to further the reach of mental health assistance, especially in low and middle-income countries (Lemmi, 2019). TPO Nepal is an NGO working in the mental health field, and after the 2015 earthquake in Nepal they conducted a mental health and psychosocial support (MHPSS) assessment from August – September 2015, supported also by the International Medical Corps (IMC) (IMC, 2016). One of their key goals was building the capacity of community health workers to improve access to services, as well as providing support through raising awareness and reducing stigma. This demonstrates the need for advocacy in the sector as awareness and stigma reduction thus enables better mental health outcomes. This is backed up by research on strengthening mental health systems and governance in six low and middle-income countries in Africa and South Asia by Petersen et al. (2017). This research included Nepal as one of the countries, with the authors reporting that within the strategies of those countries seeking to increase mental health as a public health priority, strengthening advocacy efforts was identified as fundamental.

3.5 Influence of policy and procedures for mental health in Nepal

When looking at mental health and psychosocial approaches during the Nepal conflict and the programmes that were implemented during this time, Upadhaya et al. (2014) found that NGOs have been successful in advocacy and in becoming partners in revising policy and the integration of mental health into primary health care. Stakeholders such as community health workers, NGOs, activists, media and those with lived experience are often involved in initiating

development and innovation at the grassroots level (Hayward and Cutler, 2007). Recent development practice has begun to demonstrate the possibilities of local communities engaging in local mental health policy and has been the subject of much research by the Centre for Reflection on Mental Health Policy (CRMHP, 2005). However, most policy formulation does not involve the input of the service users, therefore the gap between “top down and bottom-up styles of policy making” must be addressed (Hayward and Cutler, 2007, p. 518) and grassroots learning be applied in formulating mental health policy at the national level (Hayward and Cutler, 2007).

3.6 Summary

The focus and scope of some NGOs has shifted over time, with advocacy now seen as an effective way of impacting and creating change at the structural level as opposed to previous humanitarian interventions and its short-term impact. This chapter demonstrates the impact grassroots NGOs can have in accessing the poorest and marginalised as well as the positive impacts of NGO advocacy as demonstrated by the examples given in section 3.4.1: Examples of the power of NGO advocacy. The ABCD approach to development ties in well with NGO advocacy and links have been demonstrated, as well as its comparisons to the work of Koshish Nepal. The next chapter will move away from the theoretical components of this research and move on to outlining the methodology and methods that will be used to answer my research questions.

Chapter four: Methodology and methods

4.1 Introduction

Literature has established that NGOs working in advocacy can influence policy and raise awareness of significant issues (Desai, 2014; Rugendyke, 2007; Schneider and Libercier, 1995). This research seeks to explore the role and impact of individuals with lived experience of mental illness who now advocate for better mental health systems and greater awareness of mental health issues in Nepal, through Koshish. Outlined in this chapter is the methodology chosen in order to answer the research questions, ethical considerations for this research project, the data collection and data analysis stages as well as any limitations that were encountered.

4.2 Methodology and ethics

This research employed a qualitative methodology using multiple methods. The decision to use a qualitative methodology was based on the fact it bodes well with my research topic where I was looking to explore and describe, and generate "thick, rich description" (Stewart-Withers et al., 2014, p.61) seeking depth, rather than breadth of understanding (Stewart-Withers et al., 2014). Rich description and stories were generated through looking at the voices of those with lived experience of mental illness, and this form of research can help us to understand and find meaning because we get to understand better people's attitudes, behaviours, value systems, concerns, motivations, aspirations, culture or lifestyles (Marshall and Rossman, 2011; Stewart-Withers et al, 2014). As a result, a richness of context can be demonstrated and potentially inform change.

A case study on Koshish Nepal is the basis of this research. Case studies can lead to understanding of projects, programmes and events helping us uncover information that sheds light on an object or issue, as well as the fact that case studies are also seen as exploratory (Merriam, 1998). Case studies have the potential to give voice to the marginalised, vulnerable, disadvantaged and excluded (Denzin and Lincoln, 2018), and these voices are often given precedence within qualitative research (Stewart-Withers et al., 2014).

4.2.1 Ethical considerations

Because of the nature of the research, which focuses on people with lived experience of mental illness, a full ethics application was required and was submitted to Massey University Human Ethics Committee: Southern B for review. The most significant ethical issues identified included:

1) Discomfort or psychological harm 2) privacy and confidentiality and 3) vulnerable people. In the semi-structured interviews, the possibility of creating psychological distress or bringing to the fore sensitive emotions was possible. However, rather than assuming participants would experience negative emotions, I emphasised the wellness and agency of the people involved who now advocate for mental health changes and awareness. Through using the participant's view it can act as an empowering process, as they have an opportunity to tell their story. Banks and Scheyvens (2014) suggest that research should involve empowerment, as well as the attempt to "do no harm" (p. 160) which this research aimed to do.

All participants gave verbal consent, and two out of three participants also signed consent forms. My decision to also allow verbal consent aligns with the discussion by Stewart Withers (2016), that written consent can at times be disempowering for some people. For example, if the person being asked for consent is illiterate and asking for consent has the ability to enforce power relations.

The members of Koshish who have lived experience of mental illness have the autonomy to make their own decisions and have gone through the Koshish recovery programme, thus considered well and not as vulnerable people. As a famous Nepalese proverb states: "depend on others and you'll go hungry" (Proverbicals, n.d., para. 23), which emphasises the agency that every individual possesses. This allows the voices of those with lived experience to come through, aligning with the ABCD approach that values and utilises people's strengths.

When looking toward my findings, DeVault (1999) begs the questions of how we can ethically interpret our data, which indicates that I must ensure the participant's voice's are not skewed in the data analysis stage and so I should look to mitigate as best I can any potential bias. O'Leary (2010) supports this through advising that "the analysis of the words used needs to come from the perspective and reality of the researched, not the researcher" (p. 59). I will ensure that all

information provided by participants is in their words, allowing for data to be provided as it was given.

4.2.2 Data collection

This research used multiple methods to collect data, which were 3 semi structured interviews with key stakeholders as well as document and website analysis. I conducted two semi-structured interviews via Zoom. One was with Matrika Devkota, the founder of Koshish Nepal, and the other was with Ms. Trishna who is a psychologist working at the mental hospital [2]in Nepal. As Ms. Trishna had also been hired as my research assistant, she was able to conduct a third interview with another psychologist working within the same hospital as her (see Table 2). This posed a potential conflict, as she was also an interviewee. I understood this is not conventional, but given the situation and limited number of people I could access, it was the best I could do given the context, considering I had to revise my methodology a number of times.

Table 2: participant code

Participant	Role	Name
1	Founder of Koshish Nepal	Matrika Devkota
2	Psychologist at the Mental Hospital, Kathmandu	Dr Lata Bajracharya
3	Psychologist at the Mental Hospital, Kathmandu	Ms. Trishna Bista

The chosen data collection methods enabled me to outline the current landscape of the mental health situation in Nepal, as well as the work of Koshish and its impact. Semi-structured interviews allow the answering of the proposed interview questions, whilst remaining open to fluidity along the way, which marries well with the descriptiveness of qualitative data (Stewart-Withers et al., 2014). The documents used for analysis were the Koshish website, newsletter and Facebook page, internal documents given to me by Koshish[3], and the Nepal 1996 Mental Health Policy as a good qualitative researcher "looks and listens everywhere" (Merriam, 1998, p.142).

4.2.3 Data analysis

In attempt to extract information from the website, documents and interview transcripts (collectively known here on in as data), thematic analysis was used to identify interconnections

[2] Mental hospital is the formal name of the institution where the two psychologists interviewed work
[3] The Koshish internal documents are listed in the appendix

and patterns (O'Leary, 2017). I looked to the texts specifically for mention of advocacy work and the participation of those with lived experience of mental illness. The following words were used to help guide what I was looking for in my selected texts: 1) involvement 2) awareness 3) access 4) advocacy and 5) participation. This is also known as noting occurrences, which is "a process that quantifies the use of particular words, phrases and concepts within a given document" (O'Leary, 2017, p. 274). Once I identified information in the texts surrounding those key words, I highlighted them and began to compile them into a separate document, re-reading the text again, highlighting any key points that I had missed and began to identify key themes. These patterns were then analysed and explored as potential themes and as these themes solidified, theory was built (O'Leary and Hunt, 2017).

Once all interviews were complete, I also conducted thematic analysis following the below steps:

Step 1: Transcribe audio from interviews

Step 2: Read (and re-read) transcript and highlighting common themes

Step 3: Looking for anything discussing awareness and advocacy and highlighting this to group together in findings.

Due to the smaller nature of this research, this form of analysis for the interviews was appropriate for its size as "it is better to become intimate with your raw data and you do this by reading and re-reading your transcripts, sorting and coding and re-sorting and re-coding your data" with smaller projects (Stewart-Withers et al., 2014, p. 76). The interviews produced primarily interpretive data, which is made up of people's opinions, beliefs and reported behaviours (Denzin and Lincoln, 2018), which is conducive to the descriptive nature of qualitative research.

Often in a qualitative approach, findings can be case specific and unique, therefore generalising the findings is not an end goal, rather the aim is to think about the transferability of ideas, which seeks to transfer ideas through comparing the data to similar settings from which it originated (Stewart-Withers et al., 2014). We need to be careful of acknowledging our personal bias and making sure participants voices are privileged which is what my research aimed to do; recognising and mitigating bias so that the stories of the participants is able to come through.

4.3 Limitations of the research

Due to covid-19, strict border measures and global lockdowns; aspects of the methodology were revised several times.

Funding was granted through the Massey University Graduate Research fund, however the limitations due to covid-19 meant that I was no longer able to travel to Kathmandu to complete the data collection firsthand in country. As a result I had to hire a local research assistant who was recruited through a contact of mine (a mental health nurse based in Australia and frequently travels to Nepal to volunteer) who put me in contact with Ms. Trishna, a psychologist at the mental hospital in Kathmandu. Ms. Trishna was originally going to visit the Koshish office to interview three employees with lived experience, as well as a member from the Ministry of Health, however limitations with my research assistant not being able to travel to the Koshish office due to a second lockdown in Kathmandu meant that I could therefore only arrange to interview Matrika myself over Zoom and Ms. Trishna could only interview one other doctor at the mental hospital that she works at. Following this, I then interviewed Ms. Trishna via Zoom, meaning fewer interviews with those with lived experience of mental illness, these voices and findings had to therefore be found on the Koshish website.

4.4 Key themes

Upon analysing the texts and the three interview transcripts, four key themes were identified:

1. Stigma is seen to be the main barrier to accessing treatment and care
2. Valuing the voices of those with lived experience of mental
3. Lack of funding and government support are key barriers to service provision and access
4. Advocacy has positive benefits and helps to increase awareness of good mental health and mental health issues in Nepal

The themes of each are demonstrated in the table below:

Table 3: (texts included in thematic analysis)

Document	Explanation	Theme	Illustration of the theme
1) National Mental Health Policy, Policy Document, 1996	This document was formulated, however has still not yet been implemented, there is no mental health act.	-Lack of mental health care (due to lack of funding and government support) -Stigma -Need for improvement	"At the present time the fate of the majority of the mentally ill in Nepal is pathetic" (p. 1) "It is surprising at the present time that these are the only mental health facilities available in the public sector. It is also surprising that there are, still, many more severely mentally ill patients held in jails throughout the country often for no other offence than their illness that there are mentally ill patients in hospitals" (p. 2) When listing the policies within the document: Policy IV aims to "improve awareness about mental health, mental disorders, and the promotion of mentally healthy lifestyles, in the community by participation of community leaders and other personnel, and amongst health workers" (p. 3)
2) Koshish internal document: (Advocacy and awareness), Internal NGO document (grey literature)	This is an internal NGO document from Koshish Nepal outlining their work in advocacy and awareness.	-Advocacy & awareness through Koshish Nepal. -Valuing the voices of those with lived experience	"The organization sought to establish the right of the persons living with mental health and psychosocial problems through advocacy/self-advocacy making the rights holders/beneficiaries able to speak up and demand openly" (p. 1)
3) Koshish internal document: (CBR – Community-based rehabilitation	This is an internal NGO document from Koshish Nepal outlining their community-based	-Advocacy and awareness -Asset-based Community Development approach -Agency	"The KOSHISH CBR program ensures community involvement in both the program and the recovery process of the beneficiaries. This process supports the development of a sense of ownership by the community, people, and the agencies that make the program more sustainable. Our services cover all four level of intervention as our activities includes: 1. Advocacy and awareness" (p. 1)

document), Internal NGO document (grey literature)	rehabilitation programme.		
4) Koshish internal document: (peer support), Internal NGO document (grey literature)	This is an internal NGO document from Koshish Nepal outlining their peer support programme.	-Participation -Agency -Self-determination	"The effectiveness of peer support lies in the belief that everyone involved recognizes that participants are capable of participating and will be an integral part of their own recovery process. They explore and learn to understand to combat shame and stigma together, enhancing their self-esteem and self-efficacy. They are made aware of their rights and encouraged to speak up for it... Achievements: ·Self-advocates – 15 members" (p. 1)
5) Koshish internal document: (RRR programme), Internal NGO document (grey literature)	This is an internal NGO document from Koshish Nepal outlining their rescue-recovery-reintegration programme.	-Awareness -Advocacy - Stigma	"Awareness is created through psycho-education given in the field, through social workers, mass media or through the distribution of IEC materials" (p. 2) "Mental health has been and continues to be a neglected issue in Nepal. The worst-case scenarios are seen in rural Nepal due to a lack of awareness of the seriousness of mental health issues" (p. 1)

4.5 Summary

This chapter discussed the methodology in this research project. Due to covid-19 travel restrictions and global lockdowns, the methodology was revised a number of times with a total of 3 semi-structured interviews, one with lived experience of mental illness. However, the richness of participant stories on the Koshish website provided me with the necessary data to answer my research questions in part. This data was rich with lived experience voices and strength based voices, which bodes well with the ABCD approach, where voices are understood to be an asset, and in having an opportunity to voice ones experiences is an empowering process. Four key themes were identified, which will be discussed in further detail in the following chapter.

Chapter five: Research findings and analysis

5.1 Introduction

This chapter presents the findings from the thematic analysis of the 1996 Mental Health Policy Nepal document, Koshish Facebook page, website and blog and 4 internal NGO documents from Koshish that outline their programmes and the work that they do, as well as the 3 semi-structured interviews that were conducted. Again, there were two research questions that guided this project: 1) How are mental health advocates with lived experience involved in advocacy for mental health in Nepal through local NGO Koshish? 2) To what extent does active participation of former beneficiaries in advocacy lead to increased awareness and access to mental health services in Nepal? Four key themes were identified in the previous chapter, which will be discussed in detail.

5.2 Theme one: stigma

The first key theme identified in my analysis of documents as well as the semi-structured interviews was stigma, which is identified as one of the main barriers to people being open to seeking mental health treatment and increasing awareness in Nepal. This is noted within examination of the Nepal Mental Health policy (1996), Koshish documents, literature reviewed, and the three participant interviews with further detail outlined below.

In examining stigma and negative attitudes toward mental health in Nepal I explored the Nepal Mental Health policy (1996) and asked the document the following questions: 1) How is mental health defined? 2) Does the policy refer to people with mental illness in an empowering or disempowering manner? 3) Is it top down or does it look to facilitate participation? The following was gauged from the text.

Mental health was not given a specific definition in this policy, and overall, it felt primarily non-hopeful. For example, within the introduction of the policy it outlines that "at the present time the fate of the majority of the mentally ill in Nepal is pathetic" (Nepal Ministry of Health, 1996, p. 1). Additionally, it mentions the mentally ill who are in prison more than once in the document, but no mention of releasing them, rather providing them with services whilst remaining in jail, outlining under central coordination and implementation that they aim to work

with “the Department of Jail Administration to provide appropriate Mental Health Services to the mentally ill in jails nationwide” (Nepal Ministry of Health, 1996, p.5).

In order to work toward an effective mental health policy, awareness is viewed as important and is outlined in the document that improving awareness about “mental health, mental disorders, and the promotion of mentally healthy lifestyles” must be carried out “in the community by participation of community leaders and other personnel, and amongst health workers” (Nepal Ministry of Health, 1996, p. 3). Strategy 1 within policy IV of the document indicates that it will do this through a commitment to interaction with community structures, which includes schools, NGOs and traditional healers. This was outlined as important in order to highlight good mental health and increase awareness about mental illness through acknowledging the structures present in Nepalese culture and society. This is seen as necessary to address the root causes of lack of mental health awareness and understanding in Nepal (Nepal Ministry of Health, 1996).

The lack of mental health care and awareness about mental illness is evident when reading the policy document as it states that the main goal of the policy is to “provide at least a minimum amount of mental care to all Nepalese citizens” (Nepal Ministry of Health, 1996, p. 4), which demonstrates that at the time of formulating the policy, a minimal standard of care had not yet been reached. For the main goal to be achieved, the strategies to be adopted are the decentralisation of services, integration of mental health into general health services and the growth of community participation (Nepal Ministry of Health, 1996). These steps are required in order to address and see appropriate mental health care delivered in Nepal, which again emphasises the importance of community participation and grassroots organisations working in collaboration with government to achieve this.

Stigma was mentioned multiple times during each participant interview for this research. Participant 2, when referring to the mental hospital at which she works stated that,

> “the stigma is the main challenge we face here” (Participant 2, psychologist, 2020).

Participant 2 then proceeded to mention that stigma from family members is the main challenge the patients face at the mental hospital; therefore, it is often difficult to get patients to take medication not allowing for recovery. Participant 3 also agreed on this saying that,

> "Oh yes, they face a lot of challenges. First and foremost is the stigma, like when we treat patients and ask them to come to the mental hospital, they usually have difficulties coming to the mental hospital, fearing the stigma" (Participant 3, psychologist, 2020).

Participants noted that stigma is a main barrier to people seeking help. As a result of stigma, Participant 1 said that,

> "I have seen that due to stigma in many of the families that if someone commits suicide they say *oh heart attack* or something happened. They don't report to the police because the family would be stigmatised because of suicide" (Participant 1, Koshish founder, 2020)

He then proceeded to describe the current mental health situation in Nepal, using the term:

> "inherited[4] stigma…no matter if you've studied psychiatrics or psychology, the inherited stigma, for some people it's quite difficult" (Participant 1, Koshish founder, 2020).

This makes mental health treatment and raising awareness difficult. Therefore, within the work of Koshish Nepal, they have been providing training to mental health workers such as psychologists and social workers in order to destigmatise mental health. Inherited stigma is also observed in the form of treatment traditionally sought for mental illness, with Participant 3 outlining,

> "another important thing that we see in Nepal is people have a strong belief system toward traditional healers. So they will trust traditional healers if they are told they have some kind of mental illness, a type of disassociation or possessive symptoms" (Participant 3, psychologist, 2020).

Therefore raising awareness of mental health issues is imperative to reducing stigma and this is seen in the work of Koshish Nepal, where the voices of those with lived experience of mental illness is valued.

5.2.2 Theme two: Valuing the voices of those with lived experience

Looking firstly at data sourced from the Nepal Mental Health policy, one of the strategies alludes to inclusivity and participation of the community: "mental health care facilities will be developed

[4] Inherited stigma is referring to the ingrained stigma in Nepalese society. Family members are discriminated against if someone in their family has or is suffering from mental illness.

not as passive recipients of mentally ill patients for treatment, but as having an active and dynamic interaction with the communities they serve" (Nepal Ministry of Health, 1996, p. 3). Additionally, one of their central coordination and implementation plans is to maintain coordination with INGOs and NGOs. Despite this, those who were present at the drafting of the policy only included psychiatrists, psychologists, representatives of the National Planning Commission and the Ministry of Health who were all present at the meeting on September 21st, 1995 at the Director General of Health's Office in Teku (Nepal Ministry of Health, 1996). This appears top down, as everyone involved holds positions of power, with no NGO members or those with lived experience of mental health (also known as service users) present. Olufemi (2016) discusses the importance of including "unofficial policymakers" (p. 47) who are defined by those who are not in political or public positions, rather they offer their interests and demands in order to influence policy makers to consider and include their demands into the official policymaking process (Olufemi, 2016). Although participation is mentioned twice in the document, participation of such 'unofficial policymakers' was not acknowledged.

Regardless of mention of community participation as important for providing mental health care, there was no mention of any key actors of organisations that ought to be involved in any coordination or liaison outside of the government and no mention of who would participate and how they would participate. The policy notes that the recommendations are in line with the National Health Policy of the Ministry of Health and that the approach to mental health care will be multi-sectoral, with liaison, cooperation and involvement of other concerned government Ministries and Departments as required, listing the Ministry of Education, Ministry of Social Welfare, Ministry of Finance and the National Planning Commission (Nepal Ministry of Health, 1996). The voices of those with lived experience are missing from the policy formulation and proposed coordination

Despite the lack of voices of those with lived experience within the Nepal 1996 Mental Health policy, throughout the exploration of Koshish documents and during the interview with Participant 1, voices were prominent and act almost as a cornerstone of the work they do. Koshish works at the community level and their work advocating for mental health has seen them rescue and rehabilitate many individuals suffering from mental health issues and has raised awareness and captured attention of those working in higher levels such as the government and

smaller municipalities to advise and guide on their policy and processes. As per Participant 1, Koshish founder (2020), Koshish has now employed around ten members with lived experience of mental illness, and their main roles include raising awareness and advocating for mental health awareness and rights within smaller settings such as communities and families. This also allows them to tell their stories from their perspective.

VOICES OF KOSHISH

I have been given a new life by KOSHISH and I am truly is thankful to KOSHISH. I refuse to be bogged down by the fate and am determined to lead a dignified and wholesome life"

Urmila Thapa – Koshish website, employee with lived experience of mental illness.

Figure 3: Photo and quote by Urmila (Koshish employee). Source: Koshish Nepal, 2020.

Figure 3 is demonstration of a Koshish member of staff with lived experience of mental illness who went through their 'rescue and rehabilitation programme' herself. Voices of those with lived experience of mental illness is important in the work of Koshish and help to guide their work in advocacy, recovery and rehabilitation. Below are three stories of Koshish staff members who have lived experience of mental illness who are now well and working with Koshish Nepal.

STORY 1: BLESSED KAMALA

January 2, 2020

My name is Kamala. I am from Rasua, Nepal. I work at KOSHISH. I am very happy since I get spiritual satisfaction through my work of helping the persons with mental health and psychosocial issues as part of my job activities. I myself have non-objective fear psychosis and I have to take medicine regularly. But I don`t mind taking medicines since it makes me feel refreshed and healthy. Honest to God, I never thought I would be fortunate enough to get a job at KOSHISH. I feel blessed and blissful. However, my life was never this blissful and blessed in the past.

I was very young when my stepfather sold me into women trafficking. The persons who purchased me sent me to Calcutta for prostitution. I ran away from Calcutta and became a street peddler and a roadie and stayed on my own ever since. I never had a home ever in my childhood days. I grew up in the streets doing small chores for the passer by. I washed dishes in the restaurants, worked as a maid in rich persons house. I also got job of cleaning in hospitals, nursing homes etc.

In my growing years, I never had three meals a day. Roaming here and there in and around, looking for an ideal job I finally found vocation as a tourist guide. I liked the job of the tourist guide since there was an opportunity for a lone wanderer like me to make friends and amends for myself. However, as a tourist guide it was not regular job and there were many days without job every month. No tourists meant no job and no food.

Somehow, I survived the vagabond years of my childhood. I grew up as a tourist guide and when I was in my late adolescence I had to spend many years in the at the Kathmandu Central women prison since the police caught me with narcotics which belonged to someone else. I developed mental illness in the jail. My imprisonment brought me on the streets once again.

Almost 8-9 years in jail ripped me of all my social and financial linkages in society. That apart, I could not keep any job because of my mental illness. As a result, when I came out from the prison I had no one to contact and seek help. I landed in the streets.

Koshish rescued me from the streets and placed me in their transit center and put me onto counseling, and therapeutic activities and medicines. In the beginning I was a loner and used to sit alone, not interacting with anyone. Slowly, I opened up and started sharing my feelings with the staff and inmates at the transit center. With the interaction my health improved and eventually, I used to involve myself in bead making, painting and knitting at the transit center and the counselor used to help me revive my past in positive spirits. Before getting into counseling, I was into a vicious circle of self-pity asking always one question to myself 'what have I done to deserve this kind of life?' But the counseling helps me practice positive thinking and to look for the silver lining in every grey cloud.

Working with the colorful beads and painting colors used to help me control my paranoid emotions and it as well helped me overcome my phobias regarding meeting and talking with people.

Spending about 9 months in the transit Center, I recovered enough to lead a normal life. By the grace of God, I got a job at Koshish, which gave me a new life and new hope in my life.

Since my childhood days, I have only one identity –that of a runaway victim of the human trafficking. The years in life growing up are the foundation to the future of that person. Unfortunately, my years growing up are that of a vagabond, let alone not being formative, these years destroyed my claims to a yielding future completely. Had I not been rescued by Koshish, I probably would not have been alive today. How I wish to the gracious Lord that Koshish be able to reach the vulnerable people like me and help them just as I was helped.

STORY 2: AKAL, OVERCOMING FROM INHUMAN, DEGRADING TREATMENT!

January 2, 2020

My name is Akal bahadur Thokar. I grew up in Nyatapole Temple, which is located in Bhaktapur. My father used to work in the thanka business (Clothing Business). I studied at St. Johns English School, which is situated in Katunje, Bhaktapur. I did my SLC from Dumja, Sinduli district in 2061 [5] *with second division degree. After my SLC, I used to go to college and teach tuition for the students. Teaching was my passion and I enjoyed a lot. In my area, I am known as a "Small Teacher".*

I was affected by a psychosocial problem from an early age (13 years old). There must be many causes for this problem. But now I think that during my childhood, I lost my friend, my beloved sister Plikhi, with whom I used to go school, play and hangout with a lot. This incident was a great loss for me. I couldn't bear her demise; I was worried very much. I used to cry, laugh and walk due to which people called me psycho. After hearing this, my father came and took me with him. Immediately after that, I was taken to the private hospital in Kathmandu and got admitted. I was kept for three months for my treatment.

After three months treatment, I went back to my home in the village.

When I returned to my village, it had changed a lot. The people didn't recognize me. And I began to feel alone, by myself.

During childhood, children study and learn many things. But due to my psychosocial problem I was obligated through all these activities like education, health, friend's companion and so on.

The society tried to boycott me.

Though they tried to boycott me, I stayed in that society.

My mother used to say, "To tolerate is the great thing". In spite of what my mother used to say, I was in extreme suffering from this problem. I was again admitted to the private hospital for my treatment. This hospital used to torture me. They tortured me for six months & three days. They used to give me 33 tablets in a day, which my family didn't know.

This situation was closely observed by psychosocial health activist Matrika Prasad Devkota. He discharged me from that hospital and admitted me to a new hospital. Within a few days my medication was dropped down to three tablets a day.

The life that I am living now is my second life in Koshish. This credit goes to psychosocial health activist Mr. Matrika P. Devkota. Now, I am a poet, which was inspired by him.

Thank you!

[5] Nepal uses the Vikram Samvat calendar, a historical Hindu calendar, which is ahead of the Gregorian calendar that New Zealand uses.

STORY 3: KESHAR AT KOSHISH

January 2, 2020

I am a receptionist at KOSHISH and have a normal regular life just as others. I am deeply involved in music and I like to compose Nepali songs and music. I am well-kept and I love to meet people and make friends, especially those who have music as a passion. I am an active member of Facebook and I like to socialize. I am very happy today and I thank my stars for getting the life I have today. I have to take regular medicines for the mental health issues and also I have to take an injection every month. Honestly, I do not feel that I need to take either medicines or the injection. But the Koshish staffs persuade me to take regular medicines and injections. I do not want to hurt them that`s why I take medicines and injections.

However, my life was not like this earlier. When I was very young my family died in the Tuberculosis epidemic. Even I suffered tuberculosis but I survived after undergoing an operation in the UMN hospital in Tansen, Palpa. A foreign surgeon from Sweden adopted me and put in the prestigious school, the Gandaki boarding school in Pokhara, Nepal. I studied in that school up to class 10 and then came to Kathmandu. In Kathmandu I enrolled for the secretarial course for two years. After finishing the secretarial course, I took up jobs here and there and rented a room to stay.

One day my room was broken in to by some hooligans who took all my money and belongings, leaving me in the lurch. This incident affected me very badly and I could not keep my job. I had no money, no clothes, no shelter and I landed in the streets. I survived on the streets for the 17 years. I was at the mercy of the passer by and many a time I had to go without food for days on end.

Koshish rescued me with the assistance of the police, as I was very aggressive and reluctant to budge from my position. I did not want to come with the Koshish staff. Finally, the trained rescuers managed to rescue me and brought me to the transit center of Koshish. Initially, I was a loner at the transit home and refused to interact with anyone. At the transit center I was given counseling, medicines and put into card and box making. I was also given computer training. Slowly I recovered enough to lead a normal life.

Today, I am in a much better condition than my previous life. I have got everything at Koshish, I have not only received the intervention, but I have been given a job also. In this way I feel that Koshish is everything for me. Matrika Devkota is now my father and I am his son. Unfortunately, though there are international and domestic laws and policies for the protection and inclusion of the persons like me, still people like me have no substantial support and sustenance. I was lucky I got rescued by Koshish but there are many more like me who are waging a lonely battle for the survival.

Both Akal and Keshar use their singing and poetry in order to demonstrate their experiences of mental illness when at meetings with officials to advocate for mental health. These stories give insight into the work of Koshish and the voices of those with lived experience of mental illness, reinforcing their agency to tell their own story of recovery and now work for advocating for mental health. When describing the essential elements of Koshish's work, Participant 1, Koshish founder (2020) used the terms,

"micro level" and "bottom up" (Participant 1, Koshish founder, 2020)

Therefore, reinforcing the agency of the people. Participant 1 also attempts to amplify the voices of others and is in the process of creating a support group for people who have attempted suicide, as he attempted suicide when he was younger.

Koshish in undertaking their work do not rely on external assistance, rather they support community member's to action, encouraging advocacy and awareness as tools for change. They focus on strengths of their community members and seek to make use of their assets in the following way:

> Koshish promotes and advocate for independent living, inclusion and meaningful participation of persons with lived experiences of mental health conditions and psychosocial disability through strategic advocacy and community based mental health and psychosocial support services in line with UNCRPD, 2006 at its core (Koshish, 2020, para 3-4).

The voices of those with lived experience of mental illness is not included in the Nepal Mental Health policy, and there was no active participation in the of community members in the formulation of this policy. This contrasts with the work of Koshish who value the voices of those with lived experience of mental illness and use this as a tool to create awareness and change in the realm of mental health in Nepal. The impact of their work will be discussed further in this chapter.

5.2.3 Theme three: barriers to increasing awareness and accessing mental health service provision and access

Mental health service delivery faces many barriers such as the lack of awareness and understanding of mental health issues, stigma, lack of funding and the 1996 mental health policy still not being implemented.

Mental health is continually being pushed into the corner when it comes to government funding. Participant 3, psychologist (2020) outlined that there have been international mental health projects in Nepal, however these only occur after disasters such as the 2015 earthquake and once the relief is over, mental health is again forgotten.

> "The problem is that the amount of budget that has been given mostly for mental hospital is very low and what happens when there is low budget then obviously the recruitment purposes and the important things like plans, programmes, policies it also gets affected. Only in the crisis situation people feel the need to say there is this mental health, we need to take care of it" (Participant 3, psychologist, 2020).

Alongside the scarcity in funding, there is also a dearth of mental health workers in Nepal and a lack of awareness towards the profession. All of these factors pose a barrier to mental health treatment and access in Nepal. Participant 3 mentioned that psychologists are still in the stages of being recognised and acknowledged the barriers they face:

> "There is a dearth of psychologists in the community…people are not even aware of psychiatric social workers, psychiatric nurses who could play more important roles" (Participant 3, psychologist, 2020).

Within the hospital they have 6-7 psychiatric consultants, two clinical psychologists and barely any psychiatric social workers as well as an absence of psychiatric nurses, therefore painting the picture to me about the present condition given those figures (Participant 3, psychologist, 2020). Participant 3 envisioned a hospital where there was an appropriate ratio of psychologists and other mental health professionals, however noting that this would require government support as,

> "nurses do come and say okay we want to work with psychiatric but since there is no provision from the government, everything is in the hold so you can imagine the quality is affected" (Participant 3, psychologist, 2020).

Thus, pleading for the government to investigate this so that those working in the mental hospital,

> "would be able to provide really good support" (Participant 3, psychologist 2020).

Government collaboration with NGOs and INGOs who have been working in the area of mental health is seen as beneficial as per Participant 3 who believes that this would result in

> "good plans" (Participant 3, psychologist, 2020).

This participant suggested that rather than criticism of particular plans and policies of the government or NGOs and INGOs, due to issues they may have with one another, cooperation between the stakeholders would instead have a positive impact, otherwise,

> "who's benefitting is the question" (Participant 3, psychologist, 2020).

Another barrier, which aligns with stigma, is that Participant 3, psychologist (2020) mentioned a lot of students come to see her with presenting complaints such as low energy or learning disabilities. These patients are being forced by their parents and teachers to study hard and receive good marks whilst having no awareness of issues such as learning disabilities and other disorders that would affect children and their learning. Participant 3 suggested the following being integrated into school curriculum could be hugely beneficial to address this issue:

> "Form based behaviours of education in schools and industries, because psychology has a good impact on all these areas right - education, industries, it would be any kind of corporate sector, hospitals, just one millifactor. If the government could create certain plans, policies and implement them it's going to help all the sectors" (Participant 3, psychologist, 2020).

Mental health care in Nepal faces many barriers that must be overcome in order to see an increase in services and better mental health care and treatment in Nepal. Those working in the sector are few and all reflect on the stigma that has impacted this. It is evident that further awareness of mental illness must be spread in order to destigmatise and remove barriers to this lack in treatment and care. Koshish Nepal is working in the field of advocacy and awareness of mental illness and is having positive impact, which will be outlined below.

5.2.4 Theme four: Advocacy has positive benefits and helps to increase awareness of good mental health and mental health issues in Nepal

Figure 4: Image of rural home visit by Koshish staff. Source: Author.

The roles of the individuals working with Koshish who have lived experience of mental illness vary, but a key component of their role is leading peer support groups as well as conducting awareness programmes within the community. Figure 4 shows Matrika (left) pictured with two Koshish employees whilst on a home visit in 2017 to a former beneficiary within a small community. Through these programmes, they relay their experience with mental illness firsthand in order to destigmatise the issue, demonstrating that poor mental health is an illness and it can get better. These advocates inform others about the rights of persons with psychosocial mental disabilities have, advising them that they are

> "equal before the law" (Participant 1, Koshish founder, 2020).

They argue that barriers such as legalities and negative attitudes can be overcome, demonstrating that they themselves have overcome these barriers through their involvement with Koshish. Alongside this, those with lived experience also provide psycho-education and family counseling to those affected by mental illness and train psychologists, social workers and other mental health professionals in order to destigmatise and generate understanding of those with mental illness. This is so that they can better facilitate their recovery and realise mental illness from a

human rights perspective and the patient's legal rights as well as their right to self-determination (Participant 1, Koshish founder, 2020).

This is work outlined in Koshish's peer support programme (document four), where it states that at the time of creating the programme description there were 15 self-advocates involved in this programme which seeks to "improve integration of participants in their family and society ensuring better social life and involvement" (Koshish, n.d.). This is enabled through:

> The effectiveness of peer support lies in the belief that everyone involved recognizes that participants are capable of participating and will be an integral part of their own recovery process. They explore and learn to understand to combat shame and stigma together, enhancing their self-esteem and self-efficacy. They are made aware of their rights and encouraged to speak up for it. Through participation, they can enhance their social skills, promote their social rehabilitation and become independent (Koshish, n.d., p. 1).

Participant 1, Koshish founder (2020) placed emphasis on his determination not to give up and now it has been roughly 16 years. He stated that because of his efforts in helping people and raising awareness, he is now connected to those in government and advising them on mental health stating,

> "I'm connected with parliament to make the rules and who can order to the government cabinet, who can order to the minister, so like you know like my role now despite Koshish, we are doing bottom-up approach" (Participant 1, Koshish founder, 2020).

Therefore, as a result of his work in advocacy, he is now acting as an "unofficial policymaker" Olufemi (2016) as outlined prior.

> "Because what I realised is the power in advocacy. I would just speak and speak for the last 16 years and what I've done, whatever I've spoken I've done. And I have not just spoken, I have worked, and I have spoken, and people have seen the change and for example Jesus said in him time 'if you don't believe me, believe in my work'. The action is more powerful" (Participant 1, Koshish founder, 2020).

Participant ones work advocating for mental health has seen Koshish rescue and rehabilitate many individuals suffering from mental health issues and has raised awareness and captured

attention of those working in higher levels: ministries and government to advise and guide on their roles.

Through investigating the Koshish official Facebook page as a form of qualitative data, the following key achievements of Koshish were noted on their website and Facebook page:

- KOSHISH in collaboration with TPO Nepal carried out a Round Table Discussion on 'Interrelationships among Gender Based Violence (GBV), Mental Health and Suicide' on 6th December 2019 (Koshish Nepal, 2019, December 7).
- Orientation Program at Orchid International College about Save Life - Speak Up for Suicide Prevention (Koshish Nepal, 2020, February 6).
- An interaction program on 'integration of mental health in the general health system' on 20th February at the premises of Epidemiology and Disease Control Division with the objective to share our experiences of providing holistic mental health services with high level officials of Ministry of Health and Population (Koshish Nepal, 2020, February 28).
- Hon. Minister Parwat Gurung and the delegates from Ministry of Women, Children and Senior Citizen visited KOSHISH's Transit Care Service Center. The center provides specialized mental health care to the women and girls living with severe mental health condition and reintegrate them back to their own family/community after recovery. The Minister and delegates interacted with the beneficiaries and appreciated the KOSHISH's work (Koshish Nepal, 2020, March 19).
- KOSHISH has completed 50% of data collection for the study on "Impact of COVID 19 and Lockdown on Mental Health and Psychosocial Wellbeing of Persons with Disabilities." The study is being conducted in combine effort of the National Federation of the Disabled (NFDN) and CBM. The study has ethical approval from the National Health Research Council (NHRC). Similarly, KOSHISH has submitted a proposal to NHRC on June 17, 2020, for ethical approval to conduct a study on "Impact of COVID 19 and Extended Lockdown on Mental Health and Psychosocial Wellbeing of People in Nepal (Koshish Nepal, 2020, June 30).
- Mr. Matrika Devkota, founding chairperson of KOSHISH for being appointed as a member of the National Disability Steering Committee, which has been formed under the Ministry of Women, Children, and Senior Citizens on 5th July 2020 to facilitate policy

work related with disability. He was selected among those who have made significant contributions to promote psychosocial disability at the national level (Koshish Nepal, 2020, July 6,).

- Social Development Ministry, Gandaki Province was formally informed about KOSHISH and the project under implementation. Likewise, Dr. Ram Bahadur K.C from Health Directorate, Gandaki Province was made aware of KOSHISH's presence in the region and informed about project objective and activities. Brief introduction about the services was provided to the attendees in a provincial-level health directorate meeting of Gandaki Province that comprised all the eleven district Heads of respective Health Units. In this sphere, through a phone conversation, local-government Presidents from Gorkha, Lamjung and Tanahu districts were contacted for coordination and cooperation. In consideration to NGOs, Team Manager and Coordinator Mr Krishna Lamichhane from CBRS, an organization working in the field of disability assured to cooperate in strengthening referral mechanism. Apart from this, NFDN Gandaki Province president Mr Khum Raj Sharma visited KOSHISH's thereby expressed his opinion on rights and status of persons with disability in the region. Further, Mr Sharma showed keen interest to coordinate and cooperate in the identification and referral of persons with disability to facilitate the ongoing project (Koshish Nepal, 2020, July 23).

These key achievements demonstrate the reach of Koshish's work as a result of their work in advocacy, and that this has resulted in meetings and discussions with those in positions of power such as the Ministry of Women, Children and Senior Citizen's, high level officials of Ministry of Health and Population, health directorates and province presidents. In addition, there has been an increased awareness of mental health within the government and municipalities through the advocacy work of Koshish and work has been done to reduce stigma. This however has not yet ensured implementation of the mental health act. Despite this, the government has acknowledged the importance of NGO knowledge and specialty through inviting them to advise on the mental health aspects of healthcare, and attending multiple workshops and conferences designed and delivered by NGOs, including Koshish.

Three weeks prior to speaking with Participant 1, he had filed a Public Interest Litigation case (PIL) through the Supreme Court and Government of Nepal in order to push the government to

take further action in regard to the 1996 mental health policy and the need for its implementation, with importance placed on including mental health as a top priority. He advised that if the government does not accept this and fails to implement the policy, they would then file another serious case, which the government must act on.

> "Just 3 weeks ago file in the supreme court about this 1996 policy and its implementation, especially to start mental health in the higher priority, so we are going through the supreme court...The supreme court is the final body, if the government doesn't accept and implement then again we can file a case and that is a serious case and the government have to do. And also trying to bring the ministries together...trying to bring Ministry of Women, Ministry of Health, and also the Ministry of Education like they should come together and they should be cross-cutting like the upper health system" (Participant 1, Koshish founder, 2020).

In order to improve the mental health situation in Nepal, Participant 2 suggested the following:

> "By conducting the awareness programmes and education classes and I think in my personal opinion we can spread awareness right from the school level, especially the high secondary level and raising mental health awareness among the health professionals working in other branches of medicine like non-psychiatric branches. Those medical professionals also need awareness from us and they can also contribute a lot of to spread the awareness and reduce the stigma in the society" (Participant 2, psychologist, 2020)

Participant 2 believes it is essential that these medical professionals become aware of mental health issues and in doing so, they could contribute a lot in spreading awareness and reducing stigma within society in Nepal. In addition, both Participant 2 and 3 (psychologists working at the mental hospital in Kathmandu) agreed on the positive impact that advocacy has on mental health awareness in Nepal, with Participant 2 agreeing that advocacy roles have positive effects such as combating stigma of mental health within society.

> "Now recently, there has been a positive point where I have seen like I don't know whether it's going to be implemented or not, but they have made it that psychology should be a subject in every school, so to what extent it's going to be implemented is still unsure" (Participant 3, psychologist, 2020).

As it turns out, on the 3rd December 2020 Koshish posted on their blog that the Supreme Court had issued a show-cause order on unified multilateral national action for the suicide prevention (Koshish, 2020, para. 1). A show-cause order is defined as “a court order issued to a party in a lawsuit, directing that party to appear to give reasons why a certain action should not be put into effect by the court” (Collins, n.d., para. 1). The post outlined the show-cause as follows:

> On behalf of KOSHISH, Chairperson Shiva Ram Achhami, Executive Director Matrika Prasad Devkota and Advocate Sharmila Parajuli jointly filed a Public Interest Litigation (PIL) against the different bodies of Government of Nepal (i.e. the Prime Minister and the Office of the Council of Ministers including Ministry of Home, Ministry of Women, Children and Senior Citizen, Ministry of Health and Population and National Planning Commission) in the Supreme Court.
>
> In the hearing of this Writ Petition, a single bench of the Supreme Court comprising Honourable Justice Hari Krishna Karki, issued a show-cause order to the government in which the petitioners had sought the following relief: Immediately formulate a unified multilateral national action plan in collaboration and coordination with all stakeholders for the practical implementation and enforcement of the right to a dignified life guaranteed by Article 16 (1) of the Constitution of Nepal by preventing and reducing the increasing number of suicides and loss of life from Federal to Local Level. (Koshish, 2020, para. 1-2).

NGOs often promote a multidisciplinary team approach of service delivery (Thara & Patel, 2010) as is the case with the PIL Koshish submitted and has now progressed to a show-cause order as mental health is a multidisciplinary matter (Upadhaya et al., 2014).

5.3 Summary

The effectiveness of NGO advocacy is highlighted, and this research demonstrates that the work of Koshish does align with the ABCD approach, as the government is calling on their knowledge. The ABCD approach relies on people’s knowledge and strength to enable citizen led development, often through advocacy by utilising their existing resources for collective action (Mathie et al., 2017). This collective action is extending from the “micro level” as outlined by Participant 1, Koshish founder, as he believes community-work at the bottom-up level is effective in targeting the minorities and those living with mental illness.

Chapter six: Discussion and conclusions

6.1 Introduction

Mental health awareness and services are lacking in Nepal and there is a great deal of stigma and shame attached to having had mental illness. There is a dearth of mental health workers, as well as lack of government funding and resources, resulting in the inability to provide adequate services for the population of 28.1 million people (UNDP, 2019). Despite this, some individuals and organisations are working to promote positive change in the mental health sector in Nepal and are attempting to do so through programmes with advocacy at their core by drawing on their skills and assets; their voice of lived experience of not just illness, but recovery.

This chapter will be divided into three sections. In the first section I will discuss the findings within the Koshish internal documents as well as their website and blog to determine how mental health advocates with lived experience are involved in advocacy for mental health in Nepal through local NGO Koshish, which is what research question 1 endeavours to answer. In section two, further discussion will seek to answer research question 2; to what extent active participation of former beneficiaries in advocacy leads to increased awareness and access to mental health services in Nepal. The ABCD approach will then be considered alongside the work of Koshish. Finally the chapter will end with concluding remarks and recommendations for NGOs working in the field of advocacy. I consider also some of the challenges they may face.

6.2 Research question 1

The immense stigma surrounding mental illness in Nepal is felt widely from those experiencing mental illness to those who are working as psychologists in the sector. Throughout the investigation of Koshish documents and their website/Facebook page, as well as the interview with Participant 1 (founder of Koshish Nepal), I discovered that there are ten members of Koshish Nepal who have lived experience of mental illness alongside the founder Matrika Devkota. The involvement of these former Koshish beneficiaries as asked by research question 1, ranges from advocacy in small community settings, peer support groups with families of those who have a member with mental illness (past or present), to lobbying to larger networks such as the government and it's various ministries. Koshish's peer support programme (Document Four) outlines some of the key objectives of these peer support groups:

- Provide a safe, secure, confidential and trustworthy environment where participants can share bitter-sweet experience[s].
- Support the participants to connect with people with similar problems and enhance their social network[s] (Koshish, n.d., para. 3).

The work of Koshish allows members to provide solutions to those also suffering from mental illness and bodes well with the ABCD approach where people's strengths are celebrated in comparison to needs-based development which often disempowers those they are attempting to help (Mathie and Cunningham, 2008). Alongside this, Koshish members are involved in general administration work for Koshish, for example Keshar who is the receptionist, though he also shares his singing in order to advocate for mental health in Nepal. These members are important in aiding people to understand that mental illness is treatable, working on reducing stigma and discrimination amongst family members, communities and also towards mental health professionals. This marries well and demonstrates the transformative agenda of NGOs, where people-centred development sits at the heart of their work (Korten, 1990; Lewis et al., 2020).

Participant 1, founder of Koshish Nepal (2020) started this organisation from the ground-up by harnessing his existing assets which is his voice and social capital, seen as the cornerstones of the ABCD approach. He has now been working in the space for 16 years and continues to advocate for better mental health systems and awareness, speaking with those from the grassroots level to those in government who he now advises around mental health. Individuals and communities possess the ability to have a say in their own development and its processes (Muchina, 1995), which aligns with the "recovered" individuals working in mental health advocacy through Koshish Nepal. In the words of Muchina (1995) "a transformed people need no outside representation" (p. 4). It is suggested that the ABCD approach requires governments, donors and NGOs to rethink their own role, as if citizens are demonstrating their agency to achieve their own development, the external institutions must work with communities either in partnership or responding with action to citizen-led initiatives (Mathie et al., 2017).

The ABCD approach is evident in the work of Koshish with the members and the lived experience as the assets themself. This quote from Koshish's website supports this argument:

> Koshish promotes and advocate[s] for independent living, inclusion and meaningful participation of persons with lived experiences of mental health conditions and psychosocial disability through strategic advocacy and community based mental health and psychosocial support services in line with UNCRPD, 2006 at its core (Koshish, n.d., para 3-4).

6.3 Research question 2

Throughout the literature review and data collection, it is apparent that the government interventions and large-scale programmes in relation to mental health in Nepal are few, and it is usually NGOs that are left to fill the gap left by the government when it comes to social services and welfare provision in Nepal. When looking to answer research question 2, this case study on Koshish highlights the work that they do, and the impact that they are having not only at the grassroots level, but also with the government and its various ministries and municipalities.

There are various barriers that hinder the development of mental health care in Nepal, and the main barrier that came across in all documents studied, as well as all interviews undertaken, was stigma. When asked if people with lived experience of mental health in Nepal face any challenges, both psychologists responded:

> "Oh yes, they face a lot of challenges. First and foremost is the stigma" (Participant 3, psychologist, 2020).

> "The main challenge is the stigma in our society" (Participant 2, psychologist, 2020).

Thus in order to work toward better mental health care and awareness, stigma must be addressed. The best way to do this is through raising awareness of mental health issues; especially the idea people can receive treatment and can recover, with advocacy as a means of doing this.

Through NGOs work in advocacy they can establish a coordinating body, which has been demonstrated. For example, in Afghanistan NGOs assisted the government to establish a mental health department within the Ministry of Public Health, which had huge benefit to service coordination and policy development (Ventevogel et al., 2012). This research demonstrated that through the voices of those with lived experience of mental illness and their work in advocacy, those in higher positions of authority have been reached. Matrika (Participant 1, Koshish

founder, 2020) is now advising the government on mental health and has been invited to join the National Disability Steering Committee, which has been formed under the Ministry of Women, Children, and Senior Citizens. The role of this committee is to facilitate policy work in relation to disability. He was invited to join due to his work being noticed in advocating for psychosocial disability.

Grassroots are the “authentic voice” in advocacy (Nyamugasira, 2010, p. 303), which was evident throughout the exploration of Koshish documents and website/Facebook page. The following quote when discussing NGOs and advocacy resonates with this research:

> They see part of their mission as being to represent the political concerns of the poor, injecting the voice of the traditionally voiceless into international decision-making, facilitating the two-way now of information, and helping to make the world’s political and economic institutions more broadly accountable (Nyamugasira, 2010, p. 297).

This has been reflected in the work of Koshish, for example with Matrika (Participant 1, Koshish founder, 2020) filing the PIL in order to hold the government to take account. The connection between Koshish’s programmes and the theoretical lens of the ABCD approach is clear and is demonstrated through the various members of Koshish harnessing their existing assets to become their own “agents of development” (Mathie and Cunningham, 2008, p. 328). They have harnessed their existing assets such as their voice and social networks, to influence larger networks such as the government. Literature by Markulla (2019) recommended (based on findings) that lay psychosocial counseling be used as a fundamental part of mental health systems in low and middle-income countries. This draws on the ABCD principles, as the layperson is the asset in this instance, such as the case with Koshish and its community-based workers. This has proved beneficial in similar settings, where Upadhaya et al. (2014) stated, “in our experience, continued NGO lobbying and advocacy has made stakeholders more sensitive and responsive, resulting in increased coverage of mental health in government policies and programmes, and in the national media” (p. 118 – 119).

However, government participation is paramount to seeing long-term and structural change, as legal bodies will need to implement the mental health policy and increase budget to grow mental health services. Through a clearly defined public/private partnership approach, NGOs can

support the government. This has been seen as effective in many low and middle-income countries (Upadhaya et al., 2014). An example given is in Burundi where NGOs shifted their activities from service delivery to working with the government to strengthen their capacity and help to embed mental health and psychosocial support within existing health services and social systems (Pérez-Sales, Férnandez-Liria, Baingana and Ventevogel, 2011). Koshish is currently at the early stages of advising government, which will hopefully see improved and lasting change as time goes on. However, this will require ongoing liaison and coordination with the government. Government involvement is vital to influencing mental health policy and practice (Upadhaya et al., 2014).

6.4 Conclusion: Implications, significance, and recommendations

In conclusion, this research demonstrates that through harnessing existing assets of a small mental health community and utilising social capital, change can be made. The progression of NGOs over time has led to increased work in advocacy due to the view of advocacy having a greater effect on structural issues and root causes which perpetuate inequality and poverty. With mental illness and the promotion of good mental health sitting in the corner of priorities for the Government in Nepal, Participant 1 (founder of Koshish) has continued to work and advocate in this area and has since built up an organisation formulated of a network of people, including those with lived experience of mental illness. Koshish, as a result of its work in advocacy through its members, has made considerable impact in the field of mental health in Nepal. As Kretzmann & McKnight (1993) argued, development must start from within the community, including those who are marginalised, which is exactly what Koshish has done in effectively reaching the most marginalised through their rescue and rehabilitation programme, with some of those rehabilitated now advocating for greater awareness of mental illness in Nepal, and doing so effectively. As stated, "they will use what they have to secure what they have not" (Mathie and Cunningham, 2008, p.1).

This demonstrates that NGOs utilising their assets and working in advocacy can have a positive impact on government policy and awareness and can be applied in a broader context to other organisations working in the field of advocacy for areas lacking government support and awareness. The field of mental health in developing countries, let alone in Nepal, is an under-researched area, and further research on this topic would be beneficial in addressing the stigma

and reasons behind such neglect of the subject. Further research on this topic could also lead to increased services for those with mental illness and ensure the most vulnerable are reached. Although NGOs can be extremely effective in advocating and pushing the government to hold accountability, however, in the case of Koshish with Matrika, what will happen when this key advocate is no longer around? This is a question that would require further exploration.

6.5 Challenges

The impact of covid-19 on this research project meant that fewer participants could be involved, with the initial intention to interview 3-5 participants with lived experience of mental illness. Rich qualitative data could still be drawn from the stories and testimonials on Koshish's Facebook page and website, however in-person interviews could have provided more depth in this research. Further research on mental health in Nepal is still needed.

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Appendices

Appendix 1. Participant consent forms

[Print on Massey University departmental letterhead]
[Logo, name and address of Department/School/Institute/Section]

Beyond the stigma: Exploring the role of mental health advocates with lived experience, in advocating for better mental health systems and awareness in Nepal.

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read, or have had read to me in my first language, and I understand the Information Sheet. I have had the details of the study explained to me, any questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I agree/do not agree to the interview being sound recorded.
2. I agree/do not agree to the interview being image recorded.
3. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

I Dr. Lata Gautam hereby consent to take part in this study.

Signature: [signature] Date: 29/04/077.

If you would like a two-page summary of findings, please leave your email address below:

____

[Print on Massey University departmental letterhead]
[Logo, name and address of Department/School/Institute/Section]

Beyond the stigma: Exploring the role of mental health advocates with lived experience, in advocating for better mental health systems and awareness in Nepal.

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1. I agree/do not agree to the interview being sound recorded.
2. I agree/do not agree to the interview being image recorded.
3. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

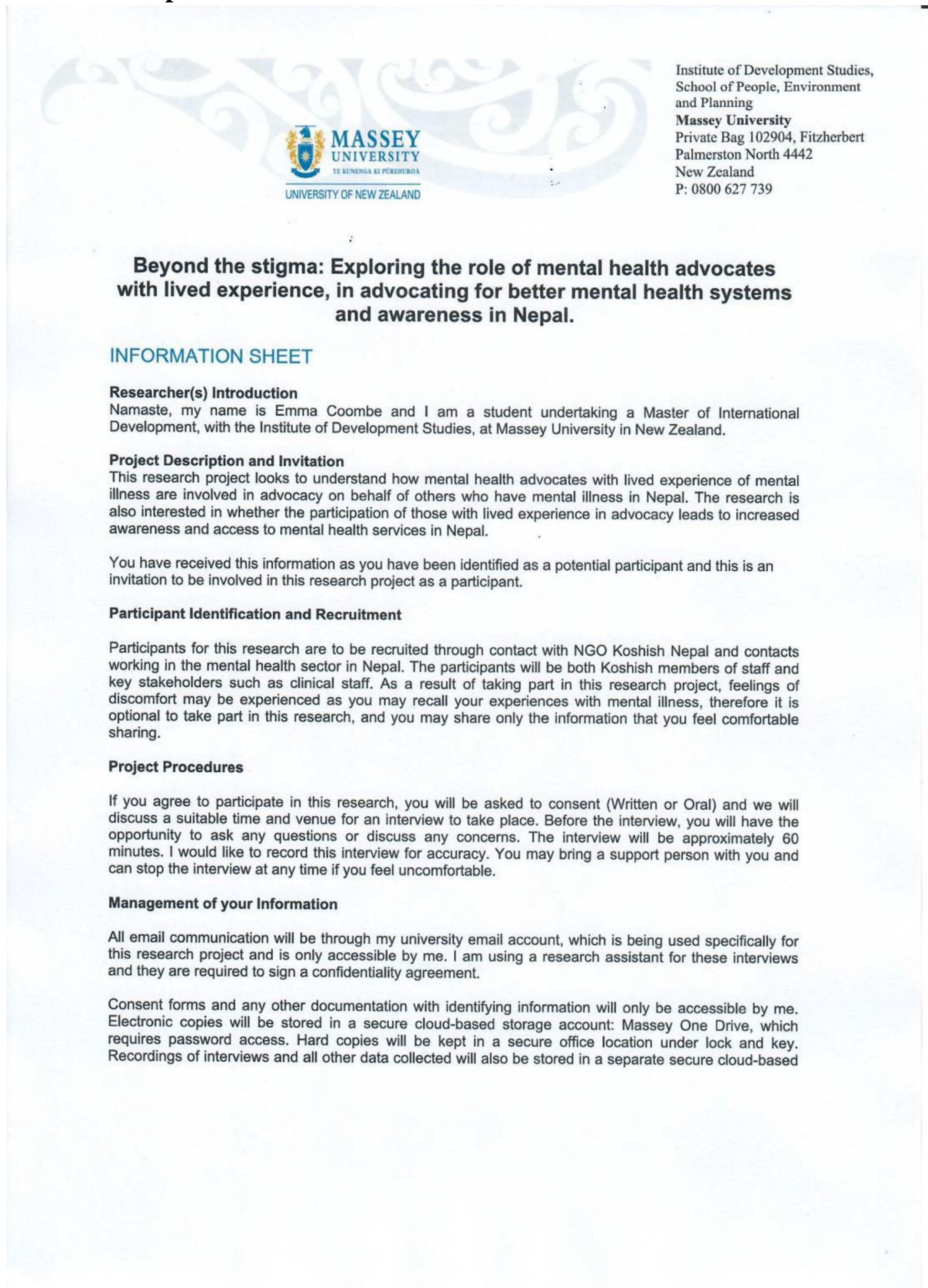
I TRISHNA [print full name] GHOSH hereby consent to take part in this study.

Signature: Trishna Date: 31st August 2020

If you would like a two-page summary of findings, please leave your email address below:

trishnaghosh@gmail.com

Appendix 2: Participant information sheet



Institute of Development Studies,
School of People, Environment
and Planning
Massey University
Private Bag 102904, Fitzherbert
Palmerston North 4442
New Zealand
P: 0800 627 739

Beyond the stigma: Exploring the role of mental health advocates with lived experience, in advocating for better mental health systems and awareness in Nepal.

INFORMATION SHEET

Researcher(s) Introduction
Namaste, my name is Emma Coombe and I am a student undertaking a Master of International Development, with the Institute of Development Studies, at Massey University in New Zealand.

Project Description and Invitation
This research project looks to understand how mental health advocates with lived experience of mental illness are involved in advocacy on behalf of others who have mental illness in Nepal. The research is also interested in whether the participation of those with lived experience in advocacy leads to increased awareness and access to mental health services in Nepal.

You have received this information as you have been identified as a potential participant and this is an invitation to be involved in this research project as a participant.

Participant Identification and Recruitment

Participants for this research are to be recruited through contact with NGO Koshish Nepal and contacts working in the mental health sector in Nepal. The participants will be both Koshish members of staff and key stakeholders such as clinical staff. As a result of taking part in this research project, feelings of discomfort may be experienced as you may recall your experiences with mental illness, therefore it is optional to take part in this research, and you may share only the information that you feel comfortable sharing.

Project Procedures

If you agree to participate in this research, you will be asked to consent (Written or Oral) and we will discuss a suitable time and venue for an interview to take place. Before the interview, you will have the opportunity to ask any questions or discuss any concerns. The interview will be approximately 60 minutes. I would like to record this interview for accuracy. You may bring a support person with you and can stop the interview at any time if you feel uncomfortable.

Management of your Information

All email communication will be through my university email account, which is being used specifically for this research project and is only accessible by me. I am using a research assistant for these interviews and they are required to sign a confidentiality agreement.

Consent forms and any other documentation with identifying information will only be accessible by me. Electronic copies will be stored in a secure cloud-based storage account: Massey One Drive, which requires password access. Hard copies will be kept in a secure office location under lock and key. Recordings of interviews and all other data collected will also be stored in a separate secure cloud-based

storage account Massey One Drive, which requires a password. This account will be accessible from my password-protected laptop.

If, as a participant, you wish not to be identified in this research, your identity will be kept confidential with the use of a pseudonym and removal of any identifiable data.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study (specify timeframe);
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B. If you have any concerns about the conduct of this research, please contact Professor Craig Johnson, Chair, Massey University Human Ethics Committee: Southern B committee, email humanethicsouth@massey.ac.nz

Project Contacts

Please feel free to contact myself or my supervisor if you have any questions about the project.

Researcher:
Name: Emma Coombe
Email: Emma.Coombe.1@uni.massey.ac.nz
Phone: +64 276259520

Supervisor:
Name: Dr. Rochelle Stewart-Withers
Email: R.R.Stewart-Withers@massey.ac.nz
Phone: +64 (06) 356 9099 ext. 83657

Dhanyabad! Thank you for taking the time to participate in this research.

Appendix 3 – Ethics approval letter

Date: 16 June 2020

Dear Emma Coombe

Re: Ethics Notification - **SOB 20/06** - **Beyond the stigma: Exploring the role of mental health advocates with lived experience, in advocating for better mental health systems and awareness in Nepal.**

Thank you for the above application that was considered by the Massey University Human Ethics

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand **T** 06 350 5573; 06 350 5575 **F** 06 355 7973
E humanethics@massey.ac.nz **W** http://humanethics.massey.ac.nz

Appendix 4 – Documents used in analysis

Document 1: National Mental Health Policy, Policy Document, 1996

Document 2: Koshish. (n.d.). *Advocacy and awareness* [White paper].

Document 3: Koshish. (n.d.). *CBR – Community-based rehabilitation* [White paper].

Document 4: Koshish. (n.d.). *Peer support* [White paper].

Document 5: Koshish. (n.d.). *RRR programme* [White paper].