

**Participation of people with psychosocial disability
in mental health policy development
in South Africa**

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**Thesis presented for the degree of
Doctor of Philosophy**



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**This thesis is dedicated, with love and thanks, to
my late mother, Mary Kleintjes and my late father, Peter Kleintjes**

University of Cape Town

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Finally, my sincere thanks to those who shared their views and experiences during the interviews for this study.

Declaration of original authorship

This thesis is presented in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD), University of Cape Town. My academic supervisors were the late Prof Alan J. Flisher, Associate Professor Crick Lund and Professor Leslie Swartz. The work on which the thesis is based is original research and has not, in whole or in part, been submitted for another degree at this or any other university. The contents of this doctoral thesis are entirely the work of the candidate, who conceptualised and carried out the research project. The five co-authored journal articles included in this thesis are directly based on the research for this degree, and constitute work for which the candidate was the lead author, and academic supervisors were co-authors. The inclusion of papers is outlined in the preface of this thesis, and the role of each author described in the introduction to each paper.

Sharon Kleintjes

20 August 2012

Preface

This doctoral thesis includes work reported in published/to be published journal articles, as per general provision 6.7 in the General Rules for the Degree of Doctor of Philosophy (PhD) of the University of Cape Town. The submission of the thesis in this format was approved by the University of Cape Town Doctoral Degrees Board on the 17 August 2012. The publications included in this thesis all relate directly to the thesis topic, and contribute to answering the aims and objectives of the study.

Conceptualisation of the study and data collection

In October 2005, I applied for the post of research officer for the South African site of a larger study which aimed to assess mental health policy development and implementation in four countries, the Mental Health and Poverty Project (MHaPP). This project offered an opportunity to embed a doctoral study in the larger study. I proposed during my interview, and confirmed during the final conceptualisation meeting of the project in November 2005, that my doctoral study would focus on the participation of people with psychosocial disability in policy development in South Africa, while working as the research officer for the South African site. The consortium members agreed to my study topic and I was assigned responsibility for designing the data collection tools for use with participants with psychosocial disability, and for integrating questions related to their participation in all other data collection tools developed for use in the first phase of the MHaPP project. This was done during 2006.

For my own doctoral study, which focused on the South African site of the study, I provided the lead intellectual drive in every case through formulation of the research project, design, data collection, analysis, and writing of the journal articles.

I conducted the bulk of the data collection myself, with the exception of data collected in isiZulu, in which instance I trained and supervised the two research assistants responsible for collecting this data in the rural site of the MHaPP project in KwaZulu-Natal, South Africa.

The MHaPP project occurred in two phases, a situational analysis phase, during which time I collected data from 56 stakeholders in the country who are involved in mental health policy development. The questions for my own study were included in the interview schedules which addressed the broader concerns of the MHaPP itself. I also interviewed twenty people with psychosocial disability during this situational analysis, using the tools I had developed for MhaPP. This was done during 2007.

The second phase of the MHaPP was intervention studies which departed from my thesis topic (2008-2010). In addition to working on the intervention studies, I also collected additional data for my thesis, comprising a further 20 interviews with people with psychosocial disability, and 11 interviews with key stakeholders working in peer organisations for people with psychosocial disability in Africa. Separate ethics clearance was obtained from the Research Ethics Committee of the Faculty of Health Sciences (REC Ref: 323/2008), University of Cape Town, for this part of the study. I also secured independent funding for these aspects of the study as the MHaPP had concluded by mid 2010, and these interviews were conducted during 2009-2011. The long data collection period was due to the difficulty I experienced locating participants for the Africa-wide aspect of the data collection (objective five). This additional funding was also used to fund my time and a research assistant's time to work on the literature review conducted during 2011.

Supervision of the study

Professor Alan Flisher provided supervision from the inception of the study in 2007 till his death in April 2010 after which Associate Professor Crick Lund assumed the role of primary supervisor for the research. Professor Leslie Swartz co-supervised throughout the work on the thesis, providing particular expertise in the area of psychosocial disability.

The three supervisors' ensured that the methodology was sound, findings stated clearly, and papers written in the format required by journals. In all instances, for my own personal growth, I chose to draft each paper to completion before submitting the draft to my supervisors for their review. The supervisors also approved the final draft of manuscripts before submission to journals.

Authorship of publications included in the study

The first 2 papers have four authors and the remaining papers have 3 authors. The candidate is the lead and corresponding author on all papers.

Ms Sara Cooper is the fourth author on the literature review (objective one). It is considered good practice to have double screening of the data during selection of included papers, and Ms Cooper provided research assistance with data collection, and double screening of papers to select the final papers included in the study. I had planned to include her for the meta-synthesis, which also uses more than one person to interrogate the data, but funding did not permit, and this aspect was done by me only, a shortcoming of my literature review. Ms Cooper reviewed the final two drafts of the manuscript before submission of the paper to a journal.

Professor Flisher is an author on the second paper (objective two) which was ready for publication at the time of his death.

After his death, Associate Professor Crick Lund assumed the role of supervisor for the research and is an author on all the papers. Professor Leslie Swartz co-supervised throughout the work on the thesis, and is also an author on all the papers.

The thesis includes work reported in the following five papers:

Kleintjes, S., Lund, C., Cooper, S., & Swartz L. The participation of people with psychosocial disability in mental health policy development: A qualitative meta-synthesis. (Submitted to the Australian and New Zealand Journal of Psychiatry on 9 August 2012)

Kleintjes, S., Lund, C., Swartz, L. & Flisher, A.J. (2010). Mental health care user participation in mental health policy development and implementation in South Africa. *International Review of Psychiatry*, December, 22(6), 568-577.

Kleintjes, S., Lund C., and Swartz, L. Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: Perspectives of policy makers, professionals, religious leaders and academics. (Submitted to BMC International Health and Human Rights on 10 August 2012)

Kleintjes, S., Lund, C.. and Swartz, L. (2012). South African mental health care service user views on priorities for supporting recovery: implications for policy and service development. *Disability & Rehabilitation*, Early Online: 1–9.

Kleintjes, S., Lund, C., and Swartz, L. (*in press*). Organising for self-advocacy in mental health: Experiences from 7 African countries. *African Journal of Psychiatry*.

The papers were submitted in the style required by the respective journals. In this thesis, a consistent referencing style has been used throughout and all references are provided at the end of the thesis.

Abstract

Title: Participation of people with psychosocial disability in mental health policy development in South Africa

Author: Sharon Kleintjes

Date submitted: 20 August 2012

This study addressed the following question: What are the barriers and strategies to support the participation of South Africans with psychosocial disability in mental health policy development in South Africa? A systematic literature review (objective 1) addressed the question: “What supports people with psychosocial disability to participate in national mental health policy development?” The WHO Checklist for Mental Health Legislation, the WHO Checklist for Mental Health Policy and Plan, and domain 4 of the World Health Organisation Assessment Instrument for Mental Health Systems (WHO-AIMS) were completed, and 96 semi-structured interviews with key stakeholders were conducted, to assess current stakeholder, mental health legislation and policy support for the participation of people with psychosocial disability in South Africa (Objective 2). Nvivo-7 software was used to analysis qualitative data, using a framework analysis approach to data analysis and interpretation. These interviews were also used to ascertain the views of 56 of the 96 South African stakeholders’ involved in mental health services, on environmental barriers to the participation of people with psychosocial disability in mental health policy development in South Africa (objective 3). The remaining 40 interviews with people with psychosocial disability documented their lived experience of barriers to their participation in policy development, and highlighted their priorities for policy development (Objective 4). Eleven key informants involved in leadership roles in peer led organisations for people with psychosocial disability in Africa were interviewed to inform understanding of opportunities for supporting people with psychosocial disability to participate in mental health policy development (Objective 5). The findings of objectives 1-5 were triangulated to inform the development of a conceptual framework for supporting South Africans with psychosocial disability to participate in mental health policy development (objective 6). The framework proposes the need for social transformation to overcome barriers to the inclusion of people with psychosocial disability in society, including as policy participants, support for self-directed agency, and opportunity for meaningful participation in policy development.

Executive Summary

The participation of people with psychosocial disability in their recovery process should include options to influence mental health policy development and implementation. No systematic research has been conducted in South Africa to investigate the scope and options for the participation of people with psychosocial disability in policy development. This study investigates this gap in our knowledge by addressing the following research question: What are the barriers and strategies to support the participation of South Africans with psychosocial disability in mental health policy development in South Africa?

The purpose of this study was to (a) contribute to the empowerment of people with psychosocial disability by providing new knowledge regarding strategies to improve their participation in public policy-making which impact on their wellbeing, and to (b) provide key stakeholders (policy makers, programme managers and service providers) with new knowledge which will enable them to better integrate the views of people with psychosocial disability into policies that are relevant to their needs.

The study had the following objectives:

1. To conduct a *systematic review of current literature* on barriers and strategies to support people with psychosocial disability participating in mental health policy development.
2. To describe *current support for participation* of people with psychosocial disability in mental health policy development in South Africa and to suggest strategies for improving participation.
3. To ascertain South African *stakeholders' views* on environmental barriers to the participation of people with psychosocial disability in mental health policy development in South Africa.
4. To document the views of South Africans with psychosocial disability on their *lived experience* of barriers to their recovery and to highlight the implications of these barriers for policy development.
5. To document *lessons from the work of peer led organisations* for people with psychosocial disability in Africa which might inform improving the participation

of people with psychosocial disability in mental health policy development in South Africa.

6. To develop a *conceptual framework* for supporting South Africans with psychosocial disability to participate in mental health policy development in South Africa.

Chapter one provides background to the importance of the area of study. It defines key terminology used in the thesis, provides a brief account of the mental health policy development process in South Africa prior to 1994. It then proposes the reasons for undertaking the current study, which focuses on the period 1994-2012, and states the aims and objectives of the study.

Chapter two addresses objective one of the study: the systematic literature review. A systematic electronic search yielded five included papers, spanning the period 1990 to 2007. Lack of power emerged as the overarching barrier to participation in policy and legislation development. Three key aspects of this lack of power were identified, namely compromised citizenship, social and economic disadvantage and the marginalisation of “voice” in the policy dialogue. Full citizenship, social and economic upliftment and prioritisation of the voices of people with psychosocial disability were suggested as key conditions to promote empowerment of people with psychosocial disability in mental health policy participation. Research to support implementation of these strategies included evaluation of interventions to reduce structural, institutional and procedural barriers to participation, and assessment of the impact of policy participation. Limitations to the study included the paucity of data available for inclusion and the quality of the included studies.

Chapter three addresses objective two of the study: current support for the participation of people with psychosocial disability in policy development in South Africa and suggests strategies for improving participation. The World Health Organization (WHO) Mental Health Policy and Plan Checklist and the WHO Mental Health Legislation Checklist were completed. Ninety-six semi-structured interviews with national, regional

and district stakeholders were conducted between August 2006 and August 2009. Most participants felt that inclusion of the perspectives of people with psychosocial disability in policy processes would improve policy development. In practice, consultation of people with psychosocial disability in policy development has been limited during the 16 years of democracy in South Africa. Strategies to create a supportive environment for policy participation include social action directed at reducing stigma, advocating for acceptance of their right to participate in policy-making, crafting a supportive regulatory framework to promote participation, and equipping providers and policy makers to support inclusion. The capacity of people with psychosocial disability to participate in policy development should be strengthened through early and effective access to treatment and support, development of a national peer-led forum for people with psychosocial disability, skills training in policy processes and practical exposure to the policy and service development environment.

Chapter four addresses objective three of the study: environmental barriers to people living with psychosocial disability participating in mental health policy development in South Africa, from the perspective of South African stakeholders involved in mental health policy development. Fifty-six semi-structured interviews with national, provincial and local South African mental health stakeholders were conducted between August 2006 and August 2009. Participants identified three main environmental barriers to participation in policy development: (a) stigmatization and low priority of mental health (b) poverty and (c) ineffective recovery and community supports. A human rights paradigm is needed to transform perceptions, policy and practice which undermine the equal participation of South Africans with psychosocial disability in all areas of social engagement, including their involvement in policy development.

Chapter five addresses objective four of the study: capturing the views of South Africans with psychosocial disability on policy directions required to support their recovery. Semi-structured interviews were conducted with forty people with psychosocial disability using mental health services and/or involved in advocacy work to support others with psychosocial disability. Their priorities to support recovery included addressing stigma, discrimination and disempowerment, and the links between mental health and poverty. They suggested that these challenges be addressed through

public awareness campaigns, legislative and policy reform for rights protection, development of a national lobby to advocate for changes, and empowerment. Participants suggested that empowerment can be facilitated through opportunities for improved social relatedness and equitable access to social and economic resources. Three strategies were proposed to bridge the gap between the rights and needs of people with psychosocial disability on one hand, and unsupportive attitudes, policies and practices on the other. These are: giving priority to their involvement in policy and service reform, creating empathic alliances to promote their priorities, and building enabling partnerships to effect these priorities.

Chapter six addresses objective five of the study: reporting on strategies which supported the establishment and sustainability of 9 mental health self-help organisations in 7 African countries. Eleven key informants were identified through snowballing and interviewed regarding their experience in these organisations. Sustainability strategies include: commitment to members' advocating for their rights and rebuilding their lives within their communities; independent decision-making, peer-led membership and leadership; financial self-sufficiency, and alliances with donor organisations, non-governmental organisations (NGOs), disabled people's organisations (DPOs) and ministries which support self-determination. Organisations' work include advocacy to destigmatise mental disorders and promote the protection of rights, activities to improve access to health care and to income generation and social support, participation in legislative and policy reform, and capacity building of members.

Chapter seven, the concluding chapter of the thesis, triangulates the main findings which emerged from chapters two to six. Based on these findings, a conceptual framework for improving the participation of people with psychosocial disability in policy development in South Africa is proposed to answer the overall research question of the thesis. Section 1 summarises the barriers to policy participation identified in earlier chapters, examining how the findings in each chapter relate to each other. Section 2 draws on the main strategies for improving participation which emerged in chapters 2-6 to derive a conceptual framework to support the participation of people with psychosocial disability in mental health policy development in South Africa. The framework comprises three aspects: social transformation, opportunity for self-directed

agency, and opportunity for meaningful participation in policy development which impact on empowerment of people with psychosocial disability. Section 3 addresses the contributions of the study to existing knowledge on the participation of people with psychosocial disability in policy development. Section 4 discusses the limitations of the research, and suggests areas for further research which emerged from chapters two to six and the conceptual framework.

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Table of contents

Dedication	i
Acknowledgments	ii
Declaration of original authorship	iii
Preface	iv
Abstract	viii
Executive Summary	ix
Table of Contents	xiv
List of Appendices	xxii
List of Figures	xxiii
List of Tables	xxiv
A personal note from the author	xxv
Chapter One: Introduction	
1.1 Outline	1
1.2 Defining service users and people with psychosocial disability	1
1.3 Context	2
1.3.1 Recovery and policy participation	2
1.3.2 Changing the social construction of disability	3
1.3.3 The rights of people with psychosocial disability	4
1.3.4 The right to be included as a policy participant	5
1.3.5 Defining participation	5
1.4 Mental health policy development in South Africa	6
1.4.1 Mental health policy development before 1994	6
1.4.1.1 Patient voice in early policy development	8

1.4.2	Post-Apartheid policy development (1994-2012)	9
1.4. 2.1	Stakeholders in policy development processes in South Africa	9
1.4.2.2	Mental health policies in South Africa	10
1.5	Current gaps in our knowledge: the participation of people with psychosocial disability in mental health policy in South Africa	11
1.5.1	Aims and objectives of the study	11
1.5.2	Objectives	12
1.6	Outline of the thesis	12

Chapter Two: The participation of people with psychosocial disability in mental health policy development: A qualitative meta-synthesis

2.1	Introduction	18
2.1.1	Aim and objectives of the review	18
2.2	Method	19
2.2.1	Search strategy	19
2.2.2	Inclusion and exclusion criteria	19
2.2.3	Identification of studies	20
2.2.4	Quality assessment	22
2.2.5	Data Analysis and synthesis	22
2.3	Results	23
2.3.1	Description of included studies	23
2.3.2	Thematic analysis and meta-synthesis	29
2.3.2.1	. Compromised citizenship	32
2.3.2.2	Poverty and social disadvantage	33
2.3.2.3	Marginalisation of “voice” in the policy dialogue	34
2.4	Discussion	37

2.4.1	Barriers to participation	37
2.4.2	Empowerment to support participation	38
2.4.3	Self-representation	42
2.4.4	Freedom in expression of voice	42
2.5	Limitations of the review	43
2.6	Future directions for research	43
Chapter Three: The participation of people with psychosocial disability		
in mental health policy development in South Africa		
3.1	Introduction	48
3.2	Method	49
3.2.1	Semi-structured interviews (SSIs)	49
3.2.2	Data collection and analysis	51
3.2.3	Document analysis	52
3.2.4	WHO AIMS	52
3.2.5	Ethics	54
3.3	Results	54
3.3.1	The involvement of people with psychosocial disability 1994-2010	54
3.3.2	Organisations of people with psychosocial disability in South Africa	56
3.3.3	Current support for policy participation of people with psychosocial disability	58
3.3.4	Strategies for increasing participation of people with psychosocial disability	59
3.3.4.1	Regulatory support for participation	60
3.3.4.2	Organising for participation	61
3.3.4.3	Building capacity for participation	63

3.4	Discussion	65
3.4.1	Creating a supportive environment	65
3.4.1.1	Advocating for participation as a rights issue	65
3.4.1.2	Building vehicles for rights-based social action	66
3.4.1.3	Crafting supportive regulatory frameworks	67
3.4.1.4	Reorienting and equipping providers and policy makers for inclusion	68
3.4.2	Developing capacity for participation	69
3.4.2.1	Treatment and support as an aid to participation	69
3.4.2.2	Practice as an aid to participation	69
3.4.3	Conclusion	70
Chapter Four: Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: Perspectives of policy makers, professionals, religious leaders and academics		
4.1	Introduction	74
4.2	Method	76
4.2.1	Respondents	76
4.2.2	Instrument development	76
4.2.3	Data collection and analysis	76
4.4.4	Ethics	77
4.3	Results	77
4.3.1	Stigma and low priority of mental health	77
4.3.2	Poverty	80
4.3.3	Ineffective recovery and community support	82
4.4	Discussion	84

Chapter Five: The views of South Africans with psychosocial disability on priorities for supporting recovery: Implications for policy and service development

5.1	Introduction	90
5.2	Methods	91
5.2.1	Design	91
5.2.2	Instrument development	92
5.2.3	Respondents	92
5.2.4	Data collection and analysis	93
5.2.5	Ethics	93
5.3	Results	93
5.3.1	Stigma and discrimination	95
5.3.2	Impoverishment	96
5.3.3	Advocacy	98
5.3.4	Empowerment	101
5.4	Discussion	104
5.4.1	Advocating for involvement in policy and service reform	104
5.4.2	Empathic alliances for civil action	105
5.4.3	Building enabling partnerships	106
5.5	Limitations of the study	107
5.6	Conclusion	108

Chapter Six: Organising for self-advocacy in mental health: Experiences from 7 African countries

6.1	Introduction	112
6.2	Methods	113
6.2.1	Document review	113
6.2.2	Semi-structured interviews	113
6.6.2.1	Informants	113
6.6.2.2	Data collection	115
6.2.2.3	Data management and analysis	115
6.2.2.4	Confidentiality	115
6.2.2.5	Data verification	115
6.2.3	Ethics	116
6.3	Results	116
6.3.1	Organisational purpose	117
6.3.2	The organisations	118
6.3.3	Membership	119
6.3.4	Staffing	119
6.3.5	Leadership and decision-making	120
6.3.6	Technical support and funding	120
6.3.7	Organisational activities	124
6.3.7.1	Advocacy	124
6.3.7.2	Legislation and policy development	125
6.3.7.3	Public health services and supports	126

6.3.7.4 Sustainable livelihoods	127
6.3.7.5 Regional collaboration and capacity development	128
6.4 Discussion	130
6.1 The value of organising	131
6.4.2 Participation	131
6.4.2.1 Advocacy and peer-led service delivery	131
6.4.2.2 Strength through diversity	133
6.4.2.3 The need for alliances	133
 Chapter Seven: Discussion and Conclusion	
7.1 Introduction	136
7.2 Summary of the findings of the study	140
7.2.1 Stakeholder support to policy participation: 1994-2012	140
7.2.2 Barriers to participation	142
7.2.2.1 Structural barriers to participation	142
7.2.2.2 Regulatory, organisational and capacity barriers to participation	146
7.3 A framework to support mental health policy participation by South Africans with psychosocial disability	148
7.3.1 Mental health policy participation...and beyond	148
7.3.2 Improving policy participation for South Africans with psychosocial disability	149
7.3.2.1 Empowerment	151
7.3.2.2 Transformation of social values	152

7.3.2.3 Opportunities for self-directed agency	154
7.3.3.4 Networks of engagement	158
7.3.2.5 Meaningful participation: Working together for policy reform	161
7.4 Contributions of the study	163
7.4.1 Contributions to existing knowledge in the field	163
7.4.2 Contributions to policy and practice	165
7.5 Limitations of the study and recommendations for further research	166
7.5.1 The research question	166
7.5.2 Qualitative research methodology	167
7.5.3 The literature review	167
7.5.4 Data verification: Framework for supporting the participation of people with psychosocial disability in policy development	168
7.6 Further research	168
7.6.1 Addressing the limitations of this research	169
7.6.2 Intervention studies	169
7.6.3 Studies which assess the impact of policy participation on policy outcomes	170
7.7 Conclusion	171
References	172
Appendices	201

List of Appendices

Appendix 1	Criteria for selection and inclusion of advocate and non-advocate service users.	201
Appendix 2	Informed consent form used for MHaPP interviews.	203
Appendix 3	Informed consent form used for doctoral study interviews with South African participants with psychosocial disability.	205
Appendix 4	Informed consent form used for interviews with key informants from Ghana, Kenya, South Africa, Zambia, Tanzania, Ruwanda and Uganda.	209
Appendix 5	Rationale for the development of the semi-structured interview schedules for participants with psychosocial disability.	213
Appendix 6	Development process for the semi-structured interview schedules for participants with psychosocial disability.	215
Appendix 7	Interview guide for district level participants with psychosocial disability.	217
Appendix 8	Interview guide for advocates with psychosocial disability	236
Appendix 9	Example of an interview guide used to interview the 56 participants from various sectors.	244
Appendix 10	Semi-structured interview: Administrative information	252
Appendix 11	SSI guide for key informants from peer led organisations for people with psychosocial disability in Africa	254
Appendix 12	Transcriber's confidentiality agreement	257
Appendix 13	List of participants	258
Appendix 14	List of reviewers: chapter seven	264

List of Figures

Figure 1	Selection process for inclusion of studies	21
Figure 2	Policy priorities to support recovery	94
Figure 3	Framework of personal and environmental supports to participation in policy development	150
Box 1	Examples of political activity to influence policy directions	157

University of Cape Town

List of Tables

Table 1	Key developments and mental health legislation and policy development in South Africa (1868-2012)	6
Table 2	Objectives, data collection method and write up of analysis.	14
Table 3	Characteristics of included studies	24
Table 4	The process of refining themes	30
Table 5	Empowerment: The key to agency in policy participation	39
Table 6	National self-help organisations for people with psychosocial disability in Africa	116
Table 7	Process of development of conceptual framework	138

A personal note from the author

I would like to locate myself within the issues I will discuss below, at the start of this thesis. My own experience has had some influence in my choice of topic, the way in which the thesis has been undertaken, and possibly, the outcomes. Although I have tried my best to be rigorous in my scientific undertaking of the research, I believe that it is important to state my personal experience and positions, in the interests of transparency, and because, in research of this nature it is very difficult to separate personal experience from academic study.

As a clinical psychologist, I have worked as a practitioner in public mental health services for the past twenty years. This has included several years as a mental health programme manager in the Western Cape Province of South Africa, where I was responsible for the implementation of national mental health policy for service development in the province. I have seen the benefits of the medical model for very many people who use the services. As a person who has successfully used mental health services myself to cope with debilitating mental and emotional distress during my late twenties, I have personal experience of the helpfulness of the practices of this system of care. Many members of my family live with enduring and severe mental and emotional distress, and access to public and private mental health care has been of great benefit to all of us living with and supporting those who experience this kind of harrowing distress in our family.

At the same time, I have had occasion to apologize to people whom I treated in some public mental health settings, because of the unhealthy and disturbing conditions under which they were receiving care. As a programme manager, I have dealt with legitimate complaints from clients who had negative experiences using public and private services. Most alienating of all for me, is a still prevalent tendency to depersonalise people using mental health services. A particular diagnosis can overshadow a person's unique identity in a system where professionals can still be heard to talk about "that borderline" or the "schizophrenics", terms which may be used to explain nigh everything that person says or does, including understandably heated complaints about harmful or uncaring service provision. Similarly, I have witnessed the weight of societal misunderstanding and lack of accommodation to clients, family and friends' struggles to rework and regain their feet at home, socially, and especially in the workplace. Given

the societal pressures which impact on a person's recovery, I feel a sense of connection to the efforts of others who take it upon themselves to advocate for change to this system of care. More broadly, I am committed to work to reduce stigma and discrimination against people with psychosocial disability at work and in wider society. This prompted me to become involved in advocacy opportunities myself, and my affiliations reflect both my professional and personal interests. I serve on the Board of the South African Federation for Mental Health, the only large national mental health non-profit organisation (NPO) in South Africa. The organisation's focus is rights advocacy and service provision. I am also a Board member of The Ubuntu Centre in Cape Town, the only registered peer-led Disabled Peoples Organisation (DPO) for people with psychosocial disability in South Africa. The focus of this organisation is advocacy. I mention this in advance as both these organisations are discussed in the thesis.

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CHAPTER ONE

INTRODUCTION

1.1 Outline

The purpose of this introductory chapter is to briefly introduce the topic of this thesis, to define some of the key concepts which inform my understanding of the topic, to provide a brief overview of mental health policy development in South Africa prior to the first democratic elections in South Africa in 1994, and to contextualise and outline the aim and objectives of the study, which focuses on the period 1994 to 2012.

1.2 Defining service users and people with psychosocial disability

Language influences meaning, and it can create and change the way in which one experiences a given situation (Swartz, 1998). The Mental Health Care Act, no 17 of 2002 of the Republic of South Africa defines a mental health care user as “a person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user, a state patient or mentally ill-prisoner...” The Act also includes prospective “users”, next of kin of users, persons authorised by law to act on behalf of users, administrators appointed in terms of the Act, and an executor of a deceased user’s estate. At the inception of this study, this was the term I used as well. In the MHAPP the term “service user” was the general term used across study sites.

As time progressed, and I interviewed people about their experiences, I found myself becoming more comfortable using the term “person with psychosocial disability” to describe people who experience significant or ongoing mental and emotional distress. In under-resourced mental health services in South Africa, and elsewhere in Africa, many people who require treatment and support and wish to use those services are unable to access them (PANUSP, 2011). My thesis includes those individuals, who are not service users but who live with psychosocial disability. Further, in the same way that diagnoses can be stigmatizing, isolating and disempowering so can the designation “service user” pigeonhole a person into the one dimensional role of patient. This thesis addresses issues which go beyond the “patient” or “service user” experiences of people with psychosocial disability to their

experience as citizens with political rights and needs. I also use this term as it is the one chosen to describe its members by the Pan African Network of People with Psychosocial Disability (PANUSP)¹.

For similar reasons, I primarily use the term “mental and emotional distress” in this thesis in recognition of the fact that terms such as “mental illness”, “mental disorder”, “schizophrenia” or “depression” relate to only a part of the person’s experience as a human being. People with psychosocial disability may seek relief from -or be forced into involuntary treatment for – the symptoms of their illness or distress. Their ultimate aim would be as soon as possible, to return to other pursuits in their lives beyond the symptoms they experience. Yet even then, people may tend to relate to them in terms of their diagnosis, if this is known. In this thesis, the focus is on their participation in mental health policy development, in their role as citizen, not only as a patient hence the use of a broader term to address their experience of distress.

1.3 Context

1.3.1 Recovery and policy participation

During the past three decades people with psychosocial disability and their allies have challenged beliefs about the inevitability of reduced capacity of people living with psychosocial disability to meaningfully contribute to decisions which impact on their lives ((Basic Needs, 2009; Chamberlin, 1978, 2010; Funk et al., 2010; McDaid, Knapp and Raja 2008, Minkowitz, 2006). Despite the psychosocial difficulties which enduring mental and emotional distress can bring, people living with psychosocial disability can experience a return of integrity of being, of desire and ability to contribute to their own or others’ wellbeing through their own choices and actions. In short, they can recover. Recovery involves a journey of empowerment, a process through which a person living with psychosocial disability learns to cope with the impact of his or her disability, to assert their intrinsic value as human beings, to develop renewed hope for a meaningful future, to re-build the self-assurance and capabilities needed to choose and act in the creation of an enjoyable life, and to regain access to the power people need to set and accomplish their goals in interaction with others in the world (Anthony, 1993; Barbato, 2006; Davidson, 2009).

¹ This Network previously known as the Pan African Network on Users and Survivors of Psychiatry is affiliated to the World Network of Users and Survivors of Psychiatry. The name change was made in October 2011 to reflect the experiences, agenda and identity of this African regional body.

Patricia Deegan, psychologist and activist, defines recovery as follows:

“ Recovery is a process, a way of life, an attitude, and a way of approaching the day’s challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. The need is to meet the challenge of the disability and to reestablish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution” (Deegan, 1988, p. 15).

“Purpose”, “aspiration” and “contribution” are not terms people with severe mental and emotional distress commonly use to describe their journey of recovery. They most often find themselves having limited supports within a biomedical approach which primarily frames psychosocial disability in terms of management and rehabilitation of impairment. Within and beyond the mental health system, people with psychosocial disability may also experience severe curtailment of their rights and decision-making powers (Gable & Gostin, 2008).

Recovery involves people with psychosocial disability having access to the personal and environmental supports people need to empower themselves to regain or develop their ability to have agency in their lives, and be supported or skilled to make choices which improve their quality of life, within the scope of their capabilities (Barbato, 2006). Such agency may be experienced at various levels: the personal, familial, community, organisational, societal and political. In this thesis, I focus on the empowerment of people with psychosocial disability to participate in political level decision-making, specifically mental health policy making.

1.3.2 Changing the social construction of disability

Traditionally, within a biomedical framework, disability has been seen as an illness, or impairment, a problem that lies within the individual (Swartz and Watermeyer, 2006). This perspective emphasises the clinical management and rehabilitation aspects of an illness, for example screening for potential mental health problems, assessing the extent of the problem, deriving a diagnosis, and working toward applying interventions which will cure or return the patient as far as possible, to “normal functioning”. There tends to be little attention to

supporting the person to overcome barriers to their optimal participation in ordinary everyday life roles of their choice. Outside of the medical field, within general society, disabled people are also viewed as impaired. Where they experience difficulty in achievement, this is ascribed to their impairment, rather than to a lack of adequate and appropriate environmental supports, the expectation being that they would be less able than able-bodied people to meet their own needs, or to contribute to the needs of others.

This individually-based perspective has been challenged by the social model of understanding disability (Swartz and Watermeyer, 2006). The social model of disability advocates for a move away from a deficit based perspective of disability which devalues and stigmatises disabled people. The deficit perspective does not allow an emphasis on the right of disabled people to equal access to the social resources and opportunities available to able-bodied and able-minded people. Proponents of this model argue that it is not physical, mental or sensory differences between people which results in disability, but rather negative perceptions, systemic barriers and societal exclusion that is disabling (Swartz and Watermeyer, 2006). Society is organised and designed for ease of living and access to social resources by able-minded and able-bodied people, while disabled people have limited, disabling social choices and opportunities. This restricts the disabled person's opportunities for optimal social engagement, and reduces ability to experience him or herself as a valued member of society, capable in all areas of personal choice, including that of influence over policies.

1.3.3 The rights of people with psychosocial disability

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted by the United Nations (UN) in 1993, shortly after the adoption of the principles for the protection of persons with mental illness and the improvement of mental health care (1991). Most recently on December 13, 2006, the UN Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (UNCRPD) and its Optional Protocol was adopted by the UN General Assembly, and entered into force on 3 May 2008. These instruments indicate a formal acknowledgment by the international community of the rights of people with disabilities to be participate in all aspects of public life. The UNCRPD (2006) now sets the gold standard for moving from limited and prejudicial views of people with disabilities as charity cases in need of medical intervention and social protection, to their right to full

inclusion in society. The Convention asserts the equal rights of people with psychosocial disability, including their right to opportunity to make decisions about their lives based on their free will and consent. It provides guidance on how these rights apply to persons with disabilities, identifies areas where adaptations may be needed for persons with disabilities to effectively exercise their rights, and addresses the protection of rights which have been violated.

1.3.4 The right to be included as a policy participant

Article 29 of the UNCRPD (2006) deals with the right of people with disabilities to participate in the political and public life of their country and community. This article addresses the right to vote, serve as an elected official, participate in the conduct of public affairs and political parties, as well as forming or becoming members of associations who represent people with disabilities in the public arena. Public policy development processes is one aspect of political life where people with disabilities should also be able to freely participate. This study specifically addresses the issue of the participation of adults with psychosocial disability in mental health policy development in South Africa. “Psychosocial disability” in this study refers to the experience of ongoing or recurring episodes of mental and emotional distress which “in interaction with various barriers...hinder people’s full and effective participation in society on an equal basis with others” (Article 1, UNCRPD, 2006).

1.3.5 Defining participation

Hicky and Kipping (1998), in their paper on client participation in service development and delivery, identify two approaches to participation, the consumerist and the democratization approaches. The consumerist approach is premised on the idea of improving the range of options available to people for a service, in the belief that people are empowered by being able to choose between services, rather than being passive recipients of what is available. Consumers are provided with information about product choice (the information/explanation approach), and/or consulted on preferences. Services are devised or improved by the provider, and consumer power is exerted through their purchasing or utilization decisions (the consultation approach). The democratization approach to participation refers to the active interface between service providers and end users in the development, revision and even execution of services. Here, people are not merely informed or consulted. Rather, they are

involved in joint decision-making around policy, content, process and practice in service development (partnerships) or responsible for making decisions themselves, with the support of others, if and when required (control). In this study, my understanding of participation in the policy context will be premised on the assumption that people with psychosocial disability have a democratic right to be included in the formulation of policies which impact on their lives and to supports which enable such participation. This obviously includes all state policies, but in this study I will focus on the formulation of national mental health policies which influence all other developments in the field at service development and delivery levels.

1.4 Mental health policy development in South Africa

1.4.1 Mental health policy development before 1994

Table 1 below, adapted from Foster et al (1997) and Jones (2012) provides a summary of the history of mental health legislation and policy development in South Africa, contextualised within other key historical events in South Africa (*italicised*) during the past century.

Table 1: Key developments in mental health legislation and policy development in South Africa (1868-2012)

Year	Milestones
1846	<i>Robben Island convict station in the Cape is used to house lunatics, lepers and poor chronically ill people</i>
1868	Natal Custody of Lunatics Law, no 1 of 1868: first legislation in Southern Africa “to provide safe custody of the dangerously insane and persons of unsound mind”
1876	<i>Grahamstown Lunatic Asylum (later Fort England Hospital) opens</i>
1880	<i>Pietermaritzburg Lunatic Asylum (later Town Hill mental hospital) opens</i>
1884	<i>Valkenberg Asylum opens in the Cape to accommodate lunatics previously held in gaols, hospitals and on Robben Island. (Psychiatric hospitals would grow in number to 23 countrywide over the next century)</i>
1910	<i>South Africa becomes a Union and part of the British Commonwealth</i>
1912	<i>The African National Congress (ANC) is established</i>
1916	Mental Disorders Act No. 38 is promulgated replacing all regional legislation

1944	Mental Disorders Amendment Act: provision for temporary patients
1948	<i>The National Party comes to power and Apartheid policies are implemented</i>
1951	<i>Bantu Authorities Act no 68: Establishment of “homelands” for black people</i> <i>Separate Registration of Voters bill: “Coloureds” placed on separate voters role</i>
1957	Mental Disorders Amendment Act: Social defective (sociopaths) category removed, and these patients are transferred to prisons. Commissioner for Mental Disorders changed to Commissioner for Mental Health.
1961	<i>South Africa becomes the Republic of South Africa</i>
1961	Mental Disorders Amendment Act: outpatient services introduced, free services for citizens unable to pay for treatment Report on the establishment of mental institutions in “homelands” for blacks
1962	<i>Nelson Mandela is jailed on Robben Island, previous home to lepers and the insane in the Cape Colony. African National Congress go underground.</i>
1963	<i>Smith Mitchell long term mental health institutions for black patients established</i>
1966	<i>Dimitri Tsafndas stabs and kills Hendrick Verwoed, the architect of Apartheid. He is declared mad and dies in a psychiatric hospital in 1999.</i>
1973	Mental Health Act no, 18 is promulgated.
1975	Proclamation on mental rehabilitation centres in “Bantu Homelands”
1976	<i>Country-wide anti-Apartheid uprisings commence after shooting of protesting children in Soweto township</i>
1976	Mental Health Amendment Act: prohibition of photographs of or information on mental institutions
1984	<i>Tri-cameral parliamentary system is established for people registered as White, Coloured and Indian under the population registration Act. People registered as Black are excluded as they are regarded as “citizens” of “independent homelands.</i>
1992	<i>Nelson Mandela is released from prison</i>
1994	<i>All citizens are eligible to vote in South Africa’s first democratic election! An ANC government is elected into power.</i>
1997	The White paper for the transformation of the health system in South Africa includes a chapter on mental health
1997	The National health policy guidelines for improved mental health in South Africa are developed but not formally published for implementation”
2002	The Mental Health Care Act no 17 of 2002 is gazetted

2004	The Mental Health Care Act no 17 of 2002 is promulgated into law
2006	A draft mental health policy is developed by the National Directorate for Mental Health and Substance Abuse (DMHSA)
2010	The 2006 draft policy is substantially revised by the DMHSA, with technical support from the Mental Health and Poverty Project.
2012	The draft mental health policy is presented for comment at the first Ministerial Summit on Mental Health in April 2012
2012	The Mental Health Care Amendment Bill, no 542 is published for comment on 20 July 2012

1.4.1.1 Patient voice in early policy development

Jones (2012) in her historical account of the development of mental health legislation and services in South Africa found no mention of patient perspectives in formal records reporting on mental health services during the period leading up to South Africa's transition to a republic in 1961. She also found a limited cache of archived court proceedings and letters written by patients who were treated in isolated mental institutions between 1939 and 1961. These accounts chronicle patient complaints about treatment conditions, and their despair about their years of predominantly involuntary detention in custodial psychiatric facilities at the time. After 1961, a period of growing repression in South Africa under the Nationalist government, information of any type was strictly controlled by the state, and there was even less evidence related to patient voices in mental health care in South Africa. Jones reports that the letters and petitions of the predominantly "white" and "coloured" literate patients in state institutions in South Africa were not kept by the State President's office in South Africa. "Black" patients in long-term institutions, many of them illiterate, had little recourse to bring attention to their wishes, while those living as citizens in "independent homelands" were deemed not the concern of the South African government.

It was only in 1994, with the first democratic election of South Africa, and the dismantling of the Bantustans that all citizens of the country were restored to full citizenship and eligible to vote and participate in public policy-making activities.

1.4.2 Post-Apartheid policy development (1994-2012)

The first ten years of the post democracy was a period during which the ANC government focused on transforming Apartheid institutions and dismantling laws and policies (Booyesen and Erasmus 2001). During this time, a vibrant democracy has emerged, with numerous channels for public participation in policy development.

1.4.2.1 Stakeholders in policy development processes in South Africa

Two broad groups are involved in policy making in South Africa. These are organs of government, and individuals or groups in civil society. The first group comprises institutions linked directly to the process of policy-making, which exert significant influence on policy development outcomes. These institutions are:

- The Constitutional court
- The National Assembly
- The National Council of Provinces
- Cabinet and Cabinet Committees
- Parliamentary portfolio committees
- Intergovernmental institutions and meetings e.g., the National Health Council (formerly known as Meeting of the national Minister and provincial ministers of executive council (MINMEC))
- National Government Departments
- Provincial Government Departments
- Provincial and Local government institutions

Civil society comprises individuals or institutions that represent wider society in government policy-making processes. Civil society participation in policy making can occur through one or more of the following strategies:

- Public or parliamentary portfolio committee hearings
- National conferences for public participation
- Community forums for policy participation
- Commissioning research to NGOs and research institutions
- Using specialists and experts from academic sector

- Special meetings with and briefings of private sector institutions
- Meetings with lobbyists.

1.4.2.2 Mental health policies in South Africa

Chapter 12 of the “White paper for the transformation of the health system in South Africa” (Department of Health, 1997b) focuses on setting out the structure of preventative, promotive and rehabilitative mental health services and programmes for the country. The White paper emphasizes deinstitutionalization from mental institutions and the development of community-based mental health care within a primary health care approach. This policy was widely consulted within post-apartheid circles, but no mention is made of patient participation in its development, although the policy itself endorses the involvement of patients, their families and communities in mental health service planning.

A national mental health policy guideline, consistent with the White paper, was also developed and approved in the same year (Department of Health, 1997a). The mental health policy guideline was drafted by the National Director for Mental Health in the Department of Health, with the encouragement of the National Minister of Health. The policy guideline was informed by the provisions of the White Paper on the transformation of the health system, 1997, and is therefore most accurately read in conjunction with the White paper.

Consultation processes for the mental health policy guideline preceded the transition to the “new” South Africa in 1994. During this time there were many consultative meetings among mental health stakeholders, and within the African National Congress (Foster, et al. 1997).

The policy guideline was used extensively by provincial health authorities to develop mental health services until the development of the Mental Health Care Act in 2002. The policy guideline was presented to the Meeting of the Health Minister and the 9 provincial Members of Executive Councils (MINMEC) in 1997. MINMEC (now called the National Health Council) is the highest decision-making body for health in South Africa, and all potential health policies need approval from this body before implementation can take place within the provinces. Approval of the policy guideline was granted by MINMEC in 1997. Despite this, the policy was not regarded as a formally adopted policy by national mental health government officials as it had not been formally distributed and published for implementation at the time (Draper et al, 2009).

From 1998 to 2002 the national Department of Health focused on the development, adoption and subsequent implementation of the Mental Health Care Act, no. 17 of 2002. This Act is consistent with international human rights standards for mental health care. It focuses primarily on supporting the implementation of services for mental health care within psychiatric hospital and general health services and specifies the development of community-based care for people with psychosocial and intellectual disability.

1.5 Current gaps in our knowledge: the participation of people with psychosocial disability in mental health policy in South Africa

There are potentially several positive spin-offs from the participation of people with psychosocial disability in policy development. Their participation would uphold their constitutional rights as citizens of South Africa, it can increase the relevance of policy development (WHO, 2005), and provides them with opportunity to have an impact on policies which have far reaching effects on their lives. Yet the inclusion of people with psychosocial disability in the formulation of these policies is a fairly recent development (Funk, 2006), particularly in the African context (Faydi, et al., 2011). In South Africa, while we have some knowledge of general and mental health policy development in the context of political transformation in South Africa, to date there has been no systematic study to investigate the participation of people with psychosocial disability in mental health policy development in South Africa.

1.5.1 Aim and objectives of this study

The focus of the current study, then, is to investigate the participation of people with psychosocial disability in the mental health policy development process in South Africa. Specifically, this study addresses the following research question: What are the barriers and strategies to support the participation of South Africans with psychosocial disability in mental health policy development in South Africa?

1.5.2 Objectives

The 6 objectives which will be addressed within the overall aim of the study are:

1. To conduct a *systematic review of current literature* on barriers and strategies to support people with psychosocial disability participating in mental health policy development.
2. To describe *current support for participation* of people with psychosocial disability in mental health policy development in South Africa and to suggest strategies for improving participation.
3. To ascertain South African *stakeholders' views* on environmental barriers to the participation of people with psychosocial disability in mental health policy development in South Africa.
4. To document the views of South Africans with psychosocial disability on their *lived experience* of barriers to their recovery and to highlight the implications of these barriers for priorities for policy development.
5. To document *lessons from the work of peer led organisations* for people with psychosocial disability in Africa which might inform the participation of people with psychosocial disability in mental health policy development in South Africa.
6. To develop a *conceptual framework* for supporting South Africans with psychosocial disability to participate in mental health related policy development in South Africa.

1.6 Outline of the thesis

A mixed methods approach was used to address the research question and objectives. These are detailed in each chapter of the thesis, but for clarity, are summarised in Table 2 below. As can be seen in Table 2, the study is primarily based on qualitative data, specifically semi-structured interviewing. This form of in-depth interviewing is well suited to identifying and describing the experiential issues and processes which are the focus of this study. Interviewing allowed for a detailed exploration of participants views and experiences, with qualitative analysis providing an appropriate means of deriving meaningful interpretations of the text collected during these interviews (Creswell, 2003; Mayan, 2001). Table 2 also links each chapter to the relevant objective of the study.

Chapter two addresses objective one of the study. It reports the findings of a systematic literature review which explored the question “What supports people with psychosocial disability to participate in national mental health policy development?” The chapter notes limitations of the review and suggests future research in line with the findings of the review.

Chapter three addresses objective two of the study. It reports on current support for the participation of people with psychosocial disability in mental health policy development in South Africa and suggests strategies for improving their participation.

Chapter four addresses objective three of the study. It reports on environmental barriers to mental health policy participation by people living with psychosocial disability, from the perspective of South African stakeholders involved in mental health policy development.

Chapter five addresses objective four of the study. It captures the experiences of South Africans with psychosocial disability with regard to barriers to their participation in mental health policy development, and highlights their priorities for policy development.

Chapter six addresses objective five of the study. It reports on strategies which supported the establishment and sustainability of 9 mental health self-help organisations in 7 African countries and elaborates on the advocacy, peer support and policy-related work of these organisations. The experiences of these organisations were explored to inform similar developments in South Africa.

Chapter seven concludes the thesis by drawing on all the data sources reported in chapters two to six, to present a conceptual framework for improving the participation of people with psychosocial disability in policy development in South Africa. The contributions and limitations of the study and suggestions for further research are also discussed in this chapter.

Table 2: Objectives, data collection method and write up of analysis.

Objectives	Literature review	Semi-structured interviews	WHO Policy Checklist	WHO Legislation Checklist	WHO AIMS	Chapter of Thesis
1. Systematic literature review	Yes					Chapter 2
2. Current support for participation		Yes	Yes	Yes	Yes	Chapter 3
3. Influential stakeholders' views on environmental barriers to participation		Yes				Chapter 4
4 Lived experience of barriers to policy participation, and policy priorities		Yes				Chapter 5
5. Lessons from peer organisations		Yes				Chapter 6
6. Conceptual framework for developing support for participation	Yes	Yes	Yes	Yes	Yes	Chapter 7

CHAPTER TWO

LITERATURE REVIEW

The participation of people with psychosocial disability in mental health policy development: A qualitative meta-synthesis

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Study objective

This chapter addresses objective 1 of the study which is to conduct a systematic review of current literature on barriers to and strategies to support people with psychosocial disability participating in mental health related policy development.

Contributions of the authors

Sharon Kleintjes drafted the research protocol for this study under the supervision of Professor Alan Flisher. She carried out or supervised the data collection, and conducted all

of the data analysis. She was the lead author on this paper. Ms Sara Cooper assisted with the data collection and reviewed the final two drafts of the paper. The remaining authors supervised the research and critically reviewed drafts of the article.

Current status

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Abstract

Objective

This qualitative meta-synthesis aims to explore the potential barriers that prevent people with psychosocial disability from participating in and influencing mental health policy development, and possible strategies for overcoming these barriers.

Method

A systematic electronic search of nine international databases was conducted in August 2011, to identify empirical studies, without restriction by date, country or study design, which investigated the participation of people with psychosocial disability in mental health policy development processes. Five papers were included, spanning the period 1990 to 2007.

Results

Lack of power emerged as the overarching barrier to participation in policy development. Three key aspects of this lack of power were identified, namely compromised citizenship, social and economic disadvantage and the marginalisation of “voice” in the policy dialogue.

Conclusion

Full citizenship, social and economic upliftment and prioritisation of the voices of people with psychosocial disability are key conditions to promote empowerment of people with psychosocial disability in mental health policy participation. Research which can support implementation of these strategies included evaluation of interventions to reduce structural, institutional and procedural barriers to participation, and assessment of the impact of policy participation. Limitations to the study included the paucity of studies available for inclusion and the quality of the included studies.

2.1 Introduction

Research on the participation of people with psychosocial disability tends to focus on their participation at individual, institutional and local government levels. This includes involvement in treatment planning (Deegan, 2010; Fox, 2008; Harding et al., 2011; Linhorst et al., 2005), service development and evaluation (Bowl, 1996; Campbell, 2001; Petersen et al., 2008; Simpson and House, 2002; Tse et al., 2012), mental health service delivery (Burti et al., 2005; Chamberlin 2005; Haigh, 2008), self help initiatives (Bassman, 2001; Cohen et al., 2012; Munn-Giddings et al., 2009;) curriculum development, education and training (Felton and Stickley, 2004; Happell, 2008) and research (Beresford, 2007; Davidson et al., 2010; Lammers and Happell, 2004; Minogue and Girdlestone, 2010).

There has been much less focus on their participation in the over-arching national mental health policy-making processes which inform these individual and local government decision-making processes (Barnes, 2002; Munro et al., 2006). This review therefore seeks to speak to this gap, by exploring what is currently known about the involvement of people with psychosocial disability in policy processes at the national level.

2.1.1 *Aim and objectives of the review*

This qualitative systematic review aims to examine empirical quantitative and qualitative studies which investigated the participation of people with psychosocial disability in national-level mental health policy development, in order to answer the following research question: “What supports people with psychosocial disability to participate in national mental health policy development?” Policy was understood in broad terms to include national government policy documents and legislation, which are intended to address a particular social, economic or health issue.

The specific objectives of the review were to identify:

- 1) Potential barriers that prevent people with psychosocial disability from participating in and influencing mental health policy development.
- 2) Potential strategies for overcoming these barriers.

The term ‘people with psychosocial disability’ is used throughout the paper, except when reporting original findings, where authors’ own terms are used. Psychosocial disability is understood by the authors to refer to people who have experienced ongoing or recurring episodes of mental ill-health which “in interaction with various barriers...hinder their full and effective participation in society on an equal basis with others” (Article 1, UNCRPD, 2006).

2.2 Method

The methods of this review were informed by the Centre for Reviews and Dissemination (CRD) guidelines for conducting systematic reviews (CRD, 2009).

2.2.1 Search strategy

The following nine databases were searched in August 2011: Academic Search Premier; Africa-Wide: NiPAD; Cochrane Library; MEDLINE; Pubmed; CINAHL; PsychInfo; Science Direct; Sabinet Online, using Medical Subject Heading (MeSH) terms (or equivalent terms) for published peer-review journal articles. Terms used to identify articles were “mental disorders” and all terms included in MESH as sub-headings of mental disorders. Terms used to identify articles relating to people with psychosocial disability were “service user”, “consumer”, “client”, “survivors”, “users”, “patient” and all terms included in MESH as sub-headings of users and patients. Additional search terms included “participate”, “involve”, “decision”, “include”, “empower”, “self-help” and “advocacy”. Given the paucity of research in the area, we decided to keep our search terms very broad, and then manually select those papers relating to our chosen conditions.

2.2.2 Inclusion and exclusion criteria

Inclusion criteria for the review were peer-reviewed academic journal publications of empirical studies, published in English without restriction by date, country or study design (both qualitative and quantitative studies included). Studies were included if they focused on people who had been assessed as having a psychiatric diagnosis according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) or the International Classification of Disorders (ICD10) and who had participated in mental health policy development processes as defined above, at the national level. Exclusion criteria were studies which focused on people diagnosed with a substance abuse disorder, intellectual disability or developmental

disorders (DSMIV or ICD10), children and adolescents, the involvement of people with psychosocial disability at the micro-level, including treatment level decision-making (decisions related to participation in own clinical plan development and treatment on an individual level), and service level decision-making (decisions related to service development or delivery at local service catchment area and organisational level).

2.2.3 Identification of studies

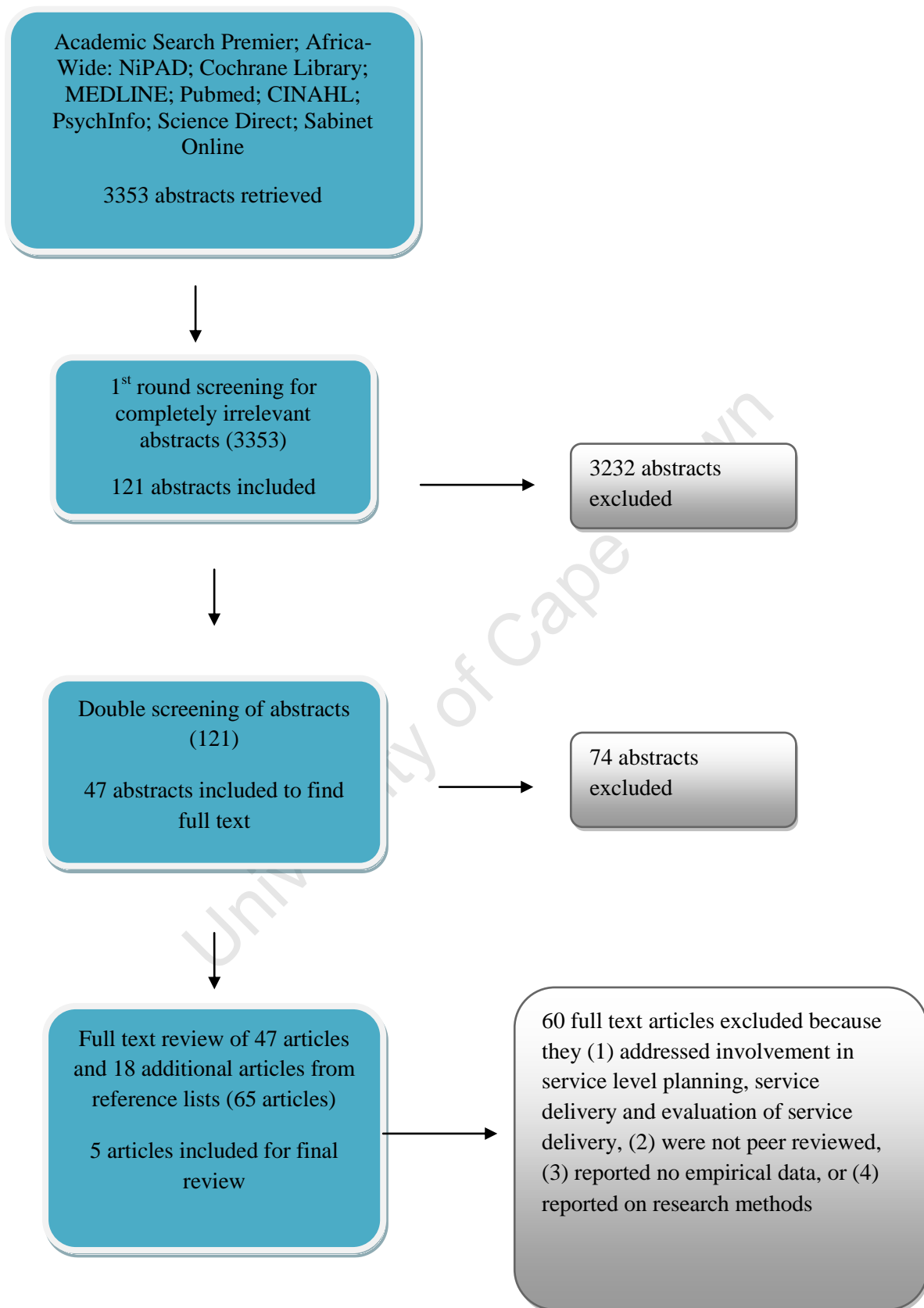
Figure 1 provides a summary of the process of identifying suitable articles for inclusion in the study. Using the search methods described above, we identified 5,636 abstracts, of which 2,265 were duplicates, leaving an initial 3,353 potential abstracts.

These abstracts underwent three stages of screening. Given the quantity, and large number of irrelevant abstracts, SC conducted the first round of screening to exclude articles that clearly did not address the research question at all. Of the 3353 titles and abstracts screened, 3232 papers were excluded.

In the second round of screening, the remaining 121 abstracts were double screened by SK and SC to identify papers potentially eligible for inclusion based on the title and abstract. Disagreements in the reviewers' decisions were resolved through discussion. At this stage, 74 papers were excluded, leaving 47 potentially eligible abstracts.

The full text articles of these 47 abstracts were obtained. The reference lists of these articles were scanned for potentially relevant studies. Review of the reference lists of these studies identified a further 18 studies for which the full text articles were obtained electronically. A total of 65 full text articles were then reviewed by SK and SC, reducing the number of relevant studies to five. The 60 excluded articles included 7 publications that were not peer reviewed articles, with the remaining peer reviewed articles focusing on non-empirical accounts of overarching policy involvement (2), involvement in service delivery level strategic and/or operational decision-making and management (18), involvement in research (4), consumer survivor organisations/initiatives (CSIs) (8), and various issues related to empowerment of people with psychosocial disability (21).

Figure 1: Selection process for inclusion of studies



2.2.4 *Quality assessment*

The 5 studies were included in the review, regardless of quality. We did however perform quality assessments of the studies, in order to evaluate the type, quality and rigour of research in this area. Different approaches to quality assessment were used for quantitative and qualitative studies. The Effective Public Health Practice Project quality assessment tool for quantitative studies was used to assess the quality of the 2 quantitative studies (www.city.hamilton.on.ca/PHCS/EPHPP). This tool assesses quality on 8 dimensions: selection bias, study design, assessment of confounders, blinding, appropriateness of data collection methods, reporting of withdrawals and dropouts, intervention integrity, and appropriateness of data analysis.

A quality assessment tool development by Walsh and Downe was used to assess the quality of the 3 qualitative studies. There is still much debate on what criteria should be used for evaluating the quality of qualitative research, and whether such an evaluation is useful. (Walsh and Downe, 2006). This particular tool was selected as it is based on a rigorous systematic synthesis of criteria used in other existing tools. It provides a grading system for the quality of the study on several dimensions, namely: clarity of aims, appropriateness of design and sampling strategy, explicitness of analytic frame, clarity of and contextualisation of interpretation process, explication of author influence on research process (reflexivity), ethical sensitivity, and discussion of the theoretical and practical relevance and transferability of the study findings. Studies were graded on each of these criteria, and an overall rating was given. These ratings can be seen in Table 3. The ratings are clarified on page 28.

2.2.5 *Data Analysis and Synthesis*

The articles were analysed to uncover qualitative themes which could build understanding of issues which could inform the research question. A standard data extraction form was developed to capture the following data: Authors' name(s), date and setting of study, purpose of study, key research questions, sample and methods used, empirical findings including impact of participation, themes which emerged from the empirical findings, discussion and recommendations.

Each article was read several times, extracting the empirical findings and entering these on the standard data extraction form. An adapted version of the meta-synthesis approach developed by Downe and Walsh (2009) was then used to conduct the meta-synthesis. Meta-

synthesis is a method of comparing and contrasting the ideas, concepts and relations across a set of studies on a similar phenomenon, retaining the meanings of the author's original ideas. "Reciprocal, contrasting and conflicting" ideas across authors are interrogated to arrive at a deeper understanding of the phenomenon or issue under study (Walsh and Downe, 2005).

In line with this method, the process followed in this review was as follows: SK read the articles several times to gain an overall impression of the emerging themes. Each article was then hand-coded for themes embedded in the empirical findings and the authors' discussion of the findings until no new themes emerged from re-reading of the article. SK then moved to the next article, logging similar ideas under themes which had emerged from previously coded articles, and novel ideas under a new theme. The ideas logged under the initial themes were reviewed several times, with the articles consulted again when necessary to more clearly identify and refine the core ideas, similarities, differences and dilemmas emerging within and across the articles. This process refined the initial 13 themes to 4 final themes as summarized in Table 4. The 4 themes are elaborated in the narrative of the results section. Empirical findings from each study are reported in Table 3.

2.3 Results

2.3.1 Description of included studies

Five articles met the inclusion criteria and were thus included in the review. They report findings from 5 studies conducted in Canada (3), the United States of America (1) and China (1). Two of the 5 studies were quantitative surveys and 3 were qualitative. Two qualitative studies were based on related research by the same author. Table 3 summarises the characteristics and empirical findings of the 5 included studies. The 2 quantitative studies were assessed as of moderate and weak quality respectively, while the qualitative studies either had no, few or some flaws, but none likely to affect the overall quality of the findings of the study. Ratings are reflected in Table 3.

Table 3: Characteristics of included studies

Author(s), year, country, journal	Focus of study	Method	Quality assessment	Key Findings and recommendations
Church and Reville, 1990, Canada Canadian Review of Social Policy	Participant experience of consumer/survivor involvement at hearings on community mental health legislation	<u>Qualitative study</u> <i>Telephone and face to face interviews, observation at hearings</i> Snowball sample of 60 consumer survivors, government staff, patient advocates, key informants	*B	Findings: User participation is not central to policy reform processes. Public media and government notices to inform participants were not readily accessible to most users. Barriers to participation include insufficient notice to prepare for participation, complex reform documentation, lack of accommodation of formal settings to layperson input, and lack of funding for user participation. <u>Impact of participation on policy decisions:</u> Not addressed. Recommendations: Users need to generate the consultation agenda, consultation environments/processes should be user friendly, user organisation development should be supported to promote representation in planning and implementation mechanisms, planning staff require training in techniques which promote user participation in policy processes.

<p>Church, 1996, Canada Canadian Journal of Community Mental Health</p>	<p>Participant experience of consumer survivor/professional/bureaucrat commissioners' interaction during public hearings on legislation</p>	<p><u>Qualitative study</u> <i>Semi-structured Interviews</i> Convenience sample of 14 mental health and government employees and 7 consumer/survivors involved in organising the public hearings</p>	<p>*B</p>	<p>Findings: Professionals, bureaucrats and users had different policy priorities. Policy maker and professional interests dominated, users' priorities were less valued. Structural barriers to participation were not accommodated (subsistence and travel costs). Lack of resources reinforced differences in power and position between user and state commissioners.</p> <p><u>Impact of participation on policy decisions:</u> User commissioners succeeded in retaining user interests in the hearings report. The report was not implemented.</p> <p>Recommendations: Capacity development needed to prepare users to participate. Anger should be seen as an appropriate political tool for aggrieved citizens.</p>
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<p>Evans and McGaha, 1998, Missouri, United States</p> <p>Community Mental Health Journal</p>	<p>Preparation and involvement of consumers and family in public mental health policy making</p>	<p><u>Quantitative study</u></p> <p><i>State wide survey.</i></p> <p><i>Convenience sample of 500 consumers living in community housing and involved in self help groups and 136 family members</i></p>	<p>**</p> <p>A=moderate</p> <p>B=moderate</p> <p>C=weak</p> <p>D=weak</p> <p>E=weak</p> <p>F=moderate</p> <p>Ov=weak</p>	<p>Findings: Just over half of consumers received information about mental health care reform processes. Consumers felt that their participation can be supported by making information easier to understand (31%), finding ways to get information to them (19.2%), providing assistance to explain what it means (17.2%), and getting information on a timely basis (15.5%). 22% of consumers felt they were able to make changes to the mental health system without support from an established group. 54% of consumers reported that they did not belong to advocacy groups, most commonly due to lack of money (27%), lack of transportation (25%), not knowing how to find an organised group (21%), health problems (13%), or disliking groups (12%).</p> <p><i>Impact of participation on policy decisions: Not addressed.</i></p> <p>Recommendations: Professionals can play an important role in informing users of policy reform processes. Providers should have information on user organisations and advocacy opportunities. Policy makers should provide training and materials to service providers and user organisations to increase their capacity to share mental health information with users.</p>
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<p>Jansen et al., 2006, Canada Journal of Community Psychology</p>	<p>Identification and exploration of systems level activities of consumer/survivor - run initiatives (CSIs)</p>	<p><u>Qualitative</u> <i>Tracking log of activities of 4 CSIs over 25 month period April 2000-April 2002.</i> <i>Four focus groups with CSI staff and members, and 13 key informant interviews with health planners and service providers</i></p>	<p>*A</p>	<p>Findings: Four interlinked activities were identified: 1) political advocacy to change social policies and practices, 2) public awareness, education to reduce stigma and promote supportive environments, 3) community planning and collaboration to change existing practice, create new supports and services, 4) action research to gather accurate information to increase influence of initiatives in 1-3.</p> <p><i>Impact of political advocacy on policy decisions:</i> Respondents felt impact was difficult to assess due to number of role-players involved. Tangible outcomes of political advocacy included changes in public policy, legislation or service funding, and improved access to planning opportunities. Research evidence supported recommendations made for policy reform.</p> <p>Recommendation: Multiple strategies are needed for systems change.</p>
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Chan and Chui, 2007, Hong Kong, China	Preparation for and involvement of consumers and family members in public mental health policy making	<u>Quantitative study</u> <i>Computer assisted telephone surveys</i> Random sample of 520 users (at eight halfway homes and three psychiatric clinics) and random sample of 507 adults from the general public	** A=strong B=moderate C=weak D=moderate E=strong F=strong O=moderate	Findings: Users were poorer, less educated and unemployed than the public group. Experience of mental illness and sense of citizenship were negatively related. Users reported higher political efficacy, trust in authorities (except the judicial system) and involvement in group protest actions than the public group. Higher political efficacy and participation in protest action did not result in higher electoral participation or a stronger sense of citizenship. Service users were less experienced in political participation than the public group. Experience of political participation boosted sense of citizenship for service users. <i>Impact of participation on policy decisions:</i> Not addressed. Recommendations: Political participation matters in forming a sense of citizenship and social inclusion, and a belief in personal power to influence social and political processes for people with mental illness. Civic group membership should be encouraged to support user political participation.
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*Downe and Walsh's qualitative assessment tool rating scale A: No, or few, flaws, study credibility, transferability, dependability and confirmability is high; B: Some flaws, unlikely to affect the credibility, transferability, dependability and/or confirmability of the study; C: Some flaws that may affect the credibility, transferability, dependability and/or confirmability of the study; D: Significant flaws very likely to affect the credibility, transferability, dependability and/or confirmability of the study.

**McMaster Effective Public Health Practice Project (EPHPP) quality assessment tool: A= selection bias; B= Study design; C=Confounders; D=Blinding; E=Data collection methods; F=Withdrawal and Dropouts; O=overall rating. .

2.3.2 *Thematic analysis and Meta-synthesis*

Table 4 depicts progressive refining of themes during thematic analysis of the data. The process of refining themes highlighted four key barriers to the participation of people with psychosocial disability in policy processes, as well as key conditions and related strategies for overcoming these obstacles. Lack of power for agency in policy processes was the key barrier to the participation of people with psychosocial disability in policy processes. This overarching theme emerges as a thread running through the three remaining barriers or sub-themes: 1) compromised citizenship, 2) social and economic disadvantage, and 3) marginalisation of “voice” in the policy dialogue. Although the separation of these issues is somewhat artificial, given their interrelatedness, in the interests of style and clarity, each barrier will be unpacked separately, together with the suggested solutions.

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Table 4: The process of refining themes

<i>First iteration</i>	<i>Second Iteration</i>	<i>Third Iteration</i>	<i>Final Iteration</i>
<i>13 themes</i>	<i>5 themes</i>	<i>3 themes</i>	1. <i>Overarching theme:</i> Unequal power for participation due to:
1. Rights	1. Citizenship	1. Citizenship	2. Compromised citizenship
2. Citizenship			
3. Political participation			
4. Poverty	2. Poverty and social disadvantage	2. Poverty and social disadvantage	3. Poverty and social disadvantage -Poor access to reform processes
5. Authentic voice	3. Interests and representation	3. Unequal Power for participation due to -Dominant Provider interests	4. Marginalisation of “Voice” in policy dialogue -Dominance of provider values and interests in
6. Interests			
7. Representation			

8. Power	4. Limited power to participate: Poor access to reform processes -Limited information about reform processes -Financial barriers -Procedural barriers -Communication styles/processes -Dominant professional values/interests	-Lack of representation by people with psychosocial disability -Communication styles/processes -Insufficient capacity for participation	policy reform - Influence of communication styles /processes. -Weak representation of people with psychosocial disability in policy reform. -Insufficient capacity for participation
9. Poor access to reform processes -Limited information about reform processes -Financial barriers -Procedural barriers			
10. Communication styles/processes			
11. Dominant professional values/interests			
12. Capacity building-people with psychosocial disability			
13. Capacity building-professionals	5. Capacity building-people with psychosocial disability/professionals		

2.3.2.1 . *Compromised citizenship*

The broader context of how citizenship is defined and practiced will influence whether these citizens will be able to be active agents of change in policy making processes (Chan and Chui, 2007; Church and Reville, 1990; Church, 1996; Jansen et al., 2006). People with psychosocial disability have historically had limitations placed on their decision-making powers both within the mental health system, and in society in general. Church (1996) notes that participation of people with psychosocial disability is an issue of “power and the redistribution of power” (page 29), of freedom of involvement in all planning and decision-making which has an impact on their lives. Evans and McGaha (1998) similarly note that people with psychosocial disability must have influence over all decisions which impact on their health and wellbeing within their broader communities.

Chan and Chiu (2007) state that the involvement of people with psychosocial disability in policy change is a political process, a voluntary “attempt to influence the formulation, passage or implementation of public policies” (p199). These authors found that experience of political participation can influence belief in power to influence social and political processes, and suggest building capacity for political participation as a strategy for empowerment. They also caution that participation *per se* may not be the influencing factor in building confidence and agency, but rather the nature and impact of the participation experience within the policy-making environment. Some people with psychosocial disability make a political decision not to participate in mental health policy making processes because of their beliefs about or experience of the mental health system as unresponsive or harmful, as a system where they have no power of influence (Church and Reville, 1990; Church, 1996; Jansen et al., 2006).

2.3.2.2 *Poverty and social disadvantage*

The priorities addressed by people with psychosocial disability during reported policy processes included issues related to deficits within the mental health service delivery system. However, the studies also addressed issues beyond this system, such as stigma, discrimination, victimisation, prejudice and exclusion, reducing poverty, and improving access to basic needs such as income, disability benefits and work, housing and transportation, and support for self-help (Church and Reville, 1990; Church, 1996; Evans and McGaha, 1998; Jansen, 2006).

The review articles commented on the influence of poverty and social disadvantage on the participation of people with psychosocial disability in reform processes. Commonly used media to inform potential participants were found to be relatively inaccessible to the vast majority of people with psychosocial disability who live on a meager income or disability benefits (Church and Reville, 1990; Evans and McGaha, 1998). Poverty also presents practical impediments to participation, such as lack of money for travel to and accommodation at public hearings. Where inclusion of their views is a policy directive, regulatory provisions and public finance accountability procedures may not have been amended to allow funding of their participation in policy forums. The unfamiliarity of affluent settings dominated by confident, resourced professionals and bureaucrats can also further inhibit the participation of these already-marginalised participants (Chan and Chui, 2007; Church and Reville, 1990; Church, 1996; Evans and McGaha, 1998).

Studies recommended that rather than limiting consultation to formal processes for reform, policy makers should include strategies which take government enquiry to hard to reach people with psychosocial disability or people who choose not to participate in formal policy-making processes. For example, community consultations should be conducted close to where people with psychosocial disability live, and the general community and in community mental health settings; non-participating people with psychosocial disability should be engaged on their own terms; and peer generated research should be funded for insight into the views of people with psychosocial

disability (Church, 1996; Evans and McGaha, 1998). Jansen et al. (2006) emphasise the value of financial support to peer- led initiatives as a means of supporting their input to policy processes.

2.3.2.3 *Marginalisation of “voice” in the policy dialogue*

Dominance of provider values and interests in policy reform. The relative weight which different stake-holders’ views are given in the policy-making process impacts on their power to influence policy directions. The views of professionals, bureaucrats and people with psychosocial disability were shown to be based on dissimilar beliefs and values, with the latter’s views having been historically disregarded as irrational (Church, 1996; Jansen et al., 2006). Embedded in the service development and delivery system, for example, policy makers and providers emphasized service-related actions as mental health priorities in setting the 14 themes for the provincial mental health reform hearings in Canada (Church 1996). These included, for example, (de)centralisation, authority structures, units and standards of care, service coordination, and financing. In contrast, the priorities of people with lived experience of mental illness honed in on the higher level priorities which service related actions should also address, for example, systemic discrimination and exclusion, poverty alleviation, and access to basic needs.

Dominance of professional perspectives in mental health policy-making processes are set in the documentation for the processes, in resources allocated to gather preparatory evidence to inform the policy process, in the allocation of resources to draw participants to speak at forums which provide opportunities for policy input, in the delegation of expert status to non-user participants to the process, and in the exercise of established practices and procedures used for public policy making processes.

Addressing these constraints to participation requires concerted action on several fronts, including revision of public policy and procedural barriers to participation, and ensuring direct representation to these processes (Church and Reville, 1990; Church, 1996; Evans and McGaha, 1998; Jansen et al., 2006). At the same time, people with psychosocial disability and their organisations can also work at supporting experience-based knowledge with other sources of influence when lobbying for their agenda. Jansen et al.

(2006), for example, highlights the power of peer organisations using a multi-pronged approach to influencing policy directions, including the use of action research to strengthen the impact of their policy priorities on the reform agenda.

Influence of communication styles and processes. Studies included in this review suggest that policy-makers do not adequately make accommodation for the fact that these members of their constituencies may not be well versed in presenting their views for policy change within formal policy communication or procedural frameworks (Church, 1996; Evans and McGaha, 1998). Providers and policy implementers are familiar with the jargon and current government priorities and are practiced in framing their contributions in the approved style. It is also easier to support a dominant view than it is to introduce an “outsider” view to the process. The way in which people with psychosocial disability communicate their views is naturally influenced by the directness of their experience with issues which may be only intellectually understood by policy makers and implementers who may have no personal experience of mental illness. People with psychosocial disability, finding the system unresponsive to their needs, can be expected to use policy reform opportunities to emotively raise their voices about issues that they perceive to be pertinent but which are outside of the established agenda for the reform process (Church, 1996).

Policy-makers are advised to start with an open agenda to allow diversity of perspectives to gain hold in the reform agenda. The range of acceptable communication styles should be expanded to include “protest style” inputs from hard-hit people unversed in formal procedures and for whom the issues discussed are not academic, but fundamental to their survival and well-being (Church, 1996).

Weak representation in policy reform. Some individuals reported satisfaction with having their voices heard even where their views were not taken up in final documents (Evans and McGaha, 1998; Jansen, 2006). However, a move to collective representation of the interests of people with psychosocial disability emerged strongly as a strategy to sustain participation in policy processes (Chan and Chui, 2007; Church, 1996; Evans and McGaha, 1998; Jansen et al., 2006). Given the social, economic and political

disadvantage of people with psychosocial disability, peer based initiatives were felt to be essential vehicles through which they can develop an agenda for change and represent their policy priorities.

People with psychosocial disability who are interested in political advocacy need to consider, and governments, not for profit organisations (NPOs) and Disabled People's Organisations (DPOs) should support, the organisation and mobilisation of their interests as a powerful collective voice in public policy making (Chan and Chui, 2007; Evans and McGaha, 1998; Jansen, 2006). However, while this might increase representation for people living in known community mental health settings, using formal mental health services or affiliated to advocacy groups, it will not target people living in the broader community who are not organized or have chosen to use independent, self help services, and eschew formal public health services and processes (Church, 1990; Jansen, 2006). Peer advocates and their supporters should address policy makers' limited awareness that people with psychosocial disability are generally not well organized (Church, 1996), and lobby for policy-makers to extend their consultation net to access the views of hard to reach people.

2.4 Discussion

This study addresses a previously under-researched area, providing a systematic review and meta-synthesis of studies which have explored the participation of people with psychosocial disability in policy development at the national level.

The papers reviewed make it clear that people with psychosocial disability should have a central role in shaping mental health policies which support their opportunities for living self-directed, satisfying, high quality lives (Kleintjes, 2010; Koskuilek, 2005). The findings also support the assertion that the views of people with psychosocial disability should be embedded in all policy and legislative reform processes which have an impact on their well-being, beyond the world of mental health services (Funk et al., 2010; Skeen et al., 2010).

2.4.1 *Barriers to participation*

The studies highlight wide-reaching structural barriers that hinder the ability of people with psychosocial disability to participate in legislation and policy reform. These include restrictions on the exercise of their rights as citizens, limited access to the social and economic resources of society which enable agency, and the marginalisation of their voice in political dialogue (Funk et al., 2010; Koskuilek, 2005; Lund et al., 2010a). Underlying these barriers is insufficient power to influence public policy making processes which impact on their lives. Decision-making is influenced by both personal power (individual capacity to recognise one's needs, to view oneself as important enough to be included in decision-making processes) and social power (the ability to act as an agent of change by articulating these needs in interaction with competing or complementary needs of others (Kelly, 2006; Koskiulek, 2005). Results of this review demonstrate how the capacity of people with psychosocial disability for this kind of agency has been constrained by structural, organisational and procedural barriers which diminish their personal and social power.

2.4.2 Empowerment to support participation

As empowerment emerged as a pervasive theme in this systematic review, it merits further exploration. Judi Chamberlin (2010), a leading activist for the rights of people with psychosocial disability, who died in 2010, notes in her paper entitled “A working definition of Empowerment”, that empowerment is widely used in service development for people with psychosocial disability, but without consensus about its meaning. Her paper documents her and other leading peer service providers’ work on defining the concept of empowerment. Chamberlin and her colleagues identified empowerment of people with psychosocial disability as central to their ability to act with agency in the world. Similarly, the results of this review suggest that empowerment is at the core of agency in policy development. We examine Chamberlin’s qualities, identified through the lived experience of leaders with psychosocial disability, to better understand the issues which need to be addressed in creating the conditions for policy participation identified in this review. Table 5 summarises the barriers to participation identified by the review (compromised citizenship, poverty and social disadvantage, marginalization of voice) and indicates links with Chamberlin’s conceptualization of empowerment.

Table 5: Empowerment: The key to agency in policy participation

Review themes	Chamberlin 2010	Area for action
Unequal power due to:	Elements of empowerment	Empowerment requires:
Compromised citizenship	Feeling part of a group; understanding that people have rights; building a positive self-image, overcoming stigma; coming out of the closet; assertiveness; being hopeful of making a difference; ongoing self-initiated growth/change	Full citizenship <i>Promote active role in civic life</i> <i>Build stakeholders' capacity to support participation in policy processes</i>
Poverty and social disadvantage -Poor access to reform processes	Access to information and resources., a range of options from which to choose	Social and economic upliftment <i>Include in initiatives aimed at improving economic and social situation of poor and marginalised people. Secure resources to improve participation</i>
Marginalisation of “voice” in the policy dialogue	Decision-making power, changing others' perceptions of one's competency and capacity to act, learning to think critically, and to see	Prioritise the voices of people with psychosocial disability in policy-making processes

<p>-Dominance of provider interests in policy reform</p> <p>-Weak representation</p> <p>-Influence of language, and communication, and emotional expression on policy processes</p>	<p>things differently; speaking in our own voice, refining who we are, what we can do, our relationships to institutionalized power, learning skills (e.g., communication) important to the individual, learning about and expressing anger.</p>	<p><i>Address procedural barriers to participation in policy reform</i></p> <p><i>Organize /strengthen peer organisation and representation</i></p> <p><i>Strengthen value of peer perspectives in policy dialogue</i></p>
<p>Disempowerment: Low opportunity to impact on policy decisions</p>	<p>Empowerment : Ability to effect change in one's life and one's community</p>	<p>Policy related empowerment: Potential for meaningful participation in policy process</p>

From the above analysis, key conditions required to improve policy participation from this analysis are: full citizenship, social and economic upliftment, and prioritization of the voices of people with psychosocial disability in policy processes.

Full citizenship: Empowerment of people with psychosocial disability requires actions which will restore them to full citizenship (Basic Needs 2009, Funk et al, 2010), to an experience of having a positive identity in relation to themselves and others in society, as elaborated by Chamberlin. As suggested in this review, people with psychosocial disability can organise themselves as pressure groups; educate and capacitate their members for political participation and take a leading role in orientating policy makers to the value of and methods for their non-discriminatory inclusion in policy reform. Providers, NGOs and DPOs should support their direct participation in policy making processes by sharing their knowledge, skills and platforms for policy reform processes with people with psychosocial disability

Poverty and social upliftment: The priorities of people with psychosocial disability extend beyond the mental health service issues which dominate providers' agenda for policy development, to initiatives which will bring about social and economic upliftment. These priorities echo the empowerment qualities raised by Chamberlin, in particular those related to having choices, and the power and resources to effect those choices. People with psychosocial disability should lobby policy makers and implementers to invest in mental health interventions that have benefits for interrupting the cycle of poverty and mental ill-health, including extending existing poverty alleviation programmes to include people with psychosocial disability (Lund et al, 2010a). NPOs and DPOs can provide technical support to ally-supported and peer-led initiatives aimed at supporting social and economic upliftment of people with psychosocial disability (Kleintjes et al., in press)

Prioritisation of the voices of people with psychosocial disability: The results support the idea that several changes are needed within the policy environment to strengthen the voices of people with psychosocial disability relative to other participants (Bennetts et al., 2011). Chamberlin also highlights the need for people with psychosocial disability to “speak in their own voice”, and to

have emotional congruence in lobbying for their issues in the policy arena. We elaborate on this below:

2.4.3 Self-representation

Service providers and policy-makers' perspectives are still the most influential in policy decision-making (Bartlett, 2006; Bennetts et al., 2011). Yet their capacity to develop a policy agenda which supports comprehensive change to the circumstances of people with psychosocial disability is limited by the scope of their own knowledge, experience and exposure, a policy agenda reinforced by like-minded colleagues, existing policy directives, and evidence consulted. A key message of this review is that policy makers need to engage people with psychosocial disability to access first hand accounts of their policy priorities, to inform comprehensive, relevant, mental health policy reform.

Important to note also, is that people with psychosocial disability do not all have the same views on policy reform. Many have benefited from and may support the current medical approach to mental health policies, some, especially in low and middle income countries, may still be fighting for access to basic mental health care (Kleintjes et al., 2012). Others who have experienced mental health care as violating their human rights are calling for fundamental changes to the system, while still others may not self-identify as people with psychosocial disability, and their views may not be reached without the concerted effort of policy-makers (Bartlett, 2006; Tait and Lester, 2005).

2.4.4 Freedom in expression of voice

Communication barriers, including policy maker difficulty in accepting the heated accounts of people who make representation to policy forums, was a key theme in this review. Chamberlin (2010) notes the importance of people with psychosocial disability being able to express the pain of their experiences with congruent affect. She notes that for people whose identity and power has been subsumed under the anonymity of "caseness" in psychiatry the telling of their life

stories in their own words is central to gaining personal power in their journey of recovery. Barnes (2008) speaks of the transformative power of anger for forging positive personal identity, developing group solidarity and motivating agency through collective action by social movements whose members' identities have been shaped by experiences of injustice and maltreatment. Rather than misreading emotive input to policy processes as evidence of loss of control, policy makers within the mental health field should be mindful of the appropriateness of these emotions for some people living with psychosocial disability. McDaid (2009), drawing on Nussbaum (1995), makes the point that emotions can bring rigour to decision-making. The forcefulness of the angry citizen can provoke policy makers' attention to their plight. Policy makers and service providers able to empathically attune to the experience of people with psychosocial disability may have a greater sense of the urgency and importance of their priorities, and their need to act on these appropriately.

2.5 Limitations of the review

There are significant limitations to this study. Firstly, non-English papers on the topic were excluded from the review. Secondly, the meta-synthesis was conducted by only one person, the first author. Thirdly, the review is based on very limited data from only five published articles, three of which were conducted in the same country, Canada. Finally, three of the studies were of moderate to weak quality, and four were based on small samples.

2.6 Future directions for research

Despite the systematic literature search conducted in a wide range of academic databases, without limitation for date or country, only a few studies could be located which reported on the participation of people with psychosocial disability in policy development. This reflects an under-researched area, which has received little attention in formal academic publications. Areas for further study include intervention studies addressing the inclusion of people with psychosocial disability in legislative and policy development; development and evaluation of peer led advocacy programmes, and programmes to enhance political participation of people with psychosocial disability; studies addressing the heterogeneity of perspectives and priorities

of people with psychosocial disability; and ethical and practical considerations in accommodating different needs for support, including supported decision-making, in legislative and policy participation. Research to inform the development and evaluation of interventions to reduce structural, institutional and procedural barriers to participation in policy development; building capacity of role-players to support inclusion of perspectives of people with psychosocial disability in policy processes; studies which highlight policy priorities of people with psychosocial disability, as well as policy participation impact studies, are pressing research issues highlighted in this review.

University of Cape Town

CHAPTER THREE

The participation of people with psychosocial disability in mental health policy development in South Africa

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Study objective

This chapter addresses objective 2 which is to describe *current support for participation* of people with psychosocial disability in policy development in South Africa and to suggest strategies for improving participation.

Contributions of the authors

This findings reported in this study were embedded in a larger study, the Mental Health and Poverty Project, conducted by the Mental Health and Poverty Project Consortium (DFID : RPC HD6 2005 – 2010). Additional interviews with people with psychosocial disability (20) were collected after the MHaPP data collection phase. Professor Alan Flisher was project director and Associate Professor Crick Lund was project coordinator of the MHaPP at the time. Sharon Kleintjes was employed as the research officer for the South African site for the duration of this four country study, and conceptualised her doctoral study within the scope of the wider study. She conceptualised the current study and its design, which focuses on South Africa, and carried out all aspects of the data collection, analysis and write up of the findings. She was the lead author on this paper. The remaining authors supervised the research, provided critical input to the drafting of the article, and approved the final manuscript before publication.

Current status

The article was submitted in August 2010, and was accepted for publication after minor revisions. It was published in the International Review of Psychiatry in December 2010.

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Abstract

Objectives

This paper describes current support for the participation of people with psychosocial disability in policy development in South Africa and suggests strategies for improving participation.

Methods

The World Health Organization (WHO) Mental Health Policy and Plan Checklist and WHO Mental Health Legislation Checklist were completed. Data on mental health resources were collected using the WHO Assessment Instrument for Mental Health Systems (WHO-AIMS) version 2.2 (WHO 2005c). This included data on family and peer led associations in the country. Ninety-six semi-structured interviews with national, regional and district stakeholders were conducted between August 2006 and August 2009.

Results

Most respondents felt that inclusion of the perspectives of people with psychosocial disability in policy processes would improve policy development. In practice, consultation of people with psychosocial disability in policy development has been limited after the transition to democratic governance in South Africa.

Discussion

Strategies to create a supportive environment for the participation of people with psychosocial disability include social action directed at reducing stigma, advocating for acceptance of their right to participate in decision-making, crafting a supportive regulatory framework to promote participation, and equipping service providers and policy makers to support inclusion. The capacity of people with psychosocial disability for participation should be strengthened through early and effective access to treatment and support, development of a national peer-forum for people with psychosocial disability, skills training and practical exposure to the policy and service development environment.

3.1 Introduction

The participation of people with psychosocial disability in policy-related decision-making can benefit their recovery process (Crane-Ross et al., 2006; Hickey & Kipling, 1998; Linhorst & Eckert, 2003). It can also have a positive impact on the relevance of mental health policy development and implementation (WHO, 2001; WHO, 2005a). Given the historical disempowerment and marginalisation of people with psychosocial disability (Crane-Ross et al., 2006; Horton, 2007; Sareceno et al., 2007; Thornicroft et al., 2008), their involvement in policy development and implementation is particularly pertinent. Such involvement has received attention at service and strategic levels in developed countries (Baggott & Forster, 2008; Boardman, 2005; HASCAS, 2005; Linhorst et al., 2001; Malins, 2006; McClean, 1995; Peck et al., 2002), but less so in developing countries (Ntulo, 2006; Katontoka, 2007; Underhill, 2005), including South Africa.

South Africa signed and ratified both the United Nations Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (UNCRPD) (United Nations, 2006) and its Optional Protocol, in October 2007. Disability rights are enshrined in South Africa's constitution (Republic of South Africa, 1996), and the White Paper on an Integrated National Disability Strategy (Republic of South Africa, 1997) supports access and participation of disabled people in all aspects of public life in South Africa. Self-determination for disabled people has long been part of the broader struggle for liberation in South Africa and the country has an active national disabled people's organisation, Disabled People South Africa (Rowland, 2001). There is a Department for Disabilities within the Ministry for Women, Children and People with Disabilities located within the Presidency. This new ministry is responsible for mainstreaming disability issues in policy development, and monitoring the implementation of policy provisions for the inclusion and empowerment of disabled South Africans (. Despite these achievements, there remain gaps between progressive policies and the challenges of full participation by disabled people in South African society (Watermeyer et al., 2006). Article 29 of the UNCRPD calls for state parties to guarantee that "persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others" and that they will "encourage their

participation in public affairs, including participation in non-governmental organizations and associations concerned with the public and political life of the country”. This paper addresses the question of such participation with respect to people with psychosocial disability. It focuses specifically on opportunities for improving their participation in mental health policy development in South Africa.

The paper draws on the findings of the first phase of the Mental Health and Poverty Project (MHaPP): a situation analysis of mental health policy development and implementation in Ghana, South Africa, Uganda and Zambia (Flisher et al., 2007).

3.2 Method

Qualitative and quantitative methods and document review were used to understand the involvement of people with psychosocial disability in mental health policy and legislation. Findings were triangulated, where possible.

3.2.1 Semi-structured interviews (SSIs)

SSIs were used to develop an understanding of stakeholders’ views on the participation of people with psychosocial disability in mental health policy development in South Africa.

Respondents

A total of 96 SSIs were conducted. Fifty-six (56) purposefully selected respondents included public sector policy makers from the Departments of Health, Education, Social Development, Housing, Justice and Constitutional Development and Correctional Services, professional regulatory council representatives for nursing, social work, psychology, occupational therapy and medicine, and representatives from non-governmental organizations (NGOs), disabled people’s organisations (DPOs), mental health interest groups, religious leaders, professional associations, universities and research institutions.

Snowballing was used to identify people with psychosocial disability involved as advocates for other people with psychosocial disability (n=20), and people with psychosocial disability who have used public mental health services in one urban (n=10) and one rural (n=10) district in two provinces. The list of respondents is included in the appendices.

Interview schedules

The SSI guides were developed over several months, as part of the process of developing the SSI guides used for the MHaPP in general. As part of this wider process, the first author (SK) formulated draft questions related to the participation of people with psychosocial disability in policy development for inclusion in the interview schedules for the 56 purposefully selected respondents interviewed from different sectors listed.

SK also drafted the interview schedule used to interview respondents with psychosocial disability involved in advocacy work for other people with psychosocial disability (advocates). She drafted a separate interview schedule to interview respondents with psychosocial disability who did not have advocacy experience. Her rationale for developing separate interview schedules for these two groups of respondents is described in Appendix 5 and the process for developing these schedules is summarized in Appendix 6. All interview schedules used for the MHaPP were reviewed at a meeting of consortium partners in Durban in July 2006, before finalisation for fieldwork. The semi-structured interviews covered the following generic areas:

1. Major development challenges facing South Africa
2. Key challenges facing the health system
3. Perceptions of mental health
4. Mental health needs and priorities in South Africa
5. The role of stigma in mental health
6. The role of government in addressing mental health needs
7. General policy making process in South Africa
8. Process of mental health policy and legislation development.
9. Role of various stakeholders in mental health policy and legislation

development

10. Content of the current mental health policy and legislation

11. Implementation of mental health policy and legislation at the national and provincial levels

12. The research agenda for mental health.

The two interview schedules for respondents with psychosocial disability, and an example of one of the interview schedules used for the purposefully selected respondents are included in the appendices.

3.2.2 Data collection and analysis

Informed consent was obtained from respondents and confidentiality assured by removal of identifying material from interviews. The informed consent forms used for the study are included in the appendices. The interviews were conducted in English, except the 10 rural district interviews which were conducted in isiZulu, an indigenous language. Interviews were recorded with respondents' permission. English interviews were transcribed verbatim. The isiZulu interviews were translated and transcribed into English by the interviewer, and back-translated by an independent bilingual speaker.

Thematic analysis of the data was guided by the themes preset in the interview schedule, with new themes added as determined by the data using a framework analysis approach (Ritchie & Spencer, 1994). This approach comprises 5 stages: familiarization, developing a coding frame, coding the text, charting or summarising the themes to arrive at a synthesis of the key ideas emerging under each theme, and mapping out the key themes and findings embedded in the coded and summarised data.

3.2.3 Document analysis

Analysis of mental health policy

The WHO Mental Health Policy and Plan Checklist (WHO, 2005b) was used to review South Africa's first post-apartheid mental health policy guidelines, the "National health policy guidelines for improved mental health in South Africa" (Department of Health, 1997a) and chapter 12 of the White Paper for the transformation of the health system in South Africa (Department of Health, 1997b) which focuses on mental health services in the country. Both documents were reviewed as the policy guidelines specifically states that it should be read in conjunction with the White Paper. The checklist includes items assessing the involvement of people with psychosocial disability in decision-making impacting on their health. SK completed the checklist in consultation with the drafter of the policy, the former national Director for Mental Health. A final review was conducted by the Mental Health and Substance Abuse Directorate, WHO, Geneva.

Analysis of mental health legislation

South Africa promulgated the Mental Health Care Act no. 17 of 2002, in 2004 (Republic of South Africa, 2002). The WHO Mental Health Legislation Checklist (WHO, 2007a) was used to review the Act. The Checklist includes items assessing legislative provision for the participation of people with psychosocial disability in policy, legislation and service development. Three national health department policy makers, the director of a national mental health NGO and 2 people with psychosocial disability involved in advocacy reviewed the document. Independent ratings were collated into one consensus document which was reviewed by the Mental Health and Substance Abuse Directorate, WHO, Geneva.

3.2.4 WHO AIMS

Quantitative data regarding the mental health system in South Africa was gathered as part of the broader MHaPP study for the calendar year 2005. The World Health Organization's Assessment Instrument for Mental Health Systems (WHO-AIMS) Version 2.2 (WHO, 2005c) was used to collect this data. The WHO-AIMS tool was developed to assess key components of

a mental health system in order to provide information for planning and strengthening mental health systems. The instrument was developed to address the 10 recommendations for a global response to mental health as a neglected priority which was set out in the World Health Report 2001, *New Understanding New Hope* (WHO, 2001). These recommendations address essential aspects of mental health system development in resource-poor settings, including the recommendations that people with psychosocial disability be centrally involved in planning and implementation of mental health initiatives. WHO-AIMS 2.2 consists of 6 interdependent domains which cover the 10 World Health Report 2001 recommendations:

- Domain 1: Policy and legislative framework
- Domain 2: Mental health services
- Domain 3: Mental health in primary care
- Domain 4: Human resources
- Domain 5: Public education and links with other sectors
- Domain 6: Monitoring and research

Domain 4 includes information on the number of associations of people with psychosocial disability in a country, which is reported in the results section.

Sample and procedure

The WHO AIMS spreadsheets were distributed to the following respondents:

- the mental health programme managers of the 9 provincial Departments of Health
- the directors of the 17 Mental Health Societies of the South African Federation for Mental Health (SAFMH),
- the heads of the professional boards of the Health Professions Council of South Africa for Psychology, Medicine and Occupational Therapy,
- the head of the South African Nursing Council, and
- the head of the South African Council of Social Service Professions, the statutory body for social work professions in South Africa.

Private-for-profit services were not included as they only provide services for a minority of the population. Although other NGOs provide services at a local or provincial level, the SAFMH is the only NGO that provides a coordinated national mental health service, and is the largest national mental health service provider in the NGO sector. It was therefore decided to collect data on mental health service provision in the NGO sector from only the SAFMH and its 17 affiliated societies. Several telephonic interviews were necessary to check the data submitted by respondents to ensure that all the items were understood and correctly completed on the instrument.

Analysis

The data were entered into separate spreadsheets for each of the provincial Departments of Health, the mental health societies and other respondents. Data from these spreadsheets were then entered into a national spreadsheet, where numeric data were aggregated. Descriptive statistical analyses of relevant items were conducted. Nationally aggregated responses to items were then entered into the WHO AIMS narrative template (WHO AIMS, 2007)

3.2.5 Ethics

Permission was obtained from the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town.

3.3 Results

3.3.1 *The involvement of people with psychosocial disability 1994-2010*

The checklist reviews and SSIs indicate limited involvement of users in policy and legislative development since the demise of the apartheid state in 1994. Three senior policy makers working in the public sector since 1994 commented on their difficulty locating advocacy groups to consult. As a result, they had primarily consulted people with psychosocial disability through available NGOs.

Interviewer (I): And organisations for people who are mental health users? Respondent

(R): ... We have one or two big ones. The other ones are very small kind of organisations.

Sometimes an individual. We need to... coordinate them better, like the other disability sectors have been coordinated. (Female, national policy maker, Health).

The Department of Health held discussions with the SAFMH during the drafting of the 1997 mental health policy guidelines. The SAFMH had begun to include people with psychosocial disability as representatives on some affiliated members' Boards of Management. At that stage, input was still led by service providers, with little direct representation of people with psychosocial disability in the development of the 1997 policy guidelines.

SSI stakeholders working as providers in mental health NGOs and policy makers felt that during 1999-2001, when the Department of Health consulted for development of the Mental Health Care Act of 2002, people with psychosocial disability had been more widely and directly consulted than in 1997 for the policy guidelines.

(R): ... this is the one piece of legislation where there was a great call for participation, and not only from the organisations or service providers, but also from the service recipients. For example (provincial advocacy body for people with mental disability) were given an opportunity to really engage with the Act and give feedback. (Female, director, provincial mental health NGO).

Advocate respondents who had participated in the consultation mentioned above, however, felt that the quality of consultation was poor.

R: ...we were informed there was this upcoming Act and here's the draft, that is the extent of the consultation... It's unacceptable...legislation developers had to take this thing seriously even if it means they had to pay people...but get them involved, so that there is real credibility. (Male advocate, urban province).

Where people with psychosocial disability were not affiliated to a consulted mental health NGO, opportunities for input into legislative, policy and service reviews were even less readily available.

R: ...those who make policies are the 'can't get' people. You have to be somebody to locate them. You know them: you really get cold shoulders, but with the help of (other national NGO) we manage sometimes to locate them and workshop them...sometimes we managed to get the directors of several departments.... (Male advocate, rural province).

A few respondents with psychosocial disability from smaller, independent advocacy groups noted that people with psychosocial disability may choose to stay out of the public domain due to their experience of being discriminated against once they reveal that they have experienced and received treatment for severe mental and emotional distress. Other respondents, across stakeholder groups, echoed their concerns about the impact of stigma on their participation in civic life. They felt that the paucity of involvement of people with psychosocial disability in policy making was in part due to policy makers, practitioners, and some people with psychosocial disability not accepting them as legitimate partners in the policy process. Some respondents suggested that more exposure to advocates with psychosocial disability could help change these stigmatising views:

R: ...the stigma is, they cannot even participate in the policy making. My point is, you can have people who are affected...being the advocates...I mean, in the advisory committee...he (referring to committee member with psychosocial disability) stood up and said his experience with it; that was also an education for me.... If we have those that are champions... that will help. (Female, national policymaker, Department of Housing).

3.3.2 Organisations of people with psychosocial disability in South Africa

The WHO AIMS data collected countrywide in 2005 confirmed the paucity of organisations or associations for people with psychosocial disability in South Africa. At that time, there was no national mental health advocacy organization for people with psychosocial disability. There were 3 provincial associations for people with psychosocial disability supported by the Mental Health Societies of the South African Federation for Mental Health): in the Eastern Cape (membership unknown to the head of that Society), Western Cape (32 members) and Gauteng provinces (70 members). The Western Cape Group, the Consumer Advocacy Body (CCAB) was the first group formed, in 1998, with support of Cape Mental Health Society in the Western Cape Province of South Africa. CCAB's activities were overseen by professional supporters within

this regional office. Its activities centre around members who use the services of the Cape Mental Health Society, the Cape Town based regional office of the SAFMH. In 2005, the SAFMH-supported associations reported receiving a subsidy from government to support their work with these associations in the Western Cape and Gauteng provinces. At that time, SAFMH-affiliated associations for people with psychosocial disability had been involved in the formulation of internal organisational policies as management board members, but had not yet been directly involved in the development of national or provincial mental health policies, plans, or legislation. Small, independently run advocacy groups had also been established in the Western Cape and Gauteng provinces, but the membership of these could not be reliably established during data gathering for the WHO-AIMs.

From the semi-structured interviews conducted between December 2008 and September 2009 with peer advocates for people with psychosocial disability, it was ascertained that the Gauteng regional office of the SAFMH appointed a person with psychosocial disability in 2006 to develop the group in Gauteng. The group was launched as the Gauteng Consumer Advocacy Movement (GCAM) in 2007. The coordinator of GCAM has made great strides growing its advocacy activities and the body draws its membership both from within and outside of the Gauteng Mental Health Society. Provincial offices of the SAFMH in the remaining 7 provinces have established small advocacy groups, with as yet limited reach of activities outside the immediate needs of group members. The SAFMH still receives limited funds to support this work from government, but has also been able to source limited donor funding for this work in more recent years.

In 2009, the SAFMH establish a working group to work toward build a national advocacy body for people with psychosocial disability in South Africa. This action was taken as an outcome of lobbying from members of its National Executive Board who represent people with psychosocial disability using the services of the SAFMH. This body launched itself as a national body, the South African Mental Health Advocacy Movement (SAMHAM) at the end of 2009. Membership is still largely drawn from the clientele of the SAFMH.

Outside of the SAFMH, a second national advocacy body, The Ubuntu Centre was registered as a DPO for people with psychosocial disability in 2007. The founder of this organization was a prominent member of CCAB, who with a handful of like-minded individuals felt a need to launch an independent, peer-led organization for people with psychosocial disability. The key focus of Ubuntu is advocacy in South Africa and on the African continent. The organization's activities are funded by self-generated donor grants and funding constraints have limited its activities within South Africa as a whole¹.

At this early stage of developments in South Africa, while SAMHAM plans to organise more widely in the country, and Ubuntu is engaged in national and international level advocacy work, neither of these organisations for people with psychosocial disability as yet have the national membership and the national programme of action they are working toward.

3.3.3 Current support for policy participation of people with psychosocial disability

Despite differences in stakeholder perceptions about the adequacy of consultation in the past, most SSI respondents across all respondent groups supported inclusion of people with psychosocial disability in legislative and policy development and implementation processes in the future. Stakeholders felt that as citizens of the country, people with psychosocial disability have a right to influence the development of public mental health policies and services. Many respondents felt that these rights extended to all people with psychosocial disability, whether private sector, service-paying or indigent beneficiaries of state support. Several respondents noted that people with psychosocial disability bring a unique perspective to mental health policy development, through their experience of severe mental and emotional distress. They felt that this could focus policy developers' attention on the most appropriate directions for local mental health programmes. Checklist reviewers concurred that invaluable insider information obtained from people with psychosocial disability can positively influence policy development.

R: We need to engage patients who have gone through a process of recovery...their personal experiences must be able to assist to formulate an understanding of mental

¹ I elaborate on the activities of SAMHAM and Ubuntu in chapter 6 on advocacy organisations in Africa.

illness, and contribute towards...the broader base of stakeholders that formulate policy. (Male, religious leader, Muslim Judicial Council).

Amongst these stakeholders the majority view was that people with psychosocial disability can participate on par with other citizens, when they are well enough to engage in public discourse.

R: ...like for example, psychiatric disability...most of them, they take their medication and they can actually participate. I: People with psychiatric disability, you feel that if they are stable, they should be consulted themselves? R: They should actually be consulted themselves, yes.(Female, national policy maker, Department of Social Development).

A few respondents did not have an opinion about the participation of people with psychosocial disability in policy development, as it was a novel concept for them. Three other respondents felt that policy development is best left to others better equipped for the task, such as policy makers and service providers.

R: ...we as traditional healers, because we practice within the community, we hear the problems that cause this mental illness that is within the family, you know what I mean? I: Dr, are you saying that you don't think it's necessary to consult clients when making a policy, that it's the traditional medical practitioners that should be consulted because they know the issues well? R: Yes, yes exactly, 100% correct. (Male, traditional healer, national organisation for traditional healers).

3.3.4 Strategies for increasing the participation of people with psychosocial disability

Respondents identified 3 broad strategies that could promote direct consultation of people with psychosocial disability in mental health policy processes, namely regulatory support, organising for participation, and building the capacity of people with psychosocial disability.

3.3.4.1 Regulatory support for participation

Mental health legislation

The Mental Health Care Act does not include provisions to “ensure that users of mental health services are involved in mental health policy, legislation development and service planning” as recommended in the WHO legislation checklist. Policy maker and practitioner reviewers felt that, as provisions of the South African constitution supersede provisions of the Act, and as the constitution provides for participation of citizens with disabilities in parliamentary and governmental processes related to legislation and policy, this need not be specified in mental health legislation. One policy maker stated that such a specific provision would be difficult to implement as a law.

R: ...I've got no problem whatsoever about consulting...but it's a very hard thing to legislate because somebody might come and say: 'the law says you must consult with consumers and we're a consumer group and you didn't consult with us so you've broken the law', but then you say: 'No, no, we consulted with those people' and they say, 'Well they weren't representative' and then it goes to court. (Male, national policy maker, Department of Health).

At most, the reviewers felt that it would be adequate to address this issue in a revised mental health policy. A few SSI respondents with psychosocial disability, and from the disability and nongovernmental sectors, however, felt that despite the support of constitutional provisions, people with psychosocial disability continue to be excluded from public processes. With South Africa's ratification of the UNCRPD, many felt that mental health legislation and regulations should be revised to broaden its scope beyond its current treatment focus to address broader mental health concerns, including the participation of people with psychosocial disability in policy and service development and implementation.

Mental health policy

Neither the White Paper on Health (Department of Health 1997b) nor the mental health policy guidelines (Department of Health 1997a) mention the involvement of people with psychosocial disability in legislative or policy development. The White Paper does provide for input from

people with psychosocial disability in the planning of mental health services while the mental health policy guidelines includes the principle that “community, and specifically users of mental health services and their families should be involved in planning and evaluation of services”. Current norms and standards for psychiatric care in South Africa provide for “greater partnership with users, their caregivers and the community in the planning and evaluation of services” (p199) (Flisher et al., 1998).

At the time of writing, the National Directorate for Mental Health and Substance Abuse in the Department of Health is in the process of drafting a new national mental health policy, with the intention of consulting people with psychosocial disability.

R: ... there will have to be...consultation which includes all the stakeholders; experts, consumers, other departments and all that. (Male, national policy maker, Department of Health).

A few mental health NGO-based practitioners and several respondents with psychosocial disability suggested that as policy sets the agenda for which issues are prioritized and funded for implementation, provisions of the new policy should explicitly promote the participation of people with psychosocial disability in all aspects of mental health policy in the country. Going further, a few respondents with psychosocial disability who favour the development of peer-led self-help projects felt that the policy should endorse strategies which emphasize self determination and support the participation of people with psychosocial disability in the implementation of these policies.

3.3.4.2 Organising for participation

Building a social movement for mental health

A few respondents noted that during the apartheid years, civil activity was focused on anti-apartheid activism, with little attention to the social agendas usually addressed by civic action during peace time.

R: One of the things is that all of us had a common enemy before: Apartheid. We knew our places, we knew that we were on the one side opposing this system. (Male, leader, professional guild).

They felt that since the demise of apartheid, grassroots social action had dwindled in the face of expectations of the new government delivering on policy provisions, but that civil society had more recently begun to voice its dissatisfaction about lags in policy implementation.

R: ... you promised them bread, you promised them cake and you're now giving them brown bread, whereas brown bread is actually very good, but not good enough...if we all go out and say 'these things take time' ...we're talking about a nation, it takes time, so you can't do it overnight. (Male, Member of Statutory Council, Health Professions Council of South Africa).

Several respondents spoke of their support for the resurgence of civic voices, and supported the growth of such a “voice” to address the needs of people with psychosocial disability.

R: ...we should be getting together - providers, consumers, programme managers and forming, you know, a very strong lobbying body, using the legislation...and getting lawyers involved when we really feel we are not getting anywhere...advocacy, and then, if necessary, legal action. (Female, psychiatrist)

Some respondents noted that there are examples of good advocacy work on a national and local level from some mental health NGOs and interest groups, but generally, respondents felt that mental health professionals, lay people and people with psychosocial disability have not taken up the challenge of a sustained and coordinated role in eradicating discriminatory practices toward people with psychosocial disability.

Building a national advocacy organisation for people with psychosocial disability.

Many stakeholders, drawn from all stakeholder groups, felt that the impact of the participation of people with psychosocial disability in social and political decision-making could be improved by building a coordinated advocacy organisation through which they can raise their voices regarding policy directions and outcomes, as an equal stakeholder.

R: The best practice that I saw at the UN was that internationally, people with mental disability are taking things into their own hands and having their own organisations and raising their own issues. There were papers written by them and...they came there as organised formations.... I: Are you in favour of this kind of organisation of mental health care users to raise their own issues? R: I think they would understand them better, and they would educate us better. (Female, policy maker, Department of Justice and Constitutional Development).

3.3.4.3 Building capacity for participation

Treatment and support

The right to accessible and effective treatment and support was seen by some respondents not only as a health right, but a necessary tool for supporting the participation of people with psychosocial disability in policy making.

I: ...input to service reviews, service improvement, and mental health policy development; what is your view around their role there? R: Ja. There is room for them. These people are not mentally ill all the time.... They have been saying that they deserve better treatment... treatment in terms of rehabilitation, treatment in terms of job opportunities for them. Treatment is just not only physical; it's psychosocial and it also has to look at economic issues. (Male, member of the Health Professions Council of South Africa).

The view that recovery support should go beyond medication provision to action which enables participation in everyday life, was shared by several respondents. The point is illustrated by the work of an advocate with psychosocial disability who runs a self-initiated recovery programme for 68 poor community members with psychosocial disability on his inherited land in a rural province.

R: Even now I think the government has tried to grow for us a Bill and say “no, you have got a right to talk” ...I was trying to connect these people who didn’t have anything, bring them together and get them something to eat and try to teach them how to do for themselves...But when you just dump them and they start to do funny things, they can’t say to you “I have the right” because you will say “you are just nothing”. But when you get them on the same place together and do for them everything which we think is better, and show government that we try to do this, then they will help us. (Male, advocate, rural province).

Skills training and experience

Respondents felt that there is a need to provide a platform for increasing the capacity of people with psychosocial disability for participation in policy issues. Training programmes in advocacy, policy participation and organisational skills, and skills development programmes to support self-help initiatives were mentioned by some respondents, but the lack of these, others felt, should not prevent the development of skills through participation itself:

R: I’ve seen the people with mental disability participating, you know, in various forums and I think that if they are given the opportunity... I take myself...I was part of developing the legislation on skills development. I didn’t have experience, I didn’t know how you do that, but because I was exposed and because I participated through the National Skills Authority, I began to grapple with the issue and I used my knowledge and my experience. I: So similarly, people with mental disability may need some time to orientate and develop capacity for it? R: Exactly. (Male, leader, national disability organization).

3.4 Discussion

Stakeholders interviewed in this study were generally in favour of the participation of people with psychosocial disability in mental health policy development. Existing policy and legislation in South Africa can also broadly be interpreted to support their participation in policy development. This is in line with the international trend away from sole reliance on professional expertise for knowledge generation and implementation, to the inclusion of health care users in developing and implementing evidence based policy and programmes (Albert, 2004; Albert & Hurst, 2004; Crane-Ross et al., 2006). The focus has moved to the synergistic interface between professional knowledge and expertise by experience in generating effective research to inform policy and programme development for recovery (Diamond et al., 2003; Marsh, 2000; Tritter & McCallum, 2006; Underhill, 2005).

Despite stakeholder, legislative and policy support, results confirm that actual participation in these processes by people with psychosocial disability has been poor since the first democratic elections in South Africa. Stakeholders identified several areas of action which could improve inclusion in mental health policy development and implementation processes. These are discussed below in terms of (a) creating a supportive environment, and (b) increasing the capacity of people with psychosocial disability to participate.

3.4.1 Creating a supportive environment

3.4.1.1 Advocating for participation as a rights issue

There is a need to recraft the existing social mores which authenticate the exclusion of people with psychosocial disability from civic life and political decision-making (Kelly, 2006). People with psychosocial disability can be disempowered by policy makers, providers, and by family and community members' tendency to relate to them primarily as sick or impaired people, once diagnosed with a mental disorder (Borg et al., 2009; Cottrell & Lanzettel, 2005; Disabled People South Africa, 2000; Watermeyer et al., 2006). The incapacities ascribed to a sick role may be used to restrict their participation in other roles in society (Kakuma, et al., 2010; Katontoka, 2007). Their access to social, political and economic opportunities and influence may dissipate under the cloak of a diagnosis of mental illness (Kelly, 2006). Stigmatising attitudes and beliefs

about people who experience severe mental and emotional distress detract from the need to focus policy and practice in the service of supporting their recovery (Borg & Kristiansen, 2004; Disabled People South Africa, 2000; Farkas et al., 2005). It also takes attention away from the need to re-build their ability to contribute to their own and others' recovery through self-help initiatives (WHO, 2008). In terms of civic participation, lack of belief in their abilities and withdrawal of their rights to participate in policy development can reduce the confidence of people living with psychosocial disability in a self-fulfilling, disabling cycle (McDaid, 2009; Tritter & McCallum, 2006; WHO, 2005a).

3.4.1.2 Building vehicles for rights-based social action

Lobbying by interest groups and NGOs has been found to have enormous potential for influencing the direction and implementation of social and health policy (WHO, 2008). Kelly (2006) notes, however, that mental health interest groups have not generated the level of influence on public processes which one might expect, given the numbers of potential members of this group in society. Kelly suggests attention be given to equipping people with psychosocial disability to engage in democratic processes, and to build “larger, more effective interest groups” for mental health. This point was supported by many respondents in this study. Firstly, some respondents suggested the formation of a coordinated social movement for mental health as one vehicle for addressing the systemic curtailment of people with psychosocial disability from engaging freely in civic life. Such a movement would build on existing efforts and draw in neglected partners to address the stigmatising beliefs, attitudes and discriminatory practices which perpetuate their exclusion on all levels of society. It would serve as a united platform to shift the current low priority given to mental health in public policy and service delivery (Kakuma, et al., 2010; Sareceno et al., 2007). It could promote the inclusion of people living with psychosocial disability in all processes related to the development and implementation of laws, policies and services in the country. Internationally, a social movement for mental health was launched in 2008. The membership of the Movement for Global Mental Health is diverse, and includes service users, practitioners, policy makers and researchers. The movement aims to use best practice to advocate to policy makers and funders to prioritise, integrate and scale up mental health services (Horton, 2007; The Lancet, 2008; The Lancet, 2009). The views of some

respondent in this study support the development of a national social movement of this nature in South Africa.

Secondly, respondents suggested the development of a country-wide peer-based advocacy lobby through which people with psychosocial disability can provide representative input to opportunities for dialogue regarding policy and service development. This echoes literature supporting the notion that meaningful involvement of people with psychosocial disability in collective action requires “representative networks of engagement” through which they can advocate for their concerns (HASCAS, 2005; Simpson & House, 2002; Tritter and McCallum, 2006). In Africa, there are already examples of such networks, for example in Zambia, Uganda, Tanzania, Kenya and South Africa (Katontoka, 2007). Networks in South Africa are in their infancy, with advocacy groups still mainly operating at local level. Given the power inequities which people with psychosocial disability still face in participating in decision-making (Kelly, 2006), robust organisation and representation by people with psychosocial disability will be needed to enable them to exert influence over policy decisions. They will need to hold their own as a stakeholder within a broader social movement for mental health, engage with powerful policy makers and legislators to influence service provision, and raise their voice within the broader disability movement. Disabled People South Africa was launched in 1984, 4 years after the establishment of Disabled People International (Rowland, 2001). Similarly, the fledging networks of people with psychosocial disability in South Africa will need time and opportunity to dialogue, mobilise and organise their agenda as a sector within the broader mental health and disability movements in the country.

3.4.1.3 Crafting supportive regulatory frameworks

Existing legislation, regulations, policies and protocols should be revised and new regulatory guides formulated to support institutional, professional and civil commitment to the rights of people with psychosocial disability to influence policy processes which impact on their lives (WHO, 2009). Sustained action is required to increase the likelihood that public policy makers and implementers will build in provisions to address the priorities of people with psychosocial disability within public policy and practice. These policies should incentivise the implementation of these provisions by institutions and organisations (HASCAS, 2005; Linhorst

& Eckert, 2003). At the institutional level, policy and practice guidelines should build in strategies to support the participation of people with psychosocial disability in organisational decision-making, and encourage practitioner implementation of these by building requirements for consultation of people with psychosocial disability into staff practice and performance reviews, and by dedicating staff time for the implementation of these requirements (Linhorst et al., 2001). The role of people with psychosocial disability as a stakeholder in policy development should be clearly spelt out (HASCAS, 2005).

3.4.1.4 Reorienting and equipping providers and policy makers for inclusion

Internationally, the move from a symptom-management approach to mental health care, to an approach which focuses on the long-term recovery, quality of life and self-determination of people with psychosocial disability has been slow (Davidson & White, 2007; Farkas, 2007). In this study, the need for this change was articulated by individuals drawn from all stakeholder groups, most often from DPOs, NGOs and people with psychosocial disability. This reorientation requires a change in the mindsets inculcated during professional training and institutional acculturation (McDaid, 2009; Thornicroft et al., 2008.). Professionals would need to be equipped to locate the biomedical tasks of “sick role” management within the broader context of life role enablement. Symptom management should be embedded in a comprehensive response to supporting and encouraging the efforts of people with psychosocial disability to return to and have agency in valued life roles such as that of citizen, family member, neighbour, friend, lover, co-worker and learner (Davidson & White, 2007).

Within the treatment setting, this involves a power-sharing collaboration between people with psychosocial disability and service providers (Borg & Kristiansen, 2004; Thornicroft et al., 2008), focused on the latter regaining or developing confidence in their ability to have agency in and exercise choice within different areas of their lives (Barbato, 2006; Kelly 2006; Koscuilek, 2005).

Within the arena of broader public processes, this involves practitioners’ policy makers’ and other policy stakeholders’ acceptance of people with psychosocial disability as “partners in the management of their own health and that of their community” (WHO, 2008). It involves the

creation of a framework for joint deliberation to encourage participation of people with psychosocial disability in policy development processes. Service providers, policy makers or programme developers also need to develop their own capacity to engage respectfully and appropriately with people with psychosocial disability within this new working alliance (McDaid, 2009).

3.4.2 Developing capacity for participation

3.4.2.1 Treatment and support as an aid to participation

Regaining one's health as soon and as far as is possible, and returning to old or new satisfying roles, can boost our sense of well-being and confidence (Ashcraft & Anthony, 2006). For people with psychosocial disability, the provision of accessible and effective treatment for symptom management, along with other social and economic supports, is crucial to promote their wellbeing. These supports may be seen as the "assistive devices" required to promote and to sustain their return to their roles in society, including that of policy and service development participant. A lack of appropriate treatments and supports can delay recovery and increase the likelihood of secondary disability, and reduce their interest, energy and belief in their ability to participate (Katontoka, 2007).

3.4.2.2 Practice as an aid to participation

Tritter and McCallum (2006) note that, at a practical level, time and expertise is needed to develop capacity to participate effectively in policy and service development. The need for time to develop skills for participation presents a dilemma for both policy makers and people with psychosocial disability alike. Policy makers are often driven by demands for urgent solutions, leaving little time for pre-consultation capacity development of participants. Less capacitated stakeholders may be left behind or given token acknowledgement within time-pressured consultation activities. This "hit and run" approach, not surprisingly, may serve to confirm ideas of the limited ability of people with psychosocial disability to participate meaningfully, both in the minds of policy and service providers, and in the minds of people subjected to this inappropriate approach. At the same time, the idea of first developing capacity and then

involving users in policy development will not be practical in a demanding policy context. Tritter & McCallum's (2006) contention that capacity can be incrementally developed through the participation process is in line with similar sentiments expressed by DPO-based participants in this study. "On the job" capacitation, however, does not exclude the need for training, mentoring and support of people with psychosocial disability in these roles.

With regard to participation in service delivery, the WHO (2009a) report on task shifting includes a recommendation that people living with HIV/AIDS should be included in recruitment drives for community health workers, a programme currently being reintroduced within the human resource development plan of South Africa (Department of Health, 2005). Further, the WHO report recommends that people living with HIV/AIDS should be equipped to take greater responsibility for aspects of their own and others' care at community level. Similarly, given the limitations of the public health services to service current levels of demand for mental health services, the sector will do well to invest in the inclusion of interested people with psychosocial disability in task-shifting plans for community-based service provision through self help and peer support initiatives (Sareceno, 2007; WHO, 2008).

3.4.3 Conclusion

People with psychosocial disability have made slow progress in participation in policy development and implementation processes in the 16 years of democracy in South Africa. Stakeholder, policy and legislative support for their inclusion in policy development and implementation processes are necessary but not sufficient for such participation to occur. Tangible strategies are needed to move support to action. Stigmatising attitudes amongst the general public and health care providers, and within public policy, need to be replaced with acknowledgment and acceptance of the right of people with psychosocial disability to participate in decision-making which affects their lives. Inclusion should be strengthened in regulatory and institutional operating frameworks, with participation roles of people with psychosocial disability clearly defined. Their capacity for participation should be strengthened through early and effective access to treatment and support, the development of a national advocacy movement, and through skills training and practical exposure to the policy and service development environment.

CHAPTER FOUR

Barriers to the participation of people with psychosocial disability in mental health policy development in South Africa: Perspectives of policy makers, professionals, religious leaders and academics

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Study objective

This chapter addresses objective 3, which is to ascertain South African *stakeholders' views* on current environmental barriers and strategies to support people with psychosocial disability to participate in mental health-related policy development in South Africa.

Contributions of the authors

As was the case with the previous chapter, the findings reported in chapter four was collected during research conducted for the Mental Health and Poverty Project, by the Mental Health and Poverty Project Consortium (DFID : RPC HD6, 2005 – 2010).

Professor Alan Flisher was project director until April 2010, at the time of his death, at which time Associate Professor Crick Lund resumed responsibility as director of the MHaPP, and agreed to supervise this study. Sharon Kleintjes was the lead author on this paper. Professor Alan Flisher contributed to review of early drafts of this paper. The remaining authors supervised the research, provided critical input to the drafting of the article, and approved the final manuscript for submission for publication.

Current status

The article was submitted to *Disability and Society* in August 2011. After peer review the authors were informed in March 2012 that the paper was found not suitable for publication in that journal. I wish to acknowledge that excellent feedback was provided by reviewers to the draft of the submitted paper, for example the need to more clearly define terms used and to have greater clarity on the nature of decision-making, which was the focus of the paper. The paper has been edited to take account of their suggestions. The paper was submitted to the *BMC International Health and Human Rights* on 10 August 2012.

Abstract

Background

This paper outlines stakeholder views on environmental barriers to people living with psychosocial disability participating in mental health policy development in South Africa.

Method

Fifty-six semi-structured interviews with national, provincial and local South African mental health stakeholders were conducted between August 2006 and August 2009. Respondents included public sector policy makers, professional regulatory council representatives, and representatives from non-profit organizations (NPOs), disabled people's organisations (DPOs), mental health interest groups, religious leaders, professional associations, universities and research institutions.

Results

Respondents identified three main environmental barriers to participation in policy development: (a) stigmatization and low priority of mental health (b) poverty and (c) ineffective recovery and community supports.

Conclusions

A human rights paradigm can inform a shift in perceptions, policy and practice to build the multi-system approach needed to transform attitudes and practices which undermine the equal participation of South Africans with psychosocial disability in all areas of social engagement in our country, including their involvement in policy development in South Africa.

4.1 Introduction

People with psychosocial disability have historically been marginalised from mainstream society by longstanding prejudicial beliefs about their right to full citizenship and their ability to contribute meaningfully to decisions which impact on their lives (Chan and Chui, 2007; Basic Needs, 2009; Funk et al., 2010.)

In this paper, we use the term psychosocial disability to refer to people who have experienced ongoing or recurring episodes of severe mental and emotional distress which “in interaction with various barriers...hinder their full and effective participation in society on an equal basis with others” (Article 1, United Nations Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 2006). We use this term to indicate our view that the barriers which impede the participation of people with psychosocial disability in decision-making which affect them are not simply a result of their mental and emotional distress, but of the way in which the organisation of society tends to limit the personal, social, political and economic power of people with disability, including people with psychosocial disability (McDaid, 2009; Wehmeyer & Cho, 2010).

Overinclusive prejudicial beliefs about lack of capacity to make rational and informed decisions has led to infringements of the rights of people with psychosocial disability to participate in political, legal, clinical and personal decisions which concern their lives (Chan & Chui, 2007; Drake & Deegan, 2009; Devi et al., 2011; Gable & Gostin, 2008, Lewis, 2009; Minkowitz, 2006). This lack of meaningful involvement in decision-making has been a hallmark of many people’s experience of the mental health system (Bassman, 2001; Campbell, 2006; Chamberlin, 1978, 1995;). Stigmatising and dehumanising experiences endured by some people with psychosocial disability within this system has led to the development of an alternative peer-based support system for recovery which operates outside of the traditional mental health system (Adame & Leitner, 2008). While some rights advocates among people with psychosocial disability who self-identify as having survived this system have chosen to seek recovery supports outside of mainstream mental health, others choose to assert their right to have better control over the policies and services within that system (Chovil, 2005).

The work of activists living with psychosocial disability over the past 30 to 40 years have also led to a growing acceptance of the importance of including people with psychosocial disability in decision-making which impact on their lives by some role-players within the formal mental health system, and a reform in the way in which they conceptualise and implement support to the recovery of people living with psychosocial disability (Anthony, 1993; Bennetts et al., 2011; Davidson et al., 2009; Farkas, 2007; Funk et al., 2010; WHO, 2001).

Common areas where people with psychosocial disability have been consulted include treatment, service development and evaluation, education and training, curriculum development and research (Tritter, 2009). While some progress has been made to develop procedural, organisational and political support for participation of people with psychosocial disability in many countries, their participation has been influential but not transforming of mainstream mental health care (Campbell, 2001). Further, their participation in over-arching policy-making processes is still infrequent (Munro et al., 2006; Nelson et al., 2006), particularly in low and middle-income countries (Mc Daid, Knapp & Raja, 2008).

South Africa is no exception to the problem of under-representation of the voices of people with psychosocial disability in these processes. In an earlier paper (Kleintjes et al., 2010), we noted that South Africans with psychosocial disability have had little opportunity to participate in the post-apartheid revision of the legislative, policy and service development framework guiding their country's new democracy. The aim of this paper is to identify environmental barriers to participation of people with psychosocial disability in the development of South Africa's over-arching national mental health-related government policies and legislation. In particular, we focus on the opinions of a range of stakeholders who have influence over mental health policy development and who are involved in the implementation of services based on these policies. These are policy makers, professionals, representatives of non-governmental organisations (NGOs) working in the mental health sector and religious leaders. These findings are drawn from data collected by the first author from August 2006 to August 2009, as part of the Mental Health and Poverty Project (MHaPP), which focused on mental health policy development and implementation in Ghana, South Africa, Uganda and Zambia (Flisher et al., 2007).

4.2 Method

4.2.1 Respondents

Semi-structured interviews (SSIs) were conducted with fifty-six (56) purposefully selected respondents to explore key barriers that might have an impact on involvement of people with psychosocial disability in mental health policy development. Respondents were drawn from sectors with potential impact on mental health policy and service development in South Africa. These respondents included eleven national public sector policy makers from the South African Presidency (1), Departments of Health (3), Education (2), Social Development (2), Housing (1), Justice and Constitutional Development (1) and Correctional Services (1), six professional regulatory council representatives for nursing (1), social work(1), psychology (1), occupational therapy(1) and medicine (2), twelve provincial health managers and a mental health review board member, nine representatives from non-profit organizations (NPOs), two disabled people's organisations (DPOs), religious leaders (5), professional guilds (3), universities and research institutions (6), and a regional representative of the World Health Organisation. These respondents were interviewed in their professional roles and were not asked to self-identify as people with experience of mental and emotional distress, or as supporters of family members with psychosocial disability, although a few spontaneously provided this information during the interviews.

4.2.2 Instrument development

Questions were developed for inclusion in the semi-structured interview guides developed for the broader MHAPP situational analysis, to elicit these stakeholders' views on the involvement of people with psychosocial disability in policy making.

4.2.3 Data collection and analysis

The scope, purpose and dissemination methods for the research was clearly spelt out in the informed consent forms. All respondents provided written informed consent, and confidentiality was assured by removal of identifying material from transcripts. SK conducted all the interviews in English. Interviews were recorded with the permission of respondents, and transcribed verbatim. A framework analysis approach (Ritchie & Spencer, 1994) was used to develop a

coding frame for analysis of the transcripts using NVivo 7 qualitative data analysis software. Transcripts were multi-coded on the basis of coding frame themes, with additional themes added to the frame as determined by the data.

4.4.4 Ethics

Permission was obtained from the Research Ethics Committee of the Faculty of Health Sciences (REC Ref: 323/2008), University of Cape Town.

4.3 Results

The three most common barriers to participation in policy development were: (a) stigmatization and low priority of mental health (b) poverty and (c) ineffective recovery and community supports.

4.3.1 Stigma and low priority of mental health

Most respondents felt that public attitudes toward people with psychosocial disability were generally negative, and spoke of the exclusion and disempowerment which stigma can bring. People with psychosocial disability may also experience accumulative discrimination on the basis of race, gender, and other socially marginalizing factors.

In another town (the independent living unit) was closed down because the community rejected the mental health service users of which...the majority...are from the black race....they don't want them in the neighbourhood....I think mental health status is coupled with colour....It boils down to being dangerous. (Rural woman, manager, Department of Health)

Negative attitudes and beliefs also permeate policy priorities. The majority of respondents mentioned the low standing and funding of mental health relative to other areas of public sector policy, resulting in little integration of mental health into the policy agendas of key government sectors.

*I: And how should they (people with psychosocial disability) be brought on board? :
From an advocacy point of view. You see. We'll do the rest of the work. .I: So, they need*

to just come and bring their views.. your office is open to that kind of consultation?. R: Ja, ja....I: Ok...I'm just curious about the strategies you use to interact with them? R: It's basically hearings, public hearings. I: Public hearings. Ok....I can't recall ever having a public hearing devoted to mental health issues? ...R: Ja, there hasn't been any. (Male, senior official, Office of the Presidency)

Respondents felt that lack of political support for mental health on the public policy agenda and competition for resources with other higher priority public concerns remain barriers to improved attention to mental health as a public sector priority. The South African government has prioritised disabled people as a target group within its activities, yet, people with psychosocial disability continue to be invisible in the implementation of its directives. Within government priorities, stigmatising beliefs may result in discriminatory policies which exclude people with psychosocial disability from available support.

Respondent: If the person meets the criteria (for housing subsidies) , then the person can qualify.... Interviewer: And if...they have a mental health problem? R: I think it would be said they are not eligible...the issue of contracting – that is the key issue there (Female national policy maker, Department of Housing).

During policy consultations, longstanding opinions about the capability of people with psychosocial disability may result in their routine exclusion from these processes.

Policy makers are very unaware of the fact that...the voices of service users need to be heard.... The voice must come from within (Urban woman, social worker, mental health NPO).

A few practitioners who spoke of their willingness to support initiatives to improve policy participation by people with psychosocial disability voiced their concern about their own lack of understanding of policy processes and advocacy skills to engage in this work.

I think you must play an active role in it...the thing is, I don't know enough about policies and how policies work... we are not all politicians....we are not all policy makers...so the more guidelines you get, the more participation you might get from people (Rural man, manager of provincial mental health NPO).

Impact on policy participation

Prejudicial views and discriminatory practices can make it a daunting task for people with psychosocial disability to step up to the task of contributing to the policy process. Stigma can negatively impact on their confidence in advocating for their own agenda during policy-making processes.

R: It's a campaign, you have to speak about it, you have to educate people and rally them behind your cause...but the difficulty with this campaign is in order for someone to take you serious, you would need a psychiatrist and a psychologist and those types of people to be ...I: Why? R: That's just how it works in society. What will they say: Die mense's mal (translation: These people are mad), why should I listen to them? Why not get the nurses and the psychologists, and the doctors to support that campaign? It's in their interest as well...As long as the users and professionals agree on the agenda, go with it...You see, if you agree on what you want, cooperate. You can fight about who controls it, and the politics later. And you will. (Urban man, leader of disabled people's organisation)

4.3.2 Poverty

Respondents from several stakeholder groups felt that the links between poverty and psychosocial disability are little known, poorly understood, and a significant contributor to the neglect of affected people's recovery in South Africa. Several respondents felt that this link should be more clearly built into government policy, and addressed in poverty alleviation programmes.

It's not brought out in policies. There should be a greater emphasis because that would also than lead to more structured preventative programs. We're always talking about HIV and poverty, for example – that kind of connection you know, has made headlines. Mental health and poverty hasn't. And that's what we need to focus on, because, you know, mental health obviously hasn't been a priority – its not...in our government's list of priorities, mental health is not number one and yet that should be, because that can affect a range of other things...The connection, the comparison to HIV and poverty, we need to have that similar kind of status, and then we can help mental health. (Female, senior official, Statutory body for Social Workers)

People with psychosocial disability may not have the resources to invest in their health and recovery, nor might family members be able to adequately care for a family member who has limited opportunity to contribute to the family's needs.

There are mentally ill people within the villages that... get the thin edge of the wedge because they're not participating in tilling the fields, looking after the goats and the cows...they're very often just locked up in a hut at the back of the village...and neglected (male member of Statutory Board, Health Professions Council of South Africa).

Respondents felt that it is more difficult for people with psychosocial disability than for most people, to enter or remain in the formal job market because of discriminatory practices. Further those who are already employed and become disabled run the risk of losing their job or career advancement opportunities, while the newly employed might be offered inferior conditions of employment. This discrimination flies in the face of South Africa's employment equity

legislation which regulates the appointment and reasonable accommodation of people with disabilities, including people with psychosocial disability.

They find ways of circumventing the law...you have a group of people who are marginalised, are in an almost permanent poverty trap, and that causes exclusion (Male, national disability policy maker).

Where people are unable to work for an income due to their disability, most respondents felt that access to social grants is essential to support recovery. A few respondents felt that difficulties qualifying for grants are due to lack of appropriate expertise and tools for assessment of psychosocial disability.

The expertise you need to be able to have to make these kinds of decisions about whether somebody should get a grant or not...It's quite subtle. ...Every group that we worked with saw this in entirely moral terms...that we're talking about lazy people. And these included health professionals... that's a major access thing, that it's invisible and stigmatized. (Urban man, mental health researcher and academic).

People may also experience difficulty relinquishing the financial aid provided by a social grant. This grant may be their household's only source of income, with the loss of the grant negatively impacting on the wellbeing, value and status within their family.

They have an income which is much higher than what a farm worker gets...it keeps more people alive than the one it is given to....they will be very nice towards the patient while there's money... but just after the money is finished, there's a lot of physical abuse again... and they don't have the self-esteem or the ability to fight for themselves (Rural man, manager of mental health NPO).

Impact of poverty on policy participation

Respondents indicated that people with psychosocial disability living in subsistence-based communities and those who have drifted into poverty as a result of disability related barriers, necessarily direct their energy at trying to meet the basic needs of their families, rather than

policy concerns. This has a material impact on the time and resources that they might be able to dedicate to advocacy and policy participation.

4.3.3 Ineffective recovery and community support

While most respondents felt that good work has been done in South Africa to transform Apartheid legislation, policies and services since South Africa's first democratic election in 1994, of concern was the perceived failure of government to effectively implement these reforms.

That is where the biggest gap is. The gap between the wonderful legislation, Bill of Rights and... the resourcing, the providing, the infrastructure for people to access services. That is either seriously lacking, or is in fact, absent (Urban man, provincial government director general).

The theme of strengthening implementation structures, especially at local level, was echoed with respect to the implementation of mental health laws and policies. Respondents felt that insufficiently available effective recovery and community support reduces the ability of people with psychosocial disability to participate in community life, including policy development.

What we have said is people must get out of psychiatric institutions and be back in the community... with whom? I'm saying this Act is such a good Act but....the resources to make the implementation viable and see it happen, they are not there (Male member of statutory board, Health Professions Council of South Africa)

Respondents from all stakeholder groups emphasised the need to improve resources for basic recovery and local community support to enable people with psychosocial disability to resume family, work and community roles as soon as possible. It was emphasized that mobilising resources for community based supports for people with psychosocial disability should be an intersectoral focus, as demonstrated by this respondent who suggested a Department of Transport travel subsidy as an adjunct to disability benefits received by people with psychosocial disability.

Ja, ja, it will make life easier because we...we have actually found out that, you know, relapses happen because the patient has nothing. She can't even go to the clinic, though

we are saying they must get to the local clinics. But you find that some of those local clinics, they require the patient to commute, you know, using transport. How is the patient going to do that if he doesn't have even a cent? (Female, provincial mental health programme manager, department of Health)

Mention was also made of the limitations of an individual approach to supports of people with psychosocial disability and the need to consider the need to widening the scope of benefits accrued to them, to include a family and community perspective. Respondents felt that a targeted programme for family support is necessary within the overall development of mental health supports.

R: if you take one individual that is disabled, be it physically or mentally, you can support that person, but my feeling is that person belongs somewhere in a family and that family belongs somewhere in a community. It's a network. When we give disabled people support we should not only be physically helping them with wheelchairs and food and a nice building, there's emotional side, there's mental support...these people need love and even if you love them...we have people who work in hospitals who happen to be sisters, nurses, doctors giving these people love but where is their family because everybody belongs somewhere. That person needs to know: I belong to this family. (Male, Elder, Christian Zionist Church of South Africa)

It was felt that effecting these intersectoral changes to policy directions would enable people with psychosocial disability who are interested to play a role in mental health policy development and community action.

I: Who should create awareness about mental health as a priority? R: One, the first, is those that are being affected....because they know their needs... The second is the community organizations or the NGOs, because they are in the community and they are an entry-point...much of government policies have been influenced by what is coming from the community (Female national policy maker, Department of Housing).

The barriers mentioned above also impact on whether people are included in community initiatives. Generally, the voices of people with psychosocial disability remain invisible in part due to the lack of accessible, accepting community structures through which they can voice their opinions. Many respondents spoke of the value of support groups and advocacy groups as vehicles through which interested people with psychosocial disability might be reached to participate in policy development.

4.4 Discussion

This paper provides qualitative insights into environmental barriers to the participation of people living with psychosocial disability in mental health policy development in South Africa. These barriers were identified by a range of stakeholders who do not identify themselves as living with psychosocial disability, but were able to provide unique insights, through their experience in the field. Barriers identified in the South African context are consistent with those from many other low and middle income countries, where people living with psychosocial disability are widely stigmatised (Ssebunnya et al., 2009; Thornicroft, 2006) and mental health is often given low policy priority (Bird et al., 2011; Ntulo, 2006;). This low priority contributes to people with psychosocial disability seldom being included in regulatory provisions for socio-economic upliftment. It also leads to inadequate access to effective supports, which can prolong episodes of mental and emotional distress, and can interfere with participation by people with psychosocial disability in the social, economic and political life of their communities (Funk et al., 2010). Further, support to people who experience mental and emotional distress is still largely thought of as a treatment issue for the attention of the health sector (Lwanga-Ntale, 2006). Results, however, reveal that beyond important treatment concerns, other barriers – poverty, stigma and discrimination – are crucial. These act in a self-reinforcing cycle of social, economic and political disadvantage, entrenching affected people's vocal and material exclusion from society. It also maintains their powerlessness to change their marginalised position (Wallerstein, 2002).

This marginalisation extends to exclusion from meaningful opportunities to transform policy directions which impact on their lives. In an earlier paper on the participation of South Africans with psychosocial disability in policy development (Kleintjes et al., 2010) we suggested legislative, policy, organisational, practitioner and personal strategies to enable people with

psychosocial disability to empower themselves to participate in mental health policy development. These strategies are as yet not in place in South Africa, and the organisation of people with psychosocial disability is in its infancy. While these provisions are necessary for the empowerment of people with psychosocial disability, they may not be sufficient to ensure meaningful participation of people with psychosocial disability in overarching policy development, nor might they improve their influence on policy outcomes in South Africa.

This paper adds to our previous findings (Kleintjes et al., 2010) by indicating that broader structural factors, including poverty, lack of policy priority and stigma, are crucial barriers that need to be addressed, in the opinions of a range of South African stakeholders. This finding is supported by other studies which suggest that it is the very socio-cultural framework within which people with psychosocial disability find themselves, which gives rise to their marginalisation in society (Masterson & Owen, 2006; McDaid, 2009; Spandler & Calton, 2009). They are not effective as they are implemented in an environment in which the dominant relational culture is one which continues to permit social acts which limit or violate the rights of people with psychosocial disability. This culture maintains their social-economic disadvantage by excluding them from the power which access to social resources can afford citizens in a socially inclusive society. This exclusion is accompanied by their automatic inclusion within the dominant bio-medical subculture with which society associates mental and emotional distress. Their journey to understanding their experiences and its significance for a meaningful, self-directed life is subsumed under their assigned patient role. Within this illness paradigm, their right and ability to participate in activities outside of their foregrounded role as patient, such as that of policy participant, is called into question.

Fundamental changes to the overall social system within which these marginalising factors exist will therefore be needed to create an environment which will enable people to regain and assert the psychological and social power enjoyed by other citizens (Masterson & Owen, 2006; McDaid, 2009). Mental health policy frameworks in several countries now emphasise participation of people with psychosocial disability in all decisions related to their own lives (Commonwealth of Australia, 2009; Government of Ireland, 2006; New Freedom Commission

on Mental Health, 2003). This is still an emergent perspective in South Africa: At the first national mental health summit convened by the Minister of Health in April 2012, a new draft mental health policy was unveiled for comment. There was active representation of people with psychosocial disability from provincial advocacy groups in the country supported by the SAFMH, and a national body, the South African Mental Health Advocacy Movement (SAMHAM). There was also representation from independent advocacy bodies for people with psychosocial disability, including The Ubuntu Centre, South Africa's only registered DPO for people with psychosocial disability, as well as from representatives of some of the smaller locally-based advocacy groups within the country. This level of participation was far greater than what occurred during South Africa's 1997 mental health policy development process, or the 2002 Mental Health Care Act development process (Kleintjes et al., 2010). This ministerial summit could provide a tentative start to what can be the building of a rights-focused mental health system in South Africa, with active participation of people with psychosocial disability. South Africa is a signatory to the UNCRPD (2006). This obligates civil society and other government sectors to work toward aligning societal mores, legal framework, national policies, organisational policies and procedural guidelines, professional curricula, clinical practice guides, research foci and funding policies to effect the systemic changes needed (Burns, 2009). Given the commitments South Africa has now made as a country, it will be important for the organisations of people with psychosocial disability, their allies, and institutional rights-monitoring mechanisms in South Africa to lobby for and track the extent to which these commitments are honoured in mental health policies and practices.

CHAPTER FIVE

The views of South Africans with psychosocial disability on priorities for supporting recovery: Implications for policy and service development

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Study objective

This chapter addresses objective four which is to document the views of South Africans with psychosocial disability on their *lived experience* of barriers to their participation in policy development, and to highlight their priorities for policy development.

Contributions of the authors

The interviews include 20 interviews conducted as part of the MHaPP project (10 advocates and 10 rural district based interviews in KwaZulu Natal) and 20 additional interviews conducted by the researcher after the MHaPP project data collection period (10 advocates and 10 urban district based interviews in the Western Cape Province). Sharon Kleintjes conceptualised the study and

its design, and carried out or supervised all aspects of the data collection and analysis of the findings. She was the lead author on this paper. The remaining authors supervised the research and critically reviewed drafts of the article.

Current status

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Abstract

Objectives

The paper documents the views of South Africans with psychosocial disability on policy directions required to support their recovery.

Methods

Semi-structured interviews were conducted with forty people with psychosocial disability using mental health services and/or involved in advocacy work to support others with psychosocial disability. A framework analysis approach was used to analyse the qualitative data.

Results

Priorities included addressing stigma, discrimination and disempowerment, and the links between mental health and poverty. They suggested that these challenges be addressed through public awareness campaigns, legislative and policy reform for rights protection, development of a national lobby to advocate for changes, and empowerment. Respondents suggested that empowerment can be facilitated through opportunities for improved social relatedness and equitable access to social and economic resources.

Conclusions

This study suggests three strategies to bridge the gap between the rights and needs of people with psychosocial disability on one hand, and unsupportive attitudes, policies and practices on the other. These are: giving priority to their involvement in policy and service reform, creating empathic alliances to promote their priorities, and building enabling partnerships to effect these priorities.

5.1 Introduction

Mental disorders have an impact on the lives of a significant proportion of South Africans. Approximately 16.5% of South Africans reported having suffered from common mental disorders such as depression, anxiety and substance abuse in the last year (Williams et al., 2007). In terms of their contribution to the burden of disease in the country, neuropsychiatric conditions rank 3rd, after HIV/AIDS and other infectious diseases (Bradshaw et al., 2007). Mental health is formally acknowledged as a public health priority in South Africa, with legislation and health policy development in place to guide service delivery to service users (Department of Health, 1997a; Republic of South Africa, 1997; Republic of South Africa, 2002).

Mental health legislation and policy development has taken place within the broader reform of the country's regulatory framework during the past 18 years of post-apartheid democracy (Foster et al., 1997). Strong civic engagement is the cornerstone of democratic governance, and these reforms have enjoyed strong civil society engagement, and more recently, civil society pressure for greater government attention to the effective implementation of policies (Lund et al., 2010c). In South Africa, with its past history of apartheid oppression of the civil will of most of the population, the South African Bill of Rights specifically articulates the right of citizens to "...participate in public processes..." (Republic of South Africa, 1996). But participation does not guarantee effective influence over policy directions (McColl & Boyce, 2003). Even where there are available opportunities for disabled people to participate in decision-making, effecting real influence over policy decisions remains a challenge (Mji et al., 2009a). This is particularly the case in the instance of people living with psychosocial disability; their participation in these processes has been noticeably lacking.

People living with psychosocial disability have the same rights as others to involvement in policy development, implementation and evaluation (Blas et al., 2008). Several examples of such participation can be found internationally (Department of Health & Ageing, 2008; Gawith & Abrams, 2006; Government of Ireland, 2006;). These developments have been occasioned by the rights-based move away from institutionalization to inclusion of disabled people in everyday living, learning, working and socialising, the rise of disability advocacy organisations (McColl &

Boyce, 2003) , and, within mental health, an emphasis on a more holistic recovery approach to wellbeing (Anthony, 1993; Linhorst & Eckert, 2003; Ramon et al., 2009). In Africa, where engagement of representation by people with psychosocial disability to these processes is not yet accepted practice, and the development of an organized consumer voice is relatively new, the participation of people with psychosocial disability in policy development is in its infancy (Barbato & Vallarino, 2010). In South Africa, research comments on the need for advocacy driven by people with psychosocial disability (Burns, 2009) and has sought their opinion on service satisfaction (Almeida & Dejummo, 2004; Trump & Hugo, 2006). To our knowledge, the question of the involvement of South Africans living with psychosocial disability in policy development to support their recovery has not yet been addressed in formal research. South Africa is currently at the early stages of reviewing its national policy on mental health. This policy review presents an ideal opportunity to engage these citizens as informants in the policy process. This paper documents the views of 40 South Africans, living with psychosocial disability, on priorities to support their recovery.

5.2 Methods

5.2.1 Design

The aim of the study was to identify the policy priorities which people with psychosocial disability felt are necessary to support their recovery. As the policy arena is an unfamiliar area of enquiry for most lay people, a pragmatic approach informed the transition from participants' experience to the identification of concrete strategies which addressed the objectives of the study. A pragmatic approach emphasises identification of problems and sourcing solutions to understand a given problem (Creswell, 2003). As detailed in Annex 5, the approach taken was to first explore participants personal experiences of barriers to their recovery, and then to enquire whether and how they thought these experiences might inform policy priorities to promote their recovery. Experience provides a useful base from which people with psychosocial disability can be engaged, with the ultimate goal of improving the responsiveness of the mental health policy development and implementation process to their recovery.

5.2.2 Instrument development

A scoping of the literature (Arksey & O'Malley, 2005) informed development of two semi-structured interview guides for advocate and non-advocate respondents (Gawith & Abrams, 2006; Slade et al., 1999; Uys, 1998; United Nations, 1991; United Nations, 2006b; WHO, 1996; WHO, 2001). Question structure allowed for varied exposure to mental health services, advocacy and policy issues. Respondents' opinions were first sought, then probes used to explore their responses. For non-advocate respondents, questions first related to their experience of services for mental illness, then explored opinions on what this could mean for policy development. Advocates' questions drew more directly on their advocacy experience, as detailed in Appendix 5.

5.2.3 Respondents

Forty people with psychosocial disability were interviewed. Twenty of these respondents included people who had experience of using mental health services in South Africa, and were also involved in mental health advocacy work to support people with psychosocial disability (advocates) in various settings throughout the nine provinces of South Africa. They were identified through snowballing. The remaining twenty respondents had experience of using mental health services but were not involved in advocacy work (non-advocates).

The national and provincial branches of two leading mental health nongovernmental organizations (NGOs) working throughout the nine provinces of South Africa, as well as individual advocates helped identify other advocates. These advocates were involved in various roles, including facilitating support groups, serving as leaders of advocacy groups and income generation projects or as members of mental hospital or nongovernmental boards of management.

Ten of the twenty non-advocate respondents attended a primary health care clinic in the rural district of Hlabisa in the KwaZuluNatal province of South Africa. The other ten non-advocate respondents volunteered to participate following an introductory presentation at an urban community based psychosocial support centre for users of public mental health services (n=4),

an email sent to two support groups attended by private mental health service users (n=2), and by word of mouth (n=4) in the Metropolitan region of the Western Cape Province. Respondents had a wide range of educational backgrounds, income status, and experience of private and/or public mental health service provision in the country. While a handful of respondents rarely experienced psychosocial difficulties related to earlier episodes of mental and emotional distress, most experienced these episodes as having an ongoing impact on their lives.

5.2.4 Data collection and analysis

All respondents provided informed consent, and confidentiality was assured by the removal of identifying material from transcripts. Interviews were conducted in English, with the exception of the 10 rural district interviews which were conducted in isiZulu, an indigenous language. Interviews were recorded with the permission of respondents and English interviews transcribed verbatim. IsiZulu interviews were translated and transcribed into English by the interviewer, and transcriptions were back-translated by an independent bilingual speaker.

A framework analysis approach (Ritchie & Spencer, 1994) was used to develop a coding frame for analysis of the transcripts using NVivo 7 qualitative data analysis software. Transcripts were multi-coded on the basis of coding frame themes, with additional themes added to the frame as determined by the data.

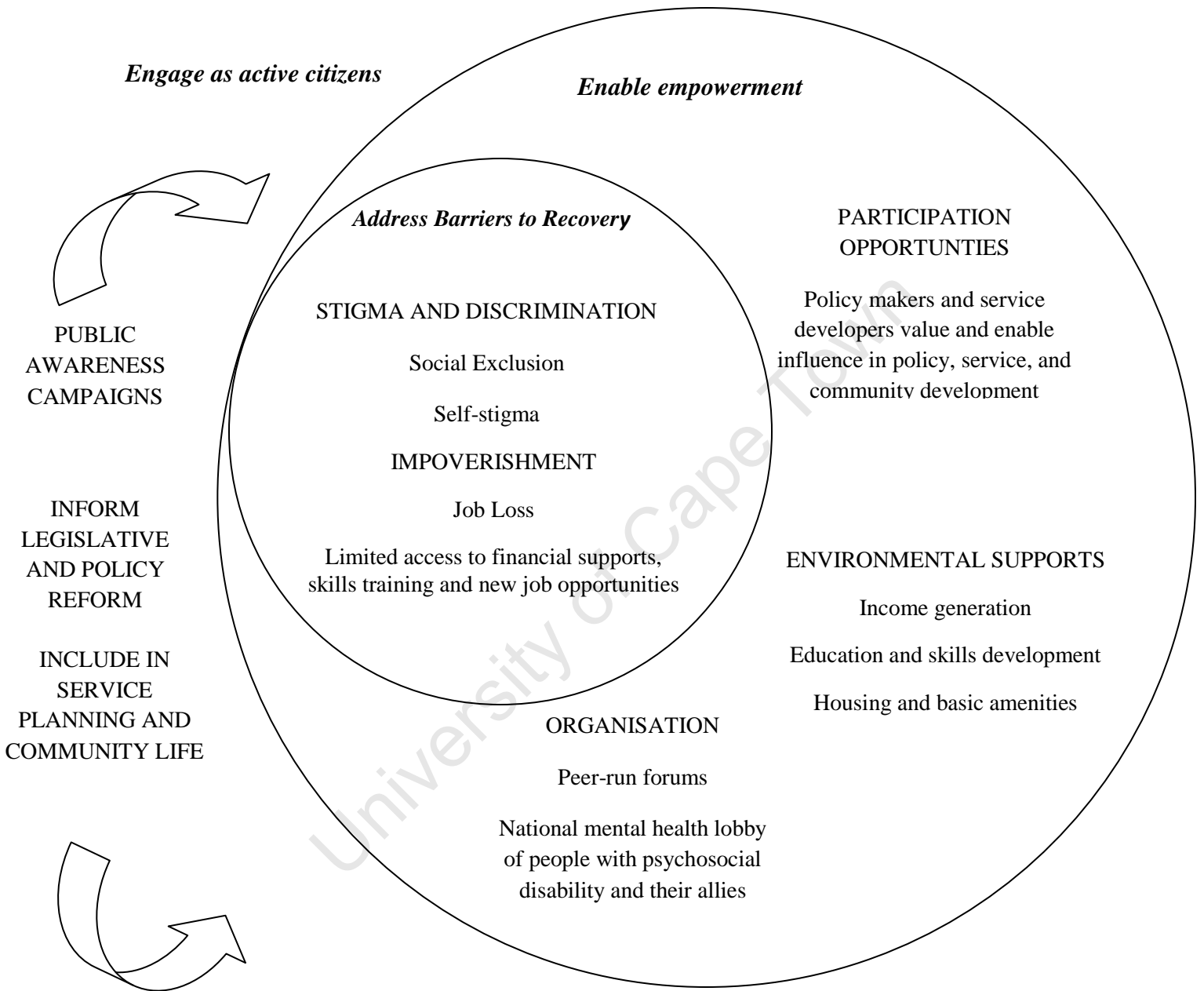
5.2.5 Ethics

Permission was obtained from the Human Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town, and the national Department of Health.

5.3 Results

The three most frequently mentioned challenges experienced by respondents were stigma and discrimination, impoverishment and disempowerment. Strategies suggested by respondents to address these challenges fell broadly within two themes: advocacy and empowerment. Figure 2 summarises the main issues addressed under these themes, as elaborated below.

Figure 2: Policy Priorities to support Recovery



5.3.1 *Stigma and discrimination*

Respondents described stigma and discrimination in a number of ways.

Exclusion: 35 of the 40 respondents spoke extensively about how others' perceptions were negatively influenced by knowledge of their mental illness. Respondents reported being overtly excluded, but also experienced withdrawal of social status very subtly.

Respondent (R): ...we were slaughtering a cow, and this one brother said that I had to step aside because they wanted somebody creative and careful to do it... . Rural man, on disability grant, service user.

Exclusionary attitudes and behaviour could be found in the most informed circles, as noted by this representative to a leadership forum within a prominent mental health NGO:

R: Mental Health themselves (referring to NGO) try to be accommodating but even they treat you as a mental patient, you can never be an equal. Urban woman, employed lawyer, advocate.

Self-stigma: Respondents were not always free of negative self evaluations, either because others' stigmatizing views coloured their self-perceptions, or as a result of living with the disabling impact of enduring mental ill-health.

R: ...it is difficult to tell other people about it because all you are aware of is your own helplessness and your profound sense of inadequacy and the guilt you have for not being able to meet your obligations. Urban man, freelance editor, service user.

Human rights violations: Respondents found stigmatising attitudes and beliefs result in discriminatory practices which violate their human rights (n=20) and their desire for acceptance and respect (n=20).

Interviewer (I): Do you know how to keep up to date with mental health policies that affect you? Respondent (R): No I don't. I: Would you like to know? R: Yes, so that I can know what to do if I am being treated badly.... Even my Induna (leader) does not take me

seriously....cows had eaten my vegetables and he did not want to listen to me. Rural woman on disability grant, non-advocate.

5.3.2 Impoverishment

Reducing economic security: Some respondents experienced stigmatising attitudes and discriminatory behaviour from their employers even when they were able to resume work after a period of treatment and support. Mental illness itself also impacted on their ability to return to their jobs. This was attributed to having insufficient recovery time before being expected back at work, lack of transitional support to resume their return to work, or lack of opportunity to retrain for a more suitable position. A few respondents were retrenched by their employers because they were struggling to resume their work.

R: ...the minute I became ill...I definitely was stigmatised and lost my job as a result. I then lost my home, I lost my car and I lost my income and that was huge...a ghastly experience. Urban woman, health sector NGO manager, advocate.

Invisibility of need: Eighteen non-advocate respondents and 10 advocates had disability grants at the time of the interview, with the remaining respondents employed in the open labour market, a few after a period of receiving a disability grant. Most had little difficulty initially accessing the grant due to the prominence of their symptoms. However, several noted their own or others' difficulty in retaining a state grant or employee disability grants, or being eligible for medical boarding or poverty alleviation support once stabilised, but still experiencing difficulty resuming their work and home responsibilities. The "invisibility" of their disability resulted in their not being regarded as disabled.

R: ...they look at me and say this is a person who can run her own life.... Unless you are really sick to such an extent that you collect papers outside and eat them, then they'll realise that you are mad. Rural woman, retrenched nurse, advocate.

Deepening the poverty of the already poor: Respondents who relied on their community for income generation spoke of being excluded from these opportunities in their community.

R: I wanted to join the chicken project. I know I could not get in because of my illness. All the women from my neighbourhood were able to, but I was told to wait. I am still waiting, even today. Rural woman on disability grant, non-advocate.

Drifting into poverty: The impact of poverty on recovery does not only affect the already-poor. Respondents from affluent families, or who had been economically stable prior to the onset of their psychosocial disability, spoke of their downward spiral to impoverishment.

R: I find that people want to employ you in a lesser status or you yourself are willing to work for less money because you're just happy to find work.... and you find a lot of frustration to get employed if you are honest about your condition. (urban male postal worker, advocate).

Some noted the impact of poverty on their advocacy work.

...I'm in the process of writing a position paper looking at psychological integrity....My problem is, I am funding my own research ...I'm living... under the headline...I: So you come from a privileged background but...you're no longer there? R: I'm no longer there. (Urban man, journalist on disability grant, user advocate)

Impoverishment through inequality in policy implementation: A few respondents felt that government-funded programmes to uplift poor communities did not reach the mentally ill poor.

R: ...people with physical disabilities and normal people, they give them skills...they don't give us the opportunities.... When people with disabilities apply, they employ people with artisan skills, and we don't have those skills. Rural man on disability grant, advocate.

Poverty and poor health: Poverty can impact on access to health care as demonstrated by this well-off advocate relating an incident of a poor woman who has the same diagnosis as she does. This woman struggled to attend appointments at the service centre 250km from her home and committed a crime while ill.

R: She is not having...adequate services...that is why she is ending up in court...she doesn't have the money like myself to pay each month to be...as normal as possible. She

is discriminated against because she doesn't have an income. Urban woman, employed lawyer, advocate.

Respondents identified two main strategies to improve inclusion of people with psychosocial disability, namely advocacy and empowerment.

5.3.3 Advocacy

Public awareness: The most frequent strategy respondents mentioned was an ongoing, national public awareness campaign to counter negative media about severe mental and emotional distress and promote positive attitudes and behaviour toward people who experience severe and enduring mental and emotional distress (n=26). Respondents felt that they are very rarely positively depicted. Public images tend to focus on illness, incapacity and even dangerousness. They felt that positive exposure to people living with psychosocial disability can break down public misconceptions and recommended prominent involvement of people with psychosocial disability in advocacy activities.

Human rights protection: Respondents also emphasized use of policy and legislation to lobby the state regarding its obligations to ensure that the rights of people with psychosocial disability are protected (n=15). They felt that the overall legislative framework in South Africa is sufficiently rights-based and disability orientated to support lobbying for the rights of people with psychosocial difficulties. A few advocates (n=5) felt that current legislation and policies for mental health are too treatment-oriented, and should be overhauled to address broader recovery and empowerment needs of people with psychosocial disability as set out in the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

Self-representation: Many respondents felt strongly that their issues are inadequately represented by people of influence.

...those that speak for us, they just speak because they are there for mental health days. They shall never go back and say "yesterday we talked about this and we will help you". No, it is finished for that day (rural male, subsistence farmer, user leader).

Others felt that the voices of people with psychosocial disability remain invisible in part due to the lack of fora through which they can voice their opinions.

The problem with us, sisi [sister], is that we are sick and we are not educated. People who talk to government are educated, so what will we say?... Forums for mentally ill people can help. (Rural man on disability grant, service user).

Many respondents spoke of the value of support groups and advocacy groups as potential vehicles through which people with psychosocial disability can be reached to participate in local community decision-making and in broader policy making initiatives. Respondents felt that advocacy initiatives should include a focus on brokering access to resources for participating in such consultations.

I: What are the core things that people have to fight for? R: Self-empowerment...your own rights. I: And what helps with achieving that? R: Activism....It comes down to having... developmental resources for functions at grassroots level...give people the opportunity to come to their own conclusions... (Urban man, journalist on disability grant, user advocate)

Advocate (n=13) and non-advocate respondents (n=8) suggested the formation of a powerful mental health “voice” through which people with psychosocial disability can take an active role in policy-making that has an impact on their recovery. Respondents who felt unable to take up their issues themselves supported the representation of their needs by others with passion for justice, and the strength and skill to take up these issues. Four respondents spontaneously mentioned the Treatment Action Campaign (TAC), the successful South African campaign launched in the late 1990s by affected people and their allies to break down HIV/AIDS- related stigma and lobby for treatment for HIV positive people. They felt that the TAC provides a good model for a similar rights-based mental health advocacy campaign by people living with psychosocial disability and their allies.

R: ...it's about fighting for...the rights of people who are mentally challenged...shout out to the doctors, the government, we need more funding, more accessibility to medication...I'd make my placards big and...walk all the way to parliament and I won't

be ashamed of who I am because I'd feel I'm with others who feel like I feel. Urban woman, switchboard operator on disability leave, service user.

Amongst the respondents to this study, however, none of the twenty non-advocate service users had provided input to policy level decision-making within their affiliate organisations or as part of national or local legislative, policy and service development processes. A few wanted to be able to express their satisfaction with their own service provision within the context of the treatment relationship, but felt that policy related decision-making should be left to mental health professionals and experts. Most expressed interest in knowing more about policy processes and how they might have their views heard, either directly, or through representation by providers, or by other people with psychosocial disability. . In the latter case, respondents doubted that they would be able to participate themselves. They either did not believe themselves skilled or informed enough to participate, that decision-makers would be interested in or take their views seriously, or were not yet ready to take this step due to the impact of their mental and emotional distress.

I'm just managing...to cope...I'm not ready to take that step right now. I mean, I still have to write a letter to the manager at (private health facility) regarding how badly I was treated there....It's not that I don't want to do it; I'm just not strong enough to do it.
... (Urban female, switchboard operator on disability leave, service user)

While a handful of the twenty non-advocates had provided input to policy level decision-making within their affiliate organisations, only five had experience providing input to national, regional or local community level mental health legislative, policy and service development processes. All 20 advocates supported the involvement of people with psychosocial disability in these processes. A few advocates spoke of a need to develop capacity through skills training, the need for preparation for a transition from supported advocacy to independent advocacy where support was in place, and the value of skills auditing to establish which core skills users need to build for their work.

R: The new facilitators...haven't been the type of support that (previous facilitator) was....I: Which approach to you prefer? R: The old one....saying OK, I will walk with you a little bit, and that's where you need to go. Not just, you need to do this, there is

your goal, go....There are some gaps... some skills gaps... (Urban man on disability grant, user leader)

Skills training aside, a few experienced advocates mentioned that, over time, exposure and experience to policy related decision-making had served to develop their capacity for this work. For several non-advocate service users, and newer advocates, the interview process itself seemed to be an eye-opener, the first time that respondents were exposed to the possibility of having a say about supports to recovery, and to the policies that influence recovery. Questions posed seemed to open them to new avenues of thinking, as demonstrated by this advocate, speaking of her plans to take up these issues with her local user advocacy group.

R: Now I am going to push whatever I have mentioned to you today... I: Your eyes are glowing. Did you talk about these things before? R: No, I am just glad that somebody came to me, because some things I didn't know...I feel more relaxed now .I want this to happen. (Urban woman on disability grant, advocate)

Alliances: Private service users and public and private sector advocates spoke of the value of alliances between themselves, service providers and policy makers around issues of treatment, policy development and planning for service provision.

R: If...there's no absolute experts...it opens the door to everybody who can make a meaningful contribution to helping human beings...human beings caring for fellow human beings. Urban male, high school educator on disability grant, leader of DPO for people with psychosocial disability.

5.3.4 Empowerment

Respondents identified several strategies which they felt could empower ordinary people with psychosocial disability to participate in their recovery.

Empowerment through social relatedness

Hope and self-regard: Many respondents spoke of the importance of overcoming the internal experience of devaluation which can accompany a diagnosis of mental illness (N=17).

Respondents spoke of fostering self acceptance and hope for recovery through the daily experience of success in building new and satisfying relationships, skills and interests.

Intimate relationships: Family acceptance and support was most frequently reported as promotive of positive self regard and hope for recovery (n=27). Respondents (n=14) also raised the need for help with their children when they are ill, and financial support for schooling and other childcare costs for parents on disability benefits. Some single respondents (n=8), spoke of their desire to attract partners and start a family of their own. Supportive friends were considered essential to recovery (n=12), particularly where family support was absent. Support groups were extensively mentioned as a valuable source of social support.

R: ...when it came to Thursday I would find I am dressing myself nice, putting lipstick on...when I left there I would feel I could face the world. Urban woman, in transitional employment programme, non-advocate.

Peer support groups as a “building block” for advocacy: Peer support groups primarily focus on support around psycho-education and management of illness and associated psycho-social difficulties. These support groups have been set up mainly by the Mental Health Societies of the SA Federation for Mental Health, the South African Depression and Anxiety Support Group (SADAG) and, in a few provinces, by the state mental health services. Many respondents felt that these support groups are cost-effective and beneficial for recovery and favoured the development of these groups throughout the country. Several respondents suggested that these support groups could provide a platform from which to consult with people regarding their needs, inform them of policy and service developments to obtain input to new policy developments, and build a local, provincial and national mental health user based lobby.

I: And do you think it’s important for people like yourself, running this kind of group...to have a voice with policy makers around the issues? R: I think so... the facts I’m saying here are not documented anywhere. I’m so exposed to the people on the ground, and then the politician doesn’t know, can’t get the facts, and I’m the one who experiences this and the facts, I might highlight it to the policy makers. (Rural male, support group facilitator and advocate)

Empowerment through access to social and economic resources

Income generation: Work was the most frequently mentioned enabler of recovery (n=24). Respondents wanted greater acceptance of (n=11) and elaboration of reasonable accommodation provisions for (n=12) people with psychosocial disability working in the open labour market. In the informal sector, respondents called for inclusion of people with psychosocial disability in income generation projects or support for income generation projects initiated by people living with psychosocial disability themselves (n=10). A few respondents mentioned the pleasure and satisfaction of meaningful occupation itself, apart from the need to generate income (n=6). This was illustrated by this prominent advocate, who had not been able to continue his graduate studies or his work within a demanding job environment, and has found reward in using his skills for national and local advocacy work.

R: I might not be earning well, but it gives me a purpose. There are people that rely on me...I take it as a duty. Urban man, disability grant recipient, leader of advocacy group for people with psychosocial disability.

Education and skills development: Respondents who experienced difficulty sustaining their work due to illness, spoke of the need for support to resume jobs, or to retrain for more suitable jobs (n=9). Education or skills development to improve job prospects were also mentioned (n=12). A university lecturer spoke of the lack of reasonable accommodation for learners who become ill while studying.

Disability benefits: Respondents felt that attention should be paid to improving employers' and state administrators' understanding of the "hidden" nature of mental disability, including an overhaul of currently inadequate assessment tools used to determine eligibility for mental disability benefits by employers or the state.

Housing and basic amenities: About half of the respondents (n=21) noted that access to housing is a problem for many people with psychosocial disability who may not have the means to secure housing either because of pre-existing poverty, or as a result of disability-related poverty. A handful of urban respondents (n=7) stressed the need for supported housing for homeless people with psychosocial disability, for people who experience difficulty managing their own home

independently, and for people discharged from hospital treatment who are not ready to return to independent living.

Concessions: Some respondents felt that people with psychosocial disability should be eligible for other financial supports, such as local government reductions on payments for basic amenities such as electricity, water, sewage and rates (n=11), and a travel grant to use public transport (n=13).

Optimal health care: Respondents wanted access to the most effective drugs for their condition (n=24), and psycho-education to support self-management of their illness (n=19).

5.4 Discussion

Although South Africa's laws are rights based and the country is a signatory to several international agreements which obligate the state to uphold the basic human right of its citizens lack of effective, affordable healthcare and access to other social and economic resources can reduce the participation of citizens with psychosocial disability in the political, social and economic life of the country (Burns, 2009), and entrench poverty and exclusion (Mji et al., 2009a). What can be done to bridge the gap between rights and needs, and unsupportive attitudes, policies and practices? Three strategies are suggested by the findings of this study. These are: (a) advocating for involvement, (b) creating empathic alliances, and (c) building enabling partnerships.

5.4.1 Advocating for involvement in policy and service reform

People with psychosocial disability need to be central actors in anti-stigma initiatives, policy development and implementation, and advocacy aimed at addressing their rights and unmet needs, as a key principle of engagement (Burns, 2009; Fudge & Robinson, 2009). Findings from other studies support respondents' contention that firsthand exposure to people with psychosocial disability engaging in activities which demonstrate their capacity for meaningful participation in policy, service development and project implementation can help change the attitudes of policy makers, service providers and community networks, and foster collaborative effort for recovery

(Gawith & Abrams, 2006; Spagnolo et al., 2008). As noted by respondents, a key principle underlying the success of the Treatment Action Campaign (TAC), in South Africa has been the prominent role played by affected and infected people. This included challenging pharmaceutical patent laws and government policies which denied HIV-infected South Africans access to life-saving antiretroviral treatment during in the early years of the pandemic (The Treatment Action Campaign, 2010). The TAC offers several lessons on advocating for the rights of people living with mental illness (Burns, 2010): advocacy should be driven by priorities identified by people with psychosocial disability, and should draw in expert allies and prominent supporters to lobby for change, with the agenda informed by a scientific base, and with a human rights focus. Alliances should promote a culture of capability amongst people with psychosocial disability, building confidence in abilities through capacity development, and the affirming experience of active participation in meeting their own needs (Lorenzo et al., 2007).

5.4.2 *Empathic alliances for civil action*

Respondents expressed the need for acceptance and support of family, friends, neighbours and practitioners. Experience from other settings has shown the value of family associations and NGOs working alongside people with psychosocial disability and their representative organisations to lobby for change in mental health related policy and services (Fudge & Robinson, 2009;Gawith & Abrams, 2006);.

While most respondents in this study supported alliances in civil action, two advocates preferred purely peer-driven advocacy, working alongside, but not enjoined with other allies. In low and middle income countries, including South Africa, mental health resources are few, and peer-led organisation for mental health advocacy is still in its infancy. In these settings, lack of adequate psychiatric care and community based supports hamper recovery (Saraceno et al., 2007; Seedat et al., 2008), leaving the majority of affected people reliant on family and community resources to meet their needs (Barbato & Vallarino, 2010). Untreated people remain poorly placed to raise their voices regarding actions that can empower them to take up their roles as citizens, workers, learners, family and community members. Under these circumstances, while mindful of power dynamics which can impact on the influence of people with psychosocial disability within alliances (Campbell, 2010; McColl & Boyce, 2003), it seems prudent to applaud all meaningful

efforts to work for change, whether peer driven or ally supported. Autonomy, the right and ability to choose, so necessary for empowerment and recovery, should not be conflated with independence (Korr et al., 2005), particularly in cultures which emphasise interdependence of human beings, and where the value, meaning and advancement of the life of the individual is embedded in that of his or her community (Mji et al., 2009b).

5.4.3 Building enabling partnerships

The state as enabler: Respondents in this study were unequivocal in their view that the state should advance their right to a decent life, in line with South Africa's Constitution and Bill of Rights. The range of priorities respondents identified as necessary for a satisfying life makes clear that the state and other partners must address the needs of people with psychosocial disability from a development, not a narrow illness, perspective (Funk et al., 2010). There are several international treaties which provide policy makers and programme implementers with clear directions for a holistic approach to protecting and enforcing their rights (Gable & Gostin, 2008). These treaties can direct formulation of a rights-based, inter-sectoral public policy framework to support user recovery. The most recent and far reaching of these is the United Nations International Convention on the Rights of People with Disabilities (United Nations, 2006). South Africa has ratified both the Convention and its Optional Protocol. Advocates and other stakeholders in South Africa who feel that the current South African mental health legislation is too treatment focussed, have begun to use the broader provisions of the Convention to lobby for legislative and policy reform which goes beyond treatment to more comprehensively address the range of priorities which people with psychosocial disability have identified as central to their recovery (Kleintjes et al., 2010).

Evidence is also available to inform government efforts for cost effective scaling up of mental health services (Lancet Global Mental Health Group, 2007). These initiatives, while emphasising the need for effective treatment for mental disorders, acknowledge that support for the full range of priorities highlighted in this paper requires the participation of all sectors of civil society and government. The delineation of the roles of other sectors in promoting mental well-being needs greater elaboration to support comprehensive inter-sectoral partnerships (Skeen et al., 2010).

The priorities respondents identified also highlight the neglected potential for local authorities to contribute to meeting the needs of people with psychosocial disability, particularly within poor communities (Breen et al., 2007).

Providers and administrators as enablers: Excellent policies are only as good as the organisational structures, protocols, procedures, and providers that are used to implement them (Linhorst & Eckert, 2003). Respondents noted how important humane, enabling professional relationships and settings are to their recovery. Policy implementers and practitioners will need support to transform their ideological and practice framework from that of expert to that of enabler of decision-making in treatment, public policy research and development, if they are to partner with people with psychosocial disability to achieving the priorities they have identified.

The community as enabler: Respondent accounts illustrate the importance of access to the benefits of community based social capital for emotional, social and economic well-being (Green et al., 2003). Decision-making for, and informal social and economic networks within communities are the settings within which the needs of people with psychosocial disability can be raised and met – or ignored. In turn, people with psychosocial disability and their communities influence on policy and planning is dependent on government commitment to the engagement of communities in these activities (McIntyre & Gilson, 2002).

5.5 Limitations of the study

The paper documents the views of only 40 South African men and women from diverse cultural, economic and ethnic backgrounds regarding issues to consider in policy directions and service development to support their recovery. These are important views, but country-wide consultation is needed to better understand the perspectives of people with psychosocial disability on policy priorities for mental health. While the views of these 40 respondents have been incorporated into the first draft of South African's current draft mental health policy as a result of government use of evidence generated by the MhaPP, further consultation opportunities, such as public hearings, need to be available to people with psychosocial disability and their allies to facilitate their influence on policy directions over time.

5.6 Conclusion

In South Africa, as in other low and middle-income countries, mental health resources are still primarily invested in institutional care, with legislative, policy and service development based on limited expectations for satisfactory outcomes of care. The focus remains on treatment for symptom management. The findings of this study highlight the need to expand this brief to include social and economic support that will enable people with psychosocial disability to enjoy the rewards of work, family, community and civic life. Poor countries need the participation of all citizens in nation-building and can ill-afford the years lost to disability which untreated, stigmatizing mental and emotional distress brings to sufferers, their families and their communities. As South Africa engages in a review of its mental health policy, work is needed to map out a recovery-informed, inter-sectoral road map. This should include service development and funding for mental health, a reconfigured professional accreditation framework for supporting health practitioners to make a transition to recovery based work, and commitment to supporting the participation of people with psychosocial disability in policy development and practice aimed at supporting their recovery.

CHAPTER SIX

Organising for self-advocacy in mental health: Experiences from 7 African countries

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Study objective

This chapter addresses objective five which is to document *lessons from the work of peer led organisations* for people with psychosocial disability in Africa which might inform improve the participation of people with psychosocial disability to participate in mental health related policy development and implementation in South Africa.

Contributions of the authors

This aspect of the work was conceptualized and conducted outside of the MHaPP project. Given that there were existing peer led initiatives for people with psychosocial disability elsewhere in Africa, it seemed important to review and learn from their work for the South African situation, including their work in the area of policy development. Sharon Kleintjes conceptualised the

study and its design, and carried out all aspects of the data collection and analysis of the findings. She was the lead author on this paper. The remaining authors supervised the research and critically reviewed drafts of the article.

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Current status

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Abstract

Objectives

This paper reports on overarching strategies which supported the establishment and sustainability of 9 mental health self-help organisations in 7 African countries.

Methods

Eleven key informants were identified through snowballing and interviewed regarding their experience in the organisations. Thematic analysis of the interview data and other documentary evidence was guided by a coding scheme derived using a framework analysis approach to defining, categorising, mapping and interpreting textual data.

Results

Sustainability strategies include: commitment to members' advocating for their rights and rebuilding their lives within their communities; independent decision-making, peer-led membership and leadership; financial self-sufficiency, alliances with donor organisations, non-governmental organisations (NGOs), disabled people's organisations (DPOs) and ministries which support self-determination and promote control over agenda-setting and responsiveness to members' needs. Organisations' work include advocacy to destigmatise psychosocial disability and promote the protection of rights; activities to improve access to health care income generation and social support; participation in legislative and policy reform and capacity building of members.

Conclusion

Self-help organisations can provide crucial support to the recovery of people with psychosocial disability in resource-poor settings in Africa. Support of Ministries, NGOs, DPOs, development agencies and professionals can assist to build organisations' capacity for sustainable support to members' recovery.

6.1 Introduction

The World Health report 2001, *Mental Health: New Understanding, New Hope*, recommends 10 broad actions which politicians, planners, implementers and civil society should address to improve mental health and reduce the impact of mental ill-health on population well-being (WHO, 2001). The report includes the recommendation that “communities, families and consumers should be included in the development and decision-making of policies, programmes and services” (WHO, 2001). More recently, the Lancet series on global mental health posed a compelling call to action for effective public health interventions to address the burden of mental ill-health, particularly in low- and middle-income countries. The call suggests that people with psychosocial disability and their families be key advocates for the prioritisation of mental health on the agenda of politicians and government departments, be involved in developing human rights-based services, as well as contributing to direct service delivery as lay workers within community programmes (Lancet Global Mental Health Group, 2007). Others have also noted the need to develop and support self-help and mutual aid initiatives, given the potential destigmatising impact of having role-models of personal competence among people with psychosocial disability who still face significant stigma attached to their mental health status (Saraceno et al., 2007). These initiatives are particularly relevant in low- and middle-income settings, where the greatest burden of enduring and disabling conditions may be found and where care is most often limited to the already meagre resources of families and community structures (Beaglehole et al., 2008). Formal human resources for mental health are insufficient in these settings, or inaccessible, and where organised family and community support programmes are available, these have limited reach relative to service needs (Alem et al., 2008; Saxena et al., 2007).

Information on the processes, practices and structures which self-help organisations for people with psychosocial disability have developed to improve their contribution to members’ recovery in low- and middle-income settings is not readily accessible to the policy makers, implementers and practitioners they should influence. This work is reported mainly in grey literature (Barbato & Vallarino, 2010) with peer reviewed publications on the state of peer-led organisations for

people with psychosocial disability in Africa sparse at present (Katontoka, 2007; Kleintjes et al., 2010). A World Health Organisation report on resources for mental health included information on 7 African countries, Burundi, the Congo, Eritrea, Ethiopia, Nigeria, South Africa and Uganda. Peer led associations were reported in 3 of 7 countries, and family associations in 2 of 6 countries (WHO, 2009). A WHO Afro-region audit of mental health resources in Africa reports data on the number of user and family associations among member states (Lund et al., 2010c). These reports provide information on the number of these organisations in these countries, but do not report on the challenges which these organisations face in supporting their members. This paper contends that the peer -led organisations for people with psychosocial disability provide “networks of engagement” (HASCAS, 2005), through which affected people can individually and collectively participate in promoting their own recovery. This paper reports on the strategies which 9 national self-help organisations in 7 African countries have employed to engage people with psychosocial disability and their supporters in promoting the recovery of people living with psychosocial disability in an African context, and provides insights into lessons from these experiences which may strengthen the development of similar organisations promoting empowerment of people living with psychosocial difficulties elsewhere in Africa.

6.2 Methods

6.2.1 Document review

Internet searches for websites, minutes of meetings, conference proceedings, training reports, and audiovisual material was conducted to help identify organisations and potential informants, and to provide background information to augment the interview data. Informants also volunteered documents on the history and activities of the organisations.

6.2.2 Semi-structured interviews

6.2.2.1 Informants

Ten national mental health self-help organisations were identified through internet searches and snowballing. Potential informants were contacted, recruited and informed consent obtained for participation via email, fax and telephone. We were unable to recruit informants from

MindFreedom, Kenya due to telecommunication difficulties. The remaining nine organisations which participated in the study were:

MindFreedom Ghana, Ghana

Mental Health Society of Ghana (MEHSOG), Ghana

Users and Survivors of Psychiatry (USPKenya), Kenya

National Organisation of Users and Survivors of Psychiatry (NOUSPR), Rwanda

South African Mental Health Advocacy Movement (SAMHAM), South Africa

The Ubuntu Centre (Ubuntu), South Africa

Mental Health Uganda (MHU), Uganda

Mental Health User Organisation of Zambia (MHUNZA), Zambia

Tanzanian Users and Survivors of Psychiatry Organisation (TUSPO)

We interviewed 4 women and 7 men prominently involved in the leadership of these organisations, based in 7 countries, namely Ghana, Kenya, Rwanda, South Africa, Tanzania, Uganda and Zambia.

Interview schedule

We drafted a semi-structured interview schedule to guide enquiry based on a scoping of the literature on peer-led mental health advocacy organisations in developed and developing countries (Arksey & O'Malley, 2005). The interview schedule was refined based on input from a review group comprised of 3 advocates with psychosocial disability and 4 public sector mental health practitioners working in mental health policy and service development, and engaged as supporters to advocacy activities for people with psychosocial disability in South Africa. They commented on appropriateness of terminology and comprehensiveness of the issues covered. The interview schedule addresses issues such as the vision and objectives of the organisation, organisational structure, setting up and sustaining the organisation, leadership, membership, technical support and funding.

6.6.2.2 Data collection

Interviews were conducted telephonically between October 2009 and July 2011. The pace of data collection was influenced by the recruitment process. Correct contact details were not readily available. Once contacted, some respondents were selected through a process of nomination by their organisations; others requested an e-introduction by the referring respondent before granting an interview. One or more interviews of approximately 90 minutes each were conducted and recorded with respondents' permission. Lines of enquiry not included in the interview guide were followed where respondents introduced new themes relevant to the study, and respondents were interviewed until it became clear that no new information on the themes were emerging from their interviews.

6.2.2.3 Data management and analysis

Recorded interviews were transcribed verbatim, and transcripts checked for accuracy. Thematic analysis of the data was guided by the themes preset in the interview schedule, with new themes added as determined by the data (Ritchie & Spencer, 1994) using a framework analysis approach. This approach comprises 5 stages: familiarization, developing a coding frame, coding the text, charting or summarising the themes to arrive at a synthesis of the key ideas emerging under each theme, and mapping out the key themes and findings embedded in the coded and summarised data. The framework analysis approach was developed for use in applied policy research directed at obtaining information which can inform actionable recommendations (Lacey & Luff, 2001) and is therefore suited to the focus of this study.

6.2.2.4 Confidentiality

Respondents' personal details are omitted and respondent quotations delinked from their organisation.

6.2.2.5 Data verification

A draft of this report was made available to respondents to review the authors' interpretation of the data. Respondent commented by telephonic interview or email.

6.2.3 Ethics

Permission to conduct the study was obtained from the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town, South Africa.

6.3 Results

Key characteristics of the organisations are summarised in Table 6.

Table 6: National self-help organisations for people with psychosocial disability in Africa

Name	Country	Inception	NPO	Members	Coverage
MindFreedom Ghana	Ghana	2004	2005	People with psychosocial disability	Capital city
Mental Health Society of Ghana (MEHSOG)	Ghana	2002	2009	People with psychosocial disability	Capital city and northern region
Users and Survivors of Psychiatry Kenya (USPKenya)	Kenya	2007	2008	People with psychosocial disability and carers	Some districts
National Organisation of Users and Survivors of Psychiatry Rwanda (NOUSPR)	Rwanda	2007	2007	People with psychosocial disability and carers	Some districts
South African Mental Health Advocacy	South Africa	2009	No	People with psychosocial disability	Advocacy group in 8 provinces

Movement (SAMHAM)					
The Ubuntu Centre	South Africa	2007	2008	People with psychosocial disability	Capital city
Mental Health Uganda MHU)	Uganda	1999	2000	People with psychosocial disability and carers	Several districts
Mental Health User Organisation of Zambia (MHUNZA)	Zambia	1997	2001	People with psychosocial disability	Capital city and surrounds
Tanzanian Users and Survivors of Psychiatry organisation (TUSPO)	Tanzania	2004	2006	People with psychosocial disability and carers	Some districts

6.3.1 Organisational Purpose

The impetus for starting the organisations, in all countries, arose from members' experience of stigma, discrimination and social exclusion, and a desire to provide members with a "voice" to advocate for their basic human rights. Members are also provided with a support system within which they can re-build their self-confidence, skills and relationships needed for purposeful living.

Respondent (R): ...stigma brings about denial of the human race and certain ignorance of ...care givers, so we've started this to break that old traditional mindset, ...to create a

platform for our voices to be heard...we are also people, we also need services, we can also contribute...economically and socially.

6.3.2 The organisations

Mental Health Uganda (MHU) and the Mental Health Users Network of Zambia (MHUNZA) were formed more than a decade ago, with the remaining organisations established three to seven years ago. Ubuntu, South Africa, MHUNZA and the Tanzanian Users and Survivors of Psychiatry Organisation (TUSPO) were founded by charismatic leadership with firm beliefs in the need to change the unequal societal participation of their members.

R: If you want my main message, it is that people with mental illness have the right to access anything that impacts on their lives, just like any other person, irrespective of gender, age, colour, religion, vocation or any other factor that can distinguish them from any other person.

MindFreedom Ghana (MFGhana), the Mental Health Society of Ghana (MEHSOG), Users and Survivors of Psychiatry Kenya (USPKenya), the National Organisation of Users and Survivors of Psychiatry (NOUSPR) Rwanda, and MHU started with a handful of motivated people pooling their collective energy to start support groups and advocacy initiatives .

R: I gave a short paper about my family's struggle with mental health problems. ...I was not the only user ...present...two of them...when they heard me they also came and spoke with me...and together...five of us, were the founder members of this organisation.

The South African Mental Health Advocacy Movement (SAMHAM) is a project of the largest mental health nongovernmental organisation (NGO) in South Africa, the South African Federation for Mental Health (SAFMH), which provides infrastructural support, mentoring and training to the movement. SAMHAM comprises a national forum for people with psychosocial disability which draws representation from provincial forums within SAFMH-affiliated NGOs based in the 9 provinces of South Africa.

6.3.3 Membership

Members are recruited through member-driven public awareness and by word of mouth through family and community members. Service providers at mental health clinics also referred members to SAMHAM, MHU and MHUNZA. Formal membership is restricted in most organisations to people with firsthand experience of mental illness, but family members, volunteers and other supporters can participate in the work of the organisations. Respondents from MEHSOG, USPKenya, NOUSPR, TUSPO, MHU and MHUNZA noted the importance of carers' involvement to the success of their work, as the majority of members live with their families.

R: In the US and in Europe...people with disabilities...are being taken care of in maybe institutions and assisted housing...they want to be independent, not be dependent on their family, I know that. For us in Africa, the family unit is everything. Now that is why we are not able to separate from the family and the caregiver because they are an integral part of the service user's life.

6.3.4 Staffing

MHU, MEHSOG and USPKenya have paid positions for limited office and/or programmatic support. One provincial forum in SAMHAM employs a skilled person with psychosocial disability to develop and manage its forum for people with psychosocial disability. Other than these few posts, organisations rely on members' and volunteers' time for organisational work. NOUSPR described their work as follows:

R: We assess medical, we assess social, we assess the economic situation of the member and then we decide according to the assessment who is the volunteer who will be giving help...after a certain period the caregiver will take over and the volunteer will visit the home to chat over the subject.

Seven of the nine organisations have mental health professionals and technical experts on their advisory boards, as paid administrative or programme managers, or to provide technical, financial and in-kind resources.

6.3.5 Leadership and decision-making

Respondents felt that key decision-making of the organisation must be driven by its members.

R: We as service users understand our issues and needs more...service users are more at ease listening to another service user.... (Organization) is a service user movement, a service user should drive the movement....

With the exception of SAMHAM, the organisations have independent leadership and membership structures and processes for organisational decision-making. Plans and activities proposed by the leadership of SAMHAM are subject to approval and funding by the governance structures of its parent body the SAFMH, at this stage of its development.

Respondents from the remaining organisations, all of which are already registered NPOs, felt that while the involvement of people without psychosocial disability in the work of the organisations is necessary, a self-determination agenda is best supported by embedding strong peer leadership and participation into the institutional culture and operating frameworks of the organizations.

R: There's a given percentage of office bearers who must be users, but also ...a culture must be cultivated where users enjoy certain rights within the organisation.... We have been very careful with the kind of service providers and professionals we engage with...those that adhere to the ideology here, which is the user-based approach.

6.3.6 Technical support and funding

The eight organisations which are registered as independent NPOs have also benefited from encouragement, technical expertise or financial support to establish and sustain these organisations. Leaders of MFGhana and Ubuntu focus primarily on advocacy, for example, and have been mentored by the World Network of Users and Survivors of Psychiatry (WNUSP), an international organisation of (ex) users/survivors of psychiatry focusing on protecting the human

rights of people with psychosocial disability. MEHSOG, USPKenya, NOUSPR, MHU and TUSPO obtained assistance with establishing peer support activities from local and international NGOs and DPOs.

Ministries have also supported a few of the organisations. In Uganda, in 1997, the Ministry of Health's strong support for establishing a "voice" for advocacy by people with psychosocial disability led to the establishment of a longstanding alliance with an international disabled people's organisation (DPO) who has over the years provided extensive technical and financial support to the development of MHU.

R: ...our peers in (DPO's country) who are our major development partners took us for a three day visit to see exactly what they do, challenges they go through and their best practices. There is a lot we learnt from that visit and also it fostered solidarity in the user/survivor movement as we continue advocating for our inherent rights.

In Zambia, the Ministry of Health linked MHUNZA to a national NGO already funded for HIV/AIDS prevention and treatment programmes. Mental health related awareness-raising is now included in the work of this NGO. Similarly, TUSPO has the verbal support of its Ministry of Health:

R: I met a mentally ill person in the game reserve, walking alone. There are elephants there. That shocked me.... I met with the Minister of Health who was also shocked.... He gave me authority to start as a CBO, to mobilise people, to train them....

Securing independent access to operational capital was seen by all the organisations as central to support independence in developing and expanding organisational activities. Ubuntu, South Africa, having made a principled stand not to partner with organisations who are not led by disabled people, enjoys peer support from fellow DPOs internationally but struggles to secure regular funding to expand its activities in South Africa.

Registration as a NGO is a key strategy to support independent fundraising for programmatic and operational costs. Eight of the nine organisations are formally registered as non-profit organisations, and had registered within one to three years of launching their organisation.

SAMHAM in South Africa saw registration as a strategy to pursue in the future, when the organisation felt more ready for independent work.

R: ...the vision that we have as service users is to eventually establish a independent organisation so we will become a NGO on our own, clearly run by service users.... Being under a Mental Health Society, we will always be seen as a baby, you know.... I think it will create more respect and people will see that the service user movement can function independently, that service users are very capable of advocating for themselves, when we establish a NGO eventually on our own.

Donor funding has accelerated the work of some of the organisations. MHU in Uganda and MHUNZA in Zambia, established in the 1990s, have both received support to access funding by their Ministries of Health. The Ugandan ministry supported donor-funded MHU to establish contact with donors for technical and grant-based financial support. MHUNZA, with its advocacy activities coupled to another government funded project, unlike MHU, has no independent funding to support expansion of its work. MHU has gone on to secure other external grants independently. External grants have also created opportunities for strengthening the capacity of MEHSOG, MFGhana and TUSPO.

R: ...mental illness and poverty is a vicious cycle. No one will employ you when you are mentally ill. Most of the mentally ill people are self-employed.... The financial aid has given us the capacity to build up what we must build up.... None of us had the financial capacity to put up the organisation that we have today.

Respondents' appreciation of the value of technical and financial support from local, continental and international NGOs, DPOs and donors, was tempered by a need for this support to be provided in ways which support self-direction and self determination. They emphasised the importance of having control over agenda-setting and the pace of development to ensure that organisations remain sustainable and responsive to members' needs within a local context.

R: ...when an organisation is very new, suppose that you write proposals to donors, you need a track record. An organisation must be two or three years old, must have audited accounts... seeing that you are just starting out, we didn't have those qualifications. So

what has happened is that we have...done some projects together in partnership with BasicNeeds, and that has enabled us to get the experience and also the capital, because once a project is funded, that gives us the chance to get some funding ourselves, to get along with our work.

For a few organisations, conflicting agendas for development required hard decisions to maintain an independent trajectory for development. For example, founder members of Ubuntu withdrew from, and MindFreedom Ghana changed the nature of its collaboration with, organisations who had provided technical and financial support to their work, because of constraints further collaboration posed to their independence.

R: (International NGO) had some self-help groups and they wanted us to merge with them, so that it becomes one big organisation.... I realised that we don't want to get lost in that...we will work hand in hand with them...initially we were thinking if there was only one national movement, that their voices will be strong. ...later we said, no, there could be three or four organisations that is fighting for the same cause, but there are various ways in which we are doing it.

A few respondents noted that expertise and financial support were not the only reasons for building international relationships. These alliances and partnerships provide invaluable opportunities for developing networks of mutual exchange which can build knowledge and capacity for advocacy at the global level, and promote greater understanding of the contextual issues which organisations for people with psychosocial disability have to address in pursuing a global agenda of empowerment, self-direction and inclusion, inclusive of an African perspective.

R: I think links with the international community is very important because we don't only need money, we're wanting to sell our ideas to other people and by interacting with the international community, we have the chance to send our message to others, to other users and survivors and hear different perspectives.... Like here in Africa, you find that it's (the views of international organisations) not very much suiting our situation here , its not very meaningful to us, like say, people from the West are talking of people who have survived the services. In Africa we don't even access those services, it's very few who can get to those services. There are so many interesting things to address so that we

can become one global unified movement which is very relevant to the needs of all people of the world.

A few respondents noted that opportunities for exchange are also needed to advance an African agenda for development of people with psychosocial disability on this continent.

R: ...but we also need such forums here in Africa. I remember, for instance, when we were starting the Africa Decade, South Africa was able to bring several of the African countries together...to review our own situation from our own point of view as Africans....

6.3.7 Organisational activities

Common threads in the organisations' work include advocacy to destigmatise psychosocial disability and promote the protection of members' rights, activities to improve access to health care and to income generation and social support, participation in legislative and policy reform, and capacity building of members and organisations.

6.3.7.1 Advocacy

Rights protection and destigmatisation through public awareness and education is a key activity of all organisations, and is directed at changing the attitudes and practices of the general public, civil leaders, policy makers and service providers.

R: ...my hope is that mentally ill people will be treated the same way as somebody with diabetes, or hypertension, or any other condition. ...that they will be treated with respect, as a human being. That is what I basically work for.

Advocacy strategies include the development of written, audio-visual and dramatic anti-stigma and rights promotion material, mass action such as awareness raising marches, as well as monitoring media discrimination and using media for antidiscrimination work. Mental health priorities are promoted through members' representation on local, national and international forums- including broader disability structures - through which they can lobby for improved access to mental health services, housing, work, education, and basic amenities. Two

respondents reported serving as representatives on international disability initiatives informing global discussions on the interpretation and implementation of the provisions of the UNCRPD.

Members of MFGhana, USPKenya, Ubuntu, MHU and MHUNZA are also regularly involved in bringing international attention – through presentations at international meetings – to the situation of people with psychosocial disability on the African continent.

R: Let us also go beyond the medical approach.... Because that large number of people being pushed on the edge can contribute to national development, who knows? ...we are asking that we put in place some deliberate policy and programmes.... Include them in developmental programmes and see how much they can contribute. So we are also attaching mental health to development.

6.3.7.2 Legislation and policy development

Informants believe that lobbying for inclusion and improved service provision will only be effective within a supportive legal and policy framework. The rights-based provisions of the UNCRPD was mentioned by nine of the informants as the basis on which this work should be premised.

R: (respondents organisation) is key in this point in history in this country to play it's role...government has to fulfill its international obligations to which it's committed in the convention...but it has to be done with consultation.

MFGhana, MEHSOG, MHU and MHUNZA are already advocating for greater consultation of people with psychosocial disability by government in legislative, policy and service reviews.

R: ...when the (legislative review) committee was set up, they should have added some users. They didn't do that...the problem is they are used to users not being heard....the onus now is on us to find ways of penetrating to be heard and to be seen.

Ghana, Kenya, Uganda and Zambia were reviewing their mental health legislation and mental health policies at the time of the interviews, and respondents confirmed that they are either working toward or are already being consulted during these crucial developments. NOUSPR in

Rwanda currently focuses on raising awareness amongst lawmakers through personal contact with and distribution of pamphlets to parliamentarians. Both South African informants felt that consultation of people with psychosocial disability in drafting the country's most recent mental health policy (1997) and legislation (2002) was cursory. At the time of writing in March 2012, the National Ministry of Health in South Africa is in the process of hosting provincial stakeholder consultations to inform a national summit on mental health policy and legislation. The involvement of people with psychosocial disability is an explicit inclusion principle of the consultation. Ubuntu and SAMHAM have respectively been asked to chair and provide input to the session on Social Mobilisation and Advocacy at the national summit. In Kenya, having missed the revision of their national policy when newly established, USPKenya earmarked impending revisions to their constitution as a first formal contribution to influencing legislative change.

R: ...if you look out for us without hearing us, we are not very sure those laws will be representing our views. ... (lawmakers) have an important role to make sure the issues about service users are included in the Constitution with sensitivity.

TUSPO in Tanzania, with relatively recent policy (2006) and legislation (2008) in place, would like to secure support to initiate a campaign focusing on law and policy implementation.

6.3.7.3 Public health services and support

Improving access to basic mental health care is a significant focus of the organisations' work. Most of the other organisations, in addition to lobbying for improved government services, also provide members and their carers with psycho-education for symptom management, and psychosocial support. NOUSPR uses members and carer volunteers to conduct home visits, facilitate community meetings and support groups, MEHSOG, USPKenya, SANHAM, South Africa and MHU run peer- led self help groups.

R: ...we enlighten them that... it's an ordinary illness....when they come to the meeting... they meet their fellow sufferers...they become happier, they stop thinking they are the only person suffering from this illness in the family, or in the community... we advise the

parents to love them while they are taking the medication...we help them with a loan...without money and without food the medication would be difficult to eat.

Some self help groups in Rwanda and Uganda also organise group savings schemes amongst its members to fund medication for members who cannot readily access this from the public service. While there is a strong emphasis on supporting capacity for self-management of their illness, organisations were clear that this does not replace members' need for and right to access public-funded mental health services. Members need for community-accessible, affordable medication was spontaneously mentioned by nine of the eleven respondents.

6.3.7.4 Sustainable livelihoods

Sustainable income generation is a strong focus of the work of MEHSOG, USPKenya, NOUSPR, TUSPO, MHU and MHUNZA because of the strong link between poverty and mental illness experienced by their members. Respondents noted that members' ability to generate income, to build their work skills, and to enjoy the self-esteem which rewarding work can bring is often severely eroded by mental illness, particularly where they have little access to effective mental health care. Families may reject sufferers due to stigma, and the financial and emotional difficulties experienced when supporting family members with untreated mental illness. While access to basic treatment can improve members' contribution to family well-being and thereby alter negative relationships within overstretched families, people in recovery still face discrimination in securing work.

R: ...there have been times when we have been successful in lobbying for services...but when people get services then they say, ah, but now we need work , I need an income, I need to look after myself...we realized that its not only just work, but we need meaningful and sustainable livelihoods.

In some countries, members and their carers are supported to identify income -generation opportunities and to develop the skills to set up, run and fund these initiatives. Members may also set up income generating cooperatives with other members. Member funded group savings schemes (Uganda, Ghana, MEHSOG, MHU and MHUNZA) provide start up capital for income

generation projects for members as local banks will not fund projects run by people with psychosocial disability.

R: ...income generating activities is one of - it is the main broker of stigma. Because if a member is capable of running a certain business with the help of the caregiver, you find they are integrated in the home.... He feels he has a place in the home, we find the income generation helps with the recovery of the member.

Community experience of the positive contribution of these projects, and those involved in them, can slowly erode negative attitudes, as well as rebuild members' confidence to step into mainstream life, as illustrated by this account of a local farmer living with a psychosocial disability:

R: ...we have promoted him as a role model...he is doing something that is quite a feat in his condition, that is sustainable and meaningful, so it earns him respect in the community.... He has been in some government programmes looking for role model farmers, and he was picked many times within his community....

6.3.7.5 Regional collaboration and capacity development

Eight of the nine respondents noted that their organisational agendas must be responsive to broader contextual issues affecting people living with psychosocial difficulties within African settings.

R: In Africa, we have to have our own situation in perspective before we roll out our advocacy agenda, we cannot just go with what western advocacy are saying.

To provide mutual support for afro-conscious development of the movement in Africa, a regional body for mental health self-help organisations, the Pan African Network of Users and Survivors of Psychiatry (PANUSP) was launched in 2005 at a conference hosted by Mental Health Uganda, in Kampala, Uganda. The purpose of the organisation is to support the development of a regional network of peer-led organisations involved in mobilising members to participate in civil society action aimed at promoting and protecting the rights of persons living with psychosocial disability in the region.

Interviewer (I): What does PANUSP hope to achieve? R: ...you must have user groups organising everywhere, on the one level it is a continental movement, on the other, its a DPO formerly representing people with psychosocial disability on a continental level.

From 2005-2011, Mental Health Uganda provided a secretariat from its own resources for a resource-constrained PANUSP, with members communicating mainly by email, teleconferencing or using available opportunity to meet at international or continental conferences where members had been funded to contribute to proceedings as part of their advocacy work. Five of the informants also reported having members of their organisations funded to provide training, mentoring and other technical support to starting similar organisations in the region.

R: The point is, we at PANUSP have people who have now gained experience in doing this organisational building stuff, we can support and help, advise, you know...and we also agree to closely co-ordinate how we're going to take leadership of the PANUSP to address our capacity challenges.... You have the same people operating on country, global, continental level and where our energies go has been very hard, especially with no funding....

The organisation has had technical support from the Office of the African Decade on Disabilities and other prominent development organisations during this time, but had not yet been able to secure independent funding to take its agenda forward as a social movement by mid 2011, 6 years after the inaugural conference. At that time, the organisation's constitution was still in draft form. It was not yet registered as a NPO, and had no operational budget. In August 2011, leadership of the organisation applied for and was awarded its first successful grant application to fund a 6 month strategic planning and capacity development exercise. Leaders of the organisations listed in Table 6, emerging leadership from Nigeria and Malawi, and leadership of SAMHAM, which is not a PANUSP-affiliated movement, were invited to participate. Twelve organisations were hosted by its South African member, the Ubuntu Centre, in Cape Town in October 2011. The 2005 priorities were reviewed and a consolidated agenda for development set. The constitution had been reviewed by country level membership and was ratified by leadership at the meeting. To strengthen its identity as a disabled peoples' organisation which

identifies with the principles and directions embedded in the UNCRPD, the organisation took a decision to change its name to the Pan African Network of Persons with Psychosocial Disabilities (PANUSP). It was also felt that “users and survivors” does not as aptly as the new name, convey the plight of Africans living with psychosocial disability who do not have access to services and supports to promote their recovery on the continent. Participants at the meeting also drafted the Cape Town Declaration, 16 October 2011, which sets out PANUSPs’ members’ hopes and aspirations for the future as a DPO for people living with psychosocial disability in Africa. We quote three excerpts from the declaration:

“There can be no mental health without our expertise. We are the knowers and yet we remain the untapped resource in mental health care. We are the experts. We want to be listened to and to fully participate in our life decisions. We must be the masters of our life journeys.... We are deeply concerned about the extent of suffering experienced by our brothers and sisters on our vast continent. Poverty, human rights violations and psychosocial disability go hand in hand. We know that there can be no dignity where poverty exists. No medicines or sophisticated western technology can eradicate poverty and restore dignity.... We wish for a better world in which all people are treated equally, a world where human rights belong to everyone. We invite you to walk beside us. We know where we want to go.”

6.4 Discussion

This study reviewed the work of 9 self-help organisations established within the past 14 years to support the recovery of people with psychosocial disability in 7 African countries. Results support the contention that self-help initiatives can serve as valuable vehicles for participation of people with psychosocial disability in their own and others’ recovery processes (Thorncroft et al., 2008). There are several threads common to the experiences of these organisations which offer insights into what motivates and can support the work of these organisations in low-resourced settings. These are discussed under two broad themes, the value of organising and the need for alliance-building.

6.4.1 *The value of organising*

Anthony (1993) describes the process of recovery as the “development of new meaning and purpose in one’s life...beyond the catastrophic effects of mental illness”. Empowerment for recovery requires a shift in one’s belief about potential for agency, real opportunity to exercise that belief through active participation in decisions and activities, and the removal of personal and external barriers to that participation. Such empowerment is the central purpose of self-help organisations for people living with psychosocial disability (Salie, 2010), providing opportunity for active participation of members in self-identified activities directed at supporting their own and others recovery.

6.4.2 *Participation*

The organisations’ primary focus is to create new hope for recovery through the experience of self-representation, self-determination, meaningful participation and mutual support (Farkas, 2007). Organisational and personal goals are set by members, and members are supported to develop their capacity for involvement in the implementation of actions aimed at achieving these goals. Active participation of members is not merely a principled approach, but the cornerstone on which members’ confidence and abilities are rebuilt to enable satisfying participation in community life (Salie, 2010).

6.4.2.1 *Advocacy and peer-led service delivery:*

A second focus of these organisations is to harness and strengthen opportunities for active participation in desired roles in society, and the removal of barriers to participation in these roles. People with psychosocial disability still face legal exclusion from or impediments to the exercising of their civic rights (for example, to contract for marriage, property and business, to choose where to live, or to freely voice opinions) and their political rights (that is, their ability to impact on the laws and policies which govern community life). These structural impediments, combined with the disempowering impact of reduced socio-economic status, and the struggles of living with a psychosocial disability, hamper their ability as individuals to advocate for change which will enable them to work toward roles of their choice in society (Chan & Chui, 2007). Drawing on the resources of members and “empathic allies” (McDaid, 2009), and on the power

of unified action by members (Kelly, 2006) self-help organisations provide a powerful, unified platform for individuals and families affected by psychosocial disability to promote their inclusion in civic, economic and political life, including active participation in policy development. They can be vehicles for concerted lobbying and action around issues which individuals and families would otherwise not have recourse to address.

At the same time, while advocating for the acceptance of the right to inclusion of people with psychosocial disability (Kakuma et al., 2010), and working to develop regulatory frameworks which support this inclusion is necessary (Faydi et al., 2011), this is not sufficient to ensure their participation in community, political, economic and social life. Results of this study indicate that even the most basic benefits which social and regulatory discourse envision are often not available to these citizens through public services in low- and middle-income countries (Alem et al., 2008; Saxena et al., 2007). People's desire for acceptance and participation as equal family and community members may be tempered by the impact of inadequate treatment and supports on their ability to meaningfully participate in family and community life. Poor ability to contribute to their own and their family's economic and social well-being may deepen the material and relational poverty within which members live (Funk, et al., 2010). Self-help organisations in these settings therefore cannot only advocate for change, if they are to remain responsive to their members' needs. They have to extend their brief to include direct peer-led service delivery, as these organisations have done, for example, through peer support programmes (such as wellness-monitoring, counseling and psycho-education in support groups) and self-help initiatives (such as the setting up of cooperatives for treatment and income-generation) (Kayiira, 2010). Limited formal resources, a philosophy of self determination and a rootedness in *Ubuntu* - humanity through interconnectedness and solidarity with others (Murithi, 2007) - seem to simultaneously influence these organisations' reliance on their members and their families for the sustainability of the organisation. Without members' work, there may be little or no access to basic treatment and support for other members. Without access to basic care and opportunity for self-sufficiency, members are less able to contribute to the work of their organisation and the key role it plays in their own and others' recovery.

6.4.2.2 *Strength through diversity:*

Results suggest that diversity in organisational development is needed to ensure that organisations stay attuned to member priorities, and to maximise the number of people and areas of expertise available to contribute to these organisations' work. In some instances, organisations in this study have focused on an advocacy agenda with their available resources, including public awareness and policy reform, while other organisations have focused on building local structures to support members' involvement in localised self-help initiatives. The pace and focus of development should at all times be set by the organisations to ensure sustainability of their work. There is a "continuum of involvement" possible and members or organisations should dictate at which levels and in which way they wish to participate (Tritter & McCallum, 2006).

6.4.2.3 *The need for alliances*

Alliance-building has been central to support self-help organisations in this study. Results support allies adopting a development focus to the establishment and expansion of these organisations: technical and economic support must contribute to self-sufficiency over time, and increased capacity to contribute to future developments within other established, and newly emerging, self-help organisations (Basic Needs, 2009). The role of ministries, public sector workers, development agencies and NGOs, and of self-help organisations in building such capacity is briefly explored below.

Ministries

The organisations in this study see the ratification of the UNCRPD (United Nations, 2006) by their governments as key to support the work of the psychosocial disability lobby within their countries. Ratification of this Convention sets the gold standard informing these organisations' rights-based lobby for change in support of members' desire for self-determination, inclusion and direct participation. Areas emerging from these results where Ministries could support the development of these organisations include ensuring that organisations are included in existing opportunities for NGO funding, and public input to policy and service development, provision of

resources for training and skills development, as well as brokering new opportunities for financial and technical support of the organisations' work.

Public sector departments and service providers

Respondents' stories identify policy makers and implementers within the health, social security, education and skills development, employment, labour, agriculture and finance sectors as key actors whose decisions are potentially enabling – or disabling – of the recovery of people with psychosocial disability. Within these sectors, acknowledgement and responsiveness to the broader social drivers which influence recovery also presents practitioners with a transformative challenge to service development and provision (Topor et al., 2011). At local level, non-discriminatory and recovery-oriented practitioner attitudes and practices, willingness to share expertise, skills and decision-making platforms can support the achievements of the collective goals and individual aspirations of members of these organisations.

Development agencies and NGOs

These young self-help organisations are simultaneously juggling establishment of good governance structures, development of capacity to be responsive to members' needs, and the generation of funds for their mental health work, a historically underfunded area of work. (Saxena et al., 2007). Donor organisations and development agencies can support these developments by expanding their brief to include funding opportunities for mental health on the continent, including funding of self-help organisations (Faydi et al., 2011). Support is needed for the establishment of self-help organisations at country level, the establishment of good governance structures, development of capacity to be responsive to members' needs, and the generation of funds for their mental health work and for skills development to sustainably operationalise country and regional activities. Organisations reviewed in this study, for example, have developed their capacity by building alliances with more established international and regional DPOs and NGOs, before launching out independently. Results point to the fact that capacity development premised on mutual exchange and learning over time can benefit both the supporter organisation and the local self-help organisation as each is exposed to the others' innovative solutions to challenges presented by local contexts.

Mental health self-help organisations

Newly established organisations can benefit from collaborating with other self-help organisations in-country, and across the region. Mutual support and cooperation has been a key strategy for dealing with the paucity of resources in individual organisations and across the region. Members of more established organisations or with specific areas of skill have volunteered their time for the conceptualisation and operationalisation of PANUSP at regional level, and are providing training and support to recently established self-help organisations.

In Africa, self-help organisations offer their members new hope for recovery and participation in community life. Their task is monumental, their key resource the very people they have set out to serve. Active participation of members in advocacy, policy reform, provision of support in accessing health and other support services and the development of income generation opportunities, in collaboration with allies, provide crucial support to members' recovery in resource-poor Africa. Ministries, NGOs, DPOs, development agencies and service providers can provide vital support to building capacity within these initiatives in the region.

CHAPTER SEVEN

Discussion and Conclusion

7.1 Introduction

This study has addressed the question: What are the barriers and strategies to support the participation of South Africans with psychosocial disability in mental health policy development in South Africa? Policy was understood in broad terms to include national government policy documents and legislation, which are intended to address a particular social, economic or health issue.

The main objectives of the study were to:

1. To conduct a *systematic review of current literature* on barriers and strategies to support people with psychosocial disability participating in mental health policy development.
2. To describe *current support for participation* of people with psychosocial disability in mental health policy development in South Africa and to suggest strategies for improving participation.
3. To ascertain South African *stakeholders' views* on environmental barriers to the participation of people with psychosocial disability in mental health policy development in South Africa.
4. To document the views of South Africans with psychosocial disability on their *lived experience* of barriers to their recovery and to highlight the implications of these barriers for priorities for policy development.
5. To document *lessons from the work of peer led organisations* for people with psychosocial disability in Africa which might inform improving the participation of people with psychosocial disability in mental health policy development in South Africa.

6. To develop a *conceptual framework* for supporting South Africans with psychosocial disability to participate in mental health related policy development in South Africa.

Chapters 2-6 address objectives 1-5. Chapter 7 will address objective 6. All research activities carried out to address objectives 1-5 has been used to develop the conceptual framework detailed in this chapter.

The conceptual framework was developed by adapting an approach used to develop a similar framework to strengthen the participation of people with psychosocial disability and carer involvement in the National Institute for Mental health England (NIMHE), an organisation attached to the National Health Service in the United Kingdom (HASCAS, 2005). Table 7 below outlines the HASCAS process and the process I followed to develop the conceptual framework for this study.

The conceptual framework was reviewed by 6 stakeholders including 2 people in leadership positions in organisations for people with psychosocial disability, a mental health policy maker, 2 academics who have worked as mental health practitioners in the public health sector, and a mental health NGO director. The review group is listed in Appendix 14. These reviewers were asked to consider the following questions in providing feedback on this concluding chapter:

- Does the chapter address all the relevant barriers to the participation of people with psychosocial disability in policy development, which you have encountered in our context? If not, what is missing?
- Does the conceptual framework address all the relevant strategies which need to be considered in promoting the participation of people with psychosocial disability in policy development, which you have encountered in our context? If not, what is missing?
- Do you have any other critical comments you wish to make?

Reviewers did not add or suggest removal of any of the barriers or strategies for support, but rather elaborated on some of the issues, from their own experience. Critical feedback was given on terminology that reviewers found inappropriate, and these have been edited in the final document.

Table 7: Process of development of conceptual framework

HASCAS Process to inform framework for user/carer involvement in NIMHE	Process for developing conceptual framework
<p>Literature scan to identify key issues, principles and good practice</p> <p>Reviewing NIHME strategy in relation to service user and carer involvement</p> <p>Collecting information on what users/carers are currently involved in</p> <p>Focused interviews with NIMHE stakeholders to identify difficulties and strengths in user/carer involvement/Questionnaire to programme leads in NIHME current involvement arrangements/Focus groups with users and carers to explore issues raised in the above process. Attending meetings of existing</p>	<p>Literature review to identify principles and strategies to support participation</p> <p>Assessment of legislative, policy and stakeholder support for participation via document analysis, WHO AIMS data, and SSIs</p> <p>Assessment of current participation via WHO AIMS and SSIs</p> <p>SSIs and key stakeholder interviews to explore approaches and barriers to participation in South Africa and Africa</p>

<p>NIMHE networks/Questionnaire to service users and carers on MindLink mailing list/Invitations to national organisations to comment</p> <p>Drafting of the framework with assistance of user/carer reference group and expert consultation.</p> <p>Consultation: Wide circulation of background report and framework for 2 months, and incorporation of comments to finalise framework.</p>	<p>Triangulation by researcher of all data sources to draft conceptual framework .</p> <p>Review of conceptual framework by core group of 5 stakeholders.</p>
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This final chapter is structured in the following manner:

Section 1 of the chapter summarises the barriers to policy participation identified in the study, examining how the findings in each chapter relate to each other. This provides an opportunity to triangulate the results from different data sources, namely the review of international literature, interviews with leaders of advocacy organisations for people with psychosocial disability in Africa, interviews with South African participants with psychosocial disability and South Africans who contribute to mental health policy and service development and provision for people with psychosocial disability, as well as documentary analysis of current South African mental health legislation and policy.

Section 2 of the chapter summarises the main strategies for improving participation documented in chapters 2-6. These findings are used to derive a framework to support the participation of

people with psychosocial disability in mental health related policy development in the South African context (objective 6). The framework is informed by the work of Kosciulek (2005).

Section 3 addresses the contributions of the study to existing knowledge on the participation of people with psychosocial disability in policy development.

Section 4 discusses the limitations of the research, and suggests areas for further research.

7.2 Summary of the findings of the study

7.2.1 Stakeholder support to policy participation: 1994-2012.

“There can be no mental health without our expertise. We are the knowers and yet we remain the untapped resource in mental health care” (Pan African Network of People with Psychosocial Disability² Cape Town Declaration, October 2011)

The 56 policy makers, providers and civil society members interviewed for this study indicated that they were generally in favour of the participation of people with psychosocial disability in national mental health policy development. Some felt that it was their constitutional right to participate in policy development. Others noted that they would bring a unique perspective to the policy process through their direct experience of mental and emotional distress.

Despite these stakeholders’ positive sentiments, the experience of the 40 people with psychosocial disability interviewed in this study seems to reflect the wider situation within South Africa: actual participation in policy development processes has been poor in the 18 years since the first democratic elections in South Africa. Only 5 of the 40 people with psychosocial disability interviewed in this study had participated in national policy development processes, despite most of them having potential access to information on these processes through provider led NPOs from whom they receive mental health services.

² This organisation was known as the Pan African Network on Users and Survivors of Psychiatry(PANUSP) until October 2011 at which time the name was changed to the Pan African Network of People with Psychosocial Disabilities. The acronym PANUSP was retained by the group after the name change.

It was noted in the literature review that policy makers themselves may not have the knowledge of how best to include and accommodate the perspectives of people with psychosocial disability in policy consultations. This appears to have been a barrier to participation in South Africa as well. It emerged that policy makers had tried to engage this stakeholder group in the policy processes for developing the mental health policy in 1997 and the Mental Health Care Act from 2000 to 2002. However, this was limited to a few individuals known to mental health NPOs consulted during the policy development processes in 1997. During the 2000-2002 Act consultation processes, it was left to well-known NPOs, DPOs and smaller advocacy groups to include the views of people with psychosocial disability. A few of the 20 non-advocate participants with psychosocial disability were satisfied with this, preferring policy-making to be left to mental health professionals and experts, but most expressed interest in participating in these processes, either directly, or through representation by providers, or by other people with psychosocial disability. In many cases, participants did not feel they were skilled or informed enough to participate, or that decision-makers would not take their views seriously. The 20 advocate participants with psychosocial disability were all dissatisfied with the level of consultation to date.

Below I examine the policy participation barriers identified by the 96 South African participants. Their views were very similar to those that emerged from the review of the international literature, and the experience of people with psychosocial disability from other African countries. These findings are integrated with the data from South African participants in the discussion which follows.

7.2.2 Barriers to participation

“Poverty, human rights violations and psychosocial disability go hand in hand. We know there can be no dignity where poverty exists. No medicines or sophisticated Western technology can eradicate poverty and restore dignity” (Pan African Network of People with Psychosocial Disability, Cape Town Declaration, October 2011).

7.2.2.1 Structural barriers to participation

Stigma and discrimination: This study foregrounds stigma and discrimination as key contributors to the exclusion of people with psychosocial disability from policy participation. Policy makers and service providers who were interviewed for this study commented on how the pervasive negative attitudes toward people with psychosocial disability can result in their exclusion and disempowerment. The 40 participants with psychosocial disability shared personal experiences of how stigmatising attitudes resulted in discriminatory practices which violated their human rights and their desire for acceptance and respect, at times effectively excluding them from community life. These experiences concur with those highlighted by participants from other African countries, and in the literature review, which pointed to people with psychosocial disability’s experience of victimization, prejudice and exclusion.

In the literature review, we noted how stigmatizing beliefs about people with psychosocial disability has provided justification for limitations on their decision-making powers both within the mental health system, and in society in general. This extends into the policy consultation process as well, where from the literature review, we saw that their participation was not central to policy reform processes which are still dominated by professional perspectives. The review suggested that professional dominance in mental health policy-making processes is influenced by the greater weight given to their verbal and written inputs to the policy process, in representation of their interests in documentation and research to set the agenda for consultation, in resource allocations for research and delegation to these processes, and in the lack of procedural accommodation to support the participation of people with psychosocial disability. Procedural barriers to participation mentioned in the review include use of media not readily accessible to people with psychosocial disability, insufficient notice to prepare for participation, complex

reform documentation, lack of accommodation of formal settings to layperson input, and lack of funding for user participation (Church and Reville, 1990, Church 1990, Evans and McGaha, 1998, Jansen, 2006).

Articles included in the literature review observed that people with psychosocial disability may make a political decision not to participate in mental health policy making processes because of their beliefs about or experience of having no power to influence the mental health system (Church and Reville, 1990; Church, 1996; Jansen et al, 2006). This was also reflected in the interviews with South African participants. A few advocate participants noted that users may choose to stay out of the public domain due to their experience of being discriminated against once they reveal that they have experienced mental or emotional distress and have used mental health care services. Other participants, across stakeholder groups, echoed their concern about the impact of stigma on their participation in civic life, ascribing their lack of involvement in policy making as partly due to lack of recognition and acceptance of people with psychosocial disability as legitimate partners in the policy process by policy makers, practitioners, civil society and people with psychosocial disability themselves. In the review, we noted that Church (1996) identified policy participation by people with psychosocial disability as an issue of “power and the redistribution of power” (page 29), of freedom of involvement in all planning and decision-making which can impact on their wellbeing.

The experience of societal stigma can impact on the stigmatized person’s internal self representations (Kakuma et al, 2010; Sorsdahl et al, 2010). South African and other African participants with psychosocial disability elaborated on their struggle to overcome the disabling impact of internalised stigma on their belief in their own abilities. These results suggest that a combination of mutually reinforcing internal (personal) and external (social) stigma can negatively impact on their confidence in self-representation of their agenda during policy-making processes (Koskiulek, 2005). Sorsdahl et al, 2010 however, in a survey of internalized stigma among 142 South Africans with psychosocial disability attending advocacy groups found that, generally, participants agreed that society views people with psychosocial difficulty negatively, but themselves reported low levels of internalized discrimination and relatively high

levels of empowerment. The authors suggest that one reason for this finding might be that participants to this study were members of an advocacy group that provided access to information, access to treatment and empowering peer support. The power of peer support and exposure to an accepting and respectful environment in countering external stigma and discrimination was demonstrated in this study as well, in some of the accounts of South Africans with psychosocial disability (chapter five) and people with psychosocial disability living elsewhere in Africa (chapter six). The results of this study indicated that some people may withdraw from engagement with society because of their experience or fear of stigma and discrimination. For others, it is the experience of their own or others exclusion that evokes a passion for and drive to advocate for change (Barnes,2008).

University of Cape Town

Poverty and social disadvantage: Current evidence demonstrates a positive association between poverty and psychosocial disability in developing countries. Not only can poverty increase the likelihood of disability, but psychosocial disability can contribute to impoverishment (Patel and Kleinman, 2003; Lund et al, 2010b). Poverty was identified as a key structural contributor to disempowerment of people with psychosocial disability in this study. The literature review highlighted the way in which people with psychosocial disability can experience difficulty accessing basic needs such as income, disability benefits and work, housing and transportation, and support for self-help (Church and Reville, 1990, Church 1998, Evans and MrGaga, 1998, Jansen, 2006). These issues were similar to those mentioned by South Africans and by informants from other African countries. South Africans with psychosocial disability felt that they were not included in government funded poverty alleviation on par with other poor people and people with physical disability, and that disability benefits were hard to secure and keep as a result of the “invisibility” of psychosocial disability. Lack of government funded or personal resources for healthcare influenced their ability to regain their health so as to contribute to their own and family economic wellbeing. Results indicated that South Africans with psychosocial disability living in poor communities have little time, energy or opportunity to participate in policy development as they focus on meeting their own and their family’s basic needs. Previously economically stable participants with psychosocial disability also spoke of reduced economic security, and the impact that lack of resources has on their advocacy work.

The literature review reported significant influence of poverty and social disadvantage on the participation of people with psychosocial disability in reform processes. Commonly used media to inform potential participants were found to be relatively inaccessible to the vast majority of people with psychosocial disability who live on a meagre income or disability benefits (Evans and McGaha, 1998; Church and Reville, 1990), as is the case with the vast majority of South Africans with psychosocial disability. Poverty also excluded people from participating because lack of resources, such as money for travel and accommodation to consultation sites. African and South African participants reported similar practical impediments to their participation.

7.2.2.2 Regulatory, organisational and capacity barriers to participation

Regulatory barriers to participation: The UNCRPD recommends that people with psychosocial disability be involved in mental health policy development and service planning (UNCRPD 2006). South Africa's post-Apartheid laws and policies were found to be generally supportive of their participation in policy development. Provisions for the protection of the human rights of citizens are well established in the Constitution of the Republic of South Africa and the equality provisions of its Bill of Rights (Republic of South Africa, 1996). South Africa is also a signatory to many United Nations Conventions, most recently the UNCRPD (2006). The Mental Health Care Act, no 17 of 2002 reflects many of these rights in relation to people with psychosocial disability. The guiding principles of the White Paper on the transformation of the health services in South Africa (Department of Health, 1997) and the 1997 mental health policy guidelines acknowledge the need to engage people with psychosocial disability in service planning and evaluation. These national policies do not however, specify their engagement in the development and revision of national policies themselves, as recommended by the World Health Organisation (WHO, 2001, WHO, 2005). A small group of practitioners working in NPOs and participants with psychosocial disability felt that South Africa's mental health legislation and policies are too treatment focused. While in principle supportive of their participation in service planning, these policies do not go far enough in their actual provisions to embed their participation in these processes, and in the overarching national policies from which the mental health service system is derived.

Limited organised representation in policy development processes: The WHO (2008) notes that interest groups and advocacy organisations have been found to have potential to influence the direction of social and health policies. South African policy makers reported difficulty engaging people with psychosocial difficulties to participate in policy processes. Stakeholders felt that participation in policy development would be made easier if there were representative organisations of people with psychosocial disability whom government can include as part of their consultations with civil society. This is in keeping with the findings of the literature review, where the organization of people with psychosocial disability to sustainably represent

their own interests in policy processes was a strong recommendation (Church, 1998; Evans and McGaha, 1998; Jansen et al, 2006, Chan and Chui, 2007). The review highlighted the differences between the interests which policy makers, providers, and people with psychosocial disability may view as core considerations on a policy development agenda. Peer based initiatives were felt to be essential vehicles through which people with psychosocial disability can develop their own agenda for change to represent their policy priorities. It was also considered an avenue through which socially and economically disadvantaged people might benefit from the power of the collective to represent their otherwise marginalized views (Evans and McGaha, 1998; Jansen, 2006, Chan and Chui, 2007). These views were substantiated by the experiences shared by informants from peer-based organisations elsewhere in Africa, and are of particular relevance in the South African context, given the nature of the barriers to participation noted earlier. Results indicate very limited formal organization of people with psychosocial disability. At this point in time, most of the policy related participation of people with psychosocial disability stems from facilitated engagement of well-known advocates through mental health NPOs. Leaders of peer led DPOs or advocacy groups also tend to be the ones invited to consultations. A limitation to organizational representation which the literature review raised is that organisations do not necessarily allow representation of people who live in areas distant from the centre of organization or who are otherwise hard to reach. This was a problem articulated by advocacy organisations, where resource constraints limited their reach, especially into rural areas (Church, 1990; Jansen, 2006).

Capacity for policy participation: A few advocates expressed a desire to develop capacity for policy participation through skills training. Other experienced advocates noted that while skills training would be helpful, the lack thereof should not inhibit participation as they had found that exposure and experience of policy development had served to develop their capacity for this work. Finally, some participants with psychosocial disability noted issues which related to their experience of ongoing or extreme mental and emotional distress which impacted on their energy and skills for participating in policy making processes. The practical accommodations to these disability-related considerations may not be well understood for people with psychosocial disability, nor might organisations and policy consultation forums have developed the necessary

flexibility to accommodate to these issues to support the participation of people with psychosocial disability in policy development.

Interestingly, several professional stakeholders noted that they lacked the requisite skills for policy participation, and wanted to develop this, both because they are expected to have the skills to participate as professionals when invited to policy consultations, and also because it is assumed they will be able to support people with psychosocial disability to develop the skills for this kind of participation

Finally, attention is needed to address procedural barriers to participating in policy development processes. These include lack of inclusion of available organisations and forums representing people with psychosocial disability in formal stakeholder consultation lists, insufficient notice to prepare for participation, complex reform documentation, lack of accommodation of formal settings to layperson input, lack of funding mechanisms to accommodate the participation of people with psychosocial disability, and lack of emphasis on the inclusion of people as potential stakeholders in the training and work of policy makers and implementers.

7.3 A framework to support mental health policy participation by South Africans with psychosocial disability

“We wish for a better world in which all people are treated equally, a world where human rights belong to everyone. We invite you to walk beside us. We know where we want to go.” (Pan African Network of People with Psychosocial Disability, Cape Town Declaration, October 2011)

7.3.1 Mental health policy participation... and beyond.

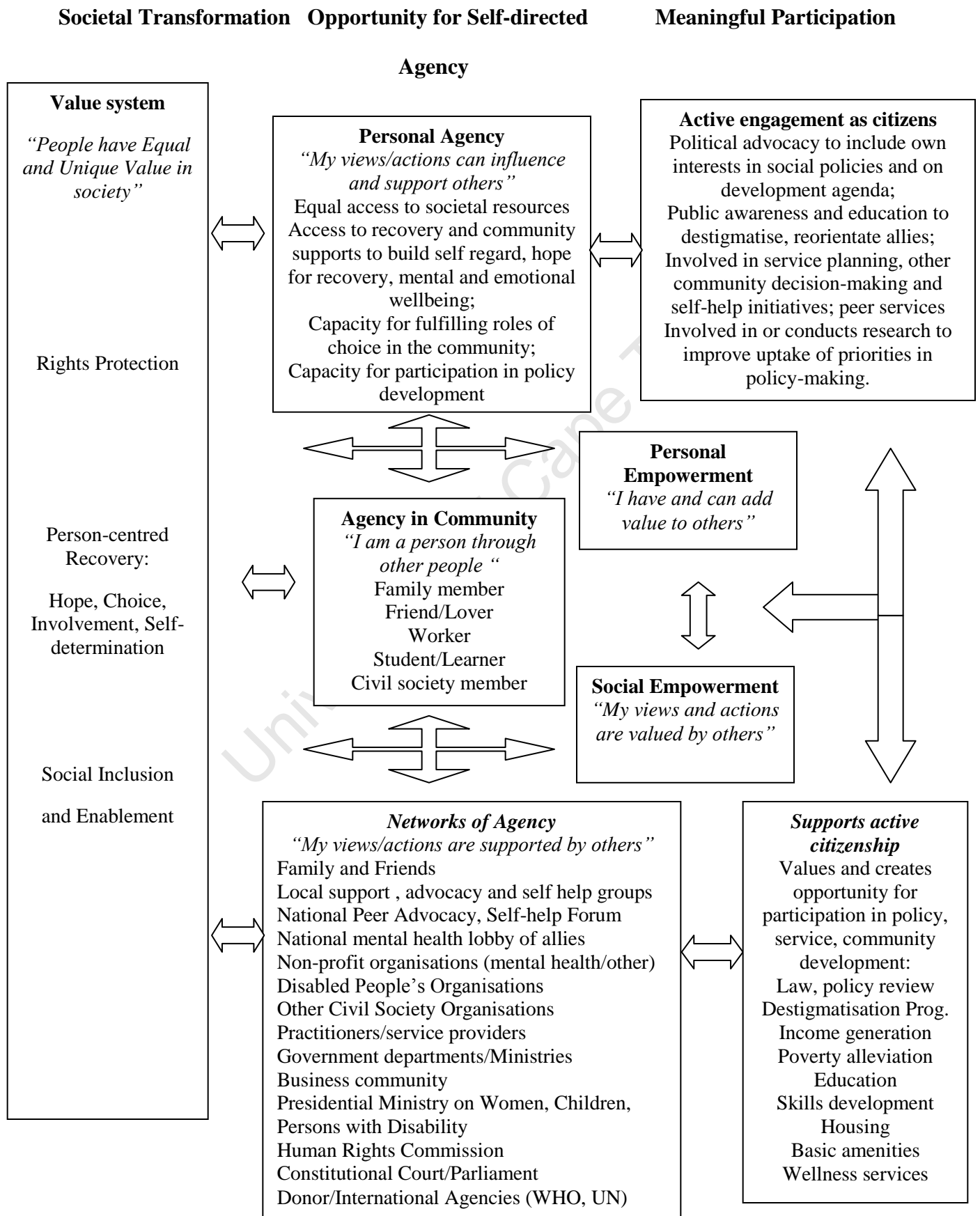
This dissertation addresses the question of how to improve the participation of people with psychosocial disability in mental health policy development. The findings of the study indicate that the mental and emotional wellbeing of people with psychosocial disability will not be met by a narrow engagement with mental health policy or practice within the mental health field (Mandiberg, 2012). The results of the study calls for a widening of perceptions about what is required to enable people with psychosocial disability to empower themselves, and to be

supported to “take back their power” as human beings, citizens, family members, service users, workers and lovers. Removal of the barriers to their wellbeing will require that they, and their allies, engage more widely in political action to address the structural impediments to their wellbeing in South Africa. There is a need to engage in social policy reform and lobby for service reform in all sectors from which stakeholders were drawn for the interviews for the study. There should be greater opportunities for people with psychosocial disability to become involved in the development of community based initiatives aimed at improving their wellbeing, and a broadening of the settings of their participation, beyond mental health service settings, to community and home, work, study and leisure, in fact, all civil society settings in which they live and wish to thrive. There is a need to challenge stigmatizing and exclusionary beliefs which people with psychosocial disability encounter in these settings, and to expand the range of stakeholders engaged in this process of transformation. Allies from all sectors should aim to work toward the removal of the barriers that people with psychosocial disability experience in taking the lead in these initiatives. The recommendations of this dissertation, made in respect of mental health policy participation, therefore, must be considered in a context that goes beyond the narrow focus of this dissertation, to the overall social environment within which people with psychosocial disability – indeed, any disability – still experience stigma and exclusion as impediments to agency and enjoyment of a meaningful life.

7.3.2 Improving policy participation for South Africans with psychosocial disability

Against this background, I turn to a description of a framework for improving policy participation of people with psychosocial disability in South Africa. The framework is derived from strategies recommended for improving their participation in Chapters 2-6. The framework is also informed by the work of John Kosciulek (Kosciulek, 1999; Kosciulek, 2005). The key elements of the framework are depicted in Figure 3 and discussed below.

Figure 3: Framework of Personal and Environmental Supports to participation in policy development



The framework comprises three aspects: social transformation, opportunity for self-directed agency, and opportunity for meaningful participation, which are in the service of empowerment of people with psychosocial disability. I discuss the concept of empowerment first, then move from left to right in Figure 3, to describe the remaining elements which make up each of the three aspects of the framework, and how they are related to each other.

7.3.2.1 Empowerment

This study identifies empowerment of people with psychosocial disability as essential to their participation in social action such as policy participation. In Kosciulek's Consumer Directed Theory of Empowerment (CDTE), empowerment involves both an internal/psychological element and a situational/social element (1999, 2005).

Internal/psychological empowerment hinges on the person's internal sense of "control, competence, confidence, responsibility, participation, solidarity, and community" and includes "flexibility, initiative, and future orientation" (page 202). Values, attitudes and beliefs based on these concepts influence self-perceptions regarding power for action in a chosen sphere, in this instance, power to participate in policy development (Kosciulek, 1999).

Kosciulek describes the social aspects of empowerment as including the person's actual "control over resources; interpersonal, work, and organizational skills; decision-making powers; self-sufficiency; mobility; and ability to 'get around' in society", as well as "living conditions, increased status, financial and social support, autonomy, information, and income" (page 202) issues raised by participants in this study as well. His model postulates that resource control enables people with disabilities to shape, direct, improve, adapt to and develop networks which can improve their life circumstances (Kosciulek, 1999). While personal and societal resources are necessary to support agency in the world, the findings of the current study suggest that it has not and will not be sufficient to ensure that people with psychosocial disability are able to exercise power within their daily lives and within in broader society. A central issue not explicated by Kosciulek's model, and added in this framework is the contention that it is people and their social structures –who have power to bequeath power to one another within the social

context. It is the societal values-and the structural evidence of those values in society- which impact on ability to benefit from opportunity on par with others in society. I elaborate below.

7.3.2.2 Transformation of social values

In Figure 3, the *Value system* element captures the point that recommendations made to improve policy participation are themselves embedded within the very socio-economic framework which gives rise to barriers to active citizenship (Chan and Chui, 2007; Spandler & Calton, 2009). The results have highlighted this in the literature review, and in description of the experiences of people with psychosocial disability interviewed in the study. To break down these participation barriers, fundamental changes are needed to the value system which underpins the overall social system within which these structural barriers exist (Kosciulek, 1999, Masterson and Owen 2006). “The ‘value system’” element contains three related perspectives which emerge from the findings, and on which work directed toward the social transformation needed to empower people with psychosocial disability should be premised.

The first is a human rights perspective. This perspective asserts that the inalienable rights of people with psychosocial disability have been historically and systematically eroded by social policy and practice that permits the violations of these human rights (Gable & Gostin, 2008). Participants felt that the fact that South Africa’s constitutional framework is already rights-based and disability orientated provides an existing base from which to lobby for expansion of mental health legislation and policy to address the broader empowerment needs of people with psychosocial disability as set out in the UNCRPD.

In the African context, the philosophy of Ubuntu mentioned in chapter 6 holds that people experience their humanity through their interconnectedness and solidarity with others (Murithi, 2007). The key tenet of this philosophy is best captured by the Xhosa phrase , “Umntu nguntu ngabantu” which has been translated as “A person is a person because of other people”.

Empowerment is understood in this framework to be a reciprocal process (Mji et al, 2011).

Personal and social empowerment are linked in Figure 3 to indicate the bidirectional nature of becoming empowered. Empowerment is a state of mind and being, a person’s belief in their

intrinsic value as a human being, and in their ability to contribute to their own and others' wellbeing (personal empowerment). At the same time, a person is embedded in social conditions within which his or her intrinsic value is recognised, respected and supported by others in the world (social empowerment). This understanding of empowerment is in keeping with some participants' view that interventions to improve the position of people with psychosocial disability in South Africa should depart from an understanding that the person's wellbeing and actions is embedded in a family and community context (chapters 4, 5 and 6).

This links to the second perspective, that of social inclusion. The historical exclusion of people with psychosocial disability from participation in mainstream society is a central theme which emerged in all chapters of the thesis. Social exclusion relates to the lived experience of people with psychosocial disability as an outcome of the violation of their human rights. In the context of this current framework, it is the erosion of the life-affirming link between personal and social empowerment, a disavowal of the belief that *people have equal and unique value* by the social networks to which people should belong and within which they need to assert their personal and social power. Social inclusion can therefore be considered the life-blood of empowerment. In this study, South Africans with psychosocial disability indicated in chapter 5 what societal level actions they felt are necessary for their social inclusion and empowerment. The activities of the 9 advocacy organisations in Africa are also directed at promoting social inclusion to support the empowerment of their members.

The third is a recovery-based approach. Masterson and Owen (2006) note that the recovery approach provides an alternative, empowering discourse on mental and emotional distress to the more prevalent stigmatizing, prescriptive and disempowering illness discourse of the bio-medical approach. The dominant view of people with psychosocial disability in this study, South Africans and other African participants, was that it was their right to expect greater access to effective and humane mental health care services from their government as a key aspect of their journey of recovery. Their dissatisfaction lay in the fact that mental health care was often the only support service they could access, was insufficient to their needs, and was separated from supports to enable the meeting of other, equally important human needs. Recovery oriented practice, a new perspective in the South African context, provides the principles and tools of

practice to facilitate an attitudinal, professional, institutional and policy shift. This requires a change from symptom management of mental and emotional distress to a comprehensive response to supporting the efforts of people with psychosocial disability to have agency in valued life roles such as that of citizen, family member, neighbour, friend, lover, co-worker and learner (Kosciulek, 1999; Davidson & White, 2007). This approach acknowledges that the person with the psychosocial disability should be at the heart of all activities related to or affecting his or her journey of recovery (Deegan, 1998). Mental health policy development is one such activity. The recovery approach illustrates the personal-social empowerment link described above as it involves a power-sharing collaboration between the person with psychosocial disability who brings expertise by experience to the encounter, and service providers who bring professional knowledge (and possibly expertise by experience) to the work (Borg & Kristiansen, 2004, Thornicroft et al, 2008). In policy development, it involves the reorientation of policy makers and practitioners from every sector to accept and reasonably accommodate the participation of people with psychosocial disability in policy development.

These interrelated perspectives provide the values base on which South Africans with psychosocial disability should argue for the inclusion of their needs and priorities in policy development. These are also the value systems that should inform the work of their allies to promote their participation. These stakeholders can play a role in moving South Africa's current narrow focus on treatment provision to one which is development-focused (Funk, et al, 2010). Treatment must be recontextualised as only one of the available supports to enable their inclusion and participation in society as a whole (Piat and Sabetti 2009). In line with the human rights and social inclusion perspectives, these role-players can support the empowerment of South Africans living with psychosocial disability through brokering interventions that will provide them with the opportunity and capacity for self-representation or supported decision-making (Minkowitz 2006), in initiatives which can bring about change to their current situation of economic and social deprivation (Burns 2009).

7.3.2.3 Opportunities for self-directed agency

Kosciulek's model suggests two key elements which facilitate the empowerment of people with disabilities. These elements are Consumer Direction and Community Integration. He defines

consumer direction as “those activities whereby consumers with disabilities develop a sense of personal control and acquire the opportunity to influence social and political systems” (Kosciulek, 1999, page 198). The concept is based on the idea that people should have control over the policies and practices that impact on their lives as they are the experts on their own needs. Consumer direction therefore is needed in disability policy and service development to promote “community integration, empowerment, and quality of life among people with disabilities” (Kosciulek, 1999, page 198). Kosciulek’s concept of Community Integration is premised on the social inclusion principle that people belong in and have a right to feel part of a community within which they can build relationships, participate in social and other interesting activities, and be productive and creative, including in civic roles such as policy development.

These two concepts within Kosciulek’s model resonate well with the literature review findings, and participants’ views on the necessity for people with psychosocial disability to be centrally involved in policy development (consumer direction), and for these policies to be in the service of enabling full participation in community life (community intergration).

In Figure 3, I expand Kosciulek’s two concepts into four elements to illustrate how they relate to the participation of people with psychosocial disability in policy development.

The *Personal Agency* element of the framework (related to Kosciulek’s Consumer Direction concept) reflects the personal power which the person with psychosocial disability needs to be able to confidently contribute to any social exchange within the community, including policy development. Most South African participants with psychosocial disability and all the informants from other African countries were clear that they wanted to have access to both medical and other social supports to enable them to find ways to enjoy their roles of choice in their communities while still living with the impact of their mental and emotional distress (Anthony, 1993).

The *Agency in Community*” element of the framework (related to Kosciulek’s Community Integration concept), reflects the areas of social engagement highlighted by the 40 people with psychosocial disability as issues which they felt contributed to their sense of empowerment. Living in and being able to participate freely in all aspects of community life is empowering.

In line with the philosophy of Ubuntu, the *Personal Agency* element is linked to the *Agency in Community* element to demonstrate that these are mutually influential: individual power for agency is embedded in community, and community power arises from the power of its collective members. Inclusion of people with psychosocial disability in social exchange can be beneficial to all citizens in their community, as voiced by participants to this study.

Linked to the *Personal Agency* element, I have introduced a new element, namely *Active Engagement as Citizens*. This new element details the key activities that emerged from the results of this research regarding the roles and activities people with psychosocial activities can play as advocates and policy participants. Box 1 summarises other political activities mentioned in the literature review which people with psychosocial disability were reported to use to influence mental health and other laws and policies.

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Box 1: Examples of political activity to influence policy directions

Protest activism:

Attending or planning a public protest meeting

Contacting political appointees, elected officials, lawmakers, policy implementers and other influential groups

Alliance building: Lobbying with social institutions to support agenda for change

Raising awareness through the mass media (radio, newspapers, television)

Dafting and circulating petitions to effect change in policies

Writing and publicizing a position paper, or other forms of written communication , such as written complaints

Civic Activism:

Representation to lawmakers/bureaucrats as individuals, advocacy groups or political parties

Presentations at public or ministerial hearings on mental health legislation or policy

Participating in government advisory committees and other structures for mental health reform

Electoral participation:

Voting for parties which best represent the interests of people with psychosocial disability

Campaigning for others' votes to support the interests of people with psychosocial disability

Contributing time and other resources to political campaigns which support interests

7.3.3.4 Networks of engagement

The literature identifies “networks of engagement”(HASCAS, 2005) as important enablers of policy participation for people with psychosocial disability in several of the chapters in this study (HASCAS, 2005). Similarly, the concept of powerful networks of agency emerged repeatedly in the literature review, and data reported in chapters 3 and chapter 6. These potential networks are made up community members in their civil society roles within the *Agency in Community* element, people who hold formal and informal positions of potential power which they can bring to bear as allies supporting the agenda of people with psychosocial disability. In the framework, therefore, *the Agency in Community* element is linked to a new element, the *Network of Agency* element. This new element lists the important allies identified in the research to support the environmental or social empowerment of people with psychosocial disability. These are the role-players in the South African community who can provide support to the participation of people with psychosocial disability in policy development. The *Supports Active Citizenship* element details key activities that these role-players can undertake to support meaningful participation in the policy process.

Over and above the actions that these role-players can effect within their designated roles and organisations, the results suggest 3 alliance-building vehicles through which people with psychosocial disability and their allies can influence policy and practice. These are included in the *Networks of Agency* element of the framework, specifically, the formation of a national lobby for mental health, strengthening collaboration with existing disability structures, and the formation of a peer-led forum for people with psychosocial disability.

Forming a national lobby to promote and protect the rights of people with psychosocial disability. The Movement for Global Mental Health was formed as an international network of people and organisations interested in working together to mobilize the political and financial commitment needed to adequately address and resource mental health concerns globally (Horton, 2007). Participants to the current study suggested that a similar national movement be formed in South Africa. Membership of this movement would be open to practitioners, researchers, mental health interest groups, and any other party interested in mobilizing political support to give priority to mental health on the policy agendas of public health and other sectors. The movement

should have people with psychosocial disability and their organisations at the centre of activities. As suggested in chapter five, advocacy should be driven by priorities identified by people with psychosocial disability, and should draw in expert allies and prominent supporters to lobby for change, with the agenda informed by a scientific base, and with a human rights focus. Through such a movement, existing advocacy efforts in South Africa could be coordinated and strengthened, with participants joining forces for a sustained national programme of action to improve the lives of people with psychosocial disability. Attention should be given by international development agencies, government NGOs and community structures to addressing the empowerment of people with psychosocial disability in South Africa.

Strengthening collaboration with disability structures: A recent WHO report reaffirms that future action to transform country level legislation and policies which impact on Disabled People must include prominent representation of people with psychosocial disability in policy development (WHO, 2011). In South Africa, Disabled People South Africa has been a strong force for change in building a democratic South Africa (DPSA, 2000). The results of this research suggest a need to improve the current meagre representation of people with psychosocial disability within the broader disability sector's engagement with policy development.

Formation of a peer-led forum for people with psychosocial disability: Within DPSA there is separate representation of various interest groups, each with its own national, provincial and local structures, for example, Association for the Blind or DEAFSA.

The formation of such an organization for people with psychosocial disability is a strong recommendation emerging from the results. Participants suggested the development of such a country-wide forum can provide people with psychosocial disability with an organization through which to provide representative input to opportunities for dialogue regarding policy and service development. At the inception of work on this study in 2006, there were no national organisations of people with psychosocial disability in South Africa. Since 2007 there have been important developments that have changed this situation.

Firstly The Ubuntu Centre, based in Cape Town registered as a DPO in 2007. The organisation is a member of PANUSP. This organization was formed to provide South Africans with psychosocial disability with a platform for an independent representative voice, opportunity for self-help, and to challenge cultural constructions of “mental illness” and abuses within the Mental Health Care System (Ubuntu, 2009). Current financial constraints pose limitations on this small organisation’s ability to fully realise its national mandate.

Secondly, the South African Mental Health Advocacy Movement (SAMHAM) a nation-wide organization of people with psychosocial disabilities, was formed, with the assistance of the South African Federation for Mental Health (SAFMH). To date however, membership of this organization is primarily drawn from clients of the 17 mental health societies of the SAFMH. Leadership of SAMHAM have expressed a desire to expand membership beyond the SAFMH and to register as an independent DPO, but resource constraints have to date has precluded such an initiative.

Several participants felt that the SAFMH could play a significant role in assisting people with psychosocial disability to form a representative forum of their peers. Others, mainly advocates with psychosocial disability were concerned that this could stymie the development of the forum as provider interests might dominate developments. They preferred support to come from DPSA or existing organisations for people with psychosocial disability. The Ubuntu Centre for example, raised funds for and organised a PANUSP regional conference in Cape Town in October 2011. Ubuntu hosted SAMHAM leadership at this meeting, even though SAMHAM is as yet not a member of PANUSP. Such collaboration can only strengthen peer-led developments in South Africa. Informants from other African countries suggested that space for multiple activities, supported by various stakeholders should be encouraged at this early stage of the development of such a forum, but that developments should ultimately support a forum or forums where decision-making is peer-led.

Organisations of people with psychosocial disability would also have a role to play in bringing to governments’ attention the likelihood that there will remain people with psychosocial disability who are not organized (Church, 1998). In South Africa, where organization of people with psychosocial disability is fairly young and with limited membership, the vast majority of rural

and urban people are hard to reach, and many people may not choose to disclose their disability in public consultation meetings. It therefore seems prudent to consider the literature review proposal that policy makers find strategies which take government enquiry to hard to reach people with psychosocial disability, as well as members of existing organisations. For example, in addition to the Ubuntu Centre and SAMHAM, there are existing national support group networks established by organisations such as the South African Depression and Anxiety Support Group (SADAG) which can be consulted through existing communication strategies. Government can also develop a database of the growing network of smaller provincial and local groups which are generally known to the mental health and community workers in a particular locality (WHO, 2001). While many South Africans will not have access to or be able to read print media, community radio is widely accessible, even in hard to reach communities (Lotter, 2007). The recent Ministerial Mental Health Summit in April 2012 was preceded by provincial consultations which informed the deliberations at the national meeting. The national meeting was attended by approximately 400 mental health-related stakeholders from all nine provinces. Funding for travel and subsistence to these 10 events was made available by the ministry, making it possible for a wide range of stakeholder groups to send representatives to the meetings, including people with psychosocial disability³. The Ubuntu Centre chaired, and SAMHAM provided a keynote address during the community mobilization session of the national summit. Financial and procedural policies of the administrative arm of government will need to be reviewed to ensure that resources are available for periodic policy consultations.

7.3.2.5 Meaningful participation: Working together for policy reform:

The final element in Kosciulek's model is Quality of Life (QOL). He asserts that a meaningful life requires that a person has control and choice within the social environment, and can assert this in the pursuit of meeting their needs and aspirations (Kosciulek, 1999). In the framework, which specifically focuses on participation in policy development as a potential aspect of a meaningful life for those who wish to engage in this kind of activity, in the stead of a general concept of QOL, I focus on two elements, that of *Active engagement as Citizens* (personal control and choice in meeting their political, social and economic needs) and *Supports Active*

³ I attended the consultation meeting in my province and served as rapporteur for the community mobilisation session at the national summit.

Citizenship (an environment which enables control and choice). *Personal Agency* and *Active engagement as Citizens* are linked to actualize personal empowerment experienced through meaningful participation in policy development processes. Similarly, *Networks of Agency* and *Supporting active Citizenship* combine to create a supportive environment within which the person with psychosocial disability can experience the social empowerment needed to facilitate meaningful participation in policy development.

In South Africa, there are several potential opportunities for a national lobby, and a national peer-led forum of people with psychosocial disability, to influence policy development. At the political level people with psychosocial disability and their allies should more actively engage with the democratic apparatus of the state. For example, there have as yet been no public mental health hearings on the status and directions needed for improving the situation of people with psychosocial disability. Public hearings could be a platform for people with psychosocial disability and their allies to lead in lobbying for a meaningful, comprehensive agenda for policy transformation, as suggested by Church, 1996. The South African Human Rights Commission (SAHRC) is a constitutionally mandated body responsible for the protection of the rights of South African citizens. People with psychosocial disability and their allies should strengthen their engagement with the SAHRC to transform policies and practices which infringe on the human rights of people with psychosocial disability. The Government of the Republic of South Africa has a Presidential Ministry of Women, Children and Persons with Disabilities responsible for oversight of the development and implementation of government policies and programmes of action with respect to women, children and disabled people. Again, people with psychosocial disability and their allies should more actively engage with this body to push for their needs and priorities on government's agenda.

This advocacy will need to be supported by practical action at the implementation level. The *Supports active Citizenship* element lists some of the key areas of action where tangible assistance can be given to improving the situation of people with psychosocial disability. These include the policy priorities identified by participants with psychosocial disability in chapter 5. On the whole, participants to this study particularly emphasized actions which can support economic upliftment, for example, income generation, education, skills development, and social

security – to support recovery and overcome exclusion. The potential for drift into poverty faced by people with psychosocial disability, and the increased vulnerability to mental and emotional distress which may be experienced by chronically poor people must be addressed in the poverty reduction policies, programmes and resourcing opportunities of government departments, development agencies and civil society organisations (Lund et al., 2010b; Skeen et al., 2010). This shift is central to enable people with psychosocial disability to move from observer or consulted status in deliberations about their lives, to central, valued role-players, including within the policy development arena. Policy makers will also need to address cultural and procedural constraints to the participation of this neglected stakeholder. Policy makers should be sensitized to the influence of power inequities that impact on the influence of the “voice” of people with psychosocial disability on the consultation process. Finally, attention is needed to improve the procedural capacity of government and civil society institutions to accommodate the equitable participation of people with psychosocial disability in policy development consultations.

7.4 Contributions of the study

7.4.1 Contributions to existing knowledge in the field

To my knowledge, this is the first study that examines the participation of South Africans with psychosocial disability in policy development. Specific contributions of the study are listed below.

1. The study provides a systematic literature review on the participation of people with psychosocial disability in policy-making processes. The review found that the key constraint to participation is a lack of empowerment as a result of restrictions to the rights of citizens with psychosocial disability and their social and economic marginalization within society, including marginalisation from the development of social policies that impact on their lives. The review identifies promotion of full citizenship, social and economic upliftment and prioritisation of the voices of people with psychosocial disability in policy development as key strategies to promote empowerment for policy participation.

2. The study is the first study in South Africa that gathered the opinions of a wide range of mental health stakeholders regarding the barriers to participation of people with psychosocial disability in policy development, and the strategies needed to overcome these barriers.
3. The study provides a novel exploration of the opinions of people with psychosocial disability (including advocates and non-advocates) regarding their priorities for policy development in South Africa.
4. This is the first study to closely document the organisational structure and functioning of a range of advocacy groups for people with psychosocial disability across 7 African countries. This provides insights into the work, successes and challenges of these organisations, and imparts lessons for peer-led organising and advocating for the rights of people with psychosocial disability in an African context.
5. The study's prime focus is on policy participation for people with psychosocial disability. Given the extreme degree to which people with psychosocial disability are marginalised in society, a meaningful examination of their participation in policy development cannot be divorced from the issues which policy transformation must address. The study highlights the mechanisms of their marginalisation, and strategies to bring about their full participation as citizens.
6. Triangulation of the findings from the review of the international literature on the topic, and the experiences of participants in this study, brings attention to the fact that while there are contextual differences to the experiences of people with psychosocial difficulties in an African context, their disempowerment, exclusion, and their striving for empowerment and respect for their rights, is fundamentally the same as that experienced by people with psychosocial disability elsewhere in the world.
7. Finally, the study synthesised the findings in a framework for the participation of people with psychosocial disability in policy development. This includes the social values that are required for such participation, the opportunities for self-directed agency that need to be in place and the conditions required for meaningful participation.

7.4.2 Contributions to policy and practice

The study identifies several strategies which policy makers, programme managers, practitioners and people with psychosocial disability and their support networks can implement to strengthen the participation of people with psychosocial disability in mental health policy development. Below, I highlight three tangible ways in which the knowledge generated by the study has been translated into practice thus far.

Revision of the South Africa National Mental Health policy: Results of the most recent research into the mental health situation in South Africa, conducted by the Mental Health and Poverty Project (MHaPP), in which the current study was partially embedded, were used to inform a first draft of a revised mental health policy for South Africa in late 2010. I was involved in the drafting process, and was able to include results of this study in the draft policy. As a result, the draft policy, presented for public review at the first South African National Ministerial of Health Summit on Mental Health in April 2012, is based on human rights and recovery based principles, and includes provisions for the involvement of people with psychosocial disability in all aspects of policy and service planning, and for support to the development of peer-led services.

Dissemination of findings: As noted in the introductory chapter, clients of the 17 provincial mental health societies of the South African Federation for Mental Health (SAFMH) represent other clients with psychosocial disability on the National Board of Management of the SAFMH. These board members requested support of the board of management for their advocacy work. A working group of these board members was formed in April 2007 to initiate this process, supported by a social worker in the national office of the SAFMH. As a fellow board member of the SAFMH, I presented the preliminary findings of this study to this group in 2009 to inform their discussions on a strategic plan for their development of a national forum, the South African Mental Health Advocacy Movement (SAMHAM, 2010). This work is at an early stage, focusing on organizing advocacy groups in each province for people with psychosocial disability who are already receiving support from the provincial mental health societies of the SAFMH.

Networking: An unplanned benefit of engaging in this work was that I met several people whom I was able to connect to each other for the benefit of building the movement in South Africa. As a board member of the SAFMH, I was able to suggest that leadership of SAMHAM be supported to attend a week long conference of leadership of 13 advocacy organisations for people with psychosocial disability held in Cape Town in October 2011, the bulk of which were PANUSP-affiliated. As a board member of Ubuntu, the PANUSP affiliated Cape Town based DPO who hosted the week long meeting, I was involved in a successful application for PANUSP delegates to receive scholarships to attend the second summit of the Global Movement for Mental Health. I chaired the human rights session at the Summit, and following dissatisfaction expressed by PANUSP delegates regarding the lack of representation of the voices of people with psychosocial disability in that session, I included three members of PANUSP in the panel presenting during the session. The PANUSP Cape Town Declaration, quoted in this dissertation, was read out by the newly elected chairperson of PANUSP during this session. The outgoing chairperson of PANUSP, whom I had suggested as a keynote speaker for the World Federation for Mental Health's biannual conference held in Cape Town in the same week, also presented the declaration as part of her keynote address at the congress.

7.5 Limitations of the study and recommendations for further research.

The study has several limitations that are acknowledged below.

7.5.1 *The research question*

The topic was limited to policy development because it would not have been possible to do justice to the complexity of a wider focus on policy implementation. In many senses this is an artificial distinction as policy development and implementation inform each other in a continuing cycle (Fisher et al., 2007). Nevertheless, documenting the complex process of policy implementation at national, provincial and local levels, and the multiple stakeholders involved in this process, would have been beyond the scope of this PhD.

7.5.2 Qualitative research methodology

The study was embedded in a larger study that utilised a policy analysis framework for conducting the qualitative data collection and analysis (Flisher et al, 2007). While this methodology was felt to be appropriate for the current study, the area is a relative new field of enquiry, and it might have been useful to use a grounded theory approach to data collection to ensure that as comprehensive as possible range of issues related to the topic was raised.

Sample: The research findings are based on a very limited sample. The study focussed on adults with psychosocial disability, excluding children and adolescents, people with intellectual disability, and people living with addiction, narrowing the range of perspectives tapped from the broader recovery community. Further, although a few South African participants with psychosocial disability had used and commented on the private sector, the main focus was on the public sector response to people with psychosocial disability. Although interviews were conducted to saturation with the available sample of people, a wider range of participants may have raised new issues not dealt with in this study. The results of the study may therefore not be representative of the views of South Africans in general, including South Africans living with psychosocial disability.

Instrumentation: The structured nature of the interview schedules may have influenced the similarity of categories of findings across the stakeholder groups. On the other hand, my familiarity with the schedules did allow me to let the participants take the lead in exploring areas of enquiry spontaneously, which they did, with further enquiry from me focusing on areas not addressed by the respondent, as the interview unfolded. It is noteworthy, also that the literature review, conducted using a different methodology and data source, still yielded findings which were congruent with the findings of the semi-structured interviews.

7.5.3 The literature review

Only articles published in English peer reviewed journals were included in the review. Non-peer reviewed work available from websites hosted by peer organisations of people with psychosocial disability, conference proceedings, work published in books, and unpublished reports were not

consulted in the review, potentially severely limiting the range of views which could be accessed from the available data. Secondly, only 5 publications could be found which met the criteria for inclusion in the study, again a limited range of data from which to draw conclusions. A further significant limitation of the literature review is that the meta-synthesis of qualitative data was only conducted by me due to funding constraints, and my subjective analysis of the data might have been influenced by my involvement in the themes which emerged from the other data sources.

7.5.4 Data verification: Framework for supporting the participation of people with psychosocial disability in policy development.

The development of the framework for supporting the participation of people with psychosocial disability would have benefited from further interrogation by wider range of participants who participated in the interviews on which the framework is based. This may have yielded a stronger indication of whether the framework resonates with participants' intentions.

7.6 Further research.

Chapter 12 of the White Paper on the transformation of the health system in South Africa (1997) suggests that mental health and substance abuse should be funded as an essential national health research focus area. Mental health research remains underfunded 15 years later (WHO AIMS report, 2007), and there is no focus on research priorities to inform policy and practice to empower South Africans with psychosocial disability. The study highlights several new directions for research in the field of policy participation of people with psychosocial disability. I will mention a few which emerge prominently from the findings and discussion, which could advance knowledge and practice in this field of enquiry.

7.6.1 Addressing the limitations of this research

The limitations of the focus of this study can be addressed by expanding the enquiry to include the following areas:

- Research focused on policy implementation, particularly between national, provincial and local implementation levels to engage people with psychosocial disability in policy development and implementation.
- Obtaining the views of a wider, more representative range of South Africans living with psychosocial disability, including the views of children and adolescents, people with intellectual disability, and people living with addiction.
- Interrogating the experiences of South African participants with psychosocial disability in the private sector, to ascertain more comprehensively what the implications of that sector might be for policy priorities. One area which was not mentioned in this study, but which is included as a stakeholder in the Network of Agency in the framework to improve policy participation, for example, is the role of the business sector in strengthening the economic position of people with psychosocial disability (Mandiberg, 2012).
- An exploration of family or carer roles, in relation to advocacy by people with psychosocial disability.
- A more comprehensive review of the literature, including unpublished grey literature may provide a wider range of perspectives on the topic than was possible in the current review.

7.6.2 Intervention studies

Further research is required to evaluate interventions which might strengthen the participation of people with psychosocial disability in policy making. This study details a range of strategies to improve policy participation of people with psychosocial disability, involving a wide range of stakeholders. Intervention studies would assist to determine whether implementation of these strategies improve the participation of people with psychosocial disability in policy development, and under what conditions. Research questions suggested by the elements of the framework, for example are:

1. *Reorientation of policy makers (value system/network of agency study)*: For example, Does reorientation of policy makers and practitioners to the value system suggested in the framework result in increased policy participation of people with psychosocial disability?
2. *Capacity development for policy participation (Personal agency study)* For example, are there factors which influence people with psychosocial disability to take on the work of advocates for other people with psychosocial disability, and can they be developed in non-advocates to improve their political interest and participation in policy development?
3. *Skills development for people with psychosocial disability (Active engagement as citizens study)*: For example, Does advocacy skills training improve the work of advocates with psychosocial disability in participating in mental health policy development.
4. Direct participation in policy development (*Personal empowerment study*): For example, does participation in political activity such as policy development result in improved personal agency and a greater sense of empowerment in people with psychosocial disability?

7.6.3 Studies which assess the impact of policy participation on policy outcomes.

Further studies could also evaluate “naturally occurring” opportunities for participation, to assess whether participation results in uptake of the views of people with psychosocial disability in policies. While interventions may result in increased participation by people with psychosocial disability, participation in policy development does not necessarily result in increased uptake of the priorities of the participants in actual policy directions (McColl & Boyce, 2003). Studies included in the literature review make only cursory reference to the impact of the participation of people with psychosocial disability in policy on actual outcomes for policy directions. Similarly, participants from South African and elsewhere in Africa have had limited opportunity to participate in actual policy development initiatives. Research to evaluate the impact on their participation in actual policy development opportunities is therefore required. In South Africa, for example, the most recent policy development consultation process which occurred in April 2012 could provide a good opportunity to assess stakeholder views on the quality and effectiveness of this participation in terms of actual uptake and retention of the views of people

with psychosocial disability in the final policy product. The consultation also offers a good opportunity to interrogate the findings of this study by consulting South African stakeholders who participated in this process about barriers they experienced and suggestions for improving their participation in the actual policy consultation situation.

Finally, the framework for participation could be consulted and developed further. Studies suggested above could provide an opportunity to examine the utility of the elements included in the framework in terms of its comprehensiveness in addressing the conditions which lead to increased participation and uptake of the priorities of people with psychosocial disability in policy development. These studies could, for example provide data to assess and fine-tune the framework, in particular the aspects of “Capacity for participation in policy development” (personal agency element) and “Political advocacy to include own interests in social policies and on development agenda” (in the active engagement as citizens element).

7.7 Conclusion

Improving the participation of people with psychosocial disability in policy making will need the involvement of a range of sectors and role-players. These include the fields of health, human rights, disability, social development, as well as practitioners, policy makers, funders and academics. For some, their experience and skills are informed by their own lived experience of psychosocial disability, which they can contribute to the required systemic changes, alongside other South Africans living with psychosocial disability (Skeen et al, 2010). Internationally, some participants in mental health are already crossing these boundaries to bring different perspectives and experiences needed to shape a common ground for the inclusion of people with psychosocial disability in all areas of social engagement. Examples of collaborative practice guidelines are already available to assist stakeholders to shift their roles and practices to foreground people living with psychosocial disability in this work (BasicNeeds 2009; Davidson 2009; Deegan 2010; Herman 2010, Minkowitz 2006; Salie, 2010; Funk et al, 2010).

In South Africa, the time to commence our contribution to this work is now.

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Appendix 1: Criteria for selection and inclusion of advocate and non-advocate service users.

General Selection Criteria (All respondents)

All respondents interviewed should meet the following criteria to be interviewed:

1. Must personally have experienced one or more episodes of severe mental and emotional distress which required mental health care/support.
2. Should not be experiencing an episode of mental and emotional distress at the time of the interview.
3. Should be fully informed of the nature and purpose of the interview and assured of confidentiality of information given during the interview.
4. Must participate voluntarily (no pressure to take part) and be aware that withdrawal is possible, or rescheduling if (s)he is not able to proceed.

Selection Criteria for Advocates

In addition to criteria 1-4 above, these respondents should also have **experience in supporting people with psychosocial disability**, as demonstrated by one or more of the following:

5. Involved in advocacy (speaks or writes about issues to promote improvement of the social situation of and services for people with psychosocial disability, provides information on the rights and needs of people with psychosocial disability to people with psychosocial disability//their families/their supporters/the general public), *and/or*
6. Provides services for people with psychosocial disability (for example, organises one or more support or advocacy groups, provides educational and other support services, *and/or*

7. Heads up or has a key role in organising a national, regional or local *organisation* or movement which takes up issues on behalf of people with psychosocial disability, *and/or*
8. Provides an *expert perspective* at international, national or local consultation processes which impact on the health and well-being of people with psychosocial disability.

The assistance of the national and provincial department of health, and other national/regional mental health organisations may be sought to identify advocates/experts in the country who meet criteria 5-8. Advocates/experts may also be aware of other advocates whom the researcher could approach.

Selection Criteria for non-advocates/service users

In addition to criteria 1-4 above, these respondents should have **experience in using mental health** and other **services** to promote their recovery, **in a selected study district**.

The assistance of the local mental health service provider, who will know the local community well, can be sought to identify suitable respondents from the district who meet criteria 1-4, and who might be willing and able to provide opinions on the service and other needs of people with psychosocial disability in the study district.

Appendix 2: Informed consent form used for MHaPP interviews.

These interviews were conducted during 2006-2007 (56 purposefully selected respondents and 10 user advocates with psychosocial disability. Ethical clearance was obtained by Mental Health and Poverty Project Consortium (DFID : RPC HD6 2005 – 2010).

Informed consent agreement

Good morning/afternoon. My name is _____ from _____. We are conducting interviews with key people, like yourself, about how mental health policies are developed and implemented in South Africa. The purpose of this study is to gather information that will help us to understand the factors necessary for the development and effective implementation of appropriate mental health policy and for mental health care user involvement in developing and implementing policies. I would like your permission to talk with you today about your ideas and experiences related to mental health policies in this country.

We will use what you tell us to improve our knowledge of mental health policy development and implementation and to better understand ways in which mental health care users may want to be involved in developing and implementing these policies. I would like to tape record our conversation. Everything you say will be kept confidential. Your name will not be used in any reports of our research findings.

It is up to you if you wish to take part in the interview. It is up to you if you wish to answer any or all of my questions. The interview should take no longer than _____ minutes, but can be stopped by you at any point.

Do you have any questions about the purpose of the interview or how the interview will be conducted?

If you agree to participate in this interview, please sign two copies of this form – one for you to keep and one for me to take away with me as a record of your agreement to participate.

I agree to take part in this interview

I agree / do not agree to this interview being tape recorded (*cross out as appropriate*)

Participant's signature _____

Date _____

Interviewer's signature _____

Date _____

If you have any further queries regarding the research or issues discussed during your interview, please contact Dr _____ (*country coordinator*) at _____ (*telephone number*).

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Appendix 3: Informed consent form used for doctoral study interviews with South African respondents with psychosocial disability.

These interviews were conducted between December 2008 and September 2009: (30 additional interviews with 10 user advocates and 20 non-advocate respondents with psychosocial disability)

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Mental Health Care User Policy Participation Study

Informed Consent Form

Dear participant

Aim of the research

The main aim of this research is to gather information about whether and how mental health care users may want to be involved in developing and implementing mental health policies. A mental health care user is someone who is currently using or has in the past used services for the treatment of their mental health problems. A mental health policy is a document in which government explains how it aims in the future to improve the mental health of South Africans, and to support the recovery of people living with mental health problems.

Sharon Kleintjes from the University of Cape Town is the main researcher for this study. Professor Alan Flisher of the University of Cape Town and Professor Leslie Swartz of Stellenbosch University, South Africa, are her co-supervisors for the study.

The research is being done to build our knowledge about mental health care user involvement in policy processes so that we can offer recommendations about how to improve the involvement of those users who want to take part in policy development and implementation in South Africa. In addition, this work will form part of Sharon Kleintjes' doctoral studies at the University of Cape Town. She plans to use the findings in her research report (thesis) to the university, in articles and through presentations at conferences and meetings.

Interviews

If you agree to participate, you will be asked to share your opinions and/or experiences about the topics under discussion. Topics include opinions or experiences of mental health care services, treatment of mental health care users, participation of mental health care users in policy development, mental health care users, need for supports to recover and your views on mental health care laws and policies.

Some of the questions may be of a personal nature, but you should not feel forced to offer information about your personal experiences. You may choose to give your views on what you have found mental health care users in general think, feel or do related to the topic under discussion. During the interview it will be up to you to choose which questions you feel comfortable to answer. *The interview should take no longer than an hour and a half, and can be stopped by you at any point, if you do not wish to continue.*

Confidentiality

These interviews/meetings will be audiotaped. Everything you say will be kept confidential. That is, your identity and participation in the research project will not be made public. In addition, what you say during the interview will not be linked to you. If anything that you say during the interview is written down as a quotation, your name will be changed so that no one will know that you are the person who spoke. The names of other people mentioned in the quotation will also be changed. The audio recording will be accessible only to the research staff who are bound to protect your confidentiality. The reports that will be written about the findings of this study will not identify you.

Risks of participation

Although we, the researchers, do not think that participation in this project will be harmful, discussions in the interview may make you feel uncomfortable or upset. Should you feel this way, please feel free to bring this to the interviewer's attention so that we might discuss and agree on how best to deal with this.

Benefits of participation

There are no anticipated direct benefits of participating in the interviews for this research.

Freedom of choice to participate

The choice to participate in this research is entirely yours, and there will be no negative consequences for you from the researchers or the University of Cape Town should you choose not to participate. If you heard about this study through your local health service, you should also know that choosing not to participate will not in any way affect the services you receive, and this research is not linked in any way to the treatment you receive. Even if you do choose to take

part in the research you may choose to stop participating in the interview at any point without any problem. You may also refuse to answer specific questions.

Participant's questions

You should feel free to ask any questions about the research before deciding to participate, and during the interview. If you have any questions about the research please talk to the person who gave you this form. If you have questions at a later time you can contact Sharon Kleintjes (+27 21 685 1223) or Prof. Alan Flisher (+27 21 685 4103), University of Cape Town, Private Bag Rondebosch, 7700.

The Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town has given permission for the research to take place. If you have any concerns about the way this research is conducted please contact Prof. Mark Blockman, Chair: Research Ethics Committee, Faculty of Health Sciences, University of Cape Town, 7700, Tel. + 27 21 – 406 6338.

If you agree to take part in the individual interviews please sign this form as a record of your agreement to participate. Return the signed form to the person who gave you the form, or if your interview is telephonic, please fax the signed form back to 021 685 1223.

I, (Print own name), AGREE to take part in the individual interview for the mental health care user policy participation study. I know why I have been asked to participate and all of my questions so far have been answered. I agree to this interview/group discussion being audiotaped.

Participant's signature _____ Date _____

Appendix 4: Informed consent form used for interviews with key informants from Ghana, Kenya, South Africa, Zambia, Tanzania, Rwanda and Uganda.

These telephonic interviews were conducted between October 2009 and July 2011.

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Mental Health Care User Policy Participation Study

Informed Consent Form for Key Informants

Dear colleague

Aim of the research

My name is Sharon Kleintjes from the University of Cape Town. The main aim of this research is to gather information about whether and how mental health care users may want to be involved in developing and implementing mental health policies. A mental health care user is someone who is currently using or has in the past used services for the treatment of their mental health problems. A mental health policy is a document in which government explains how it

aims in the future to improve the mental health of the citizens of a country, and to support the recovery of people living with mental health problems.

I, Sharon Kleintjes, am the main researcher for this study. Professor Crick Lund of the University of Cape Town, South Africa and Professor Leslie Swartz of Stellenbosch University, South Africa, are my co-supervisors for the study.

The research is being done to build our knowledge about mental health care user involvement in policy processes so that we can offer recommendations about how to improve the involvement of those users who want to take part in policy development and implementation in South Africa. In addition, this work will form part of my doctoral studies at the University of Cape Town. I plan to use the findings in my research report (thesis) to the university, in articles and through presentations at conferences and meetings.

Interviews

If you agree to participate, you will be asked to share your opinions in an individual interview. The interview will be conducted in English. The focus of the interview with you will be your views and experiences with mental health care user involvement in advocacy, policy and service development and implementation in your country. Topics include priorities for user advocacy, strategies for advocating for user priorities, setting up a user organisation, overcoming barriers to participation and improving participation of mental health care users in policy development and implementation.

During the interview it will be up to you to choose which questions you feel comfortable to answer. *The interview should take no longer than an hour and a half, and can be stopped by you at any point, if you do not wish to continue.*

Confidentiality

These interviews/meetings will be audiotaped. Everything you say will be kept confidential. That is, your identity and participation in the research project will not be made public. In addition, what you say during the interview will not be linked to you. If anything that you say during the interview is written down as a quotation, your name will be changed so that no one will know that you are the person who spoke. The names of other people mentioned in the quotation will also be changed. The audio recording will be accessible only to the research staff who are bound to protect your confidentiality. The reports that will be written about the findings of this study will not identify you in any way.

Risks of participation

Although we, the researchers, do not think that participation in this project will be harmful, discussions in the interview may make you feel uncomfortable or upset. Should you feel this way, please feel free to bring this to the researcher's attention so that we might discuss and agree on how best to deal with this.

Benefits of participation

There are no anticipated direct benefits of participating in the interviews for this research.

Freedom of choice to participate

The choice to participate in this research is entirely yours, and there will be no negative consequences for you from the researchers or the University of Cape Town should you choose not to participate. Even if you do choose to take part in the research you may choose to stop

participating in the interview at any point without any problem. You may also refuse to answer specific questions and you may choose not to participate in discussions on a particular topic.

Participant’s questions

You should feel free to ask any questions about the research before deciding to participate, and during the interview.

If you have questions at a later time you can contact Sharon Kleintjes (+27 21 4045478) or Prof. Crick Lund (+27 21 685 0120), University of Cape Town, Private Bag Rondebosch, 7700.

The Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town has given permission for the research to take place. If you have any concerns about the way this research is conducted please contact Prof. Mark Blockman, Chair: Research Ethics Committee, Faculty of Health Sciences, University of Cape Town, 7700, Tel. + 27 21 – 406 6338. If you agree to take part in the individual interviews please sign this form as a record of your agreement to participate. Return the signed form before the interview, or if your interview is telephonic, please fax the signed form back to + 27 21 7628394 (this is a confidential fax number) or email it to sr.kleintjes@uct.ac.za

I, (Print own name), AGREE to take part in the individual interview for the mental health care user policy participation study. I know why I have been asked to participate and all of my questions so far have been answered. I agree to this interview/group discussion being audiotaped.

Participant’s signature _____

Date _____

Appendix 5: Rationale and process for the development of the semi-structured interview schedules for respondents with psychosocial disability.

An agenda for change can best be framed if a researcher's grasp of the core issues has been enhanced by an in-depth understanding of the issue under investigation, as experienced by participants. In this study, the attitudes, beliefs and subjective experiences of mental health care users and other stakeholders in the policy development process are a core point of departure from which to address the research question and related objectives. Experiences provide a useful base from which mental health care users and other stakeholders can meaningfully engage in the generation of ideas to improve the mental health policy development and implementation process (Mayan, 2001; Creswell, 2003).

I have assumed that users will vary in their exposure and experience with mental health service, advocacy and policy issues. The interview schedules have therefore been designed to engage participants in discussion starting with familiar and moving to less familiar topics. The interviewing process will therefore aim to elicit information from participants in 4 areas of enquiry:

- Participants' exposure to *and experience of* mental health problems (exposure/experience level enquiry).
- Participants' opinions about *what they feel helps and is most needed to support users to cope with their mental health problem and to move to optimum wellness* (opinion level enquiry).
- Participants' ideas about what is needed to help users best *participate in decisions and actions* intended to improve their mental well-being (advocacy level enquiry), and
- Participant's ideas about *what government and other organisations can do* to improve the well-being of people with mental health problems (policy level enquiry).

During each aspect of the interview, the participants will be asked to share their *personal experience*, which is best known and most familiar to the user. From this point of familiarity the participant will be asked to *provide opinions* on that aspect, which requires the user to be able to *reflect on* their personal experience and observations of others with mental health problems/involvement in advocacy to be able to offer a meaningful response. Next, participants are asked to *share ideas* about who and what can help people with mental health problems, within government, other sectors and the user movement, a level of enquiry that may be most removed from the user's actual experience and exposure, and most difficult to answer. The participant's spontaneous opinion will first be sought, and then supplemented by additional questioning (*probes*) to support the participant to provide information as fully as possible.

Each level of enquiry therefore requires more experience and exposure to a wider range of situations and contexts than the previous level. The extent to which the participant will comfortably engage with more complex levels of enquiry will depend on their experience and exposure. For service users, for example, the entry point might relate to their experience of mental illness and services for their mental health problems, while user advocates may be more comfortable responding directly to questions related to their experiences as mental health care user advocates. The interview schedules are therefore structured to support the participant by engaging in discussion of what is familiar ("experience near" responses) before expecting more complex responses ("experience distant" responses) for each new area of discussion.

The interviewer needs to track this process with the participant, to establish what level of response is possible for the participant, and encourage participants to draw on their own experience to express their views on these more difficult (unfamiliar) levels of enquiry. It should be noted that this approach is equally applicable to other participants who are less familiar with mental health issues. This study might be the first time stakeholders in non-mental health settings are asked for their views on mental health policy development and implementation.

Appendix 6: Development process for the semi-structured interview schedules for respondents with psychosocial disability

I led the drafting of the questionnaires for mental health care users as part of the drafting process (March 2006-July 2006) for all semi-structured interview schedules.

- A first draft was developed using (a) a core set of questions developed by the MHaPP research team and (b) a review of literature pertinent to user recovery and user advocacy and participation in policy development.
- The drafts were revised based on the input of a review group comprised of 3 mental health care user advocates and 4 public sector mental health practitioners working in mental health policy and service development and service provision and user advocacy support and development. Their opinion was sought regarding the appropriateness of the terminology used in the questionnaires and the comprehensiveness of the issues covered.
- The questionnaires were reviewed by the MHaPP country research teams at a research meeting in July 2006 to ensure (a) that the scope of the questionnaire covered all relevant aspects of the research questions and (b) that the terminology used was suitable for local use in each country.
- Piloting of the user advocate questionnaire: Two user advocates were interviewed using the macro level questionnaire, with the additional request that they be available after the interview to obtain feedback on the appropriateness and ease of understanding of the questions and the comprehensiveness of the questionnaire. Notes were also taken by me regarding reframed and additional questions and probes which improved the interviewing process, and the questionnaire was revised accordingly.
- Piloting of the service user questionnaire. This questionnaire was translated from English into Zulu and back translated by the district team's research assistant, a clinical psychology Masters intern who is fluent in both Zulu and English. Interviews were held with 10 service users during the situational analysis. I interviewed the micro level research officer and research assistant at the conclusion of these interviews to obtain feedback on the

questionnaire. It was noted that the district level questionnaire was lengthy, and ideally required 2 sessions with each participant, but no superfluous questions were identified by the district level officers during their interviews. Minor changes to the questionnaire were effected on the basis of this feedback.

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Appendix 7: Interview guide for district level respondents with psychosocial disability.

QUESTIONNAIRE: SERVICE USER LEVEL MENTAL HEALTH CARE USERS.

Before the interview, ensure you are familiar with the interviewer notes.

Introduction

Thank you for agreeing to take part in this interview. The aim of the discussion is twofold: firstly, to develop an understanding of how the mental health needs of people are met in your district, and secondly to explore your experiences and needs as a person who has experienced mental distress.

	QUESTION	Notes/Key words
Section 1 – Demographic Information: <i>Interviewer says: “In this section I will briefly ask you about yourself and your background.”</i>		
a.	Gender. <i>Observe and note</i>	
b.	Urban or rural context. <i>Observe and note</i>	
c.	How old are you?	
d.	What education have you obtained?	
e.	How many children and adults live with you? (<i>Note number of adults 18 years and older and number of children under 18.</i>)	

	QUESTION	Notes/Key words
f.	What income does your household have available each month? <i>(Estimate using table of income /indices relevant to each country.)</i>	
g.	Who is the main breadwinner in your home?	
h.	What is his/her main source of income?	
i.	Does anyone receive any grants? Which ones?	
j.	<i>If not above breadwinner, ask:</i> What is your own main source of income?	
k.	Does your household receive any other help with income? <i>(If yes, ask: Please describe the help you receive.)</i>	
l.	Do any others in your household have mental health problems?	
Section 2: Help seeking and Symptom Management/Treatment: <i>Interviewer says: “Thank, you. In the next section I will ask you about your health problems and services you have received for these problems.”</i>		
2.1 Mental and Physical Health Problems		
a.	Knowledge: How do people in your community know when someone has a mental health problem? <i>(Probe: traditional beliefs, indigenous health explanations, biomedical explanations, etc.)</i>	
b.	Knowledge: Can you describe your own mental health problem? <i>(Probe: traditional beliefs, indigenous health explanations, biomedical explanations, etc.)</i>	

	QUESTION	<i>Notes/Key words</i>
c.	Naming the problem: Have you ever been given a name (diagnosis) for your mental health problem? (<i>Probe: indigenous health versus biomedical explanations.</i>)	
d.	Understanding the problem: Why do you have this mental health problem, do you think? (<i>Probe for traditional beliefs, biomedical explanations, or stress-related reasons.</i>)	
e.	Duration of mental health problem: Can you tell me how many years you have had this mental health problem? (<i>Or approximation.</i>)	
f.	Onset of Problem: How old were you when your mental health problem started? (<i>Or approximation.</i>)	
g.	Help-seeking: How old were you when you first looked for help? (<i>Or approximation.</i>)	
h.	Help-seeking: Who did you go to first for help? (<i>Probe for family member, traditional healer, doctor, priest, etc. Probe whether this has helped.</i>)	
i.	Help-seeking: Who else have you gone to for help since then? (<i>Probe for family member, traditional healer, doctor, priest. Etc. Probe whether person has helped.</i>)	
j.	Gender: Has your mental health problem affected your life as a woman (<i>man</i>) in any way? (<i>If yes, explore how, if negative impact, ask if/how person has coped.</i>)	

	QUESTION	Notes/Key words
k.	Policy: What can the health services do to make it easier for you to get the help you need for your mental health problem?	
l.	Physical Health: Do you have any physical health problems? (<i>Explore: What is the problem, how long has the problem been there? Has it affected their mental health problem?</i>)	
m.	Physical Health: Have you ever had problems getting help for your (<i>mention problem</i>) because of your mental health problem? (<i>If yes, what helped you to overcome this?</i>)	
2.2. Service access and satisfaction		
a.	Utilisation: What services have you used for your mental health problem? (<i>Guide: home visits, clinic, hospital, homes, support groups, clubs crisis care, traditional healers.</i>)	
b.	Utilisation: Are there services which you have not been able to use for any reason? (<i>Probe for barriers to using service.</i>)	
<i>Interviewer says: "Thank you. I am now going to ask you about some of the services you have received for your mental health problem."</i>		
Access and affordability		
c.	How far is your clinic from your home? Is this close enough?	
d.	What are the opening hours at your clinic/ treatment centre? Is	

	QUESTION	<i>Notes/Key words</i>
	it open enough hours a week?	
e.	How long do you have to wait to be seen for treatment at your clinic? Is this satisfactory?	
f.	Is medication for your mental health problem always available?	
g.	Can you get emergency care when you need it?	
h.	Can you get hospital care for your mental health problem in your community when you need it?	
i.	Can you get counseling and support when you need it (<i>If yes, what?</i>)	
j.	Do you have the opportunity to meet with people who have similar concerns about their mental health problems? (<i>Probe if wanted, useful/not useful and how.</i>)	
k.	Can you afford to come for treatment when you need to? (<i>Guide: travel costs, taking off work, etc.</i>)	
Service conditions and safety		
l.	Is your clinic clean and comfortable?	
m.	Is the hospital service clean and comfortable?	
n.	Do you feel safe from physical and emotional harm when getting treatment?	
o.	Have you ever been forced to take treatment you did not want or did not understand?	

	QUESTION	Notes/Key words
Staffing		
p.	Do the staff at your clinic or hospital know how to give you proper treatment and support?	
q.	Do the staff speak to you in a language you can understand when you come for treatment?	
r.	Do the staff treat you with respect and dignity at all times?	
s.	Do the staff keep your personal and treatment information private?	
Information and Psycho-education		
t.	Have you been given enough information to understand your treatment and medication?	
u.	Does your family have enough information about your mental health problem and treatment to help and support you?	
Service level participation		
v.	Do you know how to make a complaint about services if you need to? (<i>Explore how. Guide: complaints procedure, mental health review board.</i>)	
w.	Are you comfortable to give your opinion about your treatment and services?	
x.	Do you feel that your opinions about your treatment and services are given attention?	

	QUESTION	Notes/Key words
y.	Gender: Treatment: As a woman (<i>man</i>), do you have any concerns related to treatment for your mental health problem?	
Section 3 – Stigma and Discrimination: <i>Interviewer says: “In the next session we will talk about the way people have treated you since you have had the mental health problem.”</i>		
a.	Attitude: What is your view about people with mental health problems? (<i>Explore: What has influenced their attitude?</i>)	
b.	Attitude: What do people in your community say about people with mental health problems? (<i>Explore attitudes and beliefs. Do they welcome people in the community or prefer them in institutions?</i>)	
c.	Attitude: Gender: How are men and women with mental health problems treated in the community, the same or differently? (<i>Explore, if different.</i>)	
d.	Attitude of user to help-seeking: How do you feel about using professional mental health care? (<i>Explore: Attitude to seeking modern and traditional care. What has influenced their attitudes? Guide: prefer to manage on own, afraid of what might happen if they sought treatment, fear of what medication might do, fear about being seen coming for treatment because of stigma.</i>)	

	QUESTION	Notes/Key words
e.	<p>Stigma as a barrier to help-seeking: Is it better for you to come for mental health care where people come for other health care, or to attend a mental health clinic away from others? (<i>Explore concerns about negative attitudes if seen going to a mental health service. Was this a barrier to coming for help earlier, more regularly? Or does integrated services promote inclusion, break down stigma?</i>)</p>	
f.	<p>Respect and dignity: Have others ever treated you with disrespect because of your mental health problem? (<i>Explore what happened, with whom, in which setting, i.e. home, clinic community, school, work, police. Ask: "How did you deal with this?"</i>)</p>	
g.	<p>Exclusion: Has anyone ever stopped you from doing things other people are allowed to do, because of your mental health problem? (<i>What happened, with whom, where (home life, community life, education, work). Ask: "How did you deal with this?"</i>)</p>	
h.	<p>Police/Legal contact: Have you ever had any contact with the law (<i>police, courts</i>) as a result of your mental health problem? Did they know you had a mental health problem? How did they treat you?</p>	

	QUESTION	Notes/Key words
i.	Protection from discrimination: What do you think must be done so that people with mental health problems can get the same respect as other people? (<i>Probe for details, i.e. in the community, by government, etc.</i>)	
Section 4 - Advocacy and Policy level Participation: <i>Interviewer says:</i> “In this next section we will look at having your say about the mental health policies of your district. Remember, a mental health policy is the government’s written promise about what it aims to do to improve the mental health of all citizens.” (<i>Check understanding before proceeding.</i>)		
a.	Awareness: Do you know of any activities in or close to your district to make people aware of mental health and how to cope with mental health problems? (<i>If yes, explore what. If no, are these needed, and what? Guide: educational material, petitions, awareness meetings, marches, campaigns, public announcements, TV, radio.</i>)	
b.	Exposure: Do you know how to keep up to date with mental health policies which affect you? (<i>Explore: Is this important to you? Are you interested in this, or not? If yes, explore what is available. Guide: web, published directory, newsletter, newspapers, gazettes, organisational network, meetings, etc.</i>)	

	QUESTION	Notes/Key words
c.	<p>Participation: Opportunities: What opportunities are there for you to have your say about mental health policies? (Guide: <i>Responses might include: service evaluations, serving on hospital boards or health committees, community or departmental meetings about (mental) health issues, support groups, lobby groups, education/information, skills training, funding, help to set up organisations, etc.</i>)</p>	
d.	<p>Participation: Organisation: Are there any people, activities or organisations in your district to help you get your needs and ideas about services and policies heard? (<i>Explore: If no, are these needed? Why? If yes, who leads these organisations? How are people with mental health problems involved? Do they help you?</i>)</p>	
e.	<p>Participation: Interest: Are you interested in having your ideas heard when government makes mental health policies which affect you? (<i>Explore why, to what extent.</i>)</p>	
f.	<p>Participation: Barriers: Are there things that hold you back from having your say about mental health policies? (<i>Probe for effect of illness on involvement, lack of confidence, lack of skills, stigma, lack of support.</i>)</p>	
g.	<p>Participation: Gender: As a woman (<i>man</i>), are there things that hold you back from having your say about mental health policies? (<i>Explore, if different.</i>)</p>	

	QUESTION	Notes/Key words
h.	<p>Participation: Policy: Is there anything that should be done so that you can have your say about mental health policies?</p> <p><i>(Probe for details. Guide: See Table C in notes for examples of government support to user participation and organization.)</i></p>	
<p>Section 5: Basic Needs of People with mental health problems: <i>Interviewer says: “In this last section, I will ask about your experiences in your home, in the community and at work. I will also ask what you think can be done to improve your life as a person with a mental health problem.”</i></p>		
<p>5.1 Housing, Employment and Education</p>		
a.	<p>Housing: What kind of home do you have? How many rooms do you have in your home? <i>(Guide: own home, with relatives, friends, government-funded home, temporary accommodation, homeless, has basic amenities such as water, electricity, sanitation. Probe: Living in home of brick, iron, other.)</i></p>	
b.	<p>Housing: Do you need any help with housing? <i>If yes, what help is needed? (Guide: family friends to share, pay for housing, subsidised housing from local services, other? If managing on own, explore personal and family strengths)</i></p>	
c.	<p>Work: Are you working at present? <i>(If not, have you ever worked?)</i> Could you describe what kind of work you do (did) and for whom you work(ed)? <i>(Guide: self-employed, formal job, informal work, sheltered employment.)</i></p>	

	QUESTION	<i>Notes/Key words</i>
d.	Work: Have you ever had problems finding work because of your mental health problem? (<i>Probe for details.</i>)	
e.	Work: Have you ever had a drop in your income because of your mental health problem? (<i>Probe for details: What happened? How did this affect your life?</i>)	
f.	Work: <i>Only ask people who have ever worked.</i> Have you ever lost your job because of your mental health problem? (<i>Probe for details.</i>)	
g.	Work: Have you had any problems getting work or a disability grant because having the one affects the other? (<i>Probe for not working for fear of losing the grant, loss of income while crossing over from a grant to work, etc.</i>)	
h.	Work: Do you need any help with work? <i>If yes, what help is needed? (Guide: help to find paid work in open labour market, sheltered employment, daytime activities, flexible work environment, flexible work hours, supportive employer, etc. If managing on own, explore personal and family strengths.)</i>	
i.	Ed/Skills: Have you had any problems with getting education because of your mental health problem? (<i>Explore: What kind of problems? Does the person feel literate and numerate enough? What further education do they need?</i>).	

	QUESTION	<i>Notes/Key words</i>
j.	Ed/Skills: Have you had any problems with learning job skills because of your mental health problem? (<i>Explore: Access problems, ability to grasp skills, etc.</i>)	
k.	Ed/Skills: Is your education and/or your skills enough to get work which pays for your needs? (<i>Explore barriers.</i>)	
l.	Ed: Do (did) you need any help with education? <i>If yes, what help is (was) needed? (Guide: finding education, on the job support, funds for study, etc. If managing on own, explore personal and family strengths.)</i>	
m.	Skills: Do (did) you need any kind of help with skills training? <i>If yes, what help is needed? (Guide: family/village to provide training, on the job training, funds for training, etc. If managing on own, explore personal and family strengths.)</i>	
5.2 Material Supports		
a.	Food: What is your situation with food for yourself and your family, compared to others in your community? (<i>Explore, if problems.</i>)	
b.	Food: Do you need any help to get enough food? (<i>If yes, what help is needed? Guide: food supply, help to prepare food, money for food, training to grow food, agricultural supplies, training, land, etc. If managing on own, explore personal/family strengths.</i>)	

	QUESTION	<i>Notes/Key words</i>
c.	Benefits: Are there any government (state) or work benefits due to you?(<i>Guide: unemployment insurance, medical boarding payment, disability grant, old age pension, care dependency grant, child support grant, child maintenance, etc.</i>)	
d.	Benefits: Do you receive all the benefits you should get? (<i>Is the person aware of what benefits are available? Do they know which ones are due to them? Do they know how to access this benefit? For participants who have to pay child maintenance, check for barriers to do so. Is anyone withholding/abusing the participant's benefits?</i>)	
e.	Benefits: Do you need any help with getting and keeping benefits? (<i>If yes, what help is needed. Guide: from family, community, local services, etc. If managing on own, explore personal and family strengths.</i>)	
f.	Money: Do you have enough money to pay for your expenses? (For example: <i>water, electricity, sanitation, rent, clothes, household supplies, school fees, etc. Guide: can pay all expenses, selected expenses only, has no money, can't manage money, etc.</i>)	

	QUESTION	<i>Notes/Key words</i>
g.	Money: Do you need any help to be able to pay for your expenses? <i>(If yes, what help is needed? Guide: funds to pay bills monitoring of payment of bills, protection from abuse of benefits by others, etc.). If managing on own, explore personal and family strengths.)</i>	
5.3 Personal and Household Routine		
a.	Self-care: Are you able to take care of your self care needs, such as <i>washing yourself, keeping tidy, changing your clothes?</i>	
b.	Self-care: Do you need any help with taking care of your daily self care routine? <i>(If yes, what help is needed? Guide: funds for supplies, skills training, reminders, day care support, regular supervision, etc. If managing on own, explore personal and family strengths.)</i>	
c.	Household chores: Are you able to take care of household chores at home, such as doing the washing, cleaning, tidying, preparing meals? <i>(Guide: manages on own or not coping, gets help, home-based care service or little assistance.)</i>	
d.	Household chores: Do you need any help with your chores at home? <i>(If yes, what help is needed? Guide: someone to teach chores, reminders to clean, wash, tidy, day service, home-based carer, oversight/regular supervision with routine. If managing on own, explore personal and family strengths.)</i>	

	QUESTION	<i>Notes/Key words</i>
e.	Transport: Do you have any problems with transport, for example to get to work, your clinic appointment and social events? (<i>Guide: has own transport, uses public transport, lifts, walks long distances. Any physical disability complicating things?</i>)	
f.	Transport: Do you need any help with transport? <i>If yes, what help? (Guide: money, lifts, government programme, subsidy, transport grant/card). If managing on own, explore personal and family strengths.)</i>	
5.4 Social Supports		
a.	Company: Do you have enough contact with other people? (<i>Guide: able to organise enough social contact, has enough friends, attends a drop in centre, day centre, community centre/group for company, lonely, isolated, no opportunities for contact.</i>)	
b.	Company: Do you need any help to meet people/have company/make friends? (<i>If yes, what help is needed? If managing on own, explore personal and family strengths.</i>)	
c.	Intimate partner: Do you have a partner? (<i>Or relationship, lover, spouse, whichever is appropriate for the participant.</i>) Is your current situation to your satisfaction or would you like it to change? (<i>Explore, if necessary.</i>)	

	QUESTION	<i>Notes/Key words</i>
d.	Intimate partner: Do (did) you need any help to start and keep a healthy relationship? <i>If yes, explore what help is (was) needed? (Guide: introductions, support, social clubs, couple counselling, social skills training, dating line/club. If managing on own, explore personal strengths.)</i>	
e.	Childcare: Do you take care of any children younger than 18 years? Whose children are these? <i>(Guide: biological, adopted, fostered child(ren), caring for child(ren) by agreement (neighbour, village council), providing day care for child(ren).)</i>	
f.	Childcare: Do you need any help with these children? <i>(If yes, what help is needed? If managing on own, explore personal and other strengths.)</i>	
g.	Impact of mental health problem: Has your mental health problem ever resulted in problems with making friends, getting a partner or caring for your children?	
h.	Social activities: Do you have sufficient rewarding things to do or places to go during the day? At night? <i>(Explore if necessary, e.g. What kind of activities are you involved in, what kind of activities would you like to have available ? Guide: sports, leisure, recreational activities, etc.)</i>	

	QUESTION	<i>Notes/Key words</i>
i.	Social activities: Do you need help with social activities? (<i>If yes, what help is needed? Guide: advice, inclusion, arrangements, state supported service development. If managing on own, explore personal strengths.</i>)	
j.	Harm to Self: Have you ever had a problem with wanting to harm yourself? (<i>When does this happen? What would help the person to prevent this from happening? What help is needed when this happens? Guide: supportive counselling, reliable emergency contact available. If managing on own, explore personal and family strengths.</i>)	
k.	Harm to Others: Have you ever had a problem with wanting to harm others? (<i>If yes, when does this happen? What would help the person to prevent this from happening? What help is needed when this happens? If managing on own, explore personal and family strengths.</i>)	
l.	Harm by Others: Have you ever had a problem with someone wanting to harm you? (<i>If yes, when does this happen? What would help the person to prevent this from happening? What help is needed when this happens? If managing on own, explore personal and family strengths.</i>)	
m.	Gender: Have you had any difficulties at home, at work or in your relationships, because you are a woman (man) with mental health problems?	
6. General		

	QUESTION	<i>Notes/Key words</i>
•	From your experience, what do you think are the main things government should do to help people with mental health problems?	
•	Are there any other comments you would like to make regarding mental health in your district?	
•	Would you like to receive information about the results of this study? What would be the best way to get information to you about the results of this study?	
•	Finally, are there any documents or readings which you think we should use to have a better understanding of the issues we have discussed today?	

Interviewer wraps up and thanks participant. Interviewer completes Interviewer notes on SSI Summary Sheet.

Appendix 8: Interview guide for advocates with psychosocial disability

SEMI-STRUCTURED INTERVIEW GUIDE FOR KEY INFORMANTS IN THE MENTAL HEALTH MOVEMENT.

	QUESTION	Notes/Key words
1.	Can you briefly introduce yourself, tell me about your background and your interest in mental health?	
A. Now I would like to ask you some questions about mental health.		
2.	What do you think is meant by “mental health” and “mental illness”? <i>(Probe for traditional beliefs, biomedical stress-related, alternative views.)</i>	
3.	Would you say that “mental health problems”, “mental illness” and “mental disability” are the same or different issues? <i>(Prompt: How would they define these issues?)</i>	
4.	How does the general public view mental illness? Have their views changed over time? <i>(Prompt: include general public, family/friends, employers etc.)</i> <i>Are there any differences between groups, for example, rural vs. urban?)</i>	

	QUESTION	Notes/Key words
5.	<p>What key services are needed to improve people's mental health?</p> <p>(Prompt: <i>Are they available? How can this be improved.</i>)</p>	
6.	<p>What key services are needed to treat mental health problems?</p> <p>(Prompt: <i>Are they available? How can this be improved.</i>)</p>	
7.	<p>Do you know of any non-medical, non Western services which are effective for the treatment of mental health problems?</p> <p>(Prompt: ask to describe.)</p>	
8.	<p>What key initiatives are needed to address stigma and discrimination toward people with mental health problems?</p> <p>(Prompt: <i>e.g. anti-stigma campaigns, support for user advocacy and organisation, user inclusion in government activities, etc.</i>)</p>	

	QUESTION	Notes/Key words
9.	<p>Are there human rights violations occurring in mental health services known to you?</p> <p>What key initiatives are needed to address these violations, if any?</p> <p>(Prompt: <i>e.g. enforced treatment, physical and emotional harm, harmful practices, etc.</i>)</p>	
<p>Interviewer says: “A mental health problem may impact heavily on a person’s ability to manage their activities of living, either temporarily or on a long term basis. Such people may benefit from policy support for the disabling effects of their mental health problem. In this section I will ask for your views on how government can support people with mental disability in their everyday lives.”</p>		
10.	<p>What is your view on the housing needs of people with mental disability?</p> <p>(Prompt: <i>What would be the role of Housing Department, NGO’s, others?</i>)</p>	
11.	<p>Should policies address the needs of people with mental disabilities to obtain enough food and basic services, such as amenities, rent, clothes, household supplies, and school fees? How?</p> <p>(Prompt: <i>What would be the role of agriculture, social services, local government, NGO’s, others?</i>)</p>	

	QUESTION	Notes/Key words
12.	<p>Are there any support needs with regard to accessing state benefits? What basic benefits are needed?</p> <p>(Prompt: <i>What would be the role of Social development, NGOs, others?</i>)</p>	
13.	<p>Are there any support needs with regard to occupation, employment and skills training for people with mental disability?</p> <p>(Prompt: <i>What would be the role of education, social development and labour, NGOs, others?</i>)</p>	
14.	<p>What reasonable accommodation is needed in the work situation for people with mental disability?</p> <p>(Prompt: <i>e.g. flexible work environment, flexible work hours, supportive employer, work place disability policy to include mental health.</i>)</p>	
15.	<p>What is to be done regarding people with mental health problems who need help managing their daily self-care and chores at home (washing, cleaning, tidying, preparing meals, etc)?</p> <p>(Prompt: <i>community based services: family support, community health worker support for supplies, skills training, day care support, regular supervision, etc.</i>)</p>	

	QUESTION	Notes/Key words
16.	<p>What can government or other role-players do to support people with mental health problems to improve their social contacts, and have access to rewarding social activities within their community?</p> <p>(Prompt: <i>community services: drop in centres, day centres, community centre/group social clubs, couple counselling, social skills training, dating line/clubs.</i>)</p>	
<p>B. Now I would like to ask you about mental health laws and policies and user influence on the development of these policies and laws.</p>		
17.	<p>Do government policies entrench the rights of people with mental health problems to the same respect, treatment and opportunities as other citizens?</p> <p>(Prompt: <i>What are the main areas of concern? How can this be improved?</i>)</p>	
18.	<p>How well do the mental health policies and laws address the needs of people living in poverty? How can the situation be improved?</p>	
19.	<p>Can people with mental health problems keep up to date with mental health laws and policies in your country?</p> <p>(Probe: <i>What is available to expose users to policy and law?</i>)</p>	

	QUESTION	Notes/Key words
20.	Do people with mental health problems influence the development of laws, policies and services affecting them? How can participation be improved?	
21.	What holds people back from influencing mental health laws, policies and services? What can be done to overcome this? (Prompt: <i>Including issues of personal and organisational capacity, lack of recognition of users.</i>)	
22.	Are there any mental health care user organisations who are involved in developing mental health laws and policies in this country? (Prompt: <i>Are they user or provider led? Is their involvement appropriate and adequate?</i>)	
23.	Is government support for the development of the mental health care user movement needed? If already available, how can this be improved? (Prompt: <i>Explore: policy, programme, financial, technical and moral support.</i>)	

	QUESTION	Notes/Key words
24.	<p>Do you know of any NGOs, community groups or patient groups who focus primarily on mental health? Are they involved in developing mental health laws and policies in this country? How can this be improved?</p> <p><i>(Prompt: Any mental health policy networks and communities? Include (mental) health and relevant non-mental health organizations. How do they operate? Is their involvement appropriate and adequate?)</i></p>	
25.	<p>Is there any thing you would want to be included in mental health laws and policies? What are these things?</p>	
26.	<p>Are there policy considerations regarding children and adolescents which should be included in mental health laws and policies?</p>	
27.	<p>Are there policy considerations regarding boys and men, and girls and women which should be included in mental health laws and policies? What are these?</p> <p><i>(Prompt: Explore gender related issues.)</i></p>	

	QUESTION	Notes/Key words
28.	<p>Are mental health laws and policies well implemented in your country?</p> <p>(Prompt: <i>If not, what are the most important reasons for this? What can be done to overcome these problems?</i>)</p>	
<p>C. Finally I would like to ask you for some more general comments.</p>		
29.	<p>Are there any final comments you would like to make about the mental health laws and policies in your country, and in particular, the role of different people and organisations in the policy-making and implementation process?</p>	
30.	<p>Do you have any reports or documents that we might find useful for this research, for example, any government instructions / statements, annual reports, and so on?</p> <p>(Prompt: <i>Only collect if the reports are new to the project.</i>)</p>	
31.	<p>Can you suggest other individuals who we need to interview?</p>	

Appendix 9: Example of an interview guide used to interview the 56 respondents from various sectors.

TOOL 2.1 SEMI-STRUCTURED INTERVIEW GUIDE FOR PROGRAMME MANAGERS AT NATIONAL LEVEL

Background to interview

The purpose of this interview is to look for information regarding perceptions of:

- The health context
- Mental health
- Public perceptions of mental health and stigma
- Mental health policy development
- Key stakeholders in mental health policy and law development
- Mental health policy implementation

This interview is important to understand how **programme managers at national level** regard mental health. Programme managers at national level are key stakeholders. They have the responsibility to provide policy advice on mental health and oversee the implementation of mental health policies and programmes.

A secondary purpose of the interview is to check and cross-validate data gathered from other sources.

Before the meeting:

- **Send the background document on research (letter and consent form). Take additional copies with you to the interview.**
- **Go through the interview guide to make sure that you are clear as to questions and their relative importance for the particular interviewee.**

- It is important to recognise that the interview may take longer than the time available (which may be shortened or interrupted); as such highlight before the interview the critical questions for this particular respondent.
- Include any relevant extra questions or probes based on information received to date from other informants or background documents.
- Remember you do not need to ask all probes for all questions. Use probes to get more information where the respondent is not answering fully or freely, if the respondent doesn't appear to understand the question (they can be used as examples) and to follow up interesting points. **Use your judgement.**

Check the IC recorder and battery to make sure they are working.

	QUESTION	INSTRUCTIONS
1.	Can you briefly introduce yourself, tell me your current position, and how long you have been in it?	
	A. I would like to ask you some general background questions.	
2.	Can you explain to me how health services are organised in this country?	
3.	What economic, political and social factors do you think affect health care delivery in this country?	
4.	What are the key challenges that fact the health system?	

	QUESTION	INSTRUCTIONS
5.	How do international factors, or international organisations, influence the health system in this country?	
6.	What types of assistance this country receives from international community?	<i>Overall level of assistance. How is the assistance changing over time</i>
	B. Now I would like to ask you some questions about mental health	
7.	How does the general public view mental illness? Have these views changed over time?	<i>Are there any differences between groups within society?</i>
8.	How important is mental health for the government compared to other health conditions? Why is that?	<i>For example - funding patterns; media coverage; mutual links with poverty</i>
9.	How important is mental health for international agencies funding health programmes? Why is that?	

	QUESTION	INSTRUCTIONS
10.	Can you tell me any government policies outside of health that have an influence on mental health?	<i>List policies mentioned.</i> <i>For example - education, social welfare, prisons, women affairs.</i>
11.	<i>For each policy mentioned:</i> How does that policy affect mental health?	
	C. Now I would like to ask you some questions about mental health laws and policies and how they are made in this country.	
12.	Is there a mental health policy? Is there a mental health law?	<i>Where is it set out (which documents)?</i> <i>When was it developed?</i>
13.	How was the mental health policy developed?	<i>Stages of policy development,</i> <i>Participatory nature,</i> <i>Use of evidence</i>

	QUESTION	INSTRUCTIONS
14.	Which organisations and individuals are involved in the processes of developing the law and policy?	<i>How are they involved?</i> <i>At what stages of policy development are they involved (policy setting, policy development, or policy implementation)</i>
15.	<i>For each organisation or individual mentioned:</i> How are they involved?	<i>Prompt</i>
16.	Do you feel the laws and the policies are adequate? How can they be improved?	<i>Ask if there are any gaps</i>
17.	How well do mental health policies and laws address wider societal issues such as poverty and stigma? How can the situation be improved?	<i>For example, anti stigma initiatives</i>
18.	How well integrated is mental health policy with other health policies?	
19.	How over time will the policy be updated?	
20.	Do you know of any NGOs, community groups who focus primarily on mental health? Are they involved in developing mental health laws and policies in the country?	<i>Is their involvement appropriate and adequate?</i>

	QUESTION	INSTRUCTIONS
21.	Are you satisfied with the way mental health policies are developed in the country? If not, how could this be improved?	
22.	Are they individuals or organisations who are not involved in the development of mental health laws and policies, but you think should be? Why are they not involved? Can you think of any practical ways in which they could better involved?	
23.	Should mental health care users be consulted in the development of mental health laws and policy? If yes, How should they be brought on board? In which way should they be involved?	
24.	Should the government provide support to people with mental health problems to influence policies which impact on mental health?	<i>What is being done already? What is still needed?</i>
	D. Now I would like to ask you about how mental health laws and policies are implemented.	
25.	What are the key challenges that face the health sector in implementing mental health policies?	
26.	Is mental health policy well implemented?	

	QUESTION	INSTRUCTIONS
27.	<p>What are the most important reasons why mental health laws/policies are not implemented effectively?</p> <p>⇒ What can be done to overcome these problems?</p>	<i>Only ask if implementation is not happening effectively</i>
28.	To what extent are mental health policies translated into plans and budgets?	<i>National, provincial, district mental health plans and budgets</i>
29.	Who are the important organisations or individuals involved in implementing mental health laws and policies	<i>List of individuals and organisations mentioned</i>
30.	<p>Are they individuals or organisations who are not involved in the implementation of mental health laws and policies, but you think should be?</p> <p>⇒ Why are they not involved></p> <p>⇒ Can you think of any practical ways in which they could better involved?</p>	
31.	E. Are there any other comments you would like to make about the mental health policies in your country, and in particular, the role of different people and organisations in the policy making process?	
32.	Do you have any reports or documents that we might find useful for this research, for example, any statements of policy and objectives, annual reports and so on?	<i>Only collect if the reports are new to the project.</i>

	QUESTION	<i>INSTRUCTIONS</i>
33.	Do you know of any meetings or other events in the near future that you think would be useful for us to attend?	

After the interview

Thank the respondent for her/his time.

Reassure the respondent that this information will be treated confidentially, and that a written report on the research will be provided once it is completed.

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Appendix 10: Semi-structured interview: Administrative information

Interviewer	
Respondent number	
Date of interview	
Sex of respondent	
Country/Province/Region	
District	
Urban or rural district	
Consent procedure completed	
Start time of interview	
End time of interview	

Interview notes

All relevant aspects of interview completed	
Number of audio files used	
File identification marks	
Files backed-up?	
<p>Observations: Sketch an overview of the interview:</p> <p>Will this interview contribute to the analysis? (Guide: Good rapport, open participant, rich and spontaneous responses, good follow-up possible with probes, views of participant clearly expressed and verified by interviewer.)</p> <p>Where there any ideas which emerged from the interview which can contribute to our</p>	

thinking? (Guide: new, contradictory, confirming ideas, trends.)

What hypotheses/trends emerged from this interview?

Any other observations?

Continue notes overleaf or on a separate sheet of paper

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Appendix 11: SSI guide for key informants from peer led organisations for people with psychosocial disability in Africa

- Vision/Aims:** What are the main reasons for the existence of the organisation/initiatives? How and why was these foci chosen? What works to keep them on track. What ways are used to revise the focus of the organisation/initiatives, if needed? How are these aims communicated to members, partners and the public? What barriers are experienced to achieving the vision and aim, and what is being done about these?
- Activities:** What are the main activities of the organisation/initiative? Are there any barriers to carrying out these activities and what is done to overcome these? What helps to support the achievement of these activities on an ongoing basis?
- Setting Up:** What pathways were followed to establish these user organisations/initiatives? Who was involved and what roles did they play? What was done? What support was needed to get started? What barriers were experienced, and what was done about these?
- Sustaining:** What pathways are followed to sustain the user organisation/initiatives? Who is involved and what activities are directed at keeping the organisation/initiatives alive? What support does the organisation/initiatives need to keep going? How is the need for change tracked and implemented? What works? What barriers are experienced, and what is being done about these?

Structure: What kind of user organisational structure is used at local, regional and national levels and how are these aspects coordinated. Are there horizontal divisions in structures at each level, what are their purpose and how are they organised? What barriers are experienced, and what is being done about these?

Members: Is/are the organisation/initiatives led by users, providers, carers, others? How is this done? How is each group involved? Why was this way of working chosen? What works, what barriers are experienced, and what is being done about these?

Partnerships: What kind of partnerships are necessary to support the organisation's/initiatives work and development? What kind of support does the organisation/initiatives provide to the work of its partners? What works for partnership-building? What barriers are experienced, and what is being done about these?

Policy Impact: How does the organisation/initiatives impact on policy related to mental health care users? What has worked? What barriers are experienced to achieving the vision and aim? What kind of partnerships are necessary to support input to policy development and implementation. What role does each partner play to support user input to policy development and implementation? What barriers are experienced in the areas of funding and what is being done about these?

Funding:

What kind of start up funding was needed, if any? What helped to obtain this funding? How is the organisation/initiatives funded now? What needs to be done to get, keep and expand funding? What barriers are experienced in the areas of funding and what is being done about these?

Technical Support:

What kind of technical support (equipment/expertise) was needed for start up, if any? What helped to obtain this support? What forms of technical support does the organisation/initiative receive now and by whom? What needs to be done to get, keep and expand technical support, if needed? What barriers are experienced in the areas of technical support and what is being done about these?

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Appendix 12: Transcriber’s confidentiality agreement

Participation of mental health care users in mental health policy development in South Africa

Dissertation Research

I

(Full Name - printed) agree to transcribe the digital recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them.

Signature

Date

Appendix 13: List of respondents

National Policy Makers	
1.	Policy Maker: Office on the Status of Disabled Persons, The Presidency
2.	Disabled Peoples Organisation: Secretariat - African Decade of the Disabled Person
3.	National Policy Maker - Health : Noncommunicable diseases
4.	National Policy Maker - Health: Senior Manager: Strategic Planning
5.	National Policy Maker - Health: Mental Health and Substance Abuse
6.	National Policy Maker - Social Development: Disability Policy
7.	National Policy Maker - Social Development: Disability Grant Administration
8.	National Policy Maker - Education: Policy for Special Needs Education
9.	National Policy Maker - Education: Safety in Schools
10	National Policy Maker - Housing Policy
11	National Policy Maker - Justice & Constitutional Development
12	National Policy Maker - Correctional Services
Provincial Managers : Health	
13	Senior Official: Department of the Province, Western Cape
14	Mental Health Coordinator: KwaZulu Natal Province
15	Mental Health Coordinator: Eastern Cape Province
16	Mental Health Coordinator: Free State Province

17	Mental Health Coordinator: Gauteng Province
18	Mental Health Coordinator: Limpopo Province
19	Mental Health Coordinator: Mpumalanga Province
20	Mental Health Coordinator: North West
21	Mental Health Coordinator: Northern Cape
22	Mental Health Coordinator: Western Cape
Psychiatric Hospital Managers	
23	Senior Official, Psychiatric hospitals, Western Cape Province
24	Principal Specialist Psychiatrist, Provincial Psychiatric Hospital , Kwa Zulu Natal
Managers, nongovernmental mental health organisations	
25	Senior Official: Cape Mental Health Society
26	Senior Official: Durban Coastal Mental Health
27	Senior Official: Gauteng Mental Health Society
28	Senior Official: Limpopo Province
29	Senior Official : Western Cape Forum for Intellectual Disability
30	Senior Official: Comcare Residential Care
31	Senior Official: Schizophrenia and Bipolar Disorders Alliance (SABDA), Gauteng Province
32	Senior Official: South African Federation for Mental Health
33	Senior Official, South African Depression and Anxiety Support Group (SADAG)

Academics/Researchers	
34	Academic Department of Psychology, Stellenbosch University
35	Academic Department of Psychiatry, Witwatersrand University
36	Academic Department of Social Development, University of Cape Town
37	Academic Department of Psychiatry, University of KwaZulu Natal
38	Mental Health Researcher, Human Science Research Council
39	Researcher, Health Systems Trust
Religious organisations	
40	Senior Official, South African Council of Churches
41	Senior Official, Muslim Judicial Council
42	Senior Official: Jewish Board of Guardians
43	Senior Official, House of Traditional Healers
44	Senior Official, Zionist Christian Church
45	Senior Official, Disabled People South Africa
Statutory councils and organisations for professional development	
46	Senior Official :SA Council for Social Service Professions
47	Member, Medical and Dental Professions Board, Health Professions Council of South Africa (HPCSA)
48	Member: Professional Board for Occupational Therapy & Medical Orthotics/Prosthetic, HPCSA
49	Member, Professional Board for Psychology, HPCSA
50	Senior Official: South African Nurses Council

51	Representative, South African Colleague of Psychiatrists
Professional guilds	
52	Senior Official: Psychological Society of South Africa
53	Senior Official, South African Society of Psychiatrists
54	Senior Official: Association of Child and Adolescent Psychiatry and Allied Professions
Other respondents	
55	Member, Mental Health Review Board
56	Country Representative, World Health Organisation
Advocates	
57	Leader of organization for people with psychosocial disability ,
58	Leader of organization for people with psychosocial disability, Board member of mental health NGO
59	Board member of mental health NO
60	Leader of support group
61	Board member of provincial mental health NGO
62	Member of DPO for people with psychosocial disability
63	Member of DPO for people with psychosocial disability
64	Board member of mental health NGO, support group facilitator
65	Leader of organization for people with psychosocial disability

66	Board member of mental health NGO
67	Leader of provincial DPO
68	Board member of national mental health NGO
69	Member of advocacy organization for people with psychosocial disability
70	Leader of organization for people with psychosocial disability
71	Coordinator of provincial advocacy group
72	Head of DPO for people with psychosocial disability
73	Member of executive committee of provincial advocacy group for people with psychosocial disability
74	Facilitator of support group
75	Facilitator of support group
76	Facilitator of provincial advocacy group
Rural district KwaZulu Natal	
77	Person using services at local public mental health clinic
78	Person using services at local public mental health clinic
79	Person using services at local public mental health clinic
80	Person using services at local public mental health clinic
81	Person using services at local public mental health clinic
82	Person using services at local public mental health clinic
83	Person using services at local public mental health clinic

84	Person using services at local public mental health clinic
85	Person using services at local public mental health clinic
86	Person using services at local public mental health clinic
Urban District Western Cape	
87	Resident at private funded group home
88	Member of a support group
89	Person using private mental health care services
90	Person using private mental health care services
91	Member of supported employment programme
92	Resident of publically funded group home
93	Member of supported employment programme
94	Resident at publically funded group home
95	Person using public mental health care services
96	Person using public mental health care services

Appendix 14 List of reviewers: chapter seven

The review group mentioned in Table 7 comprised the following people:

- Fadia Gamielien, lecturer, Disability Studies Unit, University of Cape Town, previously a mental health service provider and facilitator for the development of support groups for people with psychosocial disability,
- Bharti Patel, CEO, South African Federation for Mental Health, South Africa
- Annie Robb, The Ubuntu Centre, Cape Town, South Africa
- Marinda Roelofse, programme manager for mental health, Department of Health, Western Cape South Africa, and
- Charlene Sunkel, Convenor: Gauteng Consumer Advocacy Movement, Gauteng, South Africa.