



Nurturing the mind to achieve its potential

The Role of Peer Support in Exercising Legal Capacity





USERS AND SURVIVORS OF PSYCHIATRY- KENYA

THE ROLE OF PEER SUPPORT IN
EXERCISING LEGAL CAPACITY



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List of abbreviations

| | |
|---------------|---|
| CBT | Cognitive Behavioral Therapy |
| CRPD | Convention on the Rights of Persons with Disabilities |
| CTP | Cash Transfer Programme |
| ECT | Electroconvulsive therapy |
| FGD(s) | Focus Group Discussion(s) |
| SACCO | Savings and Credit Cooperative Organisation |
| USPK | Users and Survivors of Psychiatry Kenya |

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About the report

Users and Survivors of Psychiatry Kenya (USPK) is a national membership organisation whose major objective is to promote and advocate for the rights of people with mental health issues/conditions (people with psychosocial disabilities) in Kenya. USPK is affiliated with the World Network of Users and Survivors of Psychiatry (WNUSP) and the Pan-African Network of People with Psychosocial Disabilities (PANPEP).³

USPK established the first peer support group in Nairobi in 2012. Since then, USPK has established a total number of 15 support groups in Nyeri, Kiambu, Nakuru, Eldoret, Makueni and Machakos through the support of the Disability Rights Initiative of The Open Society Foundation and the National Council for Persons with Disabilities, Kenya.⁴ USPK also has a virtual support group on WhatsApp. USPK peer support groups are fully community-based, operate outside Kenya's mental health system and are not linked to any mental health institution.

In 2016, Users and Survivors of Psychiatry Kenya launched a research project on peer support and legal capacity funded by the Open Society Initiative for Eastern Africa. The objective of the project is to contribute to a better understanding of the link between peer support and the exercise of legal capacity by persons with psychosocial disabilities in Kenya. The research seeks a deeper understanding of how people with psychosocial disabilities use peer support to exercise legal capacity in Kenya.

The report maps out the relationship between peer support and the exercise of legal capacity, and delves into decision-making with support, decision-making without using peer support and substituted decision-making. The kinds of decisions addressed through peer support are tracked with concrete examples of decisions taken with the support of peers. The tools used in the peer support group to support someone to make a decision are also identified. On substituted decision-making, the perspectives of caregivers as well as those of persons with disabilities are explored. The report has three appendices which explore the principles of peer support; the role played by USPK staff during peer support group meetings and generally; as well as a list of coping strategies shared in meetings, focus group discussions and interviews.

³ Further information is available at Users and Survivors of Psychiatry Kenya ><http://www.uspkkenya.org/><

⁴ USPK support groups and membership as at 25 September 2017: Nairobi Support Group (60 members); Nairobi Mind Empowerment (11 members); Kiambu Support Group (18 members); Kayaba Support Group (25 members); Karindundu Support Group (26 members); Kiamabara Support Group (22 members); Kiamariga Support Group (17 members); Karatina Support Group (29 members); Create Support Group, Machakos (17 members); Itambya Support Group (16 members); Nakuru Support Group (16 members); Jalikaz Support Group, Nakuru (13 members); Uasin Gishu (Eldoret) Support Group (21 members). The USPK virtual support group on WhatsApp has 124 members.

Prologue

The journey to and through peer support is not linear. Many members of the USPK peer support group described a distinction between the 'place before peer support' and the 'place during peer support' and also described moving back and forth between these spaces. However, peers generally described how they were before peer support and how they are now different as a result of peer support. For the most part, these voices describe life before peer support:

I was in a cocoon

I was isolated and alone

If I expressed anger, others said: "have you taken your medication?"

I was obsessed with perfection

I was given drugs, but the doctor 'forgot' to mention that they would make me drool, gain weight, sleep for sixteen hours every day and become a shadow of who I used to be

Others were ashamed of me; I learnt to become ashamed of myself

Others saw me as defective...I learnt to see myself as defective and abnormal

I cut myself off from relationships out of a belief that no one could accommodate a person with a mental health issue

I build lots of walls around myself. It was "me against the world"

I could not tell the truth about myself, and what had happened to me

I felt that I was being controlled by others

I wore a mask, many different masks. I didn't even know who I am

I was stuck in a place of loss: lost my close relationships, lost my job, lost my motivation

*I felt that no one
understood me
Others accused me of
pretending, of being lazy, of
being self-indulgent*

Nothing made sense

*The illness dominated
every waking moment of
my life and became...my
entire identity. I became the
illness.*

*I was stuck in a lonely
place...my only solace was
medication, yet the side
effects were horrible*

*I was stuck in
a place of fear*

I was groping in the dark

*I kept asking over and
over again: "why is this
happening to me?"*

*I was burning with
questions. People who
love me were burning with
questions.*

*I was so dependent on my
family ...I lost my voice*

I was stuck

*My life stagnated
I became a closed book*

*I was hiding, if I wasn't
hiding, I was running.*

*I remember being terrified,
overcome with dread*

*I didn't know what was
happening to me. I didn't
know what to do.*

*I was stuck in a hopeless
place*

*When I looked at the
future, I saw myself as 'the
perpetual patient'*

*Whatever happened or
didn't happen was my
fault. I couldn't seem to do
anything right.*

*I wanted a savior to make it
all go away*

*I couldn't see beyond
myself and my problems*

*I felt abandoned...by
everyone, including God*

1. Introduction

Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) seeks to restore recognition of legal capacity, agency and personhood to persons with disabilities. The General Comment on the Right to Equal Recognition before the Law identifies peer support as part of 'support' used by persons with disabilities in the exercise of legal capacity.⁵ Emphasis is placed on "lived experience" of similar issues; and that peers 'have acquired the knowledge and expertise to support others going through difficult moments in their lives.'⁶

Peer support has been said to 'help advance a view of autonomy and decision-making'⁷ It has many benefits and has been described as 'a pure form of supported decision-making';⁸ an important tool during 'emergency decision-making moments';⁹ an 'integral part of recovery based services';¹⁰ and a source of valuable information about an extensive range of issues enabling persons with disabilities to make informed decisions.¹¹

Peer support is not recognized under Kenya's Mental Health Act, or in any other domestic law or policy in Kenya; hence, peer support is anchored in Kenyan law through the CRPD. Kenya ratified the CRPD in 2008. The CRPD forms part of the law of Kenya by dint of Article 2(6) of the Constitution of Kenya, 2010, which states that 'Any treaty or convention ratified by Kenya shall form part of the law of Kenya under this Constitution.'

The main research question explored in this study is: what is the link between peer support and the exercise of legal capacity by persons with psychosocial disabilities in Kenya? The study explores how people with psychosocial disabilities use peer support to exercise legal capacity in Kenya.

1.2 Background: Significant contextual elements

This section lays out important elements on the context in which peer support is occurring in Kenya. This section explores: the question of guardianship for persons with psychosocial disabilities in Kenya, the high rates of poverty and unemployment among persons with psychosocial disabilities and their families, limited state funded support and services, the fact that the majority of persons with disabilities live with their families, often in situations of dependency, the poor state of mental health care and treatment in Kenya, the distinction between peer support groups in Nairobi and in rural areas, and the lack of awareness on mental health issues in Kenya and associated stigma.

The General Comment on Article 12 of the CRPD unequivocally requires States Parties to abolish guardianship and to develop laws and policies replacing regimes of substitute decision-making by supported decision-making. In Kenya, the Mental Health Act (Section 26) and the Children's Act (Section 107) allow for guardianship and for the appointment of a manager to manage property on behalf of a person with disabilities. However, many people with disabilities in Kenya are not under formal guardianship.¹² None of the members of the USPKE peer support group in Nairobi is under formal guardianship and none of the interviewees as well as the participants in the focus group discussions is under formal guardianship.

In Kenya, the substitute decision-making model that is prevalent is informal substitute decision-making, that is to say social mores, customs and practices that violate the right to legal capacity of persons with disabilities. In these cases, even when a person is not legally under guardianship, family members and other third parties take decisions on behalf of the person as if the person were formally under guardianship.¹³

Another contextual issue that is important to raise is the high rates of poverty currently experienced in the country generally, and by persons with disabilities and their families specifically. In its state report to the Committee on the Rights of Persons with Disabilities (CRPD Committee), Kenya admitted that: 'The majority of persons with disabilities live in extreme poverty.'¹⁴ Many members of the Nairobi peer support group are currently unemployed. The following issues emerged from the research regarding poverty and unemployment. Sometimes, persons with psychosocial disabilities seek alternatives to medication primarily because they cannot afford the drugs that are prescribed them. At the same time, some alternatives, such as psychotherapy are even more expensive than medication.¹⁵

5 Committee on the Rights of Persons with Disabilities, 'General comment No. 1 Article 12: Equal recognition before the law' CRPD/C/GC/1 (2014) para17

6 WHO QualityRights Training to Act, Unite and Empower for Mental Health (pilot version) 'Realising supported decision making and advance planning' (2017) pg. 44

7 Piers Gooding, 'Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law' *Psychiatry, Psychology and Law* (2012) pg. 14

8 Robert D. Dinerstein, 'Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making' (2012) *Human Rights Brief* Volume 19 | Issue 2 pg.3

9 Piers Gooding, 'Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law' *Psychiatry, Psychology and Law* (2012) pg. 14

10 United Nations General Assembly, 'Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health' A/HRC/35/21 para 83

11 WHO QualityRights Training to Act, Unite and Empower for Mental Health (pilot version) 'Realising supported decision making and advance planning' (2017) pg. 44

12 For a detailed study of decided cases on the issue of guardianship of persons and appointment of manager over property of persons with psychosocial disabilities by Kenyan courts, see Elizabeth Kamundia 'The Right to Own and Manage Property and Finances by Persons with Psychosocial Disabilities in Kenya' *East African Law Journal* (Special Issue on Disability Rights) (2016/2017) 1-28.

Importantly, unemployment and poverty lead to dependence on family members and undermine power and agency. To illustrate, in one meeting, 'Member 1' shared that she is unemployed, lives at home with her parents and is experiencing a lot of conflict. Here is the record of one of the responses from a peer:

The member giving advice added that the ideal situation would be if Member 1 were to move out of home and live independently, because as long as one lives with one's parents there are likely to be rules and interferences in one's life. However, this member noted that member 1 cannot move out of home just yet because she does not have a job of her own: "this would only happen if you had a job of your own."¹⁶

Unemployment and poverty also impact an individual's self esteem. One member shared that she felt that her parents do not appreciate her, as she does not contribute to the family economically, unlike her siblings.¹⁷ A caregiver identified that his sister has not been employed in over fifteen years and noted that this has negatively impacted his sister's sense of self, and her ability to make her own decisions.¹⁸

Many of the members of the peer support group continue to live with their families, and to depend on them for their day-to-day needs. At the same time, many peers feel that there is too much interference in their lives from family members. Staff of USPK expressed frustration that however empowering peer support is, many members remain stuck in situations where their families make decisions for them, simply because they are dependent on their families. Hence, even when a member arrives at a decision with the support of peers, in the absence of a supportive family, such a member is likely to face significant challenges executing the decision.

13 In its concluding observations to Kenya, the CRPD Committee expressed its concern about 'the de facto guardianship in families of persons with disabilities that deprive persons with disabilities of their ability to make choices in aspects such as buying food, renting a house or inheritance'. The Committee recommended that Kenya 'eliminate all forms of formal and informal substituted decision-making regimes and replace them with a system of supported decision-making'. United Nations Human Rights Office of the High Commissioner for Human Rights 'Concluding Observations on the Initial State Report of Kenya' CRPD/C/KEN/CO/1 paras 23 and 24 (a) >http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fKEN%2fCO%2f1&Lang=en (accessed on 28 September 2017)

14 United Nations Human Rights Office of the High Commissioner for Human Rights 'Initial Reports of States Parties Due in 2010: Kenya' CRPD/C/KEN/1 para 226 >http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=48&DocTypeID=29 accessed 21 February 2017

15 Observation notes, meeting 3 held on 23 July 2016

16 Observation notes, meeting 4 held on 17 September 2016

The Government of Kenya does not make any provision for the majority of people who are unable to work due to disability. For a small minority of those unable to work due to disability, the Government has designed a Cash Transfer Programme (CTP) for persons with severe disabilities.¹⁹ The eligibility criterion under the CTP includes '[a] household with a person with severe disability and extremely poor households.'²⁰ Under the CTP, the government defines persons with severe disabilities as referring to:

[T]hose who need permanent care including feeding, toiletry, protection from danger from themselves or other persons, and from the environment. They also need intensive support on a daily basis which therefore keeps their parents and guardians / caregivers at home or close to them throughout.²¹

None of the members of the USPK peer support group have qualified for the Cash Transfer Programme. In addition, none of the interviewees or the participants in the focus group discussion has qualified for the Programme. The fact that there is limited state support and services in Kenya negatively impacts the exercise of legal capacity by persons with disabilities.²²

There are limited crisis support centres and other schemes for supported living in the community in Kenya. Many interventions in mental health are donor funded rather than state funded, although the government, for the first time in 2016 allocated funding to USPK to establish peer support groups in two counties. Members who are unemployed and whose living situation at home is difficult, or who would prefer not to live with their families have no state funded alternative in terms of shelter, as demonstrated in the following quote from the first focus group discussion:

so one of our members ...comes and says "I have run away from home" and she says the reason why she has run away is because she has she feels she is being over medicated, and she says the father is you know, is sexually harassing her, you know! And she said, "I am not going to go back to that house, I would rather sleep in the streets and be raped, but I am not going to go back home. And, and of course and it was difficult because we were saying we wish we had a respite where we would send her where she could be able to stay for three to four days as we pick up the conversation but in the end... we called the sister ... she was able to go to the sister's place and well, I am assuming she is much better."²³

17 Observation notes, meeting 4 held on 17 September 2016

18 Interview with DM held on 10 May 2017

19 In 2015/2016, the programme covered 45,505 households in the entire country, see the National Social Protection Secretariat 'Cash Transfer for Persons with Severe Disabilities' <<http://www.socialprotection.or.ke/national-safety-net-program/cash-transfer-for-persons-with-severe-disabilities-pwsd-ct>> accessed 21 February 2017

20 Ministry of Gender, Children and Social Development Guidelines for Identifying Persons with Disabilities for Cash Transfer (2011)

21 Ministry of Gender, Children and Social Development Guidelines for Identifying Persons with Disabilities for Cash Transfer (2011)

In some cases, peers provide shelter for each other based on the relationships that they have developed over time.²⁴ However, these arrangements tend to be temporary and are unsustainable in the long term.²⁵ Further on the lack of schemes for supported living in the community, one interviewee, a caregiver, expressed great concern about what would happen to her adult son with a psychosocial disability when she was no longer able to take care of him.²⁶

During peer support group meetings, peers discuss a wide variety of issues. One issue that remains prominent, especially among new members, is mental health care and treatment. Peers raised the following issues with regard to mental health care (specifically on mental health professionals and facilities): lack of information from psychiatrists (including information that is key to informed consent such as information on diagnosis and on side effects of drugs and therapies including electroconvulsive therapy);^{27, 28} limited choice on doctors and a high patient to psychiatrist ratio leading to low quality of care; and poor quality facilities (including facilities that have limited space for activities such as sports or physical exercise when one has been admitted to a mental health care institution). Kenya's main mental health care institution, Mathare Mental Hospital was largely depicted as non-therapeutic, a place where one goes as a result of having no choice.²⁹ One carer explained that her son refuses to go to Mathare Mental Hospital even when unwell, having been traumatised from prior experiences in the institution.³⁰

For the large part, access to good quality medication is limited (either because some of the good quality drugs are unavailable in Kenya or because the cost of the medication is prohibitive). One member shared that sometimes she takes half a pill to ensure the medication lasts longer.³¹ During one meeting, a member inquired as to whether USPK can meet the cost of medication.³² Many members shared that generally, psychiatric medicines have awful side effects.³³ A caregiver shared that her daughter sometimes refuses to take medication primarily because the medication makes her gain too much weight.³⁴ The general feeling among peers is that mental health care does not rank high on the government's priorities, particularly when it comes to resource allocation.

22 Article 12 of the CRPD requires that States Parties remove barriers to exercising legal capacity and establish support measures for people with disabilities to fully enjoy and exercise their legal capacity.

23 First focus group discussion held on 11 March 2017

24 Interview with HE held on 25 April 2017

25 Interview with HE held on 25 April 2017

26 Interview with EJ held on 27 April 2017

27 Observation notes, meeting 1 held on 28 May 2016. In the third focus group discussion, a participant shared that his psychiatrist actually opposed his joining USPK peer support group. Third focus group discussion held on 25 March 2017.

28 During the first focus group discussion, a member of USPK shared that he only understood that he had gone through electroconvulsive therapy upon joining the peer support group and hearing others talk about it. First focus group discussion held on 11 March 2017

29 Kenya's mentally ill, locked up and forgotten. <<http://edition.cnn.com/2011/WORLD/africa/02/25/kenya.forgotten.health/index.html>> accessed 14 April 2017

There exists a lack of awareness on mental health issues among the public in Kenya. Closely related to the lack of awareness are high levels of stigma against persons with psychosocial disabilities. While there is increased reporting on mental health issues in Kenyan media in recent years, stigma remains an issue of concern in mental health.³⁵ It is important to note that stigma is not the only response to mental health from the community in Kenya. One member shared about neighbours being empathetic and supportive,³⁶ whilst one member shared that she had had similar positive experiences upon disclosing to (some) friends and family that her daughter had been diagnosed with a mental health condition.³⁷

Stereotypes about persons with psychosocial disabilities feed stigma and discrimination. One common stereotype that has a particularly negative impact on the exercise of legal capacity by persons with disabilities in Kenya is the belief that persons with disabilities are incapable of making decisions.³⁸

In addition, stigma makes it difficult for people to access the support that they need in order to thrive in society.

I think the one thing I have noticed is lack of support on the outside: from families, from employers, from friends ... people just, there is stigma. Your family thinks that if you are depressed you can just snap out of it and so there is a lack of understanding and therefore a lack of support for a lot of the members by the outside... by society.³⁹

Finally, there is a distinction between the Nairobi peer support group and peer support groups in rural Kenya.⁴⁰ For example, in rural Kenya, USPK peer support groups break into groups of men and women when addressing some issues that may not be culturally appropriate to discuss in a mixed gender group; so far, these break-out sessions have not been necessary in Nairobi.⁴¹ In addition, peer support groups in rural Kenya incorporate elements beyond sharing, in particular, livelihood elements.⁴²

30 Interview with EJ held on 27 April 2017

31 Observation notes, meeting 5 held on 12 November 2016

32 Observation notes, meeting 3 held on 23 July 2016. The answer to the question as to whether USPK can meet the cost of medication is no, but USP-K can advocate for medication for mental health to be on the list of essential drugs.

33 Observation notes, meeting 8 held on 21 January 2017

34 Observation notes, meeting 5 held on 12 November 2016

35 Users and Survivors of Psychiatry in Kenya (USPKenya) 'How the Media in Kenya Reports on Disability, Mental Health and Suicide: A Study of Three National Daily Newspapers' (2013)

36 Interview with AN held on 26 April 2017

37 Interview with IN held on 25 April 2017

38 Third focus group discussion held on 25 March 2017

39 First focus group discussion held on 11 March 2017

Further, support groups in rural areas include many carers, and hence the risk of carers dominating in the support group is much higher in rural Kenya than in Nairobi.⁴³ Generally, there is greater social connectedness in rural areas as compared to urban areas. Hence, the element of providing support to each other outside the 'formal' peer support group meetings is more established in rural areas than in Nairobi.⁴⁴

1.3 Methodology

We observed a total of ten peer support group meetings.⁴⁵ In attendance at the peer support group meetings is a mix of old and new members; but the majority of those attending are old members.⁴⁶ Participants at the meetings include users, carers, friends, USPK staff members and people who go across all those 'labels'; however, the majority in attendance at each meeting are users and survivors of psychiatry.⁴⁷ On one occasion there was a lecturer of psychology at African Nazarene University in attendance.⁴⁸ Persons attending the peer support group meetings have a broad range of mental health conditions, including: bipolar disorder, alcoholism, schizophrenia, schizoaffective disorder, depression, epilepsy, anxiety, social anxiety disorder, attention deficit hyperactivity disorder and posttraumatic stress disorder.⁴⁹ Some members identified as having multiple diagnoses. The total number of people who attended the peer support group meetings in the course of the ten meetings was 164.⁵⁰

We conducted three focus group discussions (FGDs),⁵¹ with ten, nine and six participants respectively.⁵² In total, fourteen women and eleven men participated in the FGDs. Ten participants in the FGDs have attended the support group since 2013 (or before).⁵³ Thirteen participants have attended more than ten peer support group meetings.⁵⁴ Persons attending the FGDs have a broad range of mental health conditions, including: bipolar disorder, schizoaffective disorder, depression and social anxiety disorder.⁵⁵

40 Interview with LM held on 25 April 2017; Interview with HE held on 25 April 2017. Peer support groups in rural Kenya run by USPK exist in the following counties: Nyeri, Kiambu, Nakuru, Uasin Gishu (Eldoret), Makeni and Machakos. Note that there is no restriction on USPK members of rural peer support groups attending the Nairobi peer support group if they are visiting/when in the city

41 Interview with LM held on 25 April 2017

42 Interview with LM held on 25 April 2017; by livelihood elements, is meant aspects to do with securing the basic necessities of life.

43 Interview with LM held on 25 April 2017

44 Interview with LM held on 25 April 2017

45 The researcher observed a total of ten meetings held on 28 May 2016; 11 June 2016; 23 July 2016; 17 September 2016; 12 November 2016; 26 November 2016; 11 December 2016; 21 January 2017; 3 February 2017; and 25 February 2017. Eight of the meetings were held in an indoors setting while two meetings were held outdoors (one at Karura Forest and the other at the Nairobi Arboretum Park). In the two meetings held outdoors, a yoga session was facilitated after the meetings. On two occasions, in addition to sharing experiences, members also received training on various aspects of a human rights approach to disability.

46 'Old' members refer to those who have attended more than two peer support group meetings.

47 In some instances, members attend the peer support group meetings with their caregivers; while in some instances, caregivers attend unaccompanied by those they support.

We conducted eight interviews, with four female and four male interviewees. Five of the interviewees are carers and three are staff of USPK. Six interviewees are over thirty-eight years in age.⁵⁸ Five interviewees have attended USPK peer support group meetings for over three years.⁵⁹ Five interviewees have attended USPK peer support group meetings over ten times.⁶⁰

Qualitative methodology was chosen because we wanted a deeper understanding of peer support and hence needed to capture the complexity of people's meanings and experiences.

1.4 Limits of the study

1. The research was conducted in Nairobi, focusing on the Nairobi peer support group (for the observation element of the study). Interviewees and participants in the focus group discussions were also sourced from Nairobi. There are marked differences between life in rural areas and in urban areas in Kenya, and hence it is likely that some elements that are key to rural-based peer support groups are missing from this study.

48 Observation notes, meeting 9 held on 3 February 2017

49 When members introduce themselves, they are sometimes invited to identify their diagnosis (if they choose to). In asking people to identify their diagnosis, USP staff clarify that this is not about labeling yourself, rather it is a way of creating a safe space for new members / reassuring new members that 'there is no judgment here, you are among people who understand'.

50 There were 78 females and 44 males in attendance. 42 members are unaccounted for as the researcher did not indicate the gender of those in attendance for the first three meetings.

51 Three focus group discussions (FDGs) were conducted: the first FDG was on 11 March 2017; the second on 22 March 2017 and the third on 25 March 2017.

52 In the first focus group discussion (FDG) there were 4 females and 6 males; in the second FDG there were 6 females and 3 males and in the third FDG there were 4 females and 2 males. In terms of age, three participants were aged 18-24, five participants were aged 25-31, ten participants were aged 32-38, four participants were aged 38-44 and two participants were over 44 years. One participant did not indicate his/her age.

53 Of the remaining fifteen, one participant first attended the support group in 2014; five in 2016, and two in 2017. Seven participants did not indicate when they first attended USPK peer support group meeting.

54 Four participants have attended the peer support group for less than three times, three participants have attended the peer support group between four and seven times; four participants have attended the peer support group between seven and ten times and one participant did not indicate the number of times that he/she has attended the peer support group for.

55 Seven participants indicated that they have been diagnosed with bipolar disorder; five participants have been diagnosed with schizoaffective disorder; five participants have been diagnosed with depression and two participants have been diagnosed with social anxiety disorder. Two participants indicated that they have a dual diagnosis (one participant has a diagnosis of bipolar disorder and depression; and the other participant has a diagnosis of bipolar disorder and mood disorder). Four participants did not provide information on diagnosis.

56 The researcher conducted a total of eight interviews. The first four interviews were held on 25 April 2017; the second interview was held on 26 April 2017; two interviews were held on 27 April 2017; and the final interview was held on 10 May 2017.

57 Of the carers, three are male and two are female. Of USPK staff, two are male and one is female.

58 Of the remaining two, one is aged between twenty-five to thirty one while the other is aged between thirty-two and thirty eight years.

59 The remaining three interviewees have been attending USPK peer support group meetings since 2016.

60 The remaining three interviewees have attended USPK peer support group meetings between four and seven times.

2. The relationship between peer support and the exercise of legal capacity

The relationship between peer support and the exercise of legal capacity by persons with psychosocial disabilities in Kenya is multifaceted. On one level, there is a direct link between peer support and the making of certain decisions that have legal consequences. At a second level, the link between peer support and the making of decisions that have legal consequences is indirect. In these cases, peer support boosts agency and autonomy, which in turn boost the exercise of legal capacity. At a third level is autonomous decision-making, where peers assert that they do not always need to use peer support to make a decision. At this level, sometimes peers have already made a decision and only present the decision to the peer support group to receive feedback on a decision already made.

The first level is where there exists a direct link between peer support and the making of certain decisions that have legal consequences. This is especially the case with regard to mental health treatment decision-making. During peer support group meetings, members get information from each other, for example about the side effects of certain drugs, or of electroconvulsive therapy (ECT). Members also get information about human rights, including what others can or cannot do to you legally. Once members have this information, they are able to tell their family members: "I do not want to have ECT" or to assert to their doctor that ECT should only be used as a measure of last resort.

The second level is where peer support boosts agency and autonomy, which in turn boosts the exercise of legal capacity. In these instances, after attending peer support group meetings over a period of time, members start to 'reclaim' their voice and to become more assertive. In part, this may be because they see other people, who share similar diagnosis, making their own decisions and being in control of their lives.

There are certain 'tools' that are used to boost agency and autonomy during peer support. First, peers challenge each other.

For example, a new member, when introducing herself says:
"My name is Kim and I am Bipolar."

Very often, peers will immediately say: "You are not bipolar. Bipolar Disorder is a condition you have been diagnosed with. You are a person first; you are also many other things in life, which have nothing to do with the label of 'bipolar.'"

Secondly, often, new members are preoccupied with symptoms, and medication, and the search for 'the magic pill' that will restore them to a state of mental wellbeing. Older members will often question this, and bring in other aspects of the individual's life, basically asking: "What happened to you? What else is happening in your life right now that may be causing you distress (as opposed to the bio-medical conclusion of chemicals in one's brain 'firing wrong' and needing a pill to re-balance them)?" Another approach may be that a peer asks: "have you spoken to your doctor about these side effects?"

Hence, often, peers pose questions to each other, and do not immediately jump right into the advice-giving zone. This presents opportunity for the person to be heard, room to talk, and allows the person to make sense of his or her own experiences. This is important for building relationships of trust, for self-reflection, and for enabling the person to take back their power and their voice. In essence, the individual then goes out into the world with a different outlook – as an empowered agent, rather than an object of treatment.

The third level is autonomous decision-making. Here, members of the USPK support group made it very clear that they do not always use peer support to make decisions, and that they often make decisions autonomously/without the input of peers – same as everybody else. Sometimes, the members share with their peers the already made decision, and sometimes they do not. Members of the USPK support group expressed a need to have these decisions accorded equal respect. They shared about being denied the 'dignity of risk', and how powerless this makes them feel. They spoke about having the right to make mistakes – just like everyone else.

It is important to note that for some USPK members, peer support is the main tool for decision-making, whilst for others, it is one of a range of tools that the members use to make decisions.⁶¹

61 Second focus group discussion held on 22 March 2017
62 Observation notes, meeting 4 held on 17 September 2016
63 Observation notes, meeting 4 held on 17 September 2016
64 Observation notes, meeting 5 held on 12 November 2016
65 Observation notes, meeting 2 held on 11 June 2016
66 Observation notes, meeting 6 held on 26 November 2016

3. Kinds of decisions addressed through peer support

Members of USPK (both carers and persons with psychosocial disabilities) bring a whole range of decisions for discussion during peer support group meetings. This report focuses on decision-making issues raised by persons with psychosocial disabilities and omits instances where carers sought support with decisions. Many decisions that are brought to peer support are not decisions that have legal consequences. However, as will be discussed in more details in Section 5, peer support does directly boost agency and autonomy, which in turn enhances the exercise of legal capacity by persons with psychosocial disabilities.

The following are examples of decisions discussed during peer support in the course of the research period:

- I would like to quit psychiatric medication. How do I know if it's the right thing to do?
- As a woman with a psychosocial disability, should I have children or not?
- What do I do about my jobless situation in this period when it is so difficult to get a job?⁶²
- Should I leave Kenya for the US to try out for a new life there at the invitation of my cousin?^{63 64}
- How do I deal with this problematic legal issue that has befallen my brother in the absence of support from the rest of the family?⁶⁵
- How do I deal with this situation where I have met and fallen in love with a man who does not seem to feel the same about me?⁶⁶
- I have attempted suicide since the last peer support group meeting. What is the best way to deal with suicidal feelings?⁶⁷
- I have the possibility of getting a job outside Nairobi, which would require me to live alone for the first time in many years. Should I take up this new job if it means having to live far from home?⁶⁸
- I am stressed about my sexual past. Should I disclose to my fiancé that I was sexually abused as a child and suffer from Post-Traumatic Stress Disorder? Should I tell him about having had multiple partners in the past?⁶⁹
- I no longer enjoy the career I am in, and feel that I would be in a better career if only I'd had the opportunity to pursue the vocation I wanted. I feel stuck, and don't know what to do.⁷⁰
- I have been a Sunday school teacher for a while but I no longer want to continue in this role, even though my mum thinks it's the best thing for me. What do I do?

4. Decision-making with support

This part focuses on instances where peer support is the main tool used by USPK support group members for decision-making. At the same time, it is important to point out that members often describe the importance of having multiple sources of support for decision-making⁷¹

In the first place, peer support enables members of the USPK peer support group to get into an optimal decision-making space of mind for a variety of reasons. First, peer support enables USPK members to share deeply about coping strategies.⁷² For example, often, 'advice' is in form of members sharing what they do to cope, rather than telling others what to do. Over time, new members adopt those coping strategies,⁷³ and are better able to cope with different situations in life, including decision-making. To illustrate, in the course of the third FGD, a peer identifies that before peer support, one is in a place of self-hatred.⁷⁴ In this situation, it is difficult to make good decisions, because there is little care for the self:

if ...one or two people out there who are hard to themselves, ... because when you are hard, when you hit yourself, to an certain level ... you end up making really wrong decisions because, after all who cares, you know?⁷⁵

Another participant shared that peer support has helped her have fewer relapses. Arguably, one is in a better decision-making space of mind when not in a crisis:

I am not seeing any therapist. So I feel the group has really helped me, because if I have an issue and there is no support group, I would call somebody who really understands and would give me some coping mechanisms and tell me try this, try that, you know? And then when I try, I get myself up again ...so it has made me maybe not relapse and if I was alone I would be maybe thinking I am going through this all alone, I would have relapsed I don't know how many times last year or something.⁷⁶

67 Observation notes, meeting 4 held on 17 September 2016

68 Observation notes, meeting 6 held on 26 November 2016

69 Observation notes, meeting 7 held on 11 December 2016

70 Observation notes, meeting 9 held on 3 February 2017

71 Observation notes, meeting 10 held on 25 February 2017

72 For full list of coping strategies, see Appendix 3

73 As demonstrated by peers who say that since beginning to attend peer support group regularly, they are hospitalized less and/or have reduced their reliance on psychiatric drugs.

74 Third focus group discussion held on 25 March 2017

75 Third focus group discussion held on 25 March 2017

76 Third focus group discussion held on 25 March 2017

77 Kiu was matching back and forth, mumbling to himself and occasionally shouting

78 First focus group discussion held on 11 March 2017

Secondly, peer support enables members of USPK to form relationships with each other. These relationships exist beyond the peer support group meetings, even in the absence of formal support agreements. In one instance, a member of USPK (Ewo) came across another member (Kiu) having a crisis in Nairobi town.⁷⁷ Ewo tried and failed to get the attention of Kiu. The next step that Ewo took is to call a number of peers to find out if anyone had the contact details of Kiu's relatives. One member of USPK had the contact details of Kiu's brother in law, who was called and arrived promptly. In the meantime, Ewo stayed with Kiu. Eventually, Kiu agreed to seek medical attention accompanied by his brother in law.⁷⁸ While this example may not demonstrate support for decision-making *per se*, it does show how supportive the relationships that exist among peers in the support group are.

Thirdly, the process of sifting through the different perspectives and advice given during peer support meetings was said to trigger self-reflection, which is also helpful for decision-making. As one participant noted:

one will first try and internalize [the advice given] and also look at it from the different perspectives ... but literally they really help you discover yourself and in that process they help in the decision making⁷⁹

Fourthly, peer support presents a non-coercive environment for decision-making, which reinforces individual autonomy, as the decision remains that of the individual. In other words, peer support re-affirms the individual as the decision-maker:

You know what helps? Nobody says, "You should." It is always "this has been my experience" so the whole thing you know, that whole thing of, you know somebody trying to force you, you know or trying to yeah - basically trying to force you to do XYZ is not there.⁸⁰

In peer support, the individual initiates the conversation about their situation and remains at the centre of the conversation while retaining full decision-making power.

⁸¹In cases where the discussions stray too far from the individual, staff of USPK will often bring the person back into the conversation and ask them: "Would you feel comfortable with what is being suggested?" This is a way to remind the person that the power to decide and act remains theirs, and to make sure that the peer support space does not become yet another space where the voice of the person with a psychosocial disability is taken away.⁸²

⁷⁹ Third focus group discussion held on 25 March 2017

⁸⁰ Third focus group discussion held on 25 March 2017

⁸¹ First focus group discussion held on 11 March 2017

⁸² Observation notes, meeting 10 held on 25 February 2017

⁸³ First focus group discussion held on 11 March 2017

⁸⁴ First focus group discussion held on 11 March 2017

⁸⁵ First focus group discussion held on 11 March 2017

⁸⁶ First focus group discussion held on 11 March 2017

Seeking support for decision-making from peers does not necessarily mean that one must make the decision peers think is best. There are a number of instances described in the course of interviews and FGDs where USPK members brought a decision to the peer support group, listened to the different insights offered by the group and went ahead to make a decision that is different from what the majority in the group felt would be the best decision. The following quote illustrates this aspect using a decision on education and career choice:

All of us we kept telling him "you can't finish an engineering course, you can't." The mother and the family we talked to him but he said I can ... and I will and it took him 15 years but now he is an engineer. You see, so, so, so assuming he followed what we were saying as peers and what the parents were saying?⁸³

On the same issue of making one's decision regardless of the perspectives received from peers, a different member in the first FGD stated:

I think you will go by what makes sense to you, your own view of the world ... which is different from everyone else's so your own personal truth should guide you and your own personal value should guide you into making such decisions.⁸⁴

On the issue of whether a decision is 'good' or 'bad', members of the USP-K support group make it clear that they value dignity of risk and hence have an equal right to make mistakes, same as everyone else. They also emphasized the need for respect for individual will and preferences:

At times people tend to think that us people with disabilities, it is like we are not supposed to make mistakes ...so for me it does not matter what we discuss, but if I choose a different path, it is basically the same concept with other people... It is just that in life I can choose what I want to do and live with the consequences, consequences of it. So, for me what is fundamental is respecting a person's will of preference.⁸⁵

Members of USPK peer support group explained how when they want to make certain decisions, others decide that they only want to make those decisions because they cannot possibly be 'well.' They explained about not being allowed to make mistakes or to try different options in life:

I might have all the facts and everything [towards starting a business]. I have thought it out very well, then I go tell my mom, mom I want to do a certain project, and my mom says "No, haujakunywa dawa?" (Laughter) haujakunywa dawa? [you have not taken your medicine]. And she insists even taking medication, so she can flip it around and say those medicines are not working for you ... let's go to hosi [hospital]. Right and probably if she had let me pursue that business, I would have become a success and I would have even supported her.⁸⁶

Peer support addresses this issue (of being denied the dignity of risk) by encouraging peers to try out new ways of being, to make mistakes if they must, with the knowledge that the understanding and support of peers will be there regardless of the outcome of one's decision.

In many instances, peer support acts a source of information to aid decision-making.⁸⁷ To illustrate, a member of USPK may seek to make a decision to quit medication. From the peer support group, the individual will gather information on a variety of coping strategies, and it will be up to the individual to choose whether indeed to quit medication or not and what alternatives to medication to employ.⁸⁸ In another instance, a member found out that electroconvulsive therapy (ECT) should only be used as a treatment of last resort (if at all) from the group.⁸⁹ Further on electroconvulsive therapy, one interviewee stated:

I know there are many people who have completely refused to use ECT based on what they heard and experiences of others within the peer support group. They would say "I do not want to use ECT because I have heard [a peer support group member] talk about the effect on the memory lapsing and all that...." so yeah I have seen people make yeah especially in medical decisions based on the kind of information they actually get within the support group.⁹⁰

Peers noted that even when information acquired from the peer support group meetings is not immediately applicable, a time in the future often comes when the information becomes applicable.⁹¹

In addition to being a source of information, in many instances, peer support acts as a source of advice and insights to aid decision-making.⁹²⁻⁹³ The advice and insights shared in peer support is based on personal experience (tested and tried by the individual sharing the advice) and hence is felt to be even more powerful.⁹⁴ Peer support offers a diversity of views in a non-judgmental environment and it is up to the individual to choose whether or not to use advice received from the group to make a decision.⁹⁵⁻⁹⁶ As one participant stated: 'what peer support does for me as far as decision-making is concerned is it gives me perspectives that I may not have been able to find on my own.'⁹⁷ Another participant noted that:

87 Interview with LM held on 25 April 2017

88 Interview with LM held on 25 April 2017

89 First focus group discussion held on 11 March 2017

90 Interview with LM held on 25 April 2017

91 Third focus group discussion held on 25 March 2017

92 Observation notes, meeting 2 held on 11 June 2016

93 Interview with LM held on 25 April 2017

94 Interview with AM held on 25 April 2017

95 Second focus group discussion held on 22 March 2017

96 Third focus group discussion held on 25 March 2017

97 Second focus group discussion held on 22 March 2017

what I have seen work is when one has an issue, a personal issue and then you will throw the question on the [group] and then you will get around ten to fifteen or even twenty different perspectives from different individuals and different personalities so when it comes to analyze that I am very, very sure it has helped people make good decisions.⁹⁸

Participants also felt that peers do not quickly jump to (negative) conclusions about a person's capabilities in the same way as well meaning friends and relatives do. It was emphasized that instead, peers present different options and then 'help the person weigh their options'.⁹⁹

4.1 Examples of decisions taken with the support of peers

In some instances, members of USPK make decisions directly based on advice or information received from the peer support group meetings. In the course of the first FGD, one participant made it very clear that her decision to refuse electroconvulsive therapy is directly linked to conversations about informed consent that have taken place in the peer support group meeting:

But ECT are not good you know! It [peer support] enlightens you up...I remember when we used to ...Janet, I remember she used to talk about what? Informed (MV: Consent) ya and aa we were all enlightened about ECT, you know, but you don't just go and the doctor says it is ECT and it is electricity in the brain and all that! You have to be consulted (MV & EE: Ya) whether you are sick or not even if you are still sick, your mind is still there ... and you can still remember what you have heard or what you have learned (EK: Aha) yes, so it [peer support] makes us enlightened. It is very important.¹⁰⁰

This case study presents a clear link between having attended peer support group meetings and making decisions that have legal consequences.

In some instances, members of USPK explicitly ask their peers: what decision should I make here, and in subsequent meetings describe having taken the advice of peers to make a decision. In one peer support group meeting, a member shared about her cousin asking her to take steps towards moving to the US.

98 Third focus group discussion held on 25 March 2017

99 Third focus group discussion held on 25 March 2017

100 First focus group discussion held on 11 March 2017

101 Observation notes, meeting 3 held on 23 July 2016

102 Observation notes, meeting 4 held on 17 September 2016 (including seeking more information about what her source of income would be if she relocated and disclosing her condition to her cousin)

103 Observation notes, meeting 4 held on 17 September 2016

104 Interview with HE held on 25 April 2017

105 Observation notes, meeting 6 held on 26 November 2016

She asked: "Do I go out of the country or not?"¹⁰¹ In a subsequent meeting, the member informed the group that she decided to have further discussions with her cousin who lives in the US before deciding on whether or not to apply to leave Kenya for the US.¹⁰² In a separate peer support group meeting, a member shared about having tried to commit suicide and asked how to deal with this. She received a variety of views from the group and ultimately (in the course of the same meeting) expressed that she would not try suicide again, stating: "I will die when God has decided that it is my time to go."¹⁰³ In the course of carrying out interviews, staff of USPK gave this example and said:

I will give one [example] of suicide or one wanting to take their own life and hearing advice and they don't...So I think that has been a transformation for someone from a very hopeless situation to now a situation where there are saying, now I will keep living.¹⁰⁴

In a separate peer support group meeting, a member (Member 2) sought advice about whether or not to pursue an employment opportunity that would have her working away from home and living alone for the first time since receiving her diagnosis. While she was excited about the opportunity, at the same time, she was worried about how she would cope alone and whether she would be able to manage having a new job and being away from home. She sought advice about whether taking the job is a good idea. Most USPK members encouraged her to take the risk and 'go for it'.¹⁰⁵ In a subsequent meeting, member 2 described that she had decided to take up the job and was waiting to hear more from the prospective employer.

In a separate meeting, USPK staff followed up with a member on how she was managing her finances, following a session in which she had received advice on managing personal finances. She responded that she is planning better, but financial constraints still exist:

I now pay all my bills first. In the course of the first week after receiving my salary, it is all finished. This bothers me and I wish I could get someone else to write for.¹⁰⁶

Another member decided, based on discussions in the peer support group meeting, to be employed in the family business rather than to seek employment elsewhere, given the many experiences of discrimination in the work place shared by peers.¹⁰⁷ Another participant shared that his decision to switch careers from procurement to counseling psychology came from hearing his peers (who were studying counseling psychology) share their experiences.¹⁰⁸

During the first FGD, a participant shared that the support group helped her make a decision regarding whether or not to have children.

For me, it was deciding whether I wanted to have children or not. My first meeting here ... well, I wasn't sure that I would be in a position to be able to have kids, because, you know coz of issues of transferring like whatever you know, my condition to the baby, or, being unfit in general ... they really reassured me into you know motherhood is just for everyone right? So I set aside the judgments of society and understood that so long as there is a support then I will be fine.¹⁰⁹

The foregoing example demonstrates that autonomy is relational: "because my peers have had children, are mothers and have survived and even thrived, perhaps I can too."

In a different meeting, one member shared that she was having trouble with motherhood, and that she did not want to have another baby, and was considering having tubal ligation (TL). She sought advice on this issue.¹¹⁰ Peers presented different contraceptive options and reached the consensus that it was better to take a less permanent method of contraception, because the stressful motherhood period that she was going through was bound to be short-lived.

Peer support makes it possible for individuals to try different behavior and take risks; this is especially the case with taking or not taking psychiatric drugs. Some participants shared about going off psychiatric medication as a result of discussions held in the peer support group meetings. For example, during the second FGD, a participant shared that from the peer support group meetings, she had decided to go off medication and if she ever has to go back on the drugs, it would be for a limited period of time.¹¹¹ Another participant echoed this position:

I never imagined that someone with depression could survive without medicine but here I met people who are living and you know they tell you I have not had medicine for this long and this is how I have been coping... I stopped taking medicine, I was doing quite okay I came to the group and said it.¹¹²

106 Observation notes, meeting 10 held on 25 February 2017

107 First focus group discussion held on 11 March 2017

108 First focus group discussion held on 11 March 2017

109 First focus group discussion held on 11 March 2017

110 Observation notes, meeting 5 held on 12 November 2016

111 Second focus group discussion held on 22 March 2017

112 Second focus group discussion held on 22 March 2017

In one instance, an individual shared about going off psychiatric medication for a number of years, and then resuming taking the drugs again, this time from a perspective of informed consent:

Then I was able to go off my medication, I was actually off my medication for four years, but at the point that I went back on medication last year in February I felt that I had listened over a long time to all the different opinions about medication, the different experiences with medication that for me ... I knew that at that moment in time that I was going back on the medication, it was the best thing for me at that point.¹¹³

It is clear that the participant is the decision-maker, who is making an informed treatment decision based on her own experience and the experiences of peers. She is making a choice rather than acting from compulsion.

Another treatment decision that is often made using peer support is the decision to see a therapist:

Because of the group and people going through the basics of oh, have you ever heard of CBT [Cognitive Behavioral Therapy]? Me I was like ... I had never heard of it so that is why I made the decision this year, it was now to go into proper therapy.¹¹⁴

One question posed during the FGDs regards whether members of USPK would use peer support to make decisions in the future. All the participants answered in the affirmative.¹¹⁵

4.2 Multiple sources of support beyond peer support

Members often describe the importance of having multiple sources of support for decision-making.¹¹⁶ In addition to the support of peers, members of USPK support group indicated that sometimes it helps to have someone in a neutral position assist, particularly in negotiations with family members where the bargaining power of the person with a psychosocial disability is less because of dependency of the person on the family or for other reasons. In some cases, members of USPK have developed therapeutic relationships with their psychiatrists or psychologists who are then able to play the neutral position in protecting the individual's decision from being overtaken by the family.¹¹⁷

Another participant described that he has a network of friends who offer him support around certain decisions. He added that the issue is not one of whether or not he should be allowed to make decisions, but rather 'it is an issue of what systems and supports I put in place basically to deal with those times which, which, when I might not be able to make, you know a particular decision'.¹¹⁸

Another participant highlighted the importance of having someone in her life who knows her wishes if she were in a crisis situation, in terms that described an advance health care directive.¹²⁰ She gave examples of wishes that would be important to share with a supporter: the consequences of certain drug(s) on her wellbeing, the hospital one prefers to attend, and individuals to whom to disclose (or not disclose) mental health condition to.¹²¹ On the other hand, another participant felt that even if she had an advance directive in place, her family would not take it seriously and would proceed to act against her expressed wishes.¹²² Another member suggested that involving one's family in preparing the advance directive would make it more likely for the family to uphold the directive.¹²³

There was also a discussion on advance planning for suicidal times. One member advised members to prepare a text, a 'help' text in advance, and in advance identify the three people to whom one will send the text when one feels desperate:

You are the driver of your life, we can tell you all these things, but you are in control, and you have to decide that you want to live...you are the decision-maker...you have to decide in advance that you will call someone. In this way, your friends know in advance that you might someday call on them to help you.' ¹²⁴

¹¹⁷ Second focus group discussion held on 22 March 2017; Interview with EJ held on 27 April 2017

¹¹⁸ First focus group discussion held on 11 March 2017

¹¹⁹ Third focus group discussion held on 25 March 2017

¹²⁰ The Health Act of Kenya presents an opportunity to have an advance health care directive at section 9(1)(a)

¹²¹ Third focus group discussion held on 25 March 2017

¹²² Third focus group discussion held on 25 March 2017

One participant emphasized that there is a place for peer support and a place for family support and that the two are not mutually exclusive. The participant emphasized that the important thing is that it is the person himself or herself who is choosing who should support them, and for how long. The power and agency should remain with the individual:

Sometimes they [peer support and family support] complement each and sometimes you will be like, okay, I will go towards the peer less and the family more. Practically there are situations where I cannot talk to family and there are things I can talk to family and not peers so it depends on you.¹²⁵

One participant highlighted that when it comes to financial decisions, he protects himself from making impulsive financial decisions by having a joint bank account or keeping his money in accounts that have restrictions:

I hardly keep money in accounts where I can access it or cash. So I have like SACCO [Savings and Credit Cooperative Organisation] accounts, where I can't go and get the money. I have an account with my mom, so I will take a certain part of my money every month and put in a joint account with my mom... it is basically about that long-term relationship which I have with my mom... also then I have accounts where I have made ATMs which have limited times which I can withdraw money.¹²⁶

One participant emphasized the importance of reading broadly about an issue before taking a decision in order to gain a good understanding of existing solutions or options of addressing the issue.¹²⁷

¹²³ Third focus group discussion held on 25 March 2017

¹²⁴ Observation notes, meeting 6 held on 26 November 2016

¹²⁵ Third focus group discussion held on 25 March 2017

¹²⁶ First focus group discussion held on 11 March 2017

¹²⁷ Interview with IN held on 25 April 2017

¹²⁸ Second focus group discussion held on 22 March 2017; during the first focus group discussion, one participant said that it is 'disempowering' when others make decisions for you. Another participant in the first focus group discussion stated that 'it is a thin line between making a decision, and taking the power from that person while making decisions for that person' First focus group discussion held on 11 March 2017

¹²⁹ Second focus group discussion held on 22 March 2017

¹³⁰ First focus group discussion held on 11 March 2017

Participants emphasized that there is real harm that is suffered when decisions about an individual's life are taken by other people.¹²⁸ At the same time, peers acknowledge that sometimes the impairment can affect decision-making and it may be necessary at times to have the support of others in making decisions. The important element in peer support is the consensual aspect. When peers come into contact with the impairment, their reaction is not to use force, rather it is a dialogic process in which the person is then supported to make his or her own decision.¹²⁹

Participants in the first FGD agreed that there are creative ways to seek support and protection for decision-making. The key idea is that these ways should not be disproportionately applied to the individual based on their diagnosis, should be chosen by the person herself, and should not unnecessarily restrict the person's individual choice. In addition, participants emphasized that the person one chooses to support decisions outside peers should be a person with whom a relationship of trust exists.¹³⁰

5. Peer support boosts agency and autonomy which in turn boosts the exercise of legal capacity

In many cases, peer support enhances an individual's ability to make decisions, both big and small, legal and non-legal. Members of USPK peer support group meetings may not always bring a decision to the peer support group; however, attending the peer support group meetings over time boosts their autonomy and agency and ultimately enhances their ability to exercise legal capacity.

The prologue described peer support using a journey metaphor. If one takes the journey metaphor, the beginning of the journey (constituting the period after an individual experiences their first mental health crisis) often comprises a stripping of power away from the person. Paternalism by families, friends and medical professionals; the experience of distress and side effects of psychiatric drugs can make a person feel helpless, powerless and out of control.¹³¹ Another way through which power is stripped from the person in the initial stages is when everything the person says or does is attributed to the illness, and hence a person is not seen as an individual but rather as a holder of symptoms. Distinct personal traits are disregarded and general statements such as: "that's how people with bipolar are," take the place of individuality. Peers described this 'attribution trap' as being frustrating, oppressive and ultimately disempowering.¹³²

The journey of peer support, can be seen as one of re-building what was torn down in that initial period. Journeying through peer support enables a person to develop a sense of himself or herself as a full and equal human being, and this is critical to taking back power, and ultimately, to exercising legal capacity. Peer support provides the opportunity to have others reaffirm you, encourage you, care about you, tell you that you have rights, encourage you to try new ways of being in the world – all of which are critical for re-building the person and having them make the shift from object to subject.

131 Third focus group discussion held on 25 March 2017. Before peer support, there is an over-emphasis on medication and treatment. Through peer support, individuals realize that medication is not always a panacea and that other possibilities exist for solving issues in one's life.

132 First focus group discussion held on 11 March 2017

133 First focus group discussion held on 11 March 2017

134 Interview with HE held on 25 April 2017

135 Interview with AM held on 25 April 2017

This part will explore the different ways through which peer support boosts agency and autonomy and ultimately enhances the ability of persons with psychosocial disabilities to exercise legal capacity. To start with, this part will examine some of the ways through which people are stripped of power on the basis of diagnosis.

Upon diagnosis, persons with psychosocial disabilities experience denial of their personhood in multiple ways. One member explained how she was denied the opportunity to serve in a Committee in her church because of her diagnosis. She was also denied the opportunity to sign a consent form for her husband to receive surgery because her husband's doctor knew that she has a mental health diagnosis:

You cannot sit in a church Committee you know! You can't be part of the congregation because of diagnosis, you cannot sign papers, and I wonder how many times do people sign things even without reading, ee?!¹³³

One way through which peer support boosts agency and autonomy, is by presenting an opportunity for an individual with a mental health diagnosis to witness other individuals with mental health diagnoses making decisions and exercising other rights. This challenges societal prejudices that may have been internalized by the individual, who then begins to see her life as full of possibilities beyond 'patient.' For example, one member described having decided to have children based on hearing from peers how they cope as mothers with disabilities.¹³⁴ Other members described going back to school or starting businesses as a result of interacting with peers who had taken these steps.¹³⁵

One participant described that through peer support, he shifted from seeing himself only as a holder of 'problems' into seeing himself as a person capable of having a family. Peer support presented this participant with the chance to see other peers in the role of 'spouses' and ultimately led him to see himself in the role of 'spouse.' The peers made it possible for the participant to think of himself in a different way, and showed, through sharing their lives that it is possible for people who share the diagnosis to live certain kinds of lives, or to have certain roles in society:

Yeah for me when I came here I found the likes of [names of USPK members withheld] who are married. And I was like wow! I have always had this phobia of marrying and I have issues, of bringing somebody into my problems, I always feared making that kind of decision of bringing somebody into my problems... But once we talked a lot and then these sessions gave me the courage, plus also seeing others are engaged and I decided to get married so I think it was purely the support group... I think that was one of the big things that happened. My decision [to marry], I took from this place.¹³⁶

Other meetings also demonstrated ways through which peer support boosts agency and autonomy by directly changing how people see themselves and how they act. Here is the record of one of the discussions observed during peer support group meeting:

One member stated that she could not talk in front of people just a few years ago, and now she has since gained the confidence to do so. For one member, when he first came to the support group, his mother did all the talking for him, but now he has taken back his own voice and is able to speak for himself.

A second way through which peer support boosts agency and autonomy, is by getting members of USPK to challenge relationships, which have unsatisfactory power dynamics. A commonly cited decision is the decision to question treatment decisions made by the doctor on one's behalf.¹³⁷

I think twice I have reversed a decision from the doctor to do an ECT [electroconvulsive therapy]. Yes, having already gone through it then having gone through discussions then so the best thing is I have been able to make a decision [not to have ECT] through support group.¹³⁸

Another commonly made decision regarding power imbalanced relationships is the decision to change doctors.¹³⁹

A member also reported that being in the support group had helped him make a decision on changing doctors, which was a difficult decision for him to make, and he only made it with the support of peers... Before that, he had a psychiatrist who was really 'old school' would not talk to him and only used to prescribe drugs. He thought that he had to stay with this psychiatrist that he had started off with. It was only after joining USP that it occurred to him that he had options, and he was able to make the decision to find a doctor who suited him better.¹⁴⁰

¹³⁶ Second focus group discussion held on 22 March 2017

¹³⁷ Interview with HE held on 25 April 2017

¹³⁸ Third focus group discussion held on 25 March 2017

¹³⁹ Observation notes, meeting 5 held on 12 November 2016; Interview with DM held on 10 May 2017; Interview with HE held on 25 April 2017; Second focus group discussion held on 22 March 2017. Caregivers also described changing doctors for the person they care for based on peer support: Interview with DM held on 10 May 2017 and interview with IN held on 25 April 2017

¹⁴⁰ Observation notes, meeting 5 held on 12 November 2016

¹⁴¹ Observation notes, meeting 4 held on 17 September 2016

Persons with psychosocial disabilities take back power from medical professionals in a variety of ways. One way is by rejecting labels (including psychiatric diagnosis) and defining themselves as people first. Another way is by re-defining their experiences and labeling 'symptoms' as positive. A third way is by changing unsatisfactory relationships with doctors, rejecting certain medications, and asking doctors for more information about diagnosis. A fourth way is by rejecting doom-filled messages about their own mental health. An example of the latter is where a psychiatrist says: "with this diagnosis you will depend on drugs for the rest of your life, will almost certainly never have a job, or a family." Instead of taking this dire prediction as 'truth', persons with psychosocial disabilities take back power by rejecting such messages and believing in their ability to recover and to be included in society on an equal basis with others.

Another commonly cited decision that relates to power imbalanced relationships is the decision to challenge family members, take back power from them and act in one's own interests. In one case, a member described how her husband did not support her enrolling for a degree, citing that it might be too stressful for her and that they did not have the money for her education. She saved for a year before finally being able to pay her own fees.¹⁴¹ In sharing this experience, the member modeled agency. Over time, new members hear such stories over and over again and start to create a different picture of the possibilities that exist for persons with psychosocial disabilities.

A third way through which peer support boosts agency and autonomy, is whereby members of the support group encourage each other to plan in advance for crisis situations. These 'advance plans' are often verbal, shared with a person with whom a relationship of trust exists.¹⁴² In one meeting, a member shared about having suicidal thoughts. In encouraging her to disclose this information to her fiancé, a member said:

Does your fiancé know about the suicidal thoughts? It might be important for him to know. For me, I told my fiancé the signs to look out for. If I haven't showered for 3 days for example, its downhill...If I am in pajamas all day that's also not a good sign, he should look out for these.¹⁴³

During the second FGD, one participant broke from the discussions to encourage members to look into and set up advance directives in preparation for future crisis situations. Advance directives were seen as one of the ways of taking one's power back.¹⁴⁴

¹⁴² Observation notes, meeting 7 held on 11 December 2016; Interview with EB held on 27 April 2017; Second focus group discussion held on 22 March 2017

¹⁴³ Observation notes, meeting 7 held on 11 December 2016

¹⁴⁴ Second focus group discussion held on 22 March 2017

A fourth way through which peer support boosts agency and autonomy is through self-advocacy. Participants described situations in which they were able to speak up for themselves where before they would just have been silent. In one case, a participant described how people with psychosocial disabilities are tied up and injected by force, and described that she no longer tolerates this kind of treatment:

...but me they handle me carefully even my husband, if I am sick, handle me like a person because I will get well and you will see the repercussions.¹⁴⁵

Further on self-advocacy, one member of USPK who is a teacher described how he advocated for reasonable accommodation for himself at his workplace:

Since 2009, I haven't had much problems. I went to the Principal of my school, to the Teachers Service Commission, to the District Education Officer and I took them a letter from the doctor saying I have a mental illness. Then they came to the school and they do support me. I don't attend morning duties. My lessons start at 9.30am. If I am not well, I go to the principal and say and then I go, I don't work.¹⁴⁷

Participants also described taking part in advocacy efforts generally. I also feel am headed in the right direction because through USP Kenya, the sharing gave me confidence. I have been able to participate in the community and also to do media campaigns without that stigma of "I'm feeling low." I'm able to go out there and speak to other people as well as about the condition.¹⁴⁸

A fifth way through which peer support boosts agency and autonomy is through encouraging risk taking. This is particularly the case with the decision to quit psychiatric drugs,¹⁴⁹ or to suggest to one's doctor a different approach to one's treatment.¹⁵⁰ In one case, a participant described that she quit psychiatric drugs and 'depends mostly on counseling and peer support'.¹⁵¹ In another case, a participant described explicitly telling the doctor that he would not take the drugs prescribed:

I remember when I used to see Doctor [details withheld] then he prescribed for me some very funny medication, so I look at the medicine and I am like, it is banned in the US, it is banned in Europe and I took the medicine and I threw it and I told him, for me it does not matter if you are a doctor but I am not going to take this. Because surely if your medicine is banned in the US, there must be reasons why it is banned and all that. So that for me is the power of me having voice and recognizing that...¹⁵²

145 Interview with HE held on 25 April 2017

146 First focus group discussion held on 11 March 2017

147 Observation notes, meeting 10 held on 25 February 2017

148 Interview with AM held on 25 April 2017

One participant in the second FDG who had gone off medication as a result of hearing other peers describe having quit medication explained that even if you 'fail,' there is still benefit in trying. The fact of having tried to go off medication gives the person the chance to re-write the story of their relationship with medication not as something that is imposed by outsiders, but as something that is chosen by the individual himself or herself as an appropriate tool to cope.

Further on risk taking, in the second FDG, a participant described how his father edged him out of the family business because he did not believe he was capable of running it, and how he fought back:

I had the capacity to do it [run the family business after the father's retirement] but you can imagine now the decision he [the father] made against me now, that I am not fit enough to run the business. But eventually by the way, I forced myself in to do the business and then we had a quarrel with my other relative [who had been left in charge of the business by the father] and eventually I toppled them and I did very well by the way!¹⁵³

A sixth way through which peer support boosts agency and autonomy is through emphasizing the place of human rights in the lives of persons with disabilities. Staff of USPK during interviews emphasized that USPK encourages a holistic approach that focuses not only on medication and mental health care and treatment but also on human rights and other overarching issues that affect an individual.¹⁵⁴

I think in 2011 that is when we started understanding and getting the conversation around disability rights and also understanding the CRPD and then from there on gradually the support groups are then taking a different form that yes we have conversations around diagnosis and all that but then also we started having conversations around human rights, disability rights!¹⁵⁵

USPK has had several sessions of training members on their human rights.¹⁵⁶ In addition, in the course of attending meetings, many discussions would revolve around human rights issues, even when not explicitly named as such.

Finally, it is important to emphasize that autonomy is relational, as is demonstrated by the various decisions described in this section. Peers emphasize the importance of remaining the 'decision-maker,' and at the same time are comfortable about having been influenced by the peer support group either by hearing from different people who have made similar decisions in the past or by choosing to take an option suggested by a peer in the support group.

¹⁴⁹ Second focus group discussion held on 22 March 2017

¹⁵⁰ Second focus group discussion held on 22 March 2017

¹⁵¹ Second focus group discussion held on 22 March 2017

¹⁵² First focus group discussion held on 11 March 2017

Further on autonomy being relational, peer support provides peers with the opportunity to tell a different story about 'symptoms.' The peer support space is safe enough for the person to speak to others (with whom a relationship has been built) about perspectives that might not be popular in other spaces. There is also merit in having others peers witness an individual who has a different interpretation of symptoms. Here is the record of a meeting in which a peer shared a positive take on 'symptoms.'

One member (Member 3) who is opposed to medication shared that he views schizoaffective disorder as a gift, and resents that the medication suppresses the positive bits of the condition: "I like the hallucinations, they are very powerful." Member 3 specified that the hallucinations began 11 years ago and that they changed his life. He is glad that the medication does not totally take away the hallucinations and added that if they did he would: "feel robbed."¹⁵⁷

In addition, members of the USPK peer support group encourage each other to reach out for support, which emphasizes the role of relationships in decision-making. In one case, a discussion ensued regarding a member who is impulsive in financial decisions. One member, of the peer support group suggested:

Before you do a donation, call someone you trust and tell them the situation, and what you intend to do so you can hear another opinion before giving out money.¹⁵⁸

Finally on autonomy being relational, the peer support space enables peers to try out new behaviors and new ways of acting in the world, principally based on interacting with their peers and seeing other peers be effective actors in the world.

¹⁵³ Second focus group discussion held on 22 March 2017

¹⁵⁴ Interview with LM held on 25 April 2017

¹⁵⁵ Interview with LM held on 25 April 2017

¹⁵⁶ These include meeting 8 held on 21 January 2017 and meeting 9 held on 3 February 2017

¹⁵⁷ Observation notes, meeting 6 held on 26 November 2016

¹⁵⁸ Observation notes, meeting 10 held on 25 February 2017

¹⁵⁹ First focus group discussion held on 11 March 2017, Second focus group discussion held on 22 March 2017, one member during the third focus group discussion held on 25 March 2017 gave the example that his doctor was against him attending USPK peer support group meetings/joining USPK but he joined anyway.

6. Decision-making without using peer support

Members of USPK described that sometimes they make decisions without using peer support and emphasized the value of autonomous decision-making¹⁶⁰ Members of USPK stated that just like anyone else, there are decisions they make independently without consulting anyone, and then there are decisions that they seek the support of others to make. Value is placed on having the right and power to decide for which decisions one will seek support of peers and for which one will not:

Not for everything. Some decisions you can make by yourself and some you need help. So I don't feel like all decisions should be made anyhow in a peer support group. Some decisions are personal. Yeah, some you can make by yourself, some you can look for a group to help you... I don't feel like if you are having a condition you have to go to use a support. Because you are on medications and you are able to function. So there are some decisions you can be able to make by yourself, not necessarily with a support group.¹⁶⁰

During the first FGD, some participants spoke strongly for the right to make mistakes and 'wrong' decisions. One participant was clear that some 'wrong' decisions may have a very negative impact on him; however, he still insisted on the right to make even 'wrong' decisions about his own life:

It is my money, I can drink all of it and sleep in the streets ee! Si wewe utalala ni mimi [It is not you who will sleep on the streets, it is me]. But for God's sake I have earned it ee! I think for me this reinforces the whole issue of personal preference ... at the end of the day, it is about will and preference and the fact that also we have the right to make wrong decisions just like everyone else in life, you know?¹⁶¹

Another participant clarified that she would rather live with the consequences of a decision she made herself, whether good or bad:

...what I usually tell people is that I'd rather live with my own decisions the mistakes I make, I'll make that mistake knowing that I can handle the consequences myself. So that's how I am.¹⁶²

160 First focus group discussion held on 11 March 2017

161 First focus group discussion held on 11 March 2017

162 Second focus group discussion held on 22 March 2017

163 First focus group discussion held on 11 March 2017

164 Second focus group discussion held on 22 March 2017

165 Third focus group discussion held on 25 March 2017

Another participant highlighted that people without disabilities also make mistakes; yet they are not stripped of the right to make decisions as a result, which is discrimination on the basis of disability:

So how many people start businesses and they go bankrupt? Very many, actually statistics says I don't know almost 80% of startups you know, they will collapse. So does it mean that those people are of unsound mind? No! ...I think we must be given the right to make wrong decisions. Just because we have a diagnosis does not mean we are not human. That is basically what I think, yeah.¹⁶³

Many participants were of the view that even when a person makes wrong decisions, the response should not be to take away that person's decision-making power. One participant pointed out that it is dangerous to have others make decisions for a person with a psychosocial disability, because often, such decisions come from a place of ignorance about mental health issues, and a place of negative perceptions where the person with a psychosocial disability is seen as incapable, as one who 'cannot manage anything'. The participant felt that as a result, most of the decisions made for an individual would have a negative effect on the individual's life.¹⁶⁴ On the other hand, another participant noted that even well meaning people almost always underestimate the capabilities of individuals with disabilities, and this is why they should not make decisions for them.¹⁶⁵

One participant conceded that decisions are sometimes also made for people without disabilities, but clarified that the problem arises when decisions are disproportionately made for people with disabilities on the basis of their diagnosis.¹⁶⁶ The participant challenged his peers to recognize that there is a slippery slope when we allow others to make even one decision on behalf of a person on account of the person's disability:

Because today you will take away the simple right to withdraw the money, tomorrow you will tell me I can't own land, the other day you will tell me ... I can't marry. That is where the problem begins.¹⁶⁷

¹⁶⁶ First focus group discussion held on 11 March 2017

¹⁶⁷ First focus group discussion held on 11 March 2017

¹⁶⁸ Interview with HE held on 25 April 2017

¹⁶⁹ Observation notes, meeting 1 held on 28 May 2016

¹⁷⁰ Interview with HE held on 25 April 2017

¹⁷¹ Observation notes, meeting 3 held on 23 July 2016

¹⁷² Interview with HE held on 25 April 2017

In some instances, peers come to the support group seeking the group's affirmation of a decision that has already been made. For example, in one case, a member declared: "I am taking time away from romance and intimate relationships to focus on myself."¹⁷¹

In other cases, peers have already made a decision and simply want to hear what others will say about the decision:

I can give my own personal example... because when I quit four jobs I think I was still in the support group. You come and say I want to quit my job and peers said you know you cannot quit your job unless you have a plan B ... I think sometimes even after you speak up and share these things, down there many of them have already made a decision but you just want to hear what others will say. Yeah so maybe it's just a place where you still share that you are making a decision ...¹⁷²

¹⁷³ Interview with AN held on 26 April 2017; Interview with EB held on 27 April 2017; Interview with DM held on 10 May 2017

¹⁷⁴ Interview with IN held on 25 April 2017

¹⁷⁵ Interview with EB held on 27 April 2017

¹⁷⁶ Interview with EB held on 27 April 2017

¹⁷⁷ Interview with IN held on 25 April 2017; Interview with AN held on 26 April 2017; Interview with EJ held on 27 April 2017

7. Substituted decision-making

One question posed during interviews and during the focus group discussions relates to whether substituted decision-making is ever justified. While observing meetings, the researcher also noted instances where USPK members described instances where they had experienced substituted decision-making in their own lives.

7.1 Substituted decision-making: Caregivers' perspectives

Substituted decision-making most often happens around mental health treatment decisions. During interviews, caregivers indicated that all persons, including persons with disabilities, should make their own decisions in the first place, and decisions should only be made for persons with psychosocial disabilities in certain specified situations.¹⁷³

The situations where decisions can be made for others varied from carer to carer. The first situation is when the individual 'is not lucid,'¹⁷⁴ or is experiencing 'a relapse,' or expresses 'irrational views.'¹⁷⁶ The second situation is 'when you can see they are making a bad decision' or a 'wrong decision' or a reckless decision.^{177 178} According to the carer, this could be a bad decision on any area of life, including career decisions.¹⁷⁹ Another carer gave the example of poor financial decisions.¹⁸⁰ On reckless decisions, the caregiver gave an example of where the person wants to attend a church service in the night but the person cannot explain how they will get home after the church service is finished.¹⁸¹ The third situation is where an individual in their role as caregiver feels that the illness is interfering with the person's decision-making or where the caregiver can attribute certain actions or omissions of the person they care for to the illness.¹⁸² The fourth situation is restraining a person who is in mania as that person can hurt themselves or others.¹⁸³ In this situation, the carer felt that taking the decision to restrain the person 'is for their own good.'¹⁸⁴ All the carers expressed that it would be necessary to make a decision for a person in instances where they can harm themselves or others around them.¹⁸⁵

¹⁷⁸ Interview with AN held on 26 April 2017

¹⁷⁹ Interview with IN held on 25 April 2017

¹⁸⁰ Interview with EB held on 27 April 2017

¹⁸¹ Interview with AN held on 26 April 2017

¹⁸² Interview with IN held on 25 April 2017

¹⁸³ Interview with AN held on 26 April 2017

¹⁸⁴ Interview with AN held on 26 April 2017

¹⁸⁵ Interview with DM held on 10 May 2017; Interview with AN held on 26 April 2017

The fifth situation is when the person refuses to take medication,¹⁸⁶ or to seek mental health treatment particularly if they are exhibiting symptoms of mental illness.¹⁸⁷ In this situation, caregivers also felt that a medical professional should be able to make decisions on behalf of the individual.¹⁸⁸ The sixth situation is when the person wants to do something which the caregiver knows is beyond the person's abilities.¹⁸⁹ In this case, the caregiver's son wanted to start a retail business, which the caregiver felt he was not capable of running, so she advised him to rather invest in his artistic (drawing) abilities.¹⁹⁰ Caregivers indicated that if the circumstances they identified arise in the future, they would likely still make a decision for the person they care for. One participant identified that laws exist that make it possible to make treatment decisions on behalf of persons with psychosocial disabilities.¹⁹¹

Data from observing meetings, interviews and FGDs reveal that in many cases of forced treatment in Kenya, families play a critical role. In addition, often, consent to treatment is acquired through duress, manipulation, coercion and/or domination.

In one peer support group meeting, a caregiver expressed her frustration at feeling that she has no alternative but to use force to get her sister the help she feels her sister needs. In this case, the caregiver had first tried to persuade her sister to see a therapist but the sister refused:

The caregiver...added that she finds it demoralizing to have to grab her sister so that she can be injected by force. Any attempts to explain why she [the sister] needs the medication so that she can give consent have not been successful. She [the caregiver] would like her sister to take charge of her journey, but she seems incapable of this at the moment: "so I told her I would help her when I can." She expressed frustration at not being able to do more: "I can only do so much."¹⁹²

Further on administering forced treatment on the sister, the caregiver stated: 'we do not agree on forced treatment but sometimes it helps. My sister shuts down immediately you say the words 'mental health' and will not engage in that conversation.'¹⁹³ According to this caregiver, this leaves their family no option but to use forced interventions on her sister to get her to seek medical attention. At the same time, the participant reflected that trying to 'fix' her sister by 'force' is not working. She explained that peers often encourage counseling, but her sister was not eager to attend counseling sessions. The participant concluded that 'maybe trying to force things is making it even worse.'¹⁹⁴

186 Interview with EB held on 27 April 2017

187 Interview with DM held on 10 May 2017

188 Interview with DM held on 10 May 2017

189 Interview with EJ held on 27 April 2017

190 Interview with EJ held on 27 April 2017

191 Interview with DM held on 10 May 2017

192 Observation notes, meeting 5 held on 12 November 2016

193 Observation notes, meeting 5 held on 12 November 2016

Another participant also gave an example of a situation in which he used force to ensure his sister sought treatment:

There is a time when we saw the doctor for the first time ... there is a point at which she stepped out my sister because she was very combative, she did not feel that she has a mental health challenge so she did not see the reason for her being in that session and she had walked out and walked down the flight of stairs down. So I went and I tried to reason with her and she refused and she was speaking all sorts of things and I actually grabbed her and dragged her in and she was saying she was very annoyed and she's leaving. So do I think someone needs to be admitted by force when they are not able to make their decisions? Yes I think so. I'm obviously very resistant towards it but yes I think so.¹⁹⁵

Sometimes carers also share about decisions that they made for the people they care for that had very negative effects:

One caregiver shared about the terrible effects ECT had on her sister who has a diagnosis of Schizophrenia. According to the caregiver, once ECT was performed on her sister, she could not remember anything, her memory was wiped out and it took her about a year to recover.¹⁹⁶

One interviewee, a caregiver, conceded to attempting to make a decision on coping strategies to be used by his sister who has a disability, based on information he had gathered from the peer support group meeting. He indicated that in the end, this approach did not work, and explained that caregivers fall into this trap (of trying to impose coping strategies on the people they care for) because they are 'desirous for answers'.¹⁹⁷

Caregivers gave accounts of making decisions for the people they care for through having conversations about the person with health care professionals in the person's absence. In other words, they try to influence the health care professional to in turn influence the person:

And in all instances what I have done is, I have actually made the decision but made the decision of a psychologist...so that she doesn't think that I am the one who, who is pushing for the decision... so I have tried pushing using the psychologists to try to push so she knows exactly where I stand on those decisions.¹⁹⁸

194 Interview with AN held on 26 April 2017

195 Interview with DM held on 10 May 2017

196 Observation notes, meeting 5 held on 12 November 2016

197 Interview with DM held on 10 May 2017

198 Interview with IN held on 25 April 2017

In many cases, carers seem to tie up taking medication with 'being well'.¹⁹⁹ Further, caregivers also often have their own ideas of the treatment the individual needs.²⁰⁰ One caregiver was against her daughter's decision to take bhang as an alternative to medication for her mental health condition. The caregiver stated: 'I want to push her to see the doctor ... and I also think she should see a psychologist'.²⁰¹

On the other hand, during meetings, it is predominantly caregivers who share about positive outcomes from substituted decision-making.²⁰² One caregiver described deciding that her daughter would see a therapist:

One member (a carer) also shared about accompanying her daughter to a therapy session and explaining a lot of things to the therapist, even if the daughter was not pleased and was quite upset about this initially.²⁰³

The caregiver shared that while the daughter was against seeing a therapist initially, subsequently, the daughter's health improved as a result of the therapy sessions.

Some carers put a limit on the kinds of decisions that others should make for an individual. In the view of one carer, no one should ever give consent to ECT on behalf of the person they care for:

That is something that I wouldn't like anybody to go through, even if people are being irrational or erratic. Memories are ... just part of what makes life worth living. Imagine if you lived for I don't know how many years is it 70 years, and then you have somebody take that away from you.²⁰⁴

Caregivers shared about the difficulties of caring for a person whom they feel is making 'bad' decisions. These decisions include giving one's money away to fraudulent con artist schemes,²⁰⁵ stopping to take psychiatric drugs,²⁰⁶ taking bhang,²⁰⁷ and generally putting themselves in risky situations. In one meeting a carer shared:

My sister has been raped, stabbed, name it. I asked her why, she says, "I needed to do that. That was the best action I could do." It's very hard to understand, when someone you love keeps making bad decisions."²⁰⁸

199 Interview with EB held on 27 April 2017; Interview with AN held on 26 April 2017

200 Observation notes, meeting 9 held on 3 February 2017

201 Observation notes, meeting 9 held on 3 February 2017

202 Observation notes, meeting 3 held on 23 July 2016

203 Observation notes, meeting 3 held on 23 July 2016

204 Interview with EB held on 27 April 2017

205 Observation notes, meeting 10 held on 25 February 2017

206 Interview with AN held on 26 April 2017

207 Observation notes, meeting 9 held on 3 February 2017

208 Observation notes, meeting 9 held on 3 February 2017

Caregivers stated that people with disabilities should, when making decisions, consider how they impact the lives of the caregivers:

But they also have to understand what we are going through. So we have to meet each other half way because, if you are going through mania ...and endanger your body and people around you, then you have two outcomes: you probably go to jail ...or you probably get very hurt.²⁰⁹

According to caregivers, living with others necessarily involves a tradeoff – you give and take.²¹⁰ As such, the caregiver felt that people with disabilities should involve their family members in decision-making.²¹¹

7.2 Substituted decision-making: Peers' perspectives

Peers strongly resist having other people make decisions for them. In a one meeting, one of the members of USPK shared about being forcefully treated as consent was acquired through duress, manipulation, coercion and domination:

One member (who has a diagnosis of schizoaffective disorder – Member 3) shared that his family forces him to take medication, something he resents as the drugs dull the positive aspects of having the condition. He shared that he has told his family this, but they do not understand and say that that is a manifestation of the illness. He also shared about deciding to taper off the drugs on his own. Soon after, close friends noticed that he was 'hyper' and told his family. The family authorized the friends to take him to hospital against his will. So the friends tricked him that they were taking a trip to Nairobi, but instead drove him to Avenue Hospital where he was admitted and treated without his consent: "I took the medication at the threat of force." According to Member 3, the nurses were going to treat him by force, and he did not want his friends to see this happening to him, so he acquiesced to having the injection rather than be humiliated in front of his friends. The member shared that his family is only comfortable with him if he is on medication.²¹²

209 Interview with AN held on 26 April 2017

210 Observation notes, meeting 9 held on 3 February 2017; Interview with AN held on 26 April 2017

211 Interview with AN held on 26 April 2017

212 Observation notes, meeting 6 held on 26 November 2016

213 Under rules made pursuant to the Persons with Disabilities Act, 2003, persons with disabilities who earn less than KES 150,000 are exempted from paying income tax.

214 Observation notes, meeting 10 held on 25 February 2017

215 Observation notes, meeting 10 held on 25 February 2017

216 Third focus group discussion held on 25 March 2017

217 First focus group discussion held on 11 March 2017

Another situation of substituted decision-making described by a peer involves disclosure of mental health condition. In one meeting, a member of USPK explained that she works for her father's company, but does not receive any reasonable accommodation measure at work and neither does she receive tax exemption because the father (and owner of the company) does not want other employees to know that his daughter has a psychosocial disability.^{213 214} The member also wanted to share her story in the newspaper, but her mother denied her permission and said 'it would look bad in her social circles.'²¹⁵

Another situation of substituted decision-making described by a peer involves the decision regarding where and with whom to live. This is tied up with the contextual issue identified in Section 12 above regarding high rates of unemployment and dependency on families among persons with psychosocial disabilities:

My parents have always insisted that when I move out, I should move out with one of my younger brothers so that he can take care of me and that makes me feel somewhat inadequate or weak or I cannot take care of myself, because I feel not trusted, I feel they are making a decision that I should be the one making.²¹⁶

Another situation described by one of the participants involved where to study. The member was initially meant to study abroad, but her parents decided that she would have to pursue her education in Kenya where they 'could take care of her'.²¹⁷

Another participant highlighted that while she knows that her parents have her best interests at heart, she has learnt to separate between what her parents want for her and what she wants for herself and to keep healthy boundaries.²¹⁸

While peers strongly resist having other people make decisions for them, there are however, a few members of USPK peer support group who gave exceptions when they feel that others should take decisions for them. This is not an approach that USPK subscribes to as an organisation, or that all peers agree with; however, this research aims to capture the entire range of voices on the pertinent issues, however marginal.

²¹⁸ Second focus group discussion held on 22 March 2017

²¹⁹ First focus group discussion held on 11 March 2017

²²⁰ Observation notes, meeting 10 held on 25 February 2017

²²¹ Observation notes, meeting 10 held on 25 February 2017

²²² First focus group discussion held on 11 March 2017

One participant in the FGD stated that decisions should only be made for people with psychosocial disabilities in circumstances where the substituted decision-making was not initiated on the basis of the individual having a diagnosis. In other words, the participant conceded that sometimes, decisions are also made for non-disabled people, and only in similar conditions should a decision be made for someone with a disability:

...What I always say is that when you go to an accident site when someone is badly injured, and they tell you, don't take me to the hospital, what would you do? You will take them to the hospital yeah? So, the problem I have is when, when you disproportionately make decisions for people on the basis of a diagnosis.²¹⁹

A few participants with psychosocial disabilities described situations when they would be okay with another person making decisions for them. In one case, a member's partner expressed frustration during the peer support group meeting at how gullible his partner is to con artists schemes that involve 'sorry stories.' He shared that she often ends up making poor financial decisions by 'being over-generous.'²²⁰ The member expressed that sometimes she acts without really choosing to act that way:

I know I am doing it but I cannot stop is. I am trying. I think: "I won't do it again" and then I give out again.²²¹

This participant received a lot of advice from peers on how to retain her decision-making power while at the same time safeguarding her financial wellbeing.

One participant felt that family members should make decisions for someone with a psychosocial disability when there is a risk to life, especially when there is a risk of suicide.²²² Another participant felt that whether or not a person is 'aware of reality' should be the gauging factor of whether or not they get to make their own decisions:

And I think in our cases we have to make exceptions when we are not conscious of reality, and that is important because so long as you are conscious of reality then that is when you aware of what is going on. So you could up or down a little bit and that is fine, that is fine - we all make decisions when we are angry or sad and I think the difference now comes in - are you aware of reality? Coz then if you are not, then the law or someone does have to make that decision on your behalf.²²³

²²³ First focus group discussion held on 11 March 2017

²²⁴ Second focus group discussion held on 22 March 2017

²²⁵ One of the benefits of peer support is that it helps members view life's events differently. Peers describe having re-interpreted their lives' stories.

There was heated debate about this issue in the first focus group discussion. Some participants agreed with the above sentiment while others were strongly opposed.

In the second FGD, one peer supported having others make decisions for an individual in cases where 'it is for the individual's own good' and where if the individual continued on the course they were on, the repercussions would have been worse.²²⁴ The peer explained that she reached this conclusion after attending USPK peer support group meetings in which she heard the perspective of caregivers.²²⁵ The peer however felt that there is a 'right' way to go about making decisions for others:

The group has helped me understand my carer and what they go through because within the group you also have carers and they explain how they view you, how they can tell when you are doing well and when you are down. They can tell and that is the time when they make the decision not because they hate you, not because they are condemning you but because they want the best for you but probably the best for you is they are not going through it the right way.²²⁶

Other participants in the second FGD described the issue differently, and focused instead on the substitute decision-maker rather than on the decision in question. According to this participant, if the substituted decision-maker has no awareness about what it means to have a psychosocial disability (and thinks for example that the person is just lazy), then that would be the wrong person to make a decision on one's behalf. On the other hand, if the decision-maker is 'not ignorant', then there may be cases where they are justified in making a decision for a person with a psychosocial disability.²²⁷ According to a different participant, if the substitute decision-maker has the individuals' best interest at heart, then, they may make decisions for the individual, particularly if the individuals' behavior risks their own life or the lives of others.²²⁸

Another participant in the second FGD explained that as long as one is dependent on family, one must allow the possibility that the family will make some decisions for him or her. In addition to financial dependence, the participant went into the impairment specific support that persons with psychosocial disabilities may at times require (which in the Kenyan context is mostly provided by families):

I have always believed the person who pays the piper calls the tune and so it will be unfair of us to expect the people who we depend on, aah to always go with what we want. Because we are not in a position to do certain things for ourselves, we should give them a certain amount of say because we depend on them...

²²⁶ Second focus group discussion held on 22 March 2017

²²⁷ Second focus group discussion held on 22 March 2017

²²⁸ Second focus group discussion held on 22 March 2017

²²⁹ Second focus group discussion held on 22 March 2017

They [caregivers] should have say because they support us, whether it is parents, spouses, whatever the situation is. I think they should have a certain amount of decision-making capacity for us just because they are the ones who, whether it is when we don't take our medicine, with our jobs they are the ones who now have to sort us out, whatever, whatever, they are the ones who clean up the mess after us basically... so I don't believe they [caregivers] should have responsibility without privilege so that is one of the things it depends on.²²⁹

The views of this participant were controversial and not all participants in the second FGD agreed with her. There was a view that it is better for the proposed substituted decision-maker to ask herself: "what are the consequences if the decision is not made for the person?" and only if the consequences are fatal should one make the decision for the person.

In the third FGD, some participants explained that it is okay for others to make treatment decisions for them in certain situations:

Sometimes I feel intervention in terms of treatment is necessary because for me decisions for me have been made for me in terms of seeing the doctor or going for treatment because there are times I feel I am totally oppressed. There are times in the past where I would go without medication and I'd be quiet about it because I have been trying to see I have been trying to ask myself can I be able to work without medication? Nobody notices, until when things get out of hand and then I am forced to see a doctor or to go for treatment. There are some decisions, which are actually necessary..²³⁰

Sometimes in our situation it is ...you can't tell your relapses, but other people can see a relapse, which is okay for them to do the intervention at times.²³¹

One peer made a distinction between types of decisions, indicating that he is okay with certain decisions being made for him but not others:

230 Third focus group discussion held on 25 March 2017

231 Third focus group discussion held on 25 March 2017

232 Third focus group discussion held on 25 March 2017

233 Third focus group discussion held on 25 March 2017

234 Third focus group discussion held on 25 March 2017

I think to me it would be okay if someone intervened or pushed me to see a doctor or made a decision for me to see a doctor or go for therapy, and those are the ones that are not necessarily... I feel like things like a personal decisions about relationships, things like financial issues, some things I feel like are too personal for people to make decisions for.²³²

One participant indicated that even when decisions must be made for her, she should be treated in a humane way. Another participant indicated that the important question to ask is: does the decision need to be made now? Can it wait until the person is better? If it can, the participant felt that caregivers and others should wait until the individual can make the decision herself.²³⁴

In conclusion, peers identified that personal characteristics such as age and gender increase the odds that others will make decisions for an individual. Younger people and females experience higher rates of substituted decision-making.²³⁵

8. Tools used in the group to support someone to make a decision

Peers use a variety of informal tools to support each other in decision-making. These include:

- Exchanging advice from personal experiences ^{236, 237, 238, 239, 240}
- Challenging each other ^{241, 242, 243, 244}
- Having discussions/dialogue ^{245, 246, 247}
- Encouraging each other ²⁴⁸
- Sharing information.

However, some members do not give advice, or even encourage others to adopt their approaches to issues. Such members simply state what works for them, and leave it up to the individual to decide for herself whether or not she wants to try the identified course of action.

²³⁵ Second focus group discussion held on 22 March 2017

²³⁶ Observation notes, meeting 2 held on 11 June 2016

²³⁷ Observation notes, meeting 4 held on 17 September 2016

²³⁸ Observation notes, meeting 5 held on 12 November 2016

²³⁹ Observation notes, meeting 6 held on 26 November 2016

²⁴⁰ Observation notes, meeting 10 held on 25 February 2017

²⁴¹ Observation notes, meeting 1 held on 28 May 2016

²⁴² Observation notes, meeting 5 held on 12 November 2016

²⁴³ Observation notes, meeting 6 held on 26 November 2016

²⁴⁴ Observation notes, meeting 10 held on 25 February 2017

²⁴⁵ Observation notes, meeting 2 held on 11 June 2016

²⁴⁶ Observation notes, meeting 4 held on 17 September 2016

²⁴⁷ Observation notes, meeting 10 held on 25 February 2017

²⁴⁸ Observation notes, meeting 2 held on 11 June 2016

Epilogue

For the most part, these voices describe life during and after peer support:

When I first came to peer support, I told and re-told the story of my life, the story of the person I used to be before the diagnosis. I grieve the loss of that person less and less now. I am so much more interested in the person I am becoming.

I have started to see myself differently. I don't mean big things. Small things, like recognizing that my experience is something of value that could help others.

I stand up for myself more. I stand up for others too.

My relationship with my peers has helped me re-interpret other relationships.

When I don't understand something the doctor says, I ask. When I don't agree with something the doctor proposes, I say "no" and ask for alternatives.

I started to understand why the pain, why the struggle.

Now I see what they called 'symptoms' as communication from a wise part of me saying: 'slow down' or 'stand up for yourself or let her earn your trust first'

I am growing. I am changing. The story I tell about myself is changing

Other people exist for me now and I feel connected to them

I understand how other people hurt me. I also understand how I hurt other people. I am beginning to realize what to do to make it right again.

*My empathy for my peers has helped me develop empathy for myself.
My inner voice is gentler, less critical*

I am no longer paralyzed by the thought of others 'finding out' that I have a diagnosis

I am choosing

I am willing to be seen

I am no longer looking for that 'magic pill' that will cure everything

I now have alternative explanations for life experiences. For example, feeling suicidal is not always just a 'symptom'; it is sometimes a side effect of psychiatric drugs

I do not take on other peoples' judgments of me. How other people label me matters less and less.

I now see clearly the relationship between where and with whom i live, my work environment and my state of mental wellbeing.

I feel more in control

The diagnosis is just a part of who I am, not all of who I am

I am the expert on my mental wellbeing

I keep an open mind

I may compromise for the sake of others, but the decision remains mine

I keep healthy boundaries with my family

I am more understanding towards my caregiver

I am aware of myself

I deal with my emotions

I demand for better quality service everywhere!

I trust my inner voice

I have an increasing sense of 'deservingness'

I act differently, I am surer of my actions

I celebrate the small wins of others, i celebrate my own small wins

I no longer take psychiatric drugs

I have reduced my dose of psychiatric drugs significantly

I still struggle, but it's different. Now, I am equipped with coping strategies

I am hopeful

I have many sources of support

The feeling of stagnation has left me

I am no longer alone. I depend on my peers, my peers depend on me

*My peers are my 'family'
I am surrounded by others who say "I have been in that situation before and this is what helped" without dictating what i must do*

I am building bridges

I am gaining: relationships, sense of purpose

I know some people will never understand what it's like to be me, and that's okay

I know what my triggers are

I have been challenged to try new behavior

I know when I have to come first. I am developing a healthy selfishness

I engage with life more deeply.

I feel myself to be a powerful actor in the world with something to contribute.

I am ready to raise awareness about mental health issues

I continue with life even when feeling low or discouraged

I have re-discovered my spiritual side

I am re-writing the story of my life. The perspectives are numerous.

Appendix 1 – Principles of peer support

USPK does not explicitly have a list of guiding principles. However, from observation, interviews and FGDs, the following appear to be the underlying principles of USPK peer support groups. Peer support does not always perfectly live up to these principles; however, these principles are observed at work in the USPK peer support group, which is also reported by members to be very beneficial.

1. Accommodating, tolerant and welcoming attitude towards diverse opinions and perspectives on all issues. Peer support recognizes and respects the individual nature of peoples' needs. Peer support emphasizes respect for difference even among people who share a diagnosis. It also recognizes that recovery is a journey and people are at various stages on the journey.
2. Mutuality and the sense of equality in relationships between peers. Experiences are shared back and forth and no one claims to have the authoritative voice on any issue. Members describe a sense of interdependence; where they both give and receive support.
3. Open, safe and non-judgmental space. Peers share successes and failures, hard and good times. Vulnerability is valued. Members respect each other – there is silence and focus on the person as they share, with minimal interruption. Members share on a broad range of issues: relationships, marriage, work, education, finances, children, illness and wellbeing, etc. Empathy is valued.
4. No pressure to share; no one is forced to speak if they do not want to.
5. Highly consensual model that eliminates coercion, domination and use of force. The right of the individual to choose his or her own path is highly valued. The model runs on the labour of peers – there are no professionals 'overseeing' the group.
6. Accountability – peers often report back to each other on the outcome of decisions made with the support of the group. This 'reporting back' is usually voluntary, although sometimes staff of USPK prods individual members to give feedback on certain issues.
7. Peer support encourages a sense of togetherness rather than isolation. Peers report 'being part of each other' and 'growing together.' Building relationships among members is valued.
8. Learning is encouraged. Asking questions is encouraged. Being informative, rather than prescriptive is valued. The individual's right to choose his or her own path is highly valued. Self-reflection is also valued.

9. Consistency in attending peer support group meetings is valued. Consistency in attendance provides a multiplicity of perspectives, supports personal growth and diffuses the tendency to secrecy. Consistency also helps in the building of close relationships among members.
10. A willingness to challenge and be challenged by others is encouraged. So is a willingness to address conflict, and to change.
11. Peer support is not exclusive; members share alternative strategies for coping and/or for decision-making and encourage each other to try different approaches in addition to peer support.
12. Confidentiality is valued. So is truth-telling, even about difficult issues. Building trust among members is important.
13. Flexibility is valued. Meetings may run slightly longer than allocated time if people are still sharing intensely. Separate gender specific discussions may be held if that would be more appropriate. If someone expressly asks: "what am I supposed to do now", members may offer directive, concrete and specific suggestions.
14. The USPK peer support model is rooted in human rights, hence the values of equality and non-discrimination are highly valued. Specifically, equality between men and women is recognized.
15. Peer support is informal: there is an open invitation for all and anyone can drop in and out without notice. There are no set rules (the online platform/USPK virtual support group on WhatsApp does have set rules). There are no forms to be signed to join, although if they choose, members can fill in attendance sheets after meetings.

Appendix 2 – Role played by USPK staff

This appendix highlights some of the roles played by staff members of USPK during peer support group meetings and generally.

1. Advertising meetings, directing new members to meetings as well as welcoming new members.
2. Introducing and moderating/facilitating meetings. This includes leading the introductions session, outlining the flow of the session to new members and steering the discussions.
3. Supporting members in building a new narrative of the self in a very deliberate way. Often, the comment not to define oneself based on diagnosis comes from staff of USPK. USPK staff also often bring back the conversation to the individual: "X, you have heard what peers think about your situation. Would you be comfortable taking up any of the suggestions?"
4. Building connections between members who can be of support to each other beyond the group meetings, between caregivers and if requested, between members and therapists. USPK staff also mediates in conflict between members and their families.
5. Listening – often, members contact USPK staff when in crisis either through phone calls, the virtual support group on WhatsApp, or by physically going to USPK Offices.
6. Give support in practical ways, for example calling USPK members at a certain time every morning where the member needed support getting out of bed. Or visiting members who are admitted in hospital. Or making referrals for specialist advice.
7. Following up with members for accountability. Sometimes during meetings, USPK staff will ask: "how is this issue, which you were struggling with last time going?"
8. Giving advice on coping strategies.
9. Asking prodding questions, inviting responses when there are long lulls in discussions and generally working to create a safe space that encourages maximum participation by members. In certain cases, USPK Staff may encourage contributions from a certain gender in cases where it seems that either gender is not fully engaging in the discussion.
10. Diffusing tense moments within the group during sharing as well as supporting members to address conflict that may arise between them.

11. Inviting specific individuals to speak; however, it is entirely up to the individual to decide whether or not to take up the invitation to speak. The invitation to specific individuals to speak is usually a way to welcome, particularly new members into the conversation.
12. Expressing appreciation to 'guests' who attend the meetings from time to time.
13. Bringing the conversation back to a human rights approach and the social model of disability when necessary.
14. Providing training on human rights issues. When staff of USPK or older members of USPK attend conferences or other learning meetings, there will be time set apart during the peer support group meeting for sharing insights and learning from those who attended such meetings.
15. With the permission of older members, using the stories of older members to inspire and/or motivate new members.
16. Recognising participants who may be in distress during a meeting and attending to them.
17. Crisis response: this is especially applicable regarding the online platform/virtual support group on WhatsApp, although at times members also show up at USPK offices seeking support. USPK staff often orchestrates the raising of funds from among members in order to fund the appropriate response.
18. Encouraging members to register with the National Council for Persons with Disabilities as persons with disabilities, and providing information and practical guidance on the process of registering. Registration with the National Council entitles members to tax exemption (for those who are employed) or to apply for government tenders (for those with an entrepreneurial inclination).
19. Moderating the online platform/virtual support group on WhatsApp, and using the platform to encourage members to come for the face-to-face meetings. Sometimes, USP Staff encourages persons with specific diagnosis (particularly related to heightened anxiety in social situations) to come for the face-to-face meetings.

Appendix 3 – List of coping strategies shared in meetings, focus group discussions and interviews

This Appendix lists all the strategies that peers employ to cope that came up in the course of the meetings, FGDs and interviews. Some peers use these strategies as alternatives to medication while other peers use these coping strategies alongside taking psychiatric medication. During the second FGD, one peer said the following with regard to coping strategies:

So I don't think it is just about whether those things are helping you [in terms of reducing symptoms]; but it will give you a sense of feeling that "I am in control of this, not it is in control of you." So you feel you are in control of your situation and your condition.

The coping strategies are listed in order: the most often cited strategies come first while those strategies that were not so popular come last.

1. Spirituality, including: prayer, going to church, seeking the support of spiritual leaders, faith healing, God, religion and fasting.
2. Exercise, including: yoga, running, swimming and walking.
3. USPK Peer Support Group as well as the USPK virtual support group on WhatsApp. One participant termed peer support as a 'master' coping strategy, because it encourages peers to try out other different coping strategies listed in this appendix.²⁴⁹
4. Counseling and therapy
5. Journaling, keeping a diary and sharing personal stories through writing.
6. Interventions related to sleep: eat at least 2 hours before bedtime, have chamomile and other relaxing teas, carry out relaxation techniques before bedtime, avoid violent movies before going to sleep, keep regular hours of sleeping and rising, develop a night routine that supports sleep, use calming/relaxation apps/technology, re-wire your thoughts and behavior about sleep using CBT and find soothing music to fall asleep to.
7. Self-reflection and self-awareness to understand what one's triggers are and what works to help one feel better, trusting one's own inner voice especially on medications and doctors, allowing oneself to go through the lows, managing one's finances to avoid financial stress, and minding one's own well being no matter what.

²⁴⁹ Second focus group discussion held on 22 March 2017

8. Positive self-talk, taking measures to improve one's self-esteem and using self-affirmations, having a positive outlook towards life, fixing one's mind on the one positive thing planned for the day, thinking about positive messages, choosing to focus on self-love and other positive things and motivating oneself.
9. Developing a support system around yourself, including accountability partners, supportive others who can assist with the difficult aspects, and friends.
10. Creative outlets/expressions such as making music, dancing, painting, drawing and cooking.
11. Work and employment and becoming economically empowered.
12. Having a plan for the day - even little tasks help a great deal, taking up responsibilities, keeping busy, and getting out of the house.
13. Interventions related to diet: watching diet and eliminating foods that make one crash, for example coffee, eating foods that lift mood such as dark chocolates and bananas, avoiding sugar, especially at night and eating a balanced diet.
14. Reading, including to find out more information about the condition and to distract oneself. AUK Website called 'Uncommon knowledge.co.uk' was recommended.
15. Doing things to relax including: meditation, taking time in solitude and using calming/relaxation apps.
16. Advance planning/preparing for the time when one might be unwell.²⁵⁰
17. Setting goals and pushing oneself to achieve them
18. Helping others through a variety of ways including: helping out in a children's home, giving words of wisdom to others (when these are solicited for), giving flowers and being kind and loving
19. Turning to family support and being in a family setup
20. Going back to school, pursuing a psychology degree was especially singled out as desirable
21. Taking one's medicine and finding a psychiatrist with whom one can work

²⁵⁰ Third focus group discussion held on 25 March 2017

22. Practicing gratitude
23. Defining different relationships and establishing healthy boundaries
24. Talking to people and sharing personal stories
25. Smoking
26. Giving up perfectionism
27. Wearing multi-colored clothes so that when one sweats from anxiety, one does not become self conscious
28. Avoiding places related to the method one imagines using to commit suicide, e.g. balconies
29. When feeling especially desperate, doing something to get back into one's body, including seeing, feeling or tasting something.
30. Starting the day with less challenging things, and then tackling difficult tasks when more motivated
31. Sharing power and delegating
32. Using a team to manage one's mental wellbeing: a psychiatrist for any chemical imbalance that may exist; a psychologist for CBT and helping understand patterns of thought, behavior, emotion; a religious leader for spiritual support and peer support for psychosocial support
33. Being flexible/not being so fixed to one outcome
34. Grooming oneself and looking good
35. Focusing on changing oneself rather than changing other people

